ANA AND HER WEB?

AN INVESTIGATION INTO INTERNET USE IN ADULTS WITH AN EATING DISORDER

FAYE HARRISON YUILL, BSc. (Hons), MSc.

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Portfolio Abstract

The aim of the systematic literature review was to explore the evidence regarding motivation for change and therapeutic outcome in the treatment of eating disorders. A systematic search was conducted using a predefined search strategy. Studies written in English and measuring motivation for change prior to treatment were included. Thirteen studies were included for review, the majority of studies were of high methodological quality. However, there were some methodological problems. Nonetheless, the evidence suggests that motivation for change should be taken into account prior to treating people with eating disorders.

The aim of the study was to explore the use of the internet in adults with an eating disorder. Previous evidence has suggested that people with an eating disorder are likely to access websites that are associated with their eating disorder (Wilson, Peebles, Hardy & Litt, 2006). The researcher hypothesised that the scores on measures of stage of change, self-efficacy for recovery, eating disorder symptoms, and perceived social support would be different depending upon the type of website accessed. A cross-sectional survey was administered online.

45 participants were recruited from specialist eating disorder services, support groups and via the eating disorder charity B-eat. Survey responses were anonymous and the survey content included measures related to the hypothesis as well as questions regarding internet use associated with eating disorders.

The results of this study show that the majority of the participants accessed websites associated with eating disorders. Most participants visited pro-recovery websites, some visited pro-eating disorder websites, and a small minority accessed both types of websites. The majority of the participants in this study visited these websites for social support. However, those who accessed pro-eating disorder websites also visited with the intention of triggering eating disorder behaviour. Nonetheless, no differences were found between those who accessed pro-eating disorder websites or pro-recovery websites on any measures.

However, those who accessed both types of website (pro-recovery and pro-eating disorder) had significantly higher levels of weight concern. As participants who accessed both types of website were less likely to be accessing treatment, and had more incidences of hospitalisation than those who accessed pro-recovery websites or pro-eating disorder websites exclusively, the difference in weight concern scores may be more related to whether treatment is being sought than website use. Whilst adults with an eating disorder may access websites associated with eating disorders, this does not appear to increase levels of perceived social support. Additionally, accessing pro-eating disorder websites did not appear related to eating disorder severity. Therefore this study suggests that pro-eating disorder websites may not influence behaviour as feared by professionals.

Acknowledgments

My heartfelt thanks go to all of those who have helped in the design and implementation of this research. To all of those who I'll never meet who participated in this study; thank you for your generosity. Special thanks go to Mike for his wisdom, gentle prods and enormous amounts of patience, as well as dealing with the influx of e-mails to his inbox during the final weeks of this work. I would also like to thank Heather Killock and B-eat for their support and help with recruitment.

I give special thanks to my parents who have supported me on this journey, and whose confidence in my ability has never wavered. I would also like to thank my friends, especially Andy who has made me laugh with his ridiculous antics and comforted me with his kind words. Finally, to my husband Mark who has bolstered me when my spirits were low, cooked many a meal and washed the dishes without a word. Thank you for the unconditional love and support you have given me throughout our time together. Without you, none of this would have been possible.

Statement of Contribution

This project was designed by the author (Faye Harrison Yuill) with the guidance of Dr J. Miatt, Mike Rennoldson and the DClinPsy Research tutors, who advised on recruitment, statistical analysis and write up.

The author made the application for ethical review with support from Kristy Angell Research Governance Assistant at the Research and Graduate Services, University of Nottingham. The literature review was also carried out and written solely by the author with guidance from Mike Rennoldson and the DClinPsy Research tutors.

Recruitment was carried out in a number of ways; the author contacted specialist services (and R&D departments) who agreed to help with recruitment and lead clinicians introduced the study to clients. B-eat, the eating disorder charity also agreed to be involved and sent out information to their database of people with an eating disorder who had agreed to be involved in research, a link to the study was posted on their website. Finally, support groups were contacted by the author, in the cases of those in Derby and Lincoln the author visited and presented the study to the group. Where this was not possible information about the study was sent out to support groups who either passed on or e-mailed participant information sheets to group members who were interested in be involved in the research.

Finally, the author scored the questionnaires, entered and coded the data (where appropriate) and performed the

analysis with guidance and supervision from Mike Rennoldson and the DClinPsy Research tutors.

Contents

Systematic Literature Review

Motivation for Change and Therapeutic Outcome: A Systematic Review*

Faye Harrison Yuill[1], Mike Rennoldson[2], Joanna Miatt[3]

[1] Trent Doctorate in Clinical Psychology, University of Nottingham

[2] University of Nottingham

[3] Derbyshire Healthcare NHS Foundation Trust

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Abstract

Objective: To explore the evidence regarding motivation for change and therapeutic outcome in the treatment of eating disorders. **Method:** A systematic search was conducted using a predefined search strategy. Studies written in English and measuring motivation for change prior to treatment were included. **Results:** Thirteen studies were included for review, most focused on only one eating disorder sub type. The studies used different methods to assess stage for change over different treatment models, both inpatient and outpatient treatment was investigated. Main outcome measures included the Eating Disorder Examination and Eating Disorder Inventory-2. The majority of studies were of high methodological quality, however there were some methodological problems. Nonetheless, there is evidence to suggest that motivation for change is related to treatment outcome. **Discussion:** Motivation for change should be taken into account prior to treating people with eating disorders. However, there are limitations to the current evidence due to methodological flaws.

People with eating disorders, especially those with Anorexia Nervosa are difficult to treat successfully.[1] Many are highly ambivalent about recovery, and deny there is a problem at all.[2] This can lead to problems with compliance during treatment and may end in a battle of wills between the clinician and the client, ultimately leading to early drop out and relapse.[3] Relapse rates for people with eating disorders who have recovered or partially recovered are between 32% - 48% depending upon diagnosis.[4,5] In those who drop out of treatment early, the figure is likely to be much higher. This is especially likely in Anorexia Nervosa, where a recent review found that a significant predictor of drop out was a diagnosis of this type.[6]

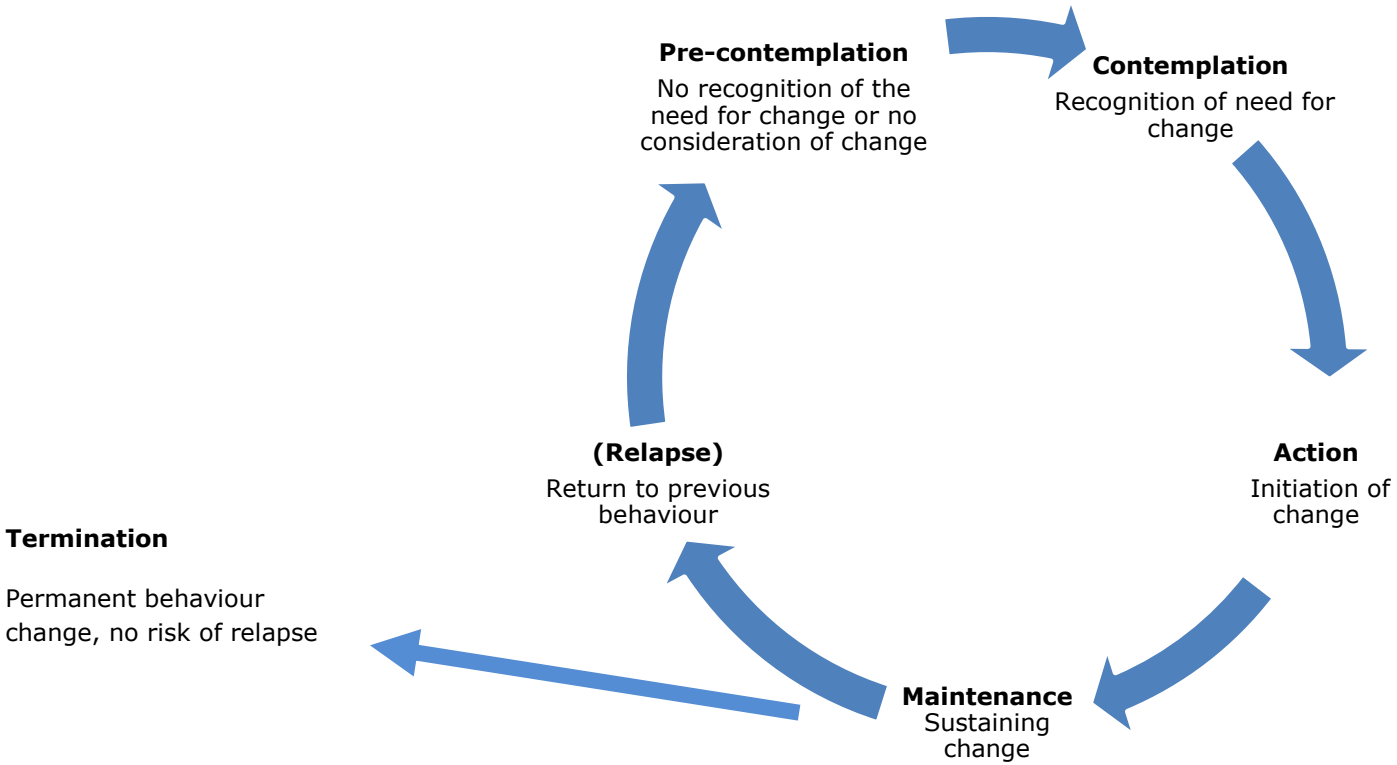
The rate of denial, ambivalence and drop-out in Anorexia Nervosa is thought to be due to the ego-syntonic nature of the disorder, where the behaviour of the person is fully consistent with their aim of being both thin and in control. This kind of denial and ambivalence is also seen in those with addiction problems, where the stages of change model has been utilised successfully.[7] Therefore it also has been used to understand and help to engage those with eating disorders in treatment.[8]

The Stages of Change model was originally developed as a way of describing and understanding the process of stopping smoking,[7] but has been successfully applied to other areas of addiction and a wide range of behaviour change such as medication compliance, depression and bullying. It suggests that there is a circular pattern to the process of change and that there are distinct stages within it (see **Figure 1**). The theory states that a person must pass through a number of stages pre-contemplation, contemplation, action, maintenance

(and relapse) during the process of change. The model further suggests that relapse can occur a number of times, leading the person to cycle back through the process until the behaviour is maintained over the long term. When a person maintains the new behaviour, has no temptation to relapse and is fully confident in sustaining the new behaviour, this is known as termination. However, in many applications of this model termination is never reached and long term maintenance is the goal.

FIGURE 1. Diagram of the Stages of Change Model

Change begins at the pre-contemplation stage and follows a number of steps until the person reaches termination.



Whilst the Stages of Change model is utilised in many areas of Psychology, it has been heavily criticised. Bandura[9] suggests that the model oversimplifies behaviour change and that it artificially imposes categories on a process that should be seen as a continuum. Furthermore, there is evidence to suggest that the stages of change questionnaires that have been developed do not support the stage structure and that some stages of the model such as action, do not emerge as a distinct factor.[10] The model has also been criticised for its simplistic view of movement between stages, which the theory suggests occurs in sequence, and there is little evidence to support this.[11] Despite these criticisms the Stages of Change model remains widely used, and is a popular theory of behaviour change.

A recent meta-analysis has suggested that the Stages of Change model is a predictor of outcome in psychotherapy across a number of psychological difficulties including eating disorders.[12] However, the meta-analysis combined studies focusing on a number of different psychiatric diagnoses. In addition to this, the largest number of studies focused on substance abuse. Only four of the 39 studies included in this meta-analysis were related to eating disorders. Therefore, it is not clear whether the model is a valid predictor of treatment outcome in this area. A review of the literature in 2004 related to eating disorders and the Stages of Change model suggested that the evidence for the use of the model for this client group was mixed,[13] however it did not explore if motivation for change (i.e. the stage a person was in) was related to treatment outcome.

The evidence for the Stages of Change model in relation to eating disorders appears to be mixed. Some argue that the concept of stages of change and the model itself is poorly defined, and that the evidence supporting its use and impact on therapeutic outcome is lacking.[13] However, many agree that the concept offers a useful and intuitive way to view behaviour change. It is often used within eating disorder treatment, discussed in treatment manuals and many clinicians find it helpful as a concept to help to engage this particularly difficult group in therapy.[2]

The aim of this systematic literature review is to explore the evidence regarding motivation for change and therapeutic outcome in the treatment of eating disorders. Specifically whether motivation for change related to treatment outcome in Anorexia Nervosa, Bulimia Nervosa and Eating Disorder Not Otherwise Specified (EDNOS).

METHOD

Search

In order to identify studies, the following electronic databases were searched using a search strategy developed prior to the search (search dates are different due to the difference in the updates of the databases; all databases were searched during the same time period):

PsycINFO, 1806 – 2011, July Week 1

Medline, 1950 – 2011, June Week 4

Embase, 1980 – 2011, Week 29

Web of Science – all databases on 4th July 2011

Each database was searched separately using the same search strategy. However, articles found using Web of Science were further refined using the following method selecting English language only, and articles. This was due to the expansive nature of the database and the increasing chance of irrelevant articles within the results. The references of all eligible primary studies and relevant review articles were also searched to identify additional studies.

Search Strategy

1. Exp motivation/ or motivation.mp
2. Motivational change.mp
3. Change.mp or exp readiness to change/ or exp "Stages of change"/
4. Resitance.mp or exp Resistance/ or exp Psychotherapeutic resistance
5. 1 or 2 or 3 or 4
6. Bulimia Nervosa.mp or exp Bulimia Nervosa/
7. Anorexia Nervosa.mp or exp Anorexia Nervosa/
8. Eating disorders.mp or exp Eating disorders/
9. 6 or 7 or 8
10. Exp Prediction/ or Predictor.mp
11. Mediator.mp
12. Mediate.mp
13. Implication.mp
14. Factor.mp
15. Affecting.mp or Psychosocial factors
16. 10 or 11 or 12 or 13 or 14 or 15
17. Treatment.mp or exp Treatment/ or exp Treatment dropouts/ or exp Treatment refusal/ or exp

Treatment termination/ or exp Treatment barriers/ or exp Treatment compliance

18. Intervention.mp or exp Intervention/
19. Therapy.mp
20. 17 or 18 or 19
21. 5 and 9 and 16 and 20

Selection

The title and abstract of all studies were read and relevant articles were selected. The criteria for selection of articles was developed prior to searching the literature, and all articles were selected on this basis alone. Where there was uncertainty, the full article was obtained and read prior to inclusion or exclusion. Conference abstracts, dissertations and other grey literature were not selected due to limited resources (see **Table 1** for full details of the selection criteria).

TABLE 1. Criteria of Inclusion for Acceptance into the Review

Area of inclusion	Criteria
Participants	All Ages
Eating Disorder	AN, BN, EDNOS
Stages of change measure	Any
Language of publication	English only
Analysis	Stage of change measured prior to treatment and compared with treatment outcome

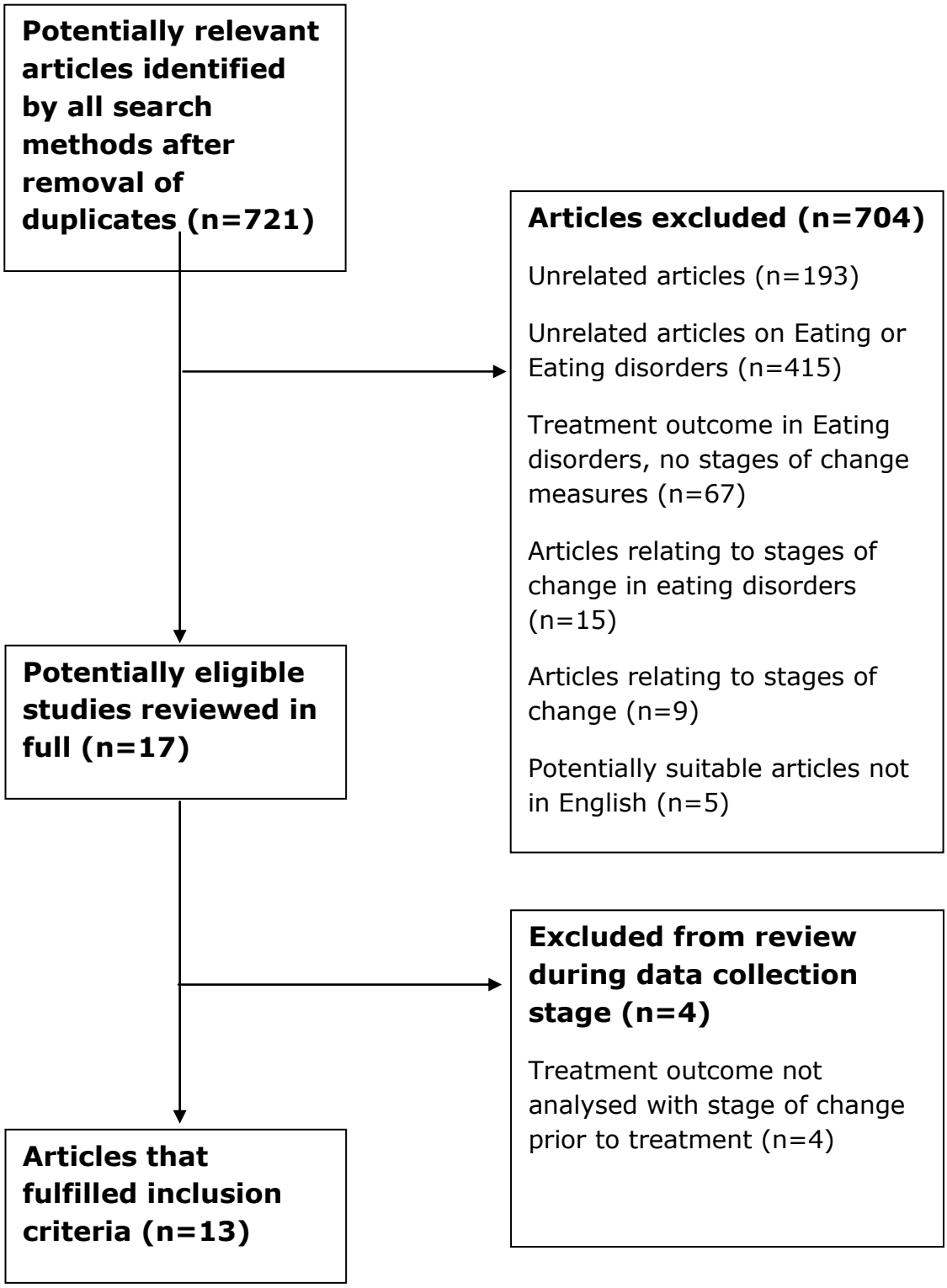
AN=Anorexia Nervosa, BN=Bulimia Nervosa, EDNOS=Eating Disorder Not Otherwise Specified

Selection criteria

The main inclusion criteria for the review was that studies should have measured motivation for change prior to treatment. As many people with eating disorders are diagnosed at a young age,[14] it was decided that there would be no restriction on age of participants in studies and that both adults and children would be included. Furthermore, as the nature of a person's eating disorder may change and many people with eating disorders display characteristics of more than one eating disorder sub-type,[15] studies relating to Anorexia Nervosa, Bulimia Nervosa and EDNOS would also be reviewed.

Articles written in languages other than the native language of the author (English) were excluded from the review. This was due to constraints on resources and the lack of easily available translations of the articles themselves. However, it is worth noting that there appeared to be a number of relevant studies that had been published in other languages. The database search returned 721 studies, after the selection criteria was applied to the studies, ten articles were identified as being suitable for review. Examination of the references of these articles led to the inclusion of a further three studies (for further information please see **Figure 2**).

FIGURE 2. QUORUM flow chart of study selection



Data abstraction

Features for each study selected was recorded they were; first author, year of publication, design of study, sample size, participant characteristics, treatment, stages of change measure and main outcomes including the measures used. Methodological quality was assessed using the Downs and Black checklist,[16] which applies the same criteria to both randomised and non-randomised trials. The checklist has been used in a number of systematic reviews,[17,18] and is a valid and reliable tool to assess study methodology.[16,19] Whilst there are other tools to assess methodological quality, such as the Critical Appraisal Skills Programme (CASP), [20] these involve using different checklists for different types of studies.

The search identified both randomised and non-randomised studies, as the Downs and Black checklist can be used regardless of the study type; it was felt that this tool was most suitable for use. The tool has been modified in a number of review by simplifying the question regarding power,[17,21] so that papers which describe a power calculation are scored 1 and those which don't score 0. The checklist was also simplified in the manner described for this review. Overall quality was calculated using the method described by Ferriter and Huband[22] in which they totalled the scores of each study and calculated the mean score. Studies were rated a high quality if they scored above this mean score and low quality if they scored below it.

Meta-analysis was of the results was considered, however the studies collated used a number of different

methods to measure stage of change. Some measures allow participants to score across the model where as other consider the stages to be discrete categories. As different constructs were used across the studies, meta-analysis was not appropriate.

RESULTS

Study Characteristics

The characteristics of the studies presented for review can be seen in **Table 2**. The majority of the studies (ten of the 13) were non randomised trials, [23-32] published between 1997 and 2011. The sample size ranged from 16-127 participants, with a mean sample size of 74 (SD 34). The study with only 16 participants was a pilot study investigating readiness for change and treatment outcome in people with Bulimia Nervosa, rather than a full trial.[23] The relatively large sample sizes of the remaining studies increases the power of the studies and allows for the study results to be applied to eating disorder populations. However, studies varied in recruitment of eating disorder sub type, with five only recruiting people with Anorexia Nervosa,[24,27,29,33] five recruiting people only with Bulimia Nervosa,[23,31,32,34,35] two including all possible diagnoses (Anorexia Nervosa, Bulimia Nervosa and EDNOS),[26,28] and one excluding people with EDNOS.[25]

The setting of treatment for people with eating disorders varied across studies, five were inpatient,[24,26,29,30,33] four were out patient,[25,27,28,31] with the rest describing the intervention but not the setting.[23,32,34,35] The variability of treatment setting may have prevented the application of results to all

eating disorder populations if the results of the studies had been mixed. Furthermore, the interventions used to treat those with an eating disorder also varied across the studies ranging from group based cognitive behavioural therapy (CBT) to a multidisciplinary approach that included individual therapy, group therapy, nutritional education and re-feeding, highlighting the range of treatment options available for people with an eating disorder.

TABLE 2. Characteristics of Included Studies

First author	Year	Design	Sample size	Participant characteristics	Treatment	Stages of Change measure used	Main Outcomes including measures
Franko	1997	Non randomised	16	Female BN	Group CBT Setting unclear	Change Assessment scale	Patients with positive treatment outcomes (50% reduction in binges and less than two binges a week) more likely to score high in action on change assessment scale. Main outcome measures: Change assessment scale, The binge eating questionnaire, The bulimic automatic thoughts test.

TABLE 2. Characteristics of Included Studies

First author	Year	Design	Sample size	Participant characteristics	Treatment	Stages of Change measure used	Main Outcomes including measures
Treasure	1999	RCT	125	Female Mean age 28 BN Illness duration 10-11 years Clinical population	Randomised to receive either MET then group CBT or individual CBT then group CBT or MET then individual CBT Setting unclear	URICA	Stage of change did not predict drop out. Those in action stage showed greater improvement and less binging. Main outcome measures: URICA, Working alliance inventory.

TABLE 2. Characteristics of Included Studies

First author	Year	Design	Sample size	Participant characteristics	Treatment	Stages of Change measure used	Main Outcomes including measures
Rieger	2000	Non-randomised	71	70 Females and 1 Male Mean age 19 AN Clinical population	Inpatient Multidisciplinary approach including therapy	URICA ANSOCQ	ANSOCQ scores predicted weight gain in participants. Main outcome measures: ANSOCQ, URICA, BDI-2, STAI, BIDR, CSD.
Geller	2001	Non-randomised	99	Women Mean age 25.7 AN BN Mean illness length 9.25 Clinical population	Outpatient Treatment unclear	Stage of change scale RMI	RMI only predicted drop out of treatment. Main outcome measures: RMI, Stage of change scale, Process of change, questionnaire, EDI-2, Brief Symptom Inventory, BIDR.
Wolk	2001	RCT	110	Females BN Clinical population	Randomised to receive 19 sessions of either CBT or IPT Setting unclear	Stage of change scale	Stage of change did not predict attrition. Stage of change did predict outcome in the IPT group. Main outcome measures: Stage of change scale, EDE.

TABLE 2. Characteristics of Included Studies

First author	Year	Design	Sample size	Participant characteristics	Treatment	Stages of Change measure used	Main Outcomes including measures
Geller	2004	Non randomised	64	Women Mean age 26.9 AN BN EDNOS Clinical population	Inpatient Treatment unclear	RMI	RMI score predicts dropout from therapy, predicts behavioural and cognitive symptom change on two subscales of the EDI-2 (Drive for thinness and body dissatisfaction) at end of treatment and maintenance of gains (subscales on EDI-2 and BMI) at 6 months. Main outcome measures: RMI, EDI-2, BMI.

TABLE 2. Characteristics of Included Studies

First author	Year	Design	Sample size	Participant characteristics	Treatment	Stages of Change measure used	Main Outcomes including measures
Rodríguez-Cano	2005	Non-randomised	67	Females Mean age 22.62 AN BN EDNOS Clinical population	Outpatient 1 year MET Psychoeducation Group CBT	ACTA	Stage of change did not predict attrition. High action score predicted changes in BMI. Main outcome measures: ACTA, EAT-40, EDI-2, BITE, BDI-2, STAI, BMI, Rosenberg self-esteem questionnaire.

TABLE 2. Characteristics of Included Studies

First author	Year	Design	Sample size	Participant characteristics	Treatment	Stages of Change measure used	Main Outcomes including measures
McHugh	2007	Non randomised	65	Girls Mean age 16.5 AN Clinical population 68% first admission	Inpatient Multidisciplinary approach including therapy	ANSOCQ	Higher readiness for change score = 5.30 times more likely to have 'improved' outcome (85% of ideal body weight and score of 14 or less on EDI-2 drive for thinness subscale) at discharge. Main outcome measures: ANSOCQ, EDI-2, BDI-2, BAI, SF-36v2.

TABLE 2. Characteristics of Included Studies

First author	Year	Design	Sample size	Participant characteristics	Treatment	Stages of Change measure used	Main Outcomes including measures
Bewell	2008	Non randomised	127	Women Mean age 25.2 AN Mean illness length 5.9 yrs Clinical population First admission	Inpatient Group therapy	None, asked single question with a 10-point Likert scale response	Readiness to change eating and weight predicted outcome (achieving a BMI of 20), but not attrition (either drop out or discharge for non-compliance). Main outcome measures: EDE, EDI-2, BMI.

TABLE 2. Characteristics of Included Studies

First author	Year	Design	Sample size	Participant characteristics	Treatment	Stages of Change measure used	Main Outcomes including measures
Wade	2009	RCT	47	45 Females and 2 Males Mean age 21.85 AN Clinical population	Inpatient Either treatment as usual or treatment as usual plus motivational interviewing	ANSOCQ and six self-report questions with a 10-point Likert scale for each	Self-report questions predicted improvement in EDE scores between baseline and 6 weeks. Change in ANSOCQ score over 2 weeks predicted change in EDE score at 6 weeks. Main outcome measures: EDE, ANSOCQ.
Castro-Fornieles	2011	Non randomised	40	Girls Mean age 16.2 BN Clinical population	Mostly outpatient Multidisciplinary approach including therapy	BNSOCQ	BNSOCQ score/motivation to change predicts decreased number of binges and reduction on the bulimia subscale of the EDI-2. Main outcome measures: BNSOCQ, EDI-2, BDI-2.

TABLE 2. Characteristics of Included Studies

First author	Year	Design	Sample size	Participant characteristics	Treatment	Stages of Change measure used	Main Outcomes including measures
Steele	2011	Non randomised, part of a larger RCT	87	85 Females and 2 Males Mean age 26 BN Mean illness length 8 years	Guided self help	None, asked 2 questions with a 10-point Likert scale for each	Motivation predicted over-evaluation of weight and shape score (on EDE), frequency of binge eating, and EDE global score immediately after treatment. Main outcome measures: EDE, Eating disorder automatic thoughts, Rosenberg self-esteem scale, Depression Anxiety Stress Scale, Frost Multidimensional Perfection scale, Screening test for co morbid personality disorders, Motivation questions.

ACTA=Attitudes towards change in Eating Disorders questionnaire, AN=Anorexia Nervosa, ANSOCQ=The Anorexia Nervosa stages of change questionnaire, BAI=Beck Anxiety Inventory, BDI-2=Beck Depression Inventory-2, BIDR=Balanced Inventory of Desirable Responding, BITE=Bulimic Inventory Test Edinburgh, BMI=Body Mass Index, BN=Bulimia Nervosa, BNSOCQ=Bulimia Nervosa stages of change questionnaire, CBT=Cognitive Behavioural Therapy, CSD=Children's Social Desirability Scale, EAT-40=Eating Attitudes Test, EDE=Eating Disorders Examination, EDI-2=Eating Disorder Inventory-2, EDNOS=Eating Disorder Not Otherwise Specified, HoNOSCA=The Health of the Nation Outcome Scales for Child and Adolescent Mental Health Services, HoNOSCA-SR=The Health of the Nation Outcome Scales for Child and Adolescent Mental Health Services–Self Rated, IPT=Interpersonal Psychotherapy, MET=Motivational Enhancement Therapy, SF36v2=Medical Outcomes Short Form 36-Item short form version, STAI=State Trait Anxiety Inventory-form, RCT=Randomised Control Trial, RMI=Readiness and Motivation Interview, URICA=University of Rhode Island Change Assessment scale, YBC-EDS=The Yale-Brown-Cornell Eating Disorder Scale.

Participant Characteristics

Participants were mostly recruited from clinical populations, often on referral to specialist eating disorder services. However, two studies did not report where they recruited the participants from which limits the ability to generalise the findings to similar populations.[23,32] The diagnosis of the participants varied; 52% of all those who participated in the studies had a diagnosis of Anorexia Nervosa, 44% were people with Bulimia Nervosa and the remaining 4% had a diagnosis of EDNOS. A number of studies focusing on either Anorexia Nervosa or Bulimia Nervosa also included participants described as 'sub-threshold' which may explain the low rate of EDNOS in the total sample.[25,32,33] Evidence suggests that within clinical populations the majority of people with eating disorders tend to have a diagnosis of EDNOS,[36] which may make the results of the studies difficult to apply to many of those seeking treatment for an eating disorder.

Of the 960 participants across the 13 studies, only six were male which is reflective of the low rate of eating disorder diagnosis in men in clinical populations.[37] The mean age of the participants in the studies was 22 (SD 4.55), ranging from 16-28, however two studies did not report this.[23,35] Studies which limited recruitment to people with Bulimia Nervosa tended to have a higher mean age than those who only recruited people with Anorexia Nervosa. This pattern is seen in those with eating disorders in practice, with people who develop Anorexia Nervosa tending to be younger (between 15 -17 years old) than those with Bulimia Nervosa.[37] Of those

who reported mean illness duration,[25,30,32,34] this ranged from 5.9 years to 11 years.

Stages of Change measures

The studies used a wide variety of stages of change measures, 54% of the studies reviewed used an eating disorder specific measure,[24-26,28,29,31,33] of those two were validating those measures.[24,25] Two studies asked participants to rate their readiness to change in response to questions asked with a Likert scale response,[30,32] and the remaining used general stages of change scales which had been validated for a number of clinical and non-clinical populations.[23,27,34,35] Only one study used both a validated eating disorder specific questionnaire and self-report questions to measure stage of change.[33] The various stages of change measures used in the studies make direct comparison between them somewhat difficult. The validation studies reviewed highlight clear differences between standard stages of change measures and eating disorder specific ones, as only the eating disorder specific scales predicted treatment outcome.[24,25] This suggests that the constructs being measured by the eating disorder specific scales may be different than the standard stage of change questionnaires.

Methodological Quality

The methodological quality of the studies was variable with scores on the Downs and Black checklist ranging from 12-19 out of a possible 27 (for a complete summary see **Table 3, 4 and 5**). The mean of the combined total score was 16.69 (SD 1.93), five studies scored below this and were therefore

rated as being of low quality.[23-27] The remaining eight studies were considered to be of high quality.[28-35]

Reporting

The reporting score (see **Table 3**) of the studies ranges from six to nine out of a possible score of ten, and was of a reasonable quality. The studies were clearly written and easily followed allowing for replication if necessary. Only one study failed to adequately report the sample in enough detail to allow generalisation of the results.[23] The others clearly described the samples and recruitment strategy allowing for a good understanding of who the results may apply to in clinical practice. Furthermore, many also clearly described the intervention given to the participants in order to treat their eating disorder. This ranged across studies and allows for the results to apply to a broad range of services and treatment modalities. Attrition and drop out was well described and comparisons made between those who completed the study and those who left the study early were made in the majority of cases.

However, four studies failed to do this,[26,27,33,35] it is therefore not clear whether there were differences between those who dropped out of the study (and/or treatment) and those who completed it. As drop-out is a problem in the treatment of eating disorders, knowing the differences between people who are likely to complete treatment and those who are not may be important. Given that the studies were investigating motivation for change, it is possible that those who dropped out of the study were likely to be less motivated than those who completed it. Therefore, the

analysis of this would have been appropriate to compared those who completed the studies with those who did not.

External Validity

Scores on external validity were variable, whilst ten studies scored two or three on this section, three scored either zero or one.[23,32,35] The studies often recruited participants from a sample of consecutive admissions or referrals to the service, and were therefore clearly representative of the population being referred. However, it was not clear whether those who agreed to take part were similar to those who refused, an analysis of this would have allowed a judgement on the representativeness of the study samples and would allow for increased generalisability to similar populations in other services. It may have also increased the external validity of some studies.[23-26,28-30,32,34,35]

Internal validity (bias and selection bias) and power

The scores regarding internal validity and bias were mediocre with the mode score being four, only one study scored six out of a possible seven.[35] The low scores on this section may be partly explained by the checklist itself. In this section the checklist rates blinding and measurement of compliance. As only three studies were RCTs,[33-35] and only one study was double blind, the scores on this section were particularly low.[35] Nonetheless, all of the studies used valid and reliable measures. As previously discussed there may have been differences in the constructs measured between measures designed for eating disorder populations and standard stage of change measures. However, it is worth noting that the studies which asked participants to rate their

readiness to change by answering questions on a 10 point Likert scale,[30,32,33] found similar results to those who used validated measures.[23-29,31,34,35] The statistical tests used to analyse the results were appropriate, using correlations and regression analysis. Whilst many studies used regression to assess the predictive validity of the correlations found,[24-26,28,30,32,38] none applied any correction to prevent type I errors even after multiple analyses.

The scores exploring selection bias were also poor, the median score was three out of a possible score of six and only two studies scored five.[32,35] The majority of the studies failed to report the recruitment period and therefore it was not clear if all participants were recruited over the same period of time. For those who did report this the recruitment period the time ranged from one to seven years,[28,30,32] which in the case of Bewell and Carter[27] seemed like an excessively long recruitment period during which the type of referral or referral criteria to the service may have changed. Only one study failed to state the number of participants lost to follow up or who dropped out. However, as previously mentioned not all studies analysed this appropriately.

As previously described the Downs and Black checklist was simplified on the question regarding power,[16] when the study mentioned a power analysis the study was scored one. All studies failed to discuss a power analysis prior to the results and it was not clear if a power or sample size calculation was completed prior to recruitment. Whilst some papers discussed power after the results,[26,34] the rest failed to acknowledge power and the possibility of a type II error in the results.

TABLE 3. Methodological Quality – Downs and Black Checklist for Reporting

Study	Aims	Outcomes	Participants	Intervention	Confounders	Findings	Variability	Adverse events	Attrition	P. values	Reporting score
Franko 1997	1	1	0	0	0	1	1	0	1	1	6
Treasure1 999	1	1	1	1	1	1	1	0	1	0	8
Rieger 2000	1	1	1	1	0	1	1	0	1	1	8
Geller 2001	1	1	1	0	0	1	1	0	1	0	6
Wolk 2001	1	1	1	1	1	1	0	0	0	1	7
Geller 2004	1	1	1	0	0	1	1	0	0	1	6
Gowers 2004	1	1	1	1	0	1	1	0	0	1	7
Rodríguez -Cano 2005	1	1	1	1	0	1	1	0	1	1	8

TABLE 3. Methodological Quality – Downs and Black Checklist for Reporting

Study	Aims	Outcomes	Participants	Intervention	Confounders	Findings	Variability	Adverse events	Attrition	P. values	Reporting score
McHugh 2007	1	1	1	1	1	1	1	0	1	1	9
Bewell 2008	1	1	1	1	1	1	1	0	1	1	9
Wade 2009	1	1	1	1	1	1	1	0	0	1	8
Castro-Fornieles, 2011	1	1	1	1	0	1	1	0	1	1	8
Steele, 2011	1	1	1	1	0	1	1	0	1	1	8

TABLE 4. Methodological Quality – Downs and Black Checklist for External Validity and Bias

Study	Sample	Population	Treatment	External score	Blinding sample	Blinding	Results	Follow up	Analysis	Compliance	Measures	Bias score
Franko, 1997	0	0	0	0	0	0	1	0	1	0	1	3
Treasure, 1999	1	0	1	2	0	0	1	0	1	0	1	3
Rieger, 2000	1	0	1	2	0	0	1	0	1	0	1	3
Geller, 2001	1	0	1	2	0	0	1	1	1	0	1	4
Wolk, 2001	0	0	1	1	1	1	1	1	1	0	1	6
Geller, 2004	1	0	1	2	0	0	1	1	1	0	1	4
Gowers, 2004	1	1	1	3	0	0	1	1	1	0	1	4
Rodríguez-Cano, 2005	1	0	1	2	0	0	1	1	1	0	1	4
McHugh, 2007	1	0	1	2	0	0	1	0	1	0	1	3

TABLE 4. Methodological Quality – Downs and Black Checklist for External Validity and Bias

Study	Sample	Population	Treatment	External score	Blinding sample	Blinding	Results	Follow Up	Analysis	Compliance	Measures	Bias score
Bewell, 2008	1	0	1	2	0	0	1	1	1	0	1	4
Wade, 2009	1	0	1	2	0	0	1	1	1	0	1	4
Castro-Fornieles, 2011	1	1	1	3	0	0	1	0	1	0	1	3
Steele, 2011	0	0	1	1	0	0	1	1	1	0	1	4

TABLE 5. Methodological Quality – Downs and Black Checklist for Selection Bias, Power, Total Score and Study Quality

Study	Recruitment population	Recruitment Time	Randomisation	Concealment	Adjustment	Loss to follow up	Selection bias score	Power	Total score	Quality
Franko, 1997	1	0	0	0	1	1	3	0	12	Low
Treasure, 1999	1	0	1	0	1	1	4	0	17	High
Rieger, 2000	1	0	0	0	1	1	3	0	16	Low
Geller, 2001	1	0	0	0	1	1	3	0	15	Low
Wolk, 2001	1	0	1	1	1	1	5	0	19	High
Geller, 2004	1	0	0	0	1	1	3	0	15	Low
Gowers, 2004	1	0	0	0	1	0	2	0	16	Low
Rodríguez-Cano, 2005	1	1	0	0	1	1	4	0	18	High
McHugh, 2007	1	0	0	0	1	1	3	0	17	High

TABLE 5. Methodological Quality – Downs and Black Checklist for Selection Bias, Power, Total Score and Study Quality

Study	Recruitment population	Recruitment Time	Randomisation	Concealment	Adjustment	Loss to follow up	Selection bias score	Power	Total score	Quality
Bewell, 2008	1	1	0	0	1	1	4	0	19	High
Wade, 2009	1	0	1	0	1	1	4	0	18	High
Castro-Fornieles, 2011	1	0	0	0	1	1	3	0	17	High
Steele, 2011	1	1	1	0	1	1	5	0	18	High

Key findings

All the studies found that motivation for change was related to treatment outcome regardless of the measure used or the eating disorder diagnosis.

Anorexia Nervosa only

Five studies in the review recruited participants with Anorexia Nervosa only,[24,27,29,30,33] of those two were considered low quality.[24,27] In the majority of studies, motivation for change predicted weight gain.[24,27,29,30] One high quality study suggested that those with higher readiness to change scores were approximately five times more likely to have an improved outcome which included weight gain and being at least at 85% of ideal body weight.[29] It further suggested that those with higher readiness for change scores and greater motivation for change were also more likely to have less of a drive for thinness as measured on the Eating Disorder Inventory (EDI-2). Those with greater motivation for change prior to treatment were also more likely to have an improvement in scores on the Eating Disorder Examination (EDE), which is a measure of eating disorder behaviour and severity.[33] However, evidence regarding drop out and non-compliance was mixed. One study suggested that those with high motivation for change were less likely to drop out of treatment,[27] whereas this was contradicted by another higher quality study.[30]

Bulimia Nervosa only

In the five studies which recruited participants with Bulimia Nervosa,[23,31,32,34,35] only one was considered to be low quality.[23] The studies suggest that those in the action stage of the model prior to treatment were more likely to reduce the

number and frequency of binges, and were more likely to no longer fulfil the criteria for Bulimia Nervosa after treatment (as measured by the EDE).[23,31,32,34,35] High motivation for change also predicted a reduction in scores on a number of eating disorder measures such as the EDI-2 and EDE.[31,32,35] However, motivation for change did not predict drop out from treatment.[34,35]

Anorexia Nervosa, Bulimia Nervosa and EDNOS

In studies which did not exclude participants according to eating disorder sub type, high motivation for change predicted both behavioural and cognitive change on the EDI-2 after treatment.[26] Furthermore, high motivation for change also predicted change in body mass index (BMI). Those with Anorexia Nervosa increased their BMI, whilst the BMI in those with Bulimia Nervosa decreased.[28] The evidence for motivation for change predicting drop out is mixed and appears to depend up on the measure used. The readiness and motivation interview (RMI) predicted drop out from treatment, [25,26] where as other measures such as the stage of change scale or attitudes towards change in eating disorders (ACTA) did not.[28] The quality of evidence in studies who did not exclude participants based on eating disorder diagnosis appears to be lower than those studies which did. Of the three studies within this section, [25,26,28] only one was considered to be of high quality.[28]

DISCUSSION

This systematic review found thirteen studies which investigated the effect of motivation for change on outcome in the treatment of eating disorders. All of the studies identified

found that motivation for change prior to treatment was correlated to, or predicted outcome at the end of treatment. The quality of evidence for Bulimia Nervosa was higher than that of Anorexia Nervosa, with 80% of studies being rated as high quality compared to 60% of studies focusing only on Anorexia Nervosa. The quality of evidence for studies that did not exclude participants based upon eating disorder diagnosis and included EDNOS was particularly poor with only one study being rated as high quality. Whilst it appears that there is some evidence to suggest that a greater motivation for change prior to treatment positively predicts outcome, there are some limitations to this.

Limitations of the research

As previously discussed some studies used more than one stage of change measure.[24,25] These were studies which were validating measures that had been developed for use in people with eating disorders. These studies found that it was only the eating disorder specific measures which predicted outcome. Whilst the studies did attempt to address this within the discussion, this suggests that the eating disorder specific measures could be assessing different concepts to the more general stage of change measures. Furthermore, the eating disorder specific measures do not assign participants to a specific stage of change, instead assessing motivation for change in either a number of areas (Anorexia Nervosa Stages of Change Questionnaire) or assigning a percentage score to each stage (Readiness and Motivation Interview). Whilst this may be more predictive of outcome, it fails to support the application of the stages of change model within the treatment of eating disorders. It also supports Bandura's [9] assertion that

change is not a categorical process as suggested by the stage of change model.

The lack of evidence that motivation for change is predictive of drop out is also problematic; the theory would suggest that participants who were in either the contemplation or pre-contemplation stage would be more likely that those in the action stage to drop out from treatment. However, there is little evidence that this is the case, out of the thirteen studies reviewed only three studies found that motivation predicted drop out.[25-27] Two of these studies used the Readiness and Motivation Interview (RMI) which as previously mentioned does not assign participants to a categorical stage. Once again, this fails to support the application of the stages of change model to people with eating disorders. Despite these limitations, motivation for change did predict outcome in people with eating disorders across the thirteen studies.

Limitations of the review

This review has a number of limitations, perhaps most importantly, it only included articles written in English. Whilst this was a pragmatic decision based upon limited resources, it should be noted that there were five articles written in languages other than English that focused on motivation for change and the treatment of eating disorders. These studies may have been suitable for review, and is a potential source of bias, as they could have affected the findings of the review.

Only one person conducted this review, best practice suggests that a team of at least three people should conduct a systematic review in order reduce both errors and bias, as well as allowing for arbitration should reviewers disagree at any stage.[39] As a team of reviewers was not feasible for this

review, there is potential that the search and selection strategy of this review is biased. In addition, as only one person conducted the search, it is possible that a larger number of studies may have been found and reviewed had a team been in place and more than one person was tasked with searching the relevant databases and references.

Implications for practice and future research

Although there are some methodological limitations to the research reviewed, the results suggest that assessing motivation for change prior to treatment may be beneficial. Notably one study which found a positive result between motivation and treatment outcome simply asked participants how ready they were to change their eating and weight.[30] Whilst motivational interviewing is common in the treatment of people with an eating disorder, engaging people in this way would allow a more targeted approach and may be a better use of limited resources, without using measures that may be methodologically flawed.

Future research could focus on extending the scope of this review and include literature that has been published in languages other than English to increase the generalisablity of the findings and reduce potential bias. Other research could also focus on producing eating disorder specific measures which assign people to a specific stage of change, or further evaluate the measures that have already been developed to assess the scale of the problems previously highlighted. There is also need for an increased number of high quality studies looking at motivation for change and treatment outcome in EDNOS.

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Journal Article

Ana and her Web? An Investigation into Internet Use in Adults with an Eating Disorder*

Faye Harrison Yuill[1], Mike Rennoldson[2], Joanna Miatt[3]

[1] Trent Doctorate in Clinical Psychology, University of Nottingham

[2] University of Nottingham

[3] Derbyshire Healthcare NHS Foundation Trust

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Abstract

Objective: This study explores the use of the internet in adults with an eating disorder. **Method:** 45 adults with an eating disorder responded to an online survey which assessed eating disorder severity, stage of change, perceived social support, self-efficacy in recovery and website use in relation to their eating disorder. **Results:** The results show that the majority of participants accessed pro-recovery websites, whereas a small number accessed pro-eating disorder websites. Most participants who visited websites associated with eating disorders did so for social support. However, those who accessed pro-eating disorder websites also intended to trigger eating disorder behaviour. No differences were found on any measures. **Conclusion:** Whilst people with eating disorders may access websites for social support this does not appear to increase perceived social support. Furthermore, accessing pro-eating disorder websites did not appear related to eating disorder severity. This study suggests that pro-eating disorder websites may not influence behaviour.

Keywords: eating disorders; adults; internet; pro-recovery; pro-ana; pro-eating disorder; self-efficacy; recovery; stage of change; social support

The number of people affected by eating disorders (see sections 2.2-2.5 for further discussion of eating disorders) is not only appearing to rise, but those diagnosed also appear to be getting younger.[1] Given the increased likelihood of death [2] and serious complications,[3] as well as the high rates of relapse,[4] it is not surprising that eating disorders and the issues surrounding them are of serious concern. This often leads to discussion and debate on the development of eating disorders and who or what can be blamed for them. One factor commonly identified is the media, indeed a recent all party parliamentary report on the causes and consequences of body image dissatisfaction has once again highlighted the presumed link between the media and the promotion of the thin ideal (for further discussion of this please see section 2.6).[5]

The promotion of the thin ideal however, goes much further than what is traditionally understood as 'the mass media', and more recently the internet has also been used to encourage the attainment of thinness at any cost. This is most clearly seen in the development of pro-anorexia (pro-ana) or Pro-eating disorder (Pro-ED) websites. Initially these sites were created with the intention of promoting the thin ideal through the utilization of extreme weight loss and weight managing techniques seen in people with an eating disorder. Greater value was placed on restricting and exercise, with less emphasis given to purging.[6]

Groups appeared on Facebook, as well as on sites such as Livejournal (which hosts online diaries and groups), and more recently pro-anorexic material has been found on Tumblr and Pinterest.[7] Due to the nature of sites such as Tumblr,

pro-ana content often takes the form of 'thinspiration' (generally pictures of very thin women) or short quotes or text, which is somewhat different to the content seen on (more traditional) pro-ED sites hosted elsewhere. In reaction to these sites, many pro-recovery websites have been created (although these are thought to be vastly out-numbered by pro-anorexia sites [8]) and charities such as Beating Eating Disorders (B-eat) have campaigned to raise awareness of the alleged dangers of these Pro-ED sites.[9]

Whilst there has been substantial interest in pro-anorexic websites and the presumed harmful effects to visitors, this has not been matched by research. Currently research has focused on four broad areas; content, philosophy and discourse, reasons for use and impact. Of the studies focusing on content, these have focused on the more traditional pro-ED sites rather than those found on social networking sites such as Facebook or Tumblr. These studies suggest that traditional pro-ana and pro-ED sites tend to have similar features. They will often contain 'thinspiration' as well as 'tips and tricks' which tend to focus on ways of reducing intake. Many also have chat forums and message boards for members to view and post messages. These messages tend to take the form of posts seeking advice and support or offering encouragement and replying to questions (see section 2.7 for further discussion of pro-anorexic and pro-eating disorder websites).[10,11] At first glance pro-ED websites appear to have the aim of motivating and supporting their visitors to continue to try to maintain their eating disorder whatever the cost. However, a closer look suggests that there are limits to this and members will post warnings about behaviours they consider being unsafe.[12]

This apparent disparity is also reflected in the philosophy of many pro-ED sites. Whilst on the surface they appear to provide and promote a community for like-minded people, there does appear to be a hierarchy where 'ana' (anorexia nervosa) reigns supreme.[6] Roberts, Strife and Rickard [13] found that websites tended to conceptualise anorexia nervosa (AN) and eating disorders in one of two ways. Sites either embraced the medical model of eating disorders, or developed an alternative understanding of eating disorders. Describing it as a lifestyle and a choice that meets their needs.

Roberts et al. [13] further suggest that the use of language differs depending on the apparent philosophy of the site. Those that offered the alternative conceptualisation (usually pro-ED websites), frequently used language that offered a sense of power and control in relation to the experience of the disorder. The idea that an eating disorder may offer power and control may be particularly attractive to those with low self-efficacy in relation to recovery. Evidence suggests that pro-ED websites may reinforce an eating disordered identity,[14,15] which may reduce self-efficacy for recovery and negatively affect the outcome of treatment (for further discussion of self-efficacy in recovery please see section 2.9).[16]

Nonetheless, there is evidence to suggest that pro-anorexic websites may be a supportive environment for someone with an eating disorder.[14] People with an eating disorder tend to be socially isolated and report less social support than those without an eating disorder (please see section 2.10 for further discussion of social support in eating disorders).[17] Some studies have suggested that pro-ana and pro-ED websites can be viewed as communities, a place for

those who realise that their views (on their eating disorder) will not be supported by those around them.[15,18,19] Furthermore, Csikpe and Horne [14] found that users who were particularly active in a pro-ED community reported better mental health after visiting and interacting with other users.

However, the immersion of a person in the world of pro-anorexia may make recovery harder due to the difficulty in developing an alternative identify without an eating disorder, and the subsequent loss of support and acceptance this may bring. Additionally, Fox, Ward and O'Rourke [20] found that on the pro-ana website they investigated, eating disorders were understood as a way of coping with difficult life situations. For those who frequented this website, the aim was to be able to continue using the eating disorder as a coping strategy in a way that was sustainable and 'safe', rather than recover.

Much has been made of the potential impact of viewing pro-ana and pro-ED websites.[21] However, there has been little research on the effects of viewing these types of websites. Those that have, used female undergraduates at an American university to investigate the effects of viewing a specially created site that was typical of traditional pro-ED sites online.[22,23] In a population without a diagnosis of an eating disorder, these studies suggest that viewing this type of information can lead to lower self-esteem, increased perception of being overweight, as well as increasing the likelihood of increasing the level of exercise and restricting calorific intake in the short term.[23]

Given that these websites can have this effect in a normal population, it is possible that as some clinicians suggest they may also effect the eating behaviour of a person

with an eating disorder.[21] This may occur through the process of social contagion.[24] As previously mentioned people with an eating disorder report low levels of social support and research suggests that many people access pro-ED sites for this reason.[14] Crandall [24] proposes that groups (such as online communities) are not initially cohesive and that as group cohesion increases over time, group members become more alike.

Furthermore, he suggests that when we are distressed, we are more likely to be open to social influence. In addition to this, the more we value the group and our membership, the more we are likely to be influenced by it. Crandall found that in his study of binge eating in sororities, women who displayed binge eating behaviour that was closer to the social norm, were more popular than those who did not.[24] In pro-ED sites where high levels of eating disordered behaviour is considered to be the norm, it is likely that those who display behaviour more aligned to this norm are more likely to be accepted. In addition to this, membership of pro-ED websites is often tightly controlled, and new members are frequently treated with suspicion.[25] Therefore, there is pressure on members to prove their eating disorder identity, in order for them to be accepted. This may increase the discussion of eating disordered behaviours and techniques.

Crandall [24] suggests that shared information can lead to increased group cohesion, and members becoming increasingly similar, leading in the case of eating disorders to increasingly disordered eating behaviour. People who access these sites are likely to value the group due to the support and understanding they feel it can provide. They are therefore, likely to be heavily influenced by it, and the behaviours they

are sharing online. However, there is currently no research to support the assertion that pro-anorexic websites are inherently dangerous to someone with a diagnosis of an eating disorder.

Whilst the research into the effects of pro-anorexic websites is currently limited, there is less information available about the effects of viewing pro-recovery websites (some of which have been set up as a direct response to the development of the 'pro-anorexia movement'). There is some evidence that whilst pro-recovery websites (please see section 2.8 for further discussion of pro-recovery websites) and forums may be helpful in the initial stages of recovery, they may hinder the process of recovery in the later stages, where the eating disorder identity needs to be relinquished.[26] Keski-Rahkonen & Tozzi [26] found that actively participating on an eating disorder discussion group delayed recovery in the later stages of change (see section 2.11 for further discussion of the stages of change model).

Furthermore, one study found that participants also found information on pro-recovery websites that helped them to maintain their eating disordered behaviours,[27] further highlighting the complexity surrounding eating disorders and internet use. Others have suggested that the use of pro-ED and pro-recovery websites may be related to stage of change, with people accessing pro-ED sites in the earlier stages of change.[19]

There has been some progress in trying to understand pro-ED websites, and the possible motivations behind those who create and use them. Furthermore, there is evidence to suggest that people with an eating disorder access pro-anorexic and/or pro-recovery websites.[27] However, there has

been little interest or focus given to the possible differences between the people who access them. Pro-anorexic websites are unlikely to disappear; they appear to be frequented by people of all eating disorder diagnoses and tend to evolve quickly. It is therefore important to discover not only who is accessing these sites, but also the differences between those who do and those who do not. Having this knowledge will aid the understanding of eating disorders, as well as highlighting the when a person may be likely to access different types of sites. Therefore, this study aimed to examine the use of both pro-ED and pro-recovery websites in adults with an eating disorder, and to investigate the associations between website use and eating disorder severity, stage of change, self-efficacy in recovery, and social support.

METHOD

Participants and procedure

People who identified with having an eating disorder (*n=45*) were recruited from specialist eating disorder services in the East Midlands, support groups across the United Kingdom and through the B-eat eating disorder research database as well as being advertised on the B-eat website (for further information regarding recruitment see section 3.5). Participants were included in the study if they identified with having an eating disorder, and they accessed the internet. Due to the questionnaires used in the study, participants also needed to have a good standard of English. Participants were excluded if they were under the age of 17.

The study was administered online, and participants completed a number of standardised questionnaires looking at

eating disordered behaviour, self-efficacy regarding treatment, stage of change and social support. Participants also answered questions about the websites they visited and their opinions on their eating disorder. Demographic information was also collected. The study received ethical approval from the NHS (for more information regarding ethical issues and ethical approval please see section 3.4).

Measures

(For more detailed information regarding the choice of measures, as well as the development of the internet use questionnaire please see sections 3.7 and 3.8)

Demographics

Participants answered questions regarding their age, gender, ethnicity, eating disorder diagnosis, current height and weight, lowest and highest weights, treatment status and length, duration of eating disorder and number of hospitalisations. This was based on information collected in previous studies.[27]

Eating Disorder Symptoms

The Eating Disorder Examination Questionnaire (EDE-Q),[28] was used to screen for eating disorder symptoms. This questionnaire is based upon the gold standard clinical interview for eating disorders the Eating Disorder Examination.[29] It focuses on eating disorder attitudes and behaviour over the past 28 days. The measure can be used to give a global score which can be used as a screening tool to identify cases of eating disorders in the community.[30] The EDE-Q has been shown to be valid and reliable, and has

Cronbach's Alpha scores of between 0.78 and 0.93 across the subscales.[31]

Stage of Change

As motivation and readiness to change is regarded as a major barrier to effective treatment with those with an eating disorder diagnosis,[32] and may be related to the type of website accessed, the University of Rhode Island Change Assessment Scale (URICA) [33] was used to assess motivation for change in participants. The measure gives scores on four stages of the model (Pre-contemplation, Contemplation, Action and Maintenance) to create a profile, but can also be used to give the stage the person is in based upon their score. The measure is valid and has acceptable reliability. Cronbach's Alpha scores are between 0.73-0.79 across a number of health related behaviours such as smoking and alcohol use.[34] It has also been used in eating disorder populations in a number of previous studies.[32,35]

Self-efficacy in recovery

Confidence in recovery was measured by The Eating Disorder Recovery Self Efficacy Questionnaire (EDRSQ).[36] This is a 23 item measure of self-efficacy in recovery from eating disorders and has been validated for use with people with a diagnosis of AN, bulimia nervosa (BN) and eating disorder not otherwise specified (EDNOS). Cronbach's Alpha scores are high with 0.97 for normative eating and 0.95 for body image. Therefore, the measure can be considered reliable.[36]

Perceived social support

The Multidimensional Scale of Perceived Social Support (MSPSS),[37] was used to measure the level of social support

participants felt they received from family, friends and significant others. It is both valid and reliable, with Cronbach's Alpha scores of 0.91 for the total score and 0.90, 0.94 and 0.95 for the subscales of support from family, friends and significant others. [38] It has also been used in a number of clinical populations. [39,40]

Use of the internet

There are no specific measures available for the use of the internet in people with eating disorders. Therefore, a measure (based upon the description of the questionnaire used by Wilson, Peebles, Hardy & Litt [27]) asking for the following information was developed and piloted prior to recruitment:

- Source of eating disorder information
- Time spent on the internet (number of hours in the last week)
- Websites visited with regards to eating disorders and how often (name of site/URL, how supportive the site is)
- Introduction to sites
- Reason for visits
- Eating disorder techniques learned and/or used
- Whether the eating disorder is a choice or illness

Data analysis

All data was analysed using IBM SPSS statistics version 19. Data was analysed for normality using Kolmogorov-Smirnov tests. The majority of the data was non-normally distributed, as a consequence non-parametric tests were used to analyse the data.

RESULTS

During the recruitment period (January 2012 to September 2012) there were 153 visits to the website hosting the survey. Of these 75 abandoned their visit after reading the information sheet but before progressing any further. 22 abandoned their visit after reading the information sheet but before filling out any questionnaires, 11 partially completed the set of questionnaires and 45 completed the questionnaires fully (see section 4 for extended results). Due to the differences in progression through the questionnaires, a comparison between the partial responders and the full responders was only made on EDE-Q scores. A Mann-Whitney U test showed those who partially completed the questionnaires had significantly lower EDE-Q scores than those who completed them in full ($z = -2.682$, $p = .007$).

Of those who completed the questionnaires in full, the majority (*n=28*) accessed pro-recovery sites exclusively. Nine accessed only pro-ED sites, five accessed both types of sites and three didn't access any websites in relation to their eating disorder. The majority of participants gained most of their information about eating disorder from either health professional (31%, *n=14*) or from the internet (36%, *n=16*). When this was examined in relation to whether they were accessing treatment for their eating disorder, 46% (*n=14*) of those in treatment gained most of their information from health professionals and 23% (*n=7*) from the internet. In comparison only 6% (*n=1*) of those not in treatment got their information from a health professional. In those not accessing treatment the internet was the main source of eating disorder information for 60% (*n=9*) participants.

Participant characteristics grouped by website visited are shown in **Table 6**, the majority of the sample were white women, although there were some men (*n=3*) who completed the questionnaires. Most of the participants (*n=27*) were accessing treatment for their eating disorder. However, 66% of those who accessed Pro-ED sites (*n=6*) and 80% of those who visited both pro-ED and pro-recovery sites (*n=4*) were not accessing any type of treatment. Between group analyses was planned for the categorical data, however due to small cell sizes this was not possible (see section 4.2 for detailed of the planned analysis).

TABLE 6. Participant characteristics in relation to the type of website they visit in related to their eating disorders

	Pro-recovery (*n=28*)			Pro-ED (*n=9*)			Both (*n=5*)			None (*n=3*)		
	n	Median	IQR	n	Median	IQR	n	Median	IRQ	n	Median	IQR
Gender												
Men	3			0			0			0		
Women	25			9			5			3		
Ethnicity												
White	27			9			5			2		
White Chinese	1			0			0			0		
American	0			0			0			1		

AN = Anorexia Nervosa, BN=Bulimia Nervosa, EDNOS = Eating Disorder Not Otherwise Specified, pro-ED = pro-eating disorder website, NP = Not possible to calculate due to small group size

TABLE 6. Participant characteristics in relation to the type of website they visit in related to their eating disorders

	Pro-recovery (*n=28*)			Pro-ED (*n=9*)			Both (*n=5*)			None (*n=3*)		
	n	Median	IQR	n	Median	IQR	n	Median	IRQ	n	Median	IQR
Age		23.0	20.3-33.0		24.0	22.0 - 28.5		27.0	18.5-35.0		27.0	NP
Eating disorder												
AN	14			4			1			1		
BN	5			3			0			1		
EDNOS	8			2			4			1		
No diagnosis	1			0			0			0		
Illness duration (months)		72.0	39.0-174.0		136.0	120.0-198.0		144.0	42.0-213.0		240.0	NP

AN = Anorexia Nervosa, BN=Bulimia Nervosa, EDNOS = Eating Disorder Not Otherwise Specified, pro-ED = pro-eating disorder website, NP = Not possible to calculate due to small group size

TABLE 6. Participant characteristics in relation to the type of website they visit in related to their eating disorders

	Pro-recovery (*n=28*)			Pro-ED (*n=9*)			Both (*n=5*)			None (*n=3*)		
	n	Median	IQR	n	Median	IQR	n	Median	IRQ	n	Median	IQR
Current treatment												
Yes	21			3			1			2		
No	7			6			4			1		
Treatment length (months)		4.0	0-18.0		4.0	0-30.0		0	0-4.5		6.0	NP
Hospitalised for ED												
Yes	12			3			4			0		
No	16			6			1			3		

AN = Anorexia Nervosa, BN=Bulimia Nervosa, EDNOS = Eating Disorder Not Otherwise Specified, pro-ED = pro-eating disorder website, NP = Not possible to calculate due to small group size

TABLE 6. Participant characteristics in relation to the type of website they visit in related to their eating disorders

	Pro-recovery (*n=28*)			Pro-ED (*n=9*)			Both (*n=5*)			None (*n=3*)		
	n	Median	IQR	n	Median	IQR	n	Median	IRQ	n	Median	IQR
Number of times in hospital		0	0-2.8		0	0-3.0		0	0.5-8.0		0	0-0

AN = Anorexia Nervosa, BN=Bulimia Nervosa, EDNOS = Eating Disorder Not Otherwise Specified, pro-ED = pro-eating disorder website, NP = Not possible to calculate due to small group size

Generally most participants (*n=32*) were in the contemplation stage of change. Some were in the pre-contemplation stage of change (*n=9*), and very few (*n=4*) were in the action stage of change. Of those in the action stage, two accessed pro-recovery websites, and somewhat surprisingly two accessed pro-ED websites. Those who accessed no websites in relation to their eating disorder had the highest mean self-efficacy in recovery score, whereas those who accessed both pro-recovery and pro-ED websites tended to have a higher global EDE-Q score and spent more time on the internet per week (See **Table 7** for further information). Kruskal-Wallis tests showed no significant differences between groups on age, length of treatment, illness duration, number of times hospitalised, eating disorder severity as measured by the EDE-Q, self-efficacy in recovery (EDSRQ) or perceived social support (MSPSS).

Table 8 shows online activity in participants who access websites in relation to their eating disorder. Of these, most read posts (*n=30*) and other information (*n=32*). Of those who accessed either pro-ED sites or both types of website, 71% (*n=10*) accessed 'thinspiration' in the form of images, this was often with the aim of triggering themselves and fuelling their eating disorder. The majority of participants (74%) regardless of the type of site accessed in relation to their eating disorder did so in order to gain support (*n=31*), and 70% of participants said they found the sites either very supportive or supportive (*n=29*). Fifty five per cent of participants accessing sites in relation to their eating disorder had learned new eating disordered behaviour online (*n=23*), and 50% (*n=21*) had used the methods that they had learned. Some of the participants had learned these behaviours from

pro-recovery websites. However, participants often mentioned that they had learned techniques from pro-ED sites, regardless of what websites they currently accessed.

TABLE 7. Scores on measures and hours spent on the internet in relation to type of website visited relating to eating disorder

	Pro-recovery (*n=28*)			Pro-ED (*n=9*)			Both (*n=5*)			None (*n=3*)		
	Range	Median	IQR	Range	Median	IQR	Range	Median	IQR	Range	Median	IQR
Stage of Change	PC-A	C		PC-A	C	-	PC-C	C	-	C	C	-
EDE-Q global score	-	4.3	3.3-5.0	-	4.5	3.9-5.2	-	5.3	5.0-5.5	-	4.5	NP
MSPSS score	-	4.4	2.9-5.0	-	4.1	3.3-5.5	-	4.19	1.6-5.4	-	4.4	NP
EDRSQ score	-	1.4	1.3-2.1	-	1.7	1.2-2.0	-	1.4	1.2-1.5	-	2.0	NP
Hours per week on the internet	1-5 – 36+	16-20	-	6-10 – 36+	21-25	-	16-20 – 36+	31-35	-	1-5 – 21-25	11-15	-

EDE-Q = Eating Disorder Examination Questionnaire, MSPSS = Multidimensional Scale of Perceived Social Support, EDRSQ = Eating Disorder Recovery Self Efficacy Questionnaire, PC=Pre-contemplation, C=Contemplation, A=Action, Pro-ED = Pro-eating disorder website, NP = Not possible to calculate due to small group size

TABLE 8. Online activity in those who access websites in relation to their eating disorder

	Pro-recovery (*n=28*)	Pro-ED (*n=9*)	Both (*n=5*)
Finding sites			
Recommended by professional	21	0	1
Recommended by friend	7	0	3
Other recommendation:		0	0
Family	1		
Support group	1		
Search engine	6	8	5
Other:	0	1	0
Link from Pro-ED site			
Activities			
Read posts	19	6	5
Read diaries	6	6	4
Post on site/forum	6	4	1
Read information	24	3	5
Reasons for use			
Information on EDs	16	2	3
Support	22	5	4
Other	7	5	5

Pro-ED = pro-eating disorder websites, EDs = Eating disorders

TABLE 8. Online activity in those who access websites in relation to their eating disorder

	Pro-recovery (*n=28*)	Pro-ED (*n=9*)	Both (*n=5*)
How supportive are the sites?			
Very supportive	4	1	1
Supportive	17	3	3
Neither supportive nor unsupportive	6	2	1
Unsupportive	1	1	0
Very unsupportive	0	2	0
Learned tips and tricks			
Yes	13	5	5
No	14	4	0
Used tips and tricks			
Yes	11	5	5
No	16	4	0

Pro-ED = pro-eating disorder websites, EDs = Eating disorders

DISCUSSION

The present study was designed to explore the internet use of adults with eating disorders, and to investigate the associations between website use and stage of change, self-efficacy in recovery, eating disorder severity, and perceived social support. This study may help to increase the understanding of internet use in eating disorders, as well as highlight some of the reasons people may access pro-recovery and pro-ED websites.

The majority of those who participated in the study accessed websites that were related to eating disorders. Furthermore, for over one third of the sample, the internet was their main source of information about eating disorders. Those not accessing treatment were more likely to use the internet for information about their eating disorder, although just under a quarter of those accessing treatment said that they used the internet as their main source of eating disorder information (see section 5.3.1 for further discussion). In addition, over half of those questioned had learned new eating disordered behaviour from the websites they have visited. These results extend the findings of Wilson et al.[27] and suggest that this phenomena is not just seen in a child and adolescent population. It may be something that is more widespread, encompassing adults too (please see section 5.3.2 for further discussion of this).

However, there were no significant differences found between participants on the scale scores of the measures according to website use. Whilst participants did not appear to be significantly different across the measures, most had low self-efficacy in relation to recovery and reported a perceived social support score that was lower than would be expected in the general population.[37] This supports previous findings that those with eating disorders report low levels of social support[17] and helps to provide an insight as to why many of those with an eating disorder may access support online.

The vast majority of those who accessed websites in relation to their eating disorder did so to gain support, and many of them found the sites they accessed either very supportive or supportive. This also included those who accessed pro-ED sites, and this study supports previous

research which has suggested that this may be one of the reasons why people access these types of websites.[14,15,18,19] However, whilst the majority of the participants on pro-recovery websites claimed that the websites they accessed were supportive, the social support scores as measured by the MSPSS were not significantly different to those accessing pro-ED sites. This suggests that whilst pro-recovery sites may be seen as being supportive, that this may not translate to increasing levels of perceived social support in real life (for further discussion of social support and eating disorders in relation to this study please see section 5.3.3.).

Many of those who accessed pro-ED sites also reported doing so in order to view 'thinspiration' pictures and to trigger themselves and their eating disorder, which may help to reinforce their eating disordered behaviour.[15] It is also worth noting that some of those who accessed pro-ED websites for these reasons, were also accessing one-to-one specialist treatment for their eating disorder. Although this highlights the highly ambivalent nature of those with an eating disorder with regards to recovery, it also highlights the need for clinicians to be aware of pro-ED sites. However, as there was no difference between EDE-Q scores on those who accessed pro-ED and pro-recovery websites, it is not clear whether these sites are actually influencing eating disorder behaviour. Furthermore, this study suggests that accessing pro-ED websites is not related to self-efficacy in relation to recovery.

This study has shown that adults with eating disorders access both pro-recovery and pro-ED websites in relation to their eating disorder. Although, there appear to be no significant differences between them on the measures used, there are some limitations to this study. Firstly, due to the

small size of the groups, much of the data could not be analysed using inferential statistics; therefore some relationships could not be explored. It is also possible that there were significant differences between the groups that were not picked up due to lack of power.

Secondly, the ratio of those with a diagnosis of AN in the study was higher than would be expected in a clinical sample [41,42] therefore the generalisability of the study may be somewhat limited. Due to this is would be appropriate to extend this research, to obtain a representative sample and to increase the sample size to be able to run the planned comparisons. Finally, there was a significant difference found on EDE-Q scores between those who completed the study in full and those who partially completed the study. It may be that those who completed the study were more invested in their eating disorder (hence the higher EDE-Q scores), and more interested in completing research that was exploring their eating disorder rather than recovery (For further discussion of the strengths and limitations of the study, as well as recommendations for future research please see sections 5.4 and 5.5).

This study explores the patterns of internet use in adults with an eating disorder, and extends the growing literature on pro-ED and pro-recovery website use by exploring factors that may be associated with use. It further highlights the lack of perceived social support in those with an eating disorder, and the ways in which adults with an eating disorder may try to remedy this. Although the participants in this study suggested that pro-recovery sites were more supportive than pro-ED sites, this did not appear to increase perceived levels of social support. Whilst those who accessed pro-ED sites also used

the sites to trigger their eating disorder behaviour, there is no evidence to suggest this was linked to an increase in severity of eating disorder symptoms or a reduction in self-efficacy for recovery. Therefore, pro-ED websites may not be as dangerous as they first appear.

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Extended Paper

Abbreviations

AN: Anorexia Nervosa

BED: Binge Eating Disorder

BN: Bulimia Nervosa

EDNOS: Eating Disorder Not Otherwise Specified

Pro-ana: Pro Anorexia

Pro-ED: Pro Eating Disorder

Terminology

Ana / Mia

Anorexia nervosa and bulimia nervosa are known on pro-ana and pro-ED websites as Ana and Mia respectively. On pro-ed and pro-ana sites the eating disorder is often externalised and this is clearly seen in both prose and poetry on the sites such in the ana creed (see Appendices B & C).

Ego-syntonic

Where the thoughts, attitudes and behaviours are both acceptable and consistent with a person's aims. In eating disorders this aim is generally in relation to being thin, the actions and thoughts of someone with an eating disorder (especially that of AN) are ego-syntonic in that they are consistent with the aim of being thin.

Pro Anorexia/Pro Eating Disorder

The broadest understanding of Pro anorexia and Pro eating disorder is the acceptance of anorexia or an eating disorder

without looking to recover or encouraging a person to recover. Some also include the aim of motivating someone, or triggering some to maintain their eating disorder under this term.

Social Support

The giving and receiving of help in everyday relationships, although there are a number of models Cutrona (1990) suggests that they share five basic dimensions:

Emotional support: Giving comfort and showing caring.

Social integration or network support: Membership in a group with others who have share similar interests and/or concerns.

Esteem support: Increasing a person's self-esteem or confidence.

Tangible aid: Giving help, service or resources.

Informational support: Giving advice or guidance.

Stages of change

A model of understanding behaviour change that is used in the understanding and treatment of eating disorders. It is split into a number of stages:

Pre-contemplation: No intention of change in behaviour. In this stage there is no recognition of the need for change or no consideration of change.

Contemplation: Recognition of a problem and of the need for change. However, there is no commitment to take action to move towards a change in behaviour.

Preparation: Intention to take action to change behaviour in the near future.

Action: Initiation of change where people change their behaviour, experience or environment to overcome the perceived problem (e.g. an eating disorder).

Maintenance: Sustaining the change made and working to prevent relapse.

Relapse: Return to the previous problem behaviour (in later versions of the model this is no longer a discrete stage).

Termination: Permanent behaviour change with no risk of relapse.

Trigger

In the case of pro anorexia and pro eating disorder websites, a trigger is something that makes the person with an eating disorder feel bad about themselves. This trigger is likely to increase the chance of the person engaging in eating disordered behaviour and often takes the form of pictures, poems/prose or quotes. However, triggering material could also be the description of eating disordered behaviour, people posting their weight, body mass index (BMI), the food they have consumed that day or the exercise they have completed. People who access pro-eating disorder websites will often try to deliberately trigger themselves in order to try to lose weight.

Wannabe/Wannarexic

The 'out' group on pro-ED websites, they are users of pro-ED websites who do not have an eating disorder or more likely would have a diagnosis of EDNOS, but want to identify with

those that have a diagnosis of AN (some may identify with a diagnosis of BN, however there is a hierarchy on pro-ED sites where AN is valued more highly). They will often use the same weight loss methods as those who are 'ana' or mia'. However, they are generally attacked on pro-ED sites and forums and this has become a pejorative term.

2 Extended Background

2.1 Section Introduction

The introduction section in the journal article briefly discussed the literature regarding the promotion of the thin ideal in the media, as well as the proliferation of pro-ED websites. In this extended background, I will attempt to provide greater context to the study, including a discussion of eating disorders themselves, as well as a more in-depth exploration of the literature around the role of the media in the causation of eating disorders. I will then go on to discuss the development of pro-ana and pro-ED websites as well as those which describe themselves as pro-recovery, before exploring the themes of self-efficacy, social support and stages of change. Finally I will look more closely at the literature regarding the use of the internet in people with eating disorder as well as discussing in more detail the aims of the current study.

2.2 Eating disorders

Eating disorders can be broadly defined as a group of psychological difficulties which focus on food and eating (Fairburn & Harrison, 2003). They are currently defined by the Diagnostic and Statistical Manual of Mental Disorders, fourth edition text revision (DSM-IV-TR; American Psychiatric Association, 2000) under three categories; anorexia nervosa

(AN), bulimia nervosa (BN) and eating disorder not otherwise specified (EDNOS). EDNOS also includes binge eating disorder (BED) as an appendix but this (BED) is not currently a formal diagnosis.

has been some considerable debate about the diagnosis of eating disorders, mostly due to the large incidence of EDNOS in clinical practise where the majority of patients are given this diagnosis (Button, Benson, Nollett, & Palmer, 2005), and some have argued that eating disorders should instead be seen on a continuum (Brooks, Rask-Anderson, Benedict, & Schiöth, 2012). Whilst this argument is unlikely to be accepted by the Diagnostic and Statistical Manual of Mental Disorders (DSM), the updated version due in May 2013 is likely to include BED as a separate diagnosis (this is due to the increasing evidence that suggests that BED is a separate and definable eating disorder with significant differences to BN), rather than one that is considered under the umbrella of EDNOS (American Psychiatric Association, n.d.).

2.3 Anorexia Nervosa

AN as defined by the DSM-IV-TR (American Psychiatric Association, 2000) accounts for a small percentage of eating disorder diagnoses (see Table 9 for the definition of AN), with one study suggesting that as little as 6% of people with an eating disorder would meet the criteria for a diagnosis of AN (Turner & Bryant-Waugh, 2004). AN tends to occur during adolescence with the majority of cases affecting females aged between 15 to 19 years old (Hoek & van Hoeken, 2003). However, there is some evidence to suggest that age of onset may be decreasing, a recent study, (Favaro, Caregaro, Tenconi, Bosello, & Santonastaso, 2009) found that between

1970 to 1981 the mean age of onset in AN reduced from 18.6 to 16.8 years old.

Whilst the life time prevalence of AN in women is thought to be small, between 0.3% - 1.9% depending upon the study (Hoek & van Hoeken, 2003; Hudson, Hiripi, Pope Jr., & Kessler, 2007; Smink, van Hoeken, & Hoek, 2012), it is even smaller in men. AN in men is rarely diagnosed, with less than 1 male per 100,000 patients as reported by GPs in the UK (Smink et al., 2012). However, although the incidence of AN is rare, it may be more prevalent in the population than figures suggest. This is likely due to the secretive nature of the illness (Nicholls & Viner, 2005), with few people accessing treatment voluntarily. In men this is further compounded by the misconception that eating disorders, especially that of AN are only found in women (Weltzin et al., 2005).

Table 9

DSM-IV-TR (American Psychiatric Association, 2000) diagnostic criteria for Anorexia Nervosa

A. Refusal to maintain body weight at or above a minimally normal weight for age and height (e.g., weight loss leading to maintenance of body weight less than 85% of that expected; or failure to make expected weight gain during period of growth, leading to body weight less than 85% of that expected).

Table 9

DSM-IV-TR (American Psychiatric Association, 2000) diagnostic criteria for Anorexia Nervosa

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B. Intense fear of gaining weight or becoming fat, even though underweight.

C. Disturbance in the way in which one's body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or denial of the seriousness of the current low body weight.

D. In postmenarcheal females, amenorrhea, i.e., the absence of at least three consecutive menstrual cycles. (A woman is considered to have amenorrhea if her periods occur only following hormone, e.g., oestrogen, administration.)

Specify type:

Restricting Type: during the current episode of Anorexia Nervosa, the person has not regularly engaged in binge eating or purging behaviour (i.e., self-induced vomiting or the misuse of laxatives, diuretics, or enemas)

Binge-Eating/ Purging Type: during the current episode of Anorexia Nervosa, the person has regularly engaged in binge eating or purging behaviour (i.e., self-induced vomiting or the misuse of laxatives, diuretics, or enemas)

2.3.1 Anorexia Nervosa Illness Course and Outcome

Given the serious nature of the illness, it is unsurprising that there is little evidence to suggest the course of AN if left untreated (National Collaborating Centre for Mental Health,

2004). However, with the significant mortality rate in those who access treatment with AN (Button, Chadalavada, & Palmer, 2010), it is reasonable to assume that a number of those who were left untreated would die for similar reasons; either through complications arising from the effects of starvation, or from suicide or other types of self-harm such as alcohol abuse. Follow up studies suggest that people with a diagnosis of AN are approximately five times more likely to die than those of a similar age and gender without AN, this is also the case after attempts to treating the disorder (Button et al., 2010; Smink et al., 2012).

2.3.2 Treatment of Anorexia Nervosa

Overall the evidence regarding the treatment of AN is poor, and there is little evidence to suggest that the disorder can be managed through the use of medication such as antidepressants or antipsychotics (Fairburn & Harrison, 2003). Drop-out rates for studies exploring the use of medication alone are high, suggesting that this type of treatment is not readily accepted in people with a diagnosis of AN (Bulik, Berkman, Brownley, Sedway, & Lohr, 2007). Furthermore, whilst there is some evidence that antidepressant medication may affect the mood of people with a diagnosis of AN, there is no evidence to suggest that this treatment will encourage weight gain alone (Bulik et al., 2007).

There is however, moderate evidence to suggest that family therapy may be appropriate for adolescents with a diagnosis of AN (Fairburn & Harrison, 2003). Nevertheless, the number of studies evaluating this type of treatment is small and the evidence is limited to those with a short duration of illness (le Grange & Lock, 2005). There is weak evidence to suggest that psychological therapies such as cognitive behavioural therapy

(CBT) or cognitive analytic therapy (CAT) may be appropriate to adults with a diagnosis of AN (Fairburn & Harrison, 2003). However, reviews of evidence-based treatment for those with AN tend to agree that the current evidence suggests the effect of psychological therapies is small, with only a slight proportion of those treated recovering in the long term (Herzog et al., 1999). In addition, many patients with AN will only partially recover and a large percentage will relapse after treatment (Bulik et al., 2007; Fairburn, 2005).

2.4 Bulimia Nervosa

BN is generally accepted as being more common than AN, with one community study finding that approximately 25% of those with an eating disorder fulfilled the criteria for BN (Turner & Bryant-Waugh, 2004) (see Table 10 for the definition of BN as defined by the DSM-IV-TR). Age of onset for BN is thought to be higher than that of AN, with those aged between 20-24 years old being more at risk of developing the disorder (Hoek & van Hoeken, 2003). There is also some evidence to suggest that in some cases, people who initially had AN may over time migrate into BN. This may help to explain the slightly older onset in this type of eating disorder (Fairburn & Harrison, 2003).

Life time prevalence of BN in women is thought to be between 0.9% - 2.9% depending upon the study reported, and between 0.1% - 0.5% in men (Hoek & van Hoeken, 2003; Smink et al., 2012). Whilst the incidence of BN appears to be relatively stable, there is some evidence to suggest that the planned change in diagnostic criteria in the forthcoming DSM-5 will lead to an increase in the prevalence of BN in the future (Smink et al., 2012).

Table 10

DSM-IV-TR (American Psychiatric Association, 2000) diagnostic criteria for Bulimia Nervosa

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A. Recurrent episodes of binge eating. An episode of binge eating is characterized by both of the following:

(1) eating, in a discrete period of time (e.g., within any 2-hour period), an amount of food that is definitely larger than most people would eat during a similar period of time and under similar circumstances

(2) a sense of lack of control over eating during the episode (e.g., a feeling that one cannot stop eating or control what or how much one is eating)

B. Recurrent inappropriate compensatory behaviour in order to prevent weight gain, such as self-induced vomiting; misuse of laxatives, diuretics, enemas, or other medications; fasting; or excessive exercise.

C. The binge eating and inappropriate compensatory behaviours both occur, on average, at least twice a week for 3 months.

D. Self-evaluation is unduly influenced by body shape and weight.

E. The disturbance does not occur exclusively during episodes of Anorexia Nervosa.

Specify type:

Purging Type: during the current episode of Bulimia Nervosa, the person has regularly engaged in self-induced vomiting or the misuse of laxatives, diuretics, or enemas

Table 10

DSM-IV-TR (American Psychiatric Association, 2000) diagnostic criteria for Bulimia Nervosa

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Non-purging Type: during the current episode of Bulimia Nervosa, the person has used other inappropriate compensatory behaviours, such as fasting or excessive exercise, but has not regularly engaged in self-induced vomiting or the misuse of laxatives, diuretics, or enemas

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2.4.1 Bulimia nervosa: Course and outcome

Without treatment the long term outcome for those with BN is poor, Fairburn, Cooper, Doll, Norman, & O'Connor (2000) found that in their study of those with BN that was left untreated, the majority of the sample still had an eating disorder with clinically significant symptoms five years after assessment. In addition, more than 40% of the sample also met the criteria for depression after this time. Whilst the mortality rates in those with BN are less than those in people with a diagnosis of AN, people with BN are 1.93 times more likely to die than a person of a similar age or gender without a diagnosis. However, it is not clear whether this is as a direct consequence of their eating disorder or if there are other factors that may be related to this increased likelihood of mortality (Arcelus, Mitchell, Wales, & Nielsen, 2011).

2.4.2 Treatment of bulimia nervosa

The evidence base for the treatment of BN is much stronger than that of AN (Fairburn & Harrison, 2003). There is considerable evidence for the effectiveness of antidepressant

medication such as fluoxetine, which has been shown to reduce binge eating behaviour in those who have been diagnosed with BN (Fairburn & Harrison, 2003; Shapiro et al., 2007). There is also strong evidence for the use of CBT in treating those with BN, with some studies suggesting that it may be more effective than other forms of therapy such as CAT or interpersonal psychotherapy (ITP) (Fairburn & Harrison, 2003). However, even after full recovery from BN after treatment, over one third of people with the diagnosis are likely to experience relapse over 7.5 years (Herzog et al., 1999).

2.5 Eating Disorder Not Otherwise Specified

EDNOS (see Table 11 for the definition of EDNOS as defined by the DSM-IV-TR) is thought to account for the majority of diagnoses in those with an eating disorder. Evidence suggests that in specialised eating disorder services in the UK who accept EDNOS referrals, approximately 50% would be considered to have this diagnosis (Button et al., 2005). In a community sample there is evidence to suggest that the incidence of EDNOS may rise to 71% of all eating disorder cases seen (Turner & Bryant-Waugh, 2004).

Whilst the incidence of EDNOS in clinical populations is high, this is not reflected in the literature. There is limited evidence regarding the average age of onset as well as incidence and prevalence in the population. This lack of evidence, is likely to be due to the nature of the diagnostic category, as EDNOS can include sub-clinical AN, sub-clinical BN as well as BED (American Psychiatric Association, 2000).Nonetheless, there is some evidence to suggest that lifetime prevalence of sub-clinical AN and sub-clinical BN for women by 20 years old is 0.6% and 1.6% respectively (Stice, Marti, Shaw, & Jaconis,

2009). Whereas research suggests that the lifetime prevalence of BED is 1.9% for women and 0.3% for men (Smink et al., 2012).

Table 11

DSM-IV-TR (American Psychiatric Association, 2000) diagnostic criteria for Eating Disorder Not Other Specified

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The Eating Disorder Not Otherwise Specified category is for disorders of eating that do not meet the criteria for any specific Eating Disorder. Examples include

1. For females, all of the criteria for Anorexia Nervosa are met except that the individual has regular menses.

2. All of the criteria for Anorexia Nervosa are met except that, despite significant weight loss, the individual's current weight is in the normal range.

3. All of the criteria for Bulimia Nervosa are met except that the binge eating and inappropriate compensatory mechanisms occur at a frequency of less than twice a week or for a duration of less than 3 months.

4. The regular use of inappropriate compensatory behaviour by an individual of normal body weight after eating small amounts of food (e.g., self-induced vomiting after the consumption of two cookies).

5. Repeatedly chewing and spitting out, but not swallowing, large amounts of food.

Table 11

DSM-IV-TR (American Psychiatric Association, 2000) diagnostic criteria for Eating Disorder Not Other Specified

6. Binge-eating disorder: recurrent episodes of binge eating in the absence of the regular use of inappropriate compensatory behaviours characteristic of Bulimia Nervosa (see Appendix B in DSM-IV-TR for suggested research criteria).

2.5.1 Eating disorder not otherwise specified: Course and outcome

Due to the nature of EDNOS and the fact that it encompasses a number of different eating disorder features, there is little information with regards to course and outcome (Fairburn & Harrison, 2003). There is however, some evidence to suggest that those with BED are likely to recover without treatment, with one study finding that after five years those who still had BED had dropped to only 18% of the initial sample (Fairburn et al., 2000). However, another study found that 33% of those with sub-clinical and clinical BED were likely to have at least one relapse (Stice et al., 2009).

2.5.2 Treatment of eating disorder not otherwise specified

As the category of EDNOS encompasses a wide range of eating disordered behaviour, there is limited evidence with regards to treatment (Fairburn & Harrison, 2003). NICE guidance suggests that that decisions regarding treatment should be based upon whether the eating disordered behaviour the client describes most reflects AN or BN (National Collaborating

Centre for Mental Health, 2004). In the case of BED there is some modest evidence supporting the use of both medication such as antidepressants, as well as for psychological therapies such as CBT and IPT (Fairburn & Harrison, 2003; National Collaborating Centre for Mental Health, 2004). However, it appears that like most eating disorders there is a high relapse rate with one study finding that 28% of those with BED treated successfully relapsed within 6 months (Safer, Lively, Telch, & Agras, 2002).

2.6 Causation

As previously mentioned in the journal article, there is considerable debate with regards to the development of eating disorders and the factors which may influence it. The origins and the subsequent development of eating disorders are complex, with many factors leading to the dietary restraint and weight and shape concerns in eating disorders. However, it is generally accepted that the cultural value of thinness and the thin ideal as perpetuated by the media may play a role (Gowers & Shore, 2001).

2.6.1. The thin ideal

The thin ideal is the culturally shared concept of the ideal female body found in Western societies. This is generally accepted as that of a very slim female with a small waist and very little body fat, and is presented as something which all females should aim to achieve (Low et al., 2003). There is increasing evidence to suggest that the size of this thin ideal is decreasing. Women that are highlighted by society as the ideal (models, actresses, etc.) are becoming increasingly thinner (Harrison & Cantor, 1997). Some studies suggest that the women highlighted as the ideal weigh 15% less than average (Jett, LaPorte, & Wanchisn, 2010), and in some cases

achieve and maintain a weight that would place them within the anorexic range (Grabe, Ward, & Shibley Hyde, 2008).

Furthermore, as the rate of female obesity is increasing, this ideal is something that is becoming even more difficult for women to achieve (Pinhas, Toner, Ali, Garfinkel, & Stuckless, 1999). It is this gap between the actual appearance of the average female and the ideal, as well as the importance placed on appearance for success in women (Stice, Schupak-Neuberg, Shaw, & Stein, 1994), that has been suggested to lead to body image concerns. This gap has also been suggested to play a role in the development of psychological difficulties such as eating disorders and depression in women (McCarthy, 1990; Pinhas et al., 1999).

2.6.2. Media role in the perpetuation of the thin ideal, and the development of body image concerns and eating disorders

Changes in the incidence and prevalence of eating disorders over the past 30 years seems to reflect the changes in the media representation over the same time period (Harrison & Cantor, 1997). As the representation of the female form in the mass media (television, films and magazines) has become slimmer, the incidence of body image dissatisfaction and eating disorders has also appeared to increase (Grabe et al., 2008; Harrison & Cantor, 1997). Cross-sectional studies show that the consumption of appearance focused media such as television soap operas or music videos is correlated with a body image concerns such as body dissatisfaction, as well as bulimic symptoms (Levine & Murnen, 2009).

Levine & Murnen (2009) further suggest as problems with body image concerns and disordered eating are found

amongst adolescents and young adults of all social classes, ethnicities and locations that this "consistent with a general sociocultural model that includes a proliferating, influential mass media" (Levine & Murnen, 2009 p.12). Studies have shown that where market driven mass media appears, increases in both body dissatisfaction and disordered eating tend to follow (Becker, Burwell, Herzog, Hamburg, & Gilman, 2002; Bilukha & Utermohlen, 2002).

Becker et al. (2002) famously found that when television was introduced to Fiji in the mid-1990s the incidence in disordered eating rose significantly. In addition, Bilukha & Utermohlen (2002) found that Ukrainian women who had greater exposure to Western media had a thinner ideal figure and were more likely to be dieting than those who did not watch Western films, television programmes or read Western magazines such as Vogue. The portrayal of thin people (especially women) by the Western media as being successful and attractive is often seen, and these types of characters are over represented in films and on television (Grabe et al., 2008). When overweight characters are used they are often portrayed as being unsuccessful and unhappy, or are the comic relief.

A number of theories may provide an explanation as to why the repeated exposure to the thin ideal through the media may lead to the acceptance and internalisation of this thin ideal. Cultivation theory suggests that the mass media (especially that of television) has become the new storyteller in society, and that it constantly repeats the myths and ideologies of the society it represents. This repetition results in a shared set of beliefs and expectations about reality across society and indeed most Western cultures (Gerbner, Gross, Morgan, Signorielli, & Shanahan, 1994). In the case of the

thin ideal, this theory suggests that the more a person is exposed to this message through the media, the more that they will believe that this is normal and attainable. In reality, only a small proportion of women can actually maintain such a low body weight. However, women begin to think that they are abnormal when they can't themselves, regardless of the fact that this is not actually the case (Hesse-Biber, Leavy, Quinn, & Zoino, 2006).

Another explanation for the link between body dissatisfaction, dieting and the media can be found in social learning theory (Bandura, 1977a). Bandura (1977a) suggests that much of the complex behaviour that we acquire is through modeling. That is; from our observations of others, we not only learn new patterns of behaviour, but we also note the consequences of these actions. The likelihood of replicating the behaviours that we have learned is then based up two things; the belief that the consequences of these actions will be positive and the belief that we are capable of performing the behaviour successfully, otherwise known as self-efficacy (Bandura, 1977b). We are most likely to engage in a behaviour if we believe that the action will be rewarded, and if we have high levels of self-efficacy in relation to that behaviour.

In the case of the thin ideal, thin celebrities and models are shown as being happy, beautiful and wealthy which are all markers of success within the Western world and are positive rewards. Links between these positive attributes and being thin are made, which lead to the attempt to attain similar levels of thinness. Other aspects of the media inform us that weight loss is simple; there is a significant amount of information about dieting and how to lose weight available from printed media sources such as magazines. This could

potentially increase self-efficacy for weight loss behaviours, increasing the likelihood of engaging in behaviours aimed to lose weight. Therefore, social learning theory may explain the high levels of dieting and restrained eating in the general population (Harrison & Cantor, 1997).

There is some evidence to support the idea of both cultivation and social learning theory with regards to the thin ideal and the development of body dissatisfaction and eating disorders. Stice et al. (1994) found a direct relationship between media exposure and eating disorder symptomology. In their study, they asked undergraduate women about their exposure to the media, such as number magazines read over the previous month as well as the number of hours of television watched. They also measured gender-role endorsement, body dissatisfaction and eating disorder symptomology. Using structural equation modelling they found that 43.5% of the variance relating to eating disorder symptoms was found to be accounted for by exposure to the media. In addition to this there is also evidence to suggest that exposure to the thin ideal through advertisements is directly related to a reduction in body satisfaction when compared to people who view other, more neutral adverts (Grabe et al., 2008).

It is therefore likely that the high number of women in Western societies that are unhappy with their body (Glauert, Rhodes, Byrne, Fink, & Grammer, 2009), may in part be due to exposure to the thin ideal through the media. A meta-analysis by Grabe et al. (2008) found a small to moderate effect linking exposure to media images of the thin ideal, to body image dissatisfaction in women. It is also known that high levels of body dissatisfaction is a key risk factor for the

development of eating disorders such as BN (Grabe et al., 2008; Stice, 2002).

However, exposure to the thin ideal through the media alone does not account for the development of eating disorders in its entirety, and ignores the fact that not all people exposed to the thin ideal through the media go on to develop body image dissatisfaction or an eating disorder (Hesse-Biber et al., 2006). There is some evidence to suggest that the more someone is dissatisfied with their body image, the more dissatisfied they become after exposure to the thin ideal through the media, and that it is this vicious circle that may lead to the development of eating disorder behaviour. However, the evidence to support this is limited (Hesse-Biber et al., 2006), and does not explain why or how women develop a poor body image. In addition to this it is also currently not clear why some women pay more attention to and are more affected by the messages and the propagation of the thin ideal by the media than others.

Nonetheless, a recent review by Levine & Murnen (2009), suggests that exposure and engagement with the mass media is a risk factor in the development of poor body image and disordered eating. They further suggested that with the development of the literature in this area, engagement with the mass media may be shown to be a causal factor. In addition to this, the media may be able to play a role in the reduction of body image dissatisfaction in women. Grabe et al. (2008) found that exposure to average-sized women in the media could reduce body image dissatisfaction, by reducing body-focused anxiety. By encouraging the media to use more naturalistic figures in advertising it is likely that body image

dissatisfaction in women could be reduced *without* reducing the effectiveness of advertising (Grabe et al., 2008).

2.7 Pro-anorexic and Pro-eating Disorder Websites

Pro-anorexic and pro-eating disorder websites probably began during the increased popularity of the internet in the late 1990s. A combination of greater access to the internet and wider availability to sites such as geocities, (who hosted personal pages that could be created by anyone, not just those with the skills to write in code) may have been the catalyst to the development of this underground phenomenon. Certainly by the beginning of the 21st century, knowledge of their existence had reached the mass media who were quick to condemn them and their users (Brown, 2001; Hill, 2001), and calls were made to service providers such as Yahoo! to remove these sites (Rouleau & von Ranson, 2011).

The attempts to remove these types of sites from the internet have not been particularly successful, and where one was removed, others replaced them. Pro-ED content has also been found on social networking sites such as Facebook and MySpace (Juarascio, Shoaib, & Timko, 2010) and more recently on newer forms of social media such as Tumblr (a microblogging and social networking site where smaller bits of information are shared such as pictures or quotes, rather than long statuses or diary entries found on traditional blogging websites) and Pinterest (a photo sharing website where users 'pin' pictures to their 'boards' around a theme or event) (Restauri, 2012). There are even pro-ana and thinspiration hashtags on Twitter (a microblogging website where users post short sentences of up to 140 characters and as well links to pictures. Hashtags are used to group posts together and can be used to search for specific content e.g. #proana,

#thinspo, #psychology) highlighting how pervasive the pro-ana and pro-ED subculture has become.

2.7.1. Content of pro-ED websites

As previously mentioned in the journal article, there has been some attempt by researchers to explore the nature of pro-ED sites. The majority of the research that has focused on content of pro-ana and pro-ED websites has looked at the more traditional purpose-built websites that were founded in the early 2000s prior to the proliferation of social networking sites such as Facebook. They found that the vast majority of websites were easily accessible and open to the public. The majority of sites, 84% (in one study) were free web addresses hosted through another website such as an internet service provider or for example by Yahoo! (Borzekowski, Schenk, Wilson, & Peebles, 2010).

The majority of traditional pro-ED and pro-ana websites have content that includes 'tips and tricks' where advice and hints on how to diet, hide behaviours, and information about fasting can be found (Overbeke, 2008). On some sites there is also information about purging, exercise and diet pills (Borzekowski et al., 2010). They also tend to contain what has become known as 'Thinspiration', these are generally pictures of thin women intended to trigger eating disordered thoughts, feelings and behaviours (see Appendix D for examples). Thinspiration may also include quotes or writings such as the 'ana creed' and the 'thin commandments' (see Appendices B & C for copies of the 'ana creed' and 'thin commandments'). Less common features of these websites are resources about eating disorders and recovery, and calculators for calculating calories burned, BMI, and basal metabolic rate (BMR) (Norris, Boydell, Pinhas, & Katzman, 2006), as well as information

regarding calorie content and negative calorie foods (Borzekowski et al., 2010).

Research suggests that many of the websites studied not only identified the purpose of the website, but also had disclaimers that not only could the material posted be distressing, but that exposure to the site may trigger eating disordered behaviour. Some sites studied also requested that those who used them be over the age of 18, and stated that they were not to be accessed by people who didn't have an eating disorder (Borzekowski et al., 2010; Norris et al., 2006). However, it is not clear the reason for this, some have speculated this may be a reflection of the litigious nature of the country many of the creators live in (Borzekowski et al., 2010). Both Borzekowski et al. (2010) and Norris et al. (2006) also identified a number of common themes of the content on the websites which included control, success, perfection, isolation, deceit and revolution. Norris et al. (2006) also commented on the religious metaphors present in a number of websites such as the 'ana creed'.

Many of the websites also included information and biographies regarding the owners and creators of the sites (some also had contact details such as e-mail addresses available), and that they identified themselves as being female (Borzekowski et al., 2010; Norris et al., 2006). Research by Dias (2003) also highlights that the women creating, accessing and posting on these sites seem to be aware of their own circumstances. Furthermore, Dias (2003) found that these women were also aware of the reasons that they choose to access the sites, and they are not the hapless victims that many media articles reported them to be. This is further supported by Norris et al. (2006) who suggested that the

majority of creators of these sites are likely to be well educated and articulate.

Whilst there is a reasonable amount of research focusing on the content of traditional pro-ED websites, there is much less on the newer types of pro-ED content found on social networking sites such as Facebook and MySpace. One such study by Juarascio et al. (2010) suggests that the content found on social networking sites may be vastly different to that on traditional pro-ED websites. They found that, whilst the majority of group creators were female like on traditional pro-ED websites, it was unlikely that the same disclaimers regarding the group would be used. Furthermore, elements such as the 'thin commandments' and 'ana creed' were much less likely to be seen on these groups. Some of the groups did however post information designed to trigger those with an eating disorder such as pictures of emaciated women and body parts as well as overweight women (known as reverse thinspiration). Groups also posted tips and tricks, and information regarding weight loss.

Juarascio et al. (2010) also found that what was posted differed depending on the website the groups were being hosted on. They found that eating disorder specific content was more likely to be found on Facebook. People posting on this site often posted information about their eating disorder and how it was affecting their life, or posted daily food diaries and exercise logs. Those who interacted on MySpace tended to use this social networking site differently to those who accessed groups on Facebook. Those on MySpace focused on social interactions such as support, friendship and discussing their thoughts and feelings with each other more than those on Facebook.

Juarascio et al. (2010) also found that content that was considered to be overly eating disorder specific, was likely to be discouraged by the users of the pro-ED groups on MySpace. However, they concluded that in general, pro-ana and pro-ED groups on these two social networking sites were designed with providing social support to those with an eating disorder, rather than *just* intending to trigger eating disordered behaviour (see 2.10 for discussion of social support in eating disorders).

Whether this is the case on other social networking sites such as Twitter, Tumblr and Pinterest is not currently known. It does appear that the nature of the website on which it is hosted affects the pro-ED content found on it. Twitter for example has a limit of 140 characters when posting text, but does allow images to be attached, whereas Tumblr and Pinterest are designed host more pictorial content. This may help to explain the differences between pro-ED content found on these sites when compared to more traditional pro-ED websites. However, there may be other explanations for the apparent change in the content in newer types of social media on the internet, such as a change in or the evolution of the pro-ana or pro-ED 'philosophy' (for further discussion of this please see 2.7.5).

2.7.2 Reasons for use

Whilst the content of these sites seem to change depending on where it is hosted, generally the reasons for using pro-ana and pro-ED websites appear to be two-fold; either wanting to lose weight or wanting to gain social support and a sense of belonging (Rodgers, Skowron, & Chabrol, 2012). Due to social support in eating disorders and the relationship to pro-ED

websites being discussed elsewhere it will not be repeated here. (Please see section 2.10 for this discussion.)

2.7.3 Identity and pro-ED websites

Research has found that identity on pro-ED websites is an important issue; Giles (2006) suggests that the need for a distinct identity occurs when groups are threatened from the outside. In the case of pro-ED website users, online identity is formed around eating disorder diagnoses, with those with 'ana' or AN being at the top of the hierarchy followed by 'mia' or BN, and finally those with EDNOS. The theme of formation of identity around the eating disorder is also supported by Riley, Rodham, & Gavin (2009), who found that users of pro-ED sites created their identity around their own bodies. They did this through talking about their bodies and their own bodily experiences, reframing potentially negative and unhealthy experiences such as purging or fasting as markers of success, and by doing this claiming group membership.

Riley et al. (2009) further suggested that the function of this body talk was not only to manage identity, but also for the right to participate on the site in a legitimate manner, not as a 'wannabe'. 'Wannabes' or 'wannarexics' are seen as a threat to the groups, access by users who are not truly eating disordered, who, "blur the boundaries between 'ana' as a state of purity and discipline and as helplessly biological/medical 'condition'." (Giles, 2006 p.474) are a large source of conflict on pro-ED sites. Giles (2006) proposed that 'wannarexics' are seen as threatening as they are fulfilling the stereotypical role given to them by the media portrayals of the pro-ana community (a dangerous, trendy lifestyle choice that young women get sucked into); he further suggests that as those with an eating disorder try to distance themselves from

construction of the illness by others, the 'wannarexics' "act as a convenient scapegoat for the enforced closures of pro-ana sites" (p.474).

Giles (2006) further suggests that conflict within the community, and the need to establish a legitimate eating disordered identity occurs due to the heightened awareness of the possibility for attack from outsiders. Many sites have been shut down by outside forces, and members of pro-ana and pro-ED groups are continually scanning for those who may not be pro-ED and may in fact be traitors looking to shut down the community. Due to this anyone who is new or perceived as an outsider in anyway is treated with suspicion, and in some cases openly attacked by more established members of the community.

2.7.4 Impact of viewing pro-ED websites

The impact of viewing pro-ana and pro-ED websites on those with an eating disorder is not yet known. However, there is evidence to suggest that these sites may have an effect on users without an eating disorder. Bardone-Cone & Cass (2006) found that after exposing female undergraduate students to a 'prototypic' pro-ana website for 25 minutes they were more likely to have an increase in negative affect, a decrease in self-esteem and a decrease in appearance self-efficacy. They were also more likely to report an increase in perceived weight status (very underweight, underweight, average, overweight, very overweight) and a decrease in how attractive they perceived themselves to be to the opposite sex.

In an extension to this study (Bardone-Cone & Cass, 2007) 235 female participants were randomly assigned to view either a pro-ana website (created for the study for both practical and

copyright reasons), a female fashion website or a home décor website. In addition to replicating the results from the previous study, they also found that those who were exposed to the pro-ana website were more likely to report lower expectations of overeating, a greater likelihood to exercise and a greater likelihood to think about their weight. Participants exposed to the pro-ana site also reported a lesser likelihood to self-induce vomiting than those exposed to the control websites. This may be due to the pro-ana site encouraging the participants exposed to the site to think about vomiting as a way of maintaining weight or losing weight or that the site had portrayed this behaviour in a way that was less desirable, whereas the control websites were unlikely to encourage someone to engage in these types of thoughts.

Whilst the participants in these studies reported changes in their self-esteem, as well as how they viewed themselves, and in their planned behaviour; it is not clear whether these changes were maintained over a period of time. Furthermore, although participants said their likelihood to overeat, exercise and induce vomiting changed after viewing the pro-ana website, this was not measured as part of the study. However, one study has shown that pro-ED websites may lead to behavioural changes in those who access them (Jett et al., 2010).

Jett et al. (2010) measured the self-reported food intake of women prior to and after exposure to one of three types of websites (pro-ED, exercise/health and tourist) and found that for women who were exposed to the pro-ED food intake significantly decreased in the week following the exposure. When asked about whether the exposure to the website resulted in any change in food intake only 56% of the 84% of

participants who reduced their food intake recognised the effect exposure to the pro-ana website appeared to have had.

However, although there appeared to be short term changes to the food intake of those exposed to pro-ana and pro-ED websites those without an eating disorder, it is not clear whether these changes were long-term. Although participants were followed up three weeks after exposure to the websites to try to ensure that there were no long term effects, they relied on participant report which they had already shown was potentially problematic due to many of the participant's lack of insight with regards to the effects of viewing the pro-ana websites.

Nonetheless, approximately one quarter of the participants exposed to the pro-ana websites did report using strategies that they had learned from the sites. This included restricting the intake of certain foods, increasing their intake of more healthy foods such as fruit and drinking more water. It is clear that whilst there were some effects of viewing these websites the behaviours described as being learned from the websites are not inherently unhealthy or dangerous. This perhaps suggests that some of the content on these sites is not dangerous in itself; it is the way in which it is used by those who view it.

2.7.5 Pro-ana and pro-ED philosophy

Whilst the media representation of pro-ana and pro-ED websites has generally been that such websites are dangerous, anti-recovery and anti-therapist, as well as that they promote the use of eating disorder strategies to further entrap young women in their illness (Hill, 2001; Jackson & Elliott, 2004), the reality may in fact be somewhat different

and much more complex. As previously mentioned in the journal article a study by Fox, Ward, & O'Rourke, (2005) found that the understanding of anorexia by those who accessed one pro-ana website was very different to other models of understanding eating disorder such as the medical, psycho-social or feminist models. They suggested that the pro-ana model of eating disorders, (especially that of AN) understood them as something that was "experientially and aspirationally defined" and "a response to a difficult life situation" (Fox et al., 2005, p964), and one from which recovery was not wanted and indeed not necessary if managed appropriately.

However, content analysis of pro-ana and pro-ED websites suggests that this model of understanding is not always shared by all websites or by all of those who access and post on such sites (Borzekowski et al., 2010; Norris et al., 2006). Whilst most websites agree with the idea that recovery from their eating disorder is not appropriate or wanted, not all understood eating disorders using a 'pro-ana' lens. Borzekowski et al. (2010) and Norris et al. (2006) found that whilst some websites appeared to support this view describing and understanding eating disorders as a choice and lifestyle, some understood their eating disorder in terms of the medical model describing it as an illness.

This is supported by Roberts Strife & Rickard (2011), in their study examining the conceptualisation of the pro-anorexic perspective they found that the 'community' did not seem to share the same philosophy and understanding of eating disorders. They also found that the use of empowering language differed between those who defined anorexia as an illness and those who defined it as a choice, with those who utilised the pro-ana model using more empowering language.

In addition to this, many pro-ED websites also offer information with regards to recovery (Borzekowski et al., 2010), and some authors have highlighted that when the idea of recovery is mentioned on the forums of pro-ED and pro-ana websites, the posts by other members in response are generally supportive and helpful, offering advice and information (Williams & Reid, 2007). Furthermore, in a recent study looking at the motivations behind the creation of pro-ana and pro-ED blogs it was found that the majority of those who wrote in blogs with pro-ED content did so in order to reach out to others and not feel alone (Yeshua-Katz & Martins, 2012). More recently there also appears to have a been a change in the stance of some pro-ED websites, sites that once aligned themselves with the 'pro-ana' movement have highlighted the development and change of the sites philosophy.

Whereas sites that may have been started with a philosophy more aligned to the traditional pro-ana or pro-ED stance:

"**Ana is beautiful**, it is the key to true beauty. Ana gives you a reason to live, to strive for perfection, to show to yourself that you're WORTH a damn!
Stay Strong, don't give up and don't waste your life being disatisfied [*sic*] with yourself! Ana **believes** in you, and it is my only escape.
Anyway, have fun browsing, and remember, Nothing Tastes As Good As Thin Feels" ("Pro Ana Lifestyle," n.d.)

Some have highlighted a change in role and philosophy with regards to eating disorders:

"In the beginning, we were associated more with the 'pro-anorexia' movement; however over the years, as our site has

grown and developed, our stance has changed. We now consider our site to be not 'pro-anorexia', but 'pro-reality'. Our mission is to educate people from all backgrounds about what exactly an eating disorder is, as well as providing knowledge of the dangers and threats associated with the issue." ("CeruleanButterfly" n.d.)

Whilst it is not clear how many pro-ana and pro-ED websites have followed the change highlighted above, it is clear that the pro-ana and pro-ED subculture is varied and is continually developing. This may be for many reasons; in response to the removal of sites and the backlash that has been felt in the community since the knowledge of these sites have been made public (and therefore a need to move away from the stereotypical identity of pro-ana) (Brotsky & Giles, 2007), or in relation to the way in which communication via the internet is evolving through the development of social media and social networking (Juarascio et al., 2010).

2.8 Pro-recovery

The concept of pro-recovery and the subsequent development of pro-recovery websites appeared to develop as a direct response to pro-ana and pro-ED websites. Many of these sites (e.g. www.somethingfishy.org and www.eatingdisorderhope.com) make direct reference to the pro-ana and pro-ED movement and the philosophy stated on these sites appears to be at direct odds with the message that pro-ED websites promote. Chesley, Alberts, Klein, & Kreipe (2003) found that pro-recovery sites tended to present "introspective first person viewpoints on AN" (p.124) and that they generally focused on the negative aspects of having an eating disorder. However, they felt that these sites were less

well organised and less numerous than their pro-ED counterparts.

The research exploring pro-recovery websites is sparse, with much of the literature focusing on online support groups for people with eating disorders. Such studies suggest that in many ways they are similar to support groups found outside of the internet, with the same types of helping strategies being utilised in support groups both online and in real life (Winzelberg, 1997). In addition Winzelberg (1997) also found that a number of themes emerged from the postings on these online support groups. These included coping with increasing weight, external pressures from family and friends, as well as reactions to cultural pressures to be thin, reminiscing about the eating disorder behaviours they once engaged in, discussions about negative effect of these behaviours, and recommendations and reflections on psychological treatment.

A more recent study exploring online support groups for people with BN found that (on the forum that was studied) users of a pro-recovery website tended to post during times that real life support structures were less likely to be accessible, such as late at night (Wesemann & Grunwald, 2008). They also found that those posting on pro-recovery forums used the website as a way of a giving and gaining support, and suggested that pro-recovery forums for eating disorders should be valued as an important resource for people with eating disorders who are trying to recover. Nonetheless, there is some evidence to suggest that pro-recovery websites may not be helpful to all people who are in the process of recovering from an eating disorder. In their study of an eating disorder discussion group, Keski-Rahkonen & Tozzi (2005) found that whilst the participation in these

groups was initially helpful, it appeared that active participation in them during later stages could delay recovery.

2.9 Self-efficacy

Self-efficacy (as previously mentioned in section 2.6.2) is the belief a person has that they will be successful in executing the behaviour needed to produce the desired outcome (Bandura, 1977b). Bandura (1977b) suggests that efficacy expectations are the mediating factor between the person and the behaviour. Even if a person is certain that the behaviour will produce the desired outcome, if they do not believe they are capable of completing the behaviour successfully, this knowledge (of the expected outcome) will not influence their behaviour.

2.9.1 Self-efficacy in recovery

Until recently, self-efficacy in recovery from eating disorders has not received much attention in the literature. Nonetheless, Carter, Blackmore, Sutandar-Pinnock, & Woodside (2004) suggested that previous failed treatment attempts (a predictor of relapse in AN) may contribute to relapse by decreasing self-efficacy in regards to both recovery, and maintaining the gains made during treatment. Furthermore, Pinto, Heinberg, Coughlin, Fava, & Guarda (2008) found that the self-efficacy in recovery score as measured by the Eating Disorder Recovery Self Efficacy Questionnaire (EDRSQ), not only predicted the length of stay but was also positively related to weight gain during inpatient treatment of underweight patients with an eating disorder.

More recently, confidence to succeed as measured by the response to the question 'if you decided to change, how confident are you that you would succeed?' in those with BN

predicted frequency of binge eating, over-evaluation of weight and shape, and eating disorder examination (EDE) score at the end of a guided self-help treatment. This meant that the more confident a person was with regards to successfully overcoming their disorder, the smaller the number of binges, the less they over-evaluated shape and weight and lower the score on the EDE after treatment (Steele, Bergin, & Wade, 2011).

2.10 Social Support

Social support is defined as the giving and receiving of help within relationships when coping with stressful events or daily problems (Bierhoff, 2001). Although there are a number of different systems for classifying social support, these tend to be multi-dimensional and their components show equivalence (Cutrona, 1990; Cutrona & Russell, 1990). Cutrona & Russell, (1990) compared models of social support, and suggest that most of the models contained five dimensions of social support: emotional support, social integration or network support, esteem support, tangible aid, and informational support. However, the help given needs to match the needs of the recipient, and should be related to the type of stressful event that is being experienced (Bierhoff, 2001). Cutrona & Russell suggest that controllability (how much the stressful events can be controlled) and domain (type of stressful event) have the greatest impact on social support needs.

Their model, 'the optimal matching hypothesis' suggests that there are optimal types of social support for different types of stressful events (see Table 12). In her review, Cutrona (1990) found that the matching hypothesis significantly predicted mental or physical health outcomes in two-thirds of life events tested. Although, the 'optimal matching hypothesis' did

predict a number of mental and physical health outcomes, different psychological needs arise over the course of a stressful event and ability to cope with stress may also be linked to personality. Furthermore, some events such as bereavement needed a broad range of social support components, and specific, optimal components could not be identified.

Table 12

Optimal Matching Model of Stress and Social Support, from Cutrona (1990)

Type of Stressful Event	Optimal Social Support
Controllable	Instrumental support
(Behaviour can prevent even from occurring or reduce or eliminate consequences)	Esteem support
Uncontrollable	Emotional Support
(Behaviour cannot prevent event from occurring or reduce or eliminate consequences)	
Life domain in which loss occurs:	
Assets	Tangible support
Relationships:	
Intimate	Attachment
Casual, group	Network support
Achievement	Esteem support
Social role *(change, loss or gain)*	Network support

2.10.1 Social support in eating disorders

It is well documented that those with an eating disorder report lower levels of social support than their non-eating disordered peers (Tiller et al., 1997). Tiller et al. (1997) found that those with eating disorders not only tended to report lower levels of emotional support; they also had lower expectations as to the ideal level of emotional support they required. Furthermore, those with an eating disorder also had impaired social networks when compared to a comparison group of university students of a similar age. More recently, evidence has suggested that social support may be a key element of recovery from an eating disorder. Linville, Brown, Sturm, & McDougal (2012) found that when they asked 22 women who had recovered from their eating disorder about the factors that aided the recovery process, it was the importance of the reconnection of social networks and social support that was highlighted. These women suggested that it was this reconnection to others and the increasing social support that significantly helped the process of recovery from their eating disorder.

However, whilst increase in social support appears to be a key factor in recovery, and there is evidence to suggest that social support tends to improve after recovery, it appears that this may not match the levels of social support enjoyed by those without an eating disorder (Rorty, Yager, Buckwater, & Rossotto, 1999). Rorty et al. (1999) compared the social support networks of those actively engaging in BN behaviours (ABN), those who had recovered from BN one year previously (RBN) and those who had never had an eating disorder. They found that whilst those in the RBN group had more social support than the ABN group, they did not have as good a

social support network as those who had never had an eating disorder. Furthermore, those who had experienced an eating disorder (regardless of recovery status) reported being more dissatisfied with the quality of social support that they received. This dissatisfaction with social support may lead to those with an eating disorder looking for support through other means, and may help to explain the apparent popularity and proliferation of pro-ana and pro-ED websites on the internet.

2.10.2 Use of pro-ana sites for social support

As previously mentioned, those with an eating disorder tend to report lower satisfaction and lower levels of social support than those without an eating disorder (Rorty et al., 1999; Tiller et al., 1997). Due to this it is likely that they may try to gain social support through other means. In her commentary on pro-ana and pro-ED websites, Tierney (2008) suggested that one of the main benefits of those with an eating disorder to accessing such websites is the potential sense of belonging and acceptance they could receive from interacting with other people with similar views and feelings. These ideas were not novel and were suggested by studies prior to Tierney's (2008) commentary. Indeed the idea of acceptance and identity has also been identified by Giles (2006), who found that members of these groups fiercely defended the construct of 'pro-ana' against perceived attacks from outsiders, or from people that they felt didn't have an eating disorder who they termed 'wannabes' or 'wannarexics' .

This defence of the pro-ana movement was also found by Brotsky & Giles (2007) who described the 'initiation' (and eventual acceptance) that one author 'SB' went through in order to be considered a member of the pro-ana groups she

joined. Brotsky & Giles (2007) suggested that whilst members didn't appear to share the same outlook or understanding of eating disorders, those who were members of the group may have joined (and remained) out of a desire to belong to a community who shared a similar experience, something they appeared to lack in the real world. This theme of social support has also been found by other studies looking at the phenomenon of pro-ana and pro-ED websites.

Csipke & Horne (2007) found that 43% of those questioned about their use of pro-ana and pro-ED websites reported receiving emotional support on them. They also found that those who actively participated on these sites felt that they had more in common with other visitors, and felt better about themselves after visiting them. Furthermore, reports of increased self-esteem and decreased loneliness were correlated with visiting pro-ED website, and some said that visiting these types of sites led them to engage in the recovery process. Other studies such as Mulveen & Hepwoth (2006) and Gavin, Rodham, & Poyer (2008) also found that for users of pro-ana internet forums these websites were places to gain social support.

Gavin et al. (2008) proposed that pro-ana websites "provide an acceptance that is integral to their feelings of self-esteem and worth, but remains unavailable to these women in the real world" (p.331). Nonetheless, Gavin et al. (2008) acknowledged that this social support may be inappropriate as it was likely to normalise both their eating disorder and associated behaviours. Furthermore, it may in turn reduce the likelihood of them seeking social support elsewhere, most critically in the real world. This supports the finding of Csipke & Horne (2007), who found that 42% of those questioned felt

that pro-ED websites did not encourage members to access treatment or aim for recovery. Both Gavin et al. (2008) and Mulveen & Hepworth (2006) suggested that this may be related to stages of change, in that those who access pro-ED websites could be at an earlier stage of change than those who do not (see 2.11 for discussion on the stages of change model) and that this warranted further investigation.

2.11 Stages of Change

People with eating disorders are difficult to treat successfully with both relapse and drop out from treatment being a problem (Bowers, 2001; Richard, Bauer, & Kordy, 2005; Wilson, Grilo, & Vitousek, 2007). Many of those with an eating disorder display high levels of ambivalence as well as denial (Sullivan & Terris, 2001), in the case of AN this is thought to be due to its ego-syntonic nature whereas in BN this may be in relation to distress from loss of control and purging (Blake, Turnbull, & Treasure, 1997). As the ambivalence and denial seen in those with an eating disorder is also seen in those with addiction problems, the Stages of Change model (Prochaska & DiClemente, 1983) has been used to understand and engage people with an eating disorder in treatment (2.11.3 for discussion of this).

2.11.1 The Stages of Change model

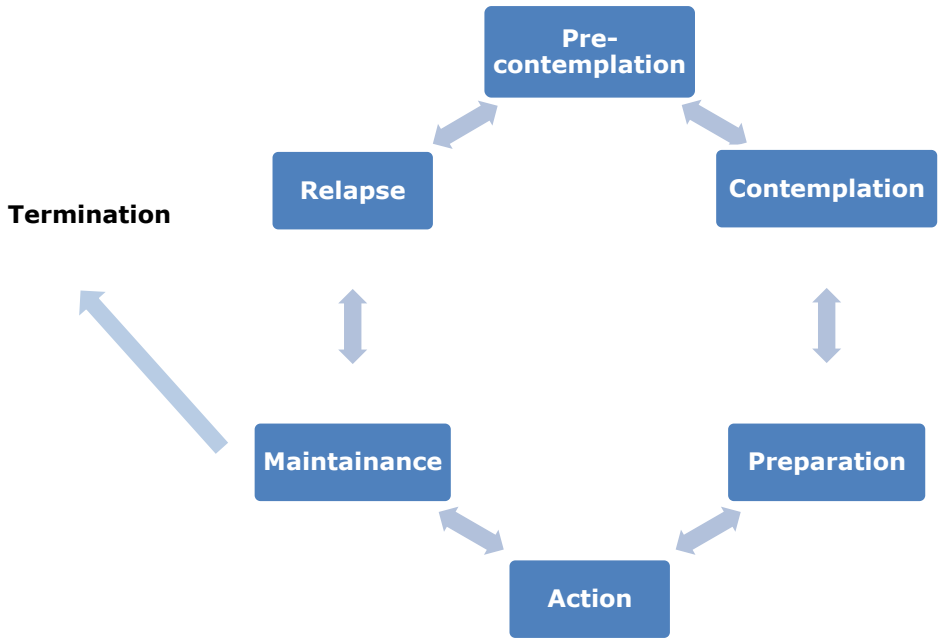

Figure 3. Diagram of the Stages of Change model. Change begins at the pre-contemplation stage and follows a number of steps until the person reaches termination.

The Stages of Change model (Prochaska & DiClemente, 1983) was originally developed to help to explain change in health related behaviour. Initially the work of Prochaska and DiClemente (and colleagues) focused on smoking cessation but this was later extended to include other groups such as overeaters and those with alcohol dependence (Littell & Girvin, 2002). The model suggests that there are a number of different stages of behaviour change: pre-contemplation, contemplation, preparation, action, maintenance, relapse and finally termination. Initially the model suggested that this was a circular process and that people moved though a serious of changes in one direction, however this was later changed to

acknowledge that people could move backwards in this model (Figure 3). Later on, the model was again modified removing relapse as a stage in itself, instead viewing it as an example of moving backwards within the model (Prochaska, DiClemente, & Norcross, 1992). The representation of the model was therefore changed to an upward spiral representing the progression through stages of change towards maintenance and finally termination (Figure 4).

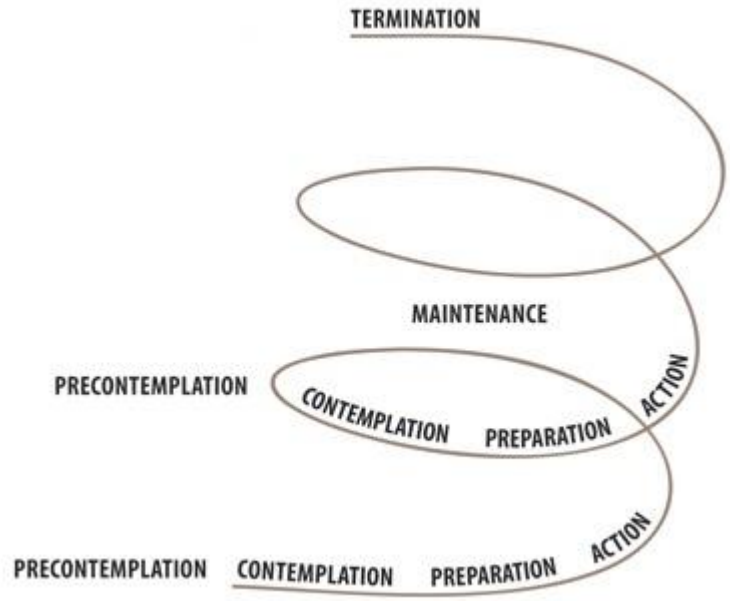

Figure 4. Diagram of the revised Stages of Change Model From Procaska, DiClemente & Norcross (1992)

In addition to describing the process of behaviour change, the stages of change model also suggests that that different strategies known as 'processes' are involved in progressing through the different stages (Prochaska et al., 1992; Prochaska & Velicer, 1997). They further suggest that different stages are associated with different beliefs and that interventions to promote change should be appropriate to the current stage a person may be in (West, 2005). Prochaska & Velicer (1997) also found that matching intervention to the

stage of change a person was likely to increase its effectiveness, whereas earlier research suggested that a mismatch of stage and treatment was likely to be correlated with the reporting of the failure of the treatment or intervention (Prochaska et al., 1992).

As previously mentioned, since its inception in explaining the process of behaviour change in smoking cession, the stages of change model has been applied to many other behaviours. A recent meta-analysis on the application of the stages of change model in psychotherapy (Norcross, Krebs, & Prochaska, 2011) has only served to highlight this. They found evidence of its use across many difficulties including domestic abuse, post-traumatic stress disorder and substance abuse, as well as in eating disorders (see 2.11.3 for discussion of the Stages of Change model in relation to eating disorders). Furthermore, they found across these studies the Stages of Change model reliably predicted outcomes in psychotherapy (meta-analysis indicated a medium effect size of d = .46), in that the amount of progress made during treatment tended to be correlated with their stage of change immediately prior to treatment.

2.11.2 Criticisms of the Stages of Change model

Despite the apparent success of the Stages of Change model in understanding behaviour change, the model has not been without its critics (West, 2005). Like all stage models, the Stages of Change model has been charged with oversimplifying the nature of behaviour change by ascribing discrete stages to a continuous process (Bandura, 1998). Others also argue that classifying a person into one of these discrete stages makes an assumption that individuals make plans that are both rational and stable (West, 2005) whereas

evidences suggests that this may not the be the case. For example Larabie (2005) found that more than half of the reported attempts to stop smoking in his sample involved no conscious thought or planning whatsoever.

A comprehensive review of the Stages of Change model by Littell & Girvin (2002) also highlighted weaknesses. They found that evidence supporting the discrete stages of the model was weak and that much of the evidence suggested that whilst participants could be placed into categories via algorithms often participants did not do this through their answers alone. Littell & Girvin (2002) found that with the exception of pre-contemplation, individuals showed differing levels of involvement with each stage at the same time. They also found little evidence to support the idea of either sequential transitions between stages, or the cyclical progression described in later version of the model, and suggested that a continuous readiness for change model be adopted and developed instead. Whilst they found little evidence to support the Stages of Change model, they did accept that value of the model in offering new and useful ways of thinking about how people change, and highlighted the contributions the model had made in understanding behaviour change.

Others however have not been so kind, in his editorial West (2005) postulated that the Stages of Change model should be abandoned as it "has been little more than a security blanket for researchers and clinicians . . . is likely to lead to effective interventions not being offered . . . (and) fails to take account of the strong situational determinants of behaviour" (P.1038). However, regardless of these criticisms the model remains

widely used, and is seen as a useful way viewing behaviour change (Littell & Girvin, 2002).

2.11.3 Application of the Stages of Change model to eating disorders

As previously mentioned the Stages of Change model appears to have been applied to those with an eating disorder for a number of reasons including; high levels of ambivalence, relapse and drop out from treatment (Bowers, 2001; Richard, Bauer, & Kordy, 2005; Wilson, Grilo, & Vitousek, 2007). Early studies in the application of the Stages of Change model to those with an eating disorder focused on self-change, and highlighted the apparent correlation between the factors influencing change and the processes highlighted by Prochaska and DiClemente (Stanton, Rebert, & Zinn, 1986). Stanton et al. (1986) suggested that treatment for BN may be improved through the use of the processes highlighted by those who had successfully overcome the disorder themselves, without the need for formal treatment or intervention.

In addition, Ward, Troop, Todd, & Treasure (1996) suggested that the Stages of Change model may be appropriate for use in thinking about and treating those with AN. The use of the Stages of Change model in eating disorders was further supported by Blake et al. (1997) who the extended the application of the model to outpatients who had a diagnosis of either AN or BN. They found that whilst the majority of those with a diagnosis of BN were in the action stage, this was not the case with those with AN. In this study, those with AN were mostly in the pre-contemplation or contemplation stages of change which they associated with the nature of the disorder. I.e. that many people with AN are pushed into

treatment they are not ready for due to their emaciated appearance.

Blake et al. (1997) also found that the transition between stages was associated with a change in the proportion of pros and cons, with those in the action stage having more pros than those in the pre-contemplation stage. They further suggested that applying a motivational interviewing style to those with an eating disorder may help to move a client into a stage more aligned to therapy. However, others have highlighted the difficulty of extending the scope of a model designed to look at a dichotomous variable like smoking to a more complex set of behaviours such as eating disorders (Sullivan & Terris, 2001). Nonetheless, the Stages of Change model has continued to be applied to eating disorders and there is some evidence to suggest that it can be used to predict treatment outcome.

Franko (1997) found that the Stages of Change model predicted the outcome of therapy when applied to those with BN. She found that those who had a lower frequency of binges post treatment were more likely to have been in the action stage of change immediately prior to treatment. This is further supported by Wolk & Devlin (2001) who found that those with BN who entered treatment in the pre-contemplation stage did not achieve remission by the end of therapy. Furthermore, the stage of change a person was in significantly predicted treatment outcome for those with BN who were randomised to receive IPT. Additionally, the Stages of Change model has also been shown to predict outcome in AN and EDNOS (Castro-Fornieles et al., 2007; Geller, Drab-Hudson, Whisenhunt, & Srikameswaran, 2004; Wade, Frayne, Edwards, Robertson, & Gilchrist, 2009).

2.12 Literature Regarding Internet Use in People with Eating Disorders

There is very little literature regarding internet use in people with an eating disorder. However, one study suggests that around half of adolescents with an eating disorder do not access any websites in relation to their disorder (Wilson, Peebles, Hardy, & Litt, 2006). In this study, of those who did access eating disorder specific sites, 15.8% accessed pro-recovery sites only, 10.5% accessed pro-ED sites only and 25% accessed both types of site. The study found no differences between groups in regards to health outcomes, impact of their eating disorder on time spent with friends or other extracurricular activities. However, those who accessed pro-ED sites reported spending less time on school work and school activities as a result of their eating disorder. Wilson et al. (2006) did however find that users of pro-ED and pro-recovery sites reported more hospitalisations than users of neither site, and that users of pro-ED sites only tended to have a longer duration of illness than other internet users with an eating disorder.

Nonetheless, the number of people only accessing pro-ED sites in this study was very small (8 out of 76), this meant that the comparison between those who accessed these sites exclusively was limited. Furthermore, the study only looked at internet use in adolescents and it is not currently clear whether the same pattern of internet use is found in adults with an eating disorder. Other studies investigating Pro-ED websites suggest that adults may be accessing these sites (Csipke & Horne, 2007; Rodgers et al., 2012), yet it is not clear how many of these had been diagnosed with an eating disorder by a professional or if any were accessing treatment.

2.13 Section Summary

The development and proliferation of pro-ED websites and pro-ED groups on social networking sites has caused serious concern amongst both professionals and the public alike. Research focusing on such sites is still in its infancy, although there is some agreement that both users and creators of these websites are seeking support and have taken advantage of the opportunities provided by increasing access to the internet to develop an underground community where they no longer feel isolated and alone. In recent years the nature of pro-ED sites appears to have changed and the philosophy has evolved to highlight this need for support. Nonetheless, the triggering content still remains; and often there is no sense of wishing to recover from the disorder. In response to such sites, pro-recovery websites have been developed, although evidence suggests that they may be fewer in number and less well organised.

Current evidence suggests that pro-ED websites may have some potentially negative effects on their users, however this has only been demonstrated in a population without an eating disorder. Whilst it is reasonable to assume that the effects in an eating disorder population may be similar, the question remains whether visitors with an already poor body image and low self-esteem would find such sites making much of an impact in these areas, or whether as some evidence suggests they would find the sites supportive. Whilst there is some evidence to suggest that some children and adolescents with an eating disorder visit pro-ED websites, there is little evidence with regards to adults. Furthermore, there is little understanding of the differences between those who visit websites in relation to their disorder (either pro-ED or pro-

recovery) and those who don't, and even less of the differences between those who access pro-ED and pro-recovery sites exclusively.

2.14 Aims of the Study

This study aims to explore the use of the internet in adults with an eating disorder. It is hoped that this will aid the understanding of the use of both pro-ED and pro-recovery websites in this population. Firstly, it will help to highlight the extent to which these sites are accessed by adults with an eating disorder, which will offer some insight into the scale of use in this population. Whilst there is some information to suggest that children and adolescents with a diagnosis of an eating disorder access these sites, there is little information to substantiate their use in adults with the same diagnosis.

In addition by extending the Wilson et al. (2006) study to include a number of measures, such as self-efficacy for recovery, stage of change and social support it may be possible to explore in more detail some of the factors that may affect the use of these sites. Understanding the differences between those who access pro-ED and pro-recovery sites may help to provide not only an understanding of when someone may be likely to access such sites, but also point to ways of supporting those with an eating disorder during treatment to fully engage in the process of recovery.

3 Extended Method

3.1 Section Introduction

The method section in the journal article briefly discussed the design of the study and the process of recruiting participants. In this extended section I will discuss the design, including my

own epistemological position, and the process of gaining ethical approval. I will also focus on the process of recruitment in greater depth, and will discuss the choice of the measures used, the decision making process and the development of the questionnaire on internet use.

3.2 Design

The research aimed to extend the evidence base regarding internet use in people with eating disorders, and was based upon research by Wilson et al., (2006). This study involved children and adolescents who had been assessed and diagnosed with an eating disorder in a children's hospital in Stanford, USA between 1997 and 2004 as well as their parents. It explored the internet use of these children and adolescents as well as their parents' knowledge with regards to pro-ED websites. The present study extended the scope of this paper by exploring internet use in adults and also including additional measures that assessed self-efficacy regarding recovery, stage of change and social support, which were all factors that were hypothesised to be related to the type of website participants accessed.

The study was administered online, given that the purpose of the study was to investigate internet use it was felt that method was particularly suitable. It allowed for ease of access at any time of the day or night and was entirely anonymous, which was felt to be important given the controversial nature of pro-ED websites. The website which was created by the researcher was hosted by surveygizmo.com. This is a professionally run service which hosts questionnaires and surveys securely using password protected systems, and is used by services and companies such as the University of Nottingham, Vodafone and Walgreens.

This provider was chosen as they clearly state that they will not use or trade the information collected, and they are also compliant to the European Union's guidelines for the protection of personal data. Additionally, the company provide the ability to destroy all files, database records and backups of this data when requested, and data cannot be recovered after this is performed. This meant that the data could be downloaded and securely stored by the University of Nottingham in accordance with good clinical practise guidelines.

The design of the study was a cross-sectional observational design and was chosen for a number of reasons. The main reason for using this type of design was due to ethical considerations, primarily concerns about introducing people with an eating disorder to websites that may negatively affect them and cause them harm. As there is some evidence to suggest that pro-ED websites can impact people without an eating disorder by lowering self-esteem and reducing calorific intake (Bardone-Cone & Cass, 2006, 2007), there is reason to believe that they may have a similar effect in someone with an eating disorder. Given the serious and dangerous consequences of eating disorders and eating disorder behaviour, it was felt that it would be inappropriate to ask people whether or not they accessed pro-ED websites. Instead, participants were asked to list the websites that they accessed in relation to their eating disorder. This also gave the researcher the opportunity to see whether people also accessed pro-recovery websites at the same time as pro-ED sites or instead of them.

In addition, the evidence regarding the use of both pro-ED and pro-recovery websites is currently very limited, and it is not clear what proportion of adults with an eating disorder may

access these types of websites. As observational studies are often used when there is little research in an area, it seemed appropriate to use this type of design as it can lead to the generation of experimental hypothesis. Additionally, observational studies can have strong ecological validity, and as the survey was completed anonymously, it was hypothesised that people who accessed pro-ED websites would be more likely to disclose the websites that they visited. Finally, due to both the financial and time constraints on producing research as part of a doctorate in clinical psychology, it was felt that this type of design was the most appropriate method of exploring website use in adults with eating disorders within a positivist model as it was low cost and had the potential to be accessed by anyone with an internet connection.

However, there are limitations to using a cross-sectional observational design in research. The main drawback of using this type of design is the inability to make causal inferences; for example whilst there may be evidence to suggest that the type of website accessed may be correlated with length of eating disorder or self-efficacy in recovery, it would not be possible to say whether there was a causal relationship between these factors and website use. However, due to the ethical and practical considerations previously discussed, this type of study design was chosen as it would provide a useful insight into an area that has not been well researched, and could lead to further research in the area.

3.3 Epistemology

As briefly mentioned previously, the research was based within the positivist tradition. For the purpose of research, the researcher believes that phenomena can be measured, that

knowledge is testable, and that the scientific method is suited to this. Positivism was founded by Comte, who believed that science needed a universal method of enquiry; this became known as the scientific method (Brysbaert & Rastle, 2009). It was readily accepted across the natural sciences, and was used by psychology to position itself as a legitimate discipline within these sciences (Leahey, 2004).

Positivism asserts that knowledge is objective and it aims to describe, predict and explain phenomena with the ultimate aim of producing a set of universal laws (Breen & Darlaston-Jones, 2008). It further states that science and the scientific method is the way in which such knowledge should be obtained. The scientific method is a set of techniques that aim to test hypotheses to build knowledge and understanding of the world. Positivism asserts that to build this knowledge, predictions should be made in order to establish cause and effect. It also states that variables should be defined and measurable, and that any measures used should be reliable and valid. This allows for the replication of experiments and verification of knowledge by others.

Verification of knowledge according to logical positivism (the union of empiricism and formal logic in the 20th century and the successor of traditional positivism) leads to fact and therefore truth. This has become the dominant epistemology in psychology, despite the concerns of others in the field with regards to the relevance of this model to psychological phenomena (Breen & Darlaston-Jones, 2008).

3.4 Ethical Issues and Ethical Approval

There were a number of ethical considerations that were addressed prior to gaining ethical approval for the study.

Firstly, part of the researcher's interest in exploring the use of the internet by people with an eating disorder included phenomena known as pro-anorexia and pro-eating disorder websites. Since the reaction to them has been particularly hostile in the press (Hill, 2001) and a cause of concern for professionals working with individuals with an eating disorder (Grunwald, Wesemann, & Rall, 2008; Royal College of Psychiatrists & Beat, 2009), care was taken to design the study in such a way that there was no mention of these types of website in any of the participant materials. It was felt that whilst some individuals were likely to access this type of material, there would be others who had no knowledge of or no desire to access these sites.

As there is no clear evidence as to whether this type of material is harmful to those with an eating disorder, the researcher felt that it was better to err on the side of caution rather than inadvertently introduce people to these types of website. Therefore the decision was made to ask participants to name the websites they accessed, so that the researcher could visit them to assess whether they would be considered pro-anorexic/pro-ED or pro-recovery.

Secondly, the researcher was aware, that in some rare cases, people may find answering questionnaires about their eating disorder upsetting. It was therefore decided that it would be appropriate to include a link to the website of the eating disorder charity B-eat. This website contains information about eating disorders and where to get treatment, as well as a forum that people can join to get support and information from others. Finally, there were a number of ethical considerations with regards to the method of data collection. As the study was run as an online survey, there were

additional issues with anonymity and security of data. Care was taken to choose a service provider that allowed for a secure login, that did not access the data stored on their servers, and that destroyed the data in such a way that it was irretrievable when the account was closed. Furthermore, participants were able to choose whether they wished to receive a summary of the results. This information was collected as part of a separate survey and independently of the main results. This ensured that the two types of data were not linked, and that it was not possible to match participant answers to e-mail addresses.

Ethical approval was sought from NRES committee East Midlands – Nottingham 1 in December 2011 (See Appendix I). The study received a favourable opinion with additional conditions. These were minor amendments to the study which were the removal of the electronic consent form and some minor grammatical and typographical changes to the supporting documents such as the participant information sheet. Approval was then sought from the research and development (R&D) departments of two NHS trusts in Derbyshire and Lincoln; in both cases this was granted, and allowed the recruitment of participants from specialist eating disorder services in these regions (See Appendices J, K & L for R&D approval documents).

3.5 Recruitment

Participants were recruited in a number of ways. The charity B-eat was contacted, as they hold a database of people who are interested in participating in research focusing on eating disorders. Researchers who wish to utilise this database, are required to send the charity information regarding their study; this includes the participant information sheet, poster

advertising the study, as well as their ethical approval. B-eat then e-mail the information regarding the study to those on the database. People who are interested in participating in the study can then contact researchers, or in the case of this study, access the online survey. In addition to sending information about the study to their database members, they also provide information about the study on their website, which included a link to the site the survey was being hosted on. The charity provide this service free of charge but do require that, on publication acknowledgement be made of their part in the recruitment process. They also suggest that, if the study is funded, a donation be made.

Support groups were also contacted and informed of the study, and they were asked if they would be able to help with recruiting participants. Initially this was limited to support groups in the East Midlands area (Nottingham, Derby and Lincoln). Later, however support groups outside this area were also contacted. Support groups helped with recruitment in various ways. Those who were accessible to the researcher were visited, and the research project was presented to available members during a meeting. This was done in an informal manner, with the researcher giving a brief overview of the study and what participation would entail. Participant information sheets and details of the website were handed out, and potential participants were able to take the time to make a decision as to whether they wanted to take part in the study. Support groups outside of the local area tended to e-mail the details of the study to their members. This generally consisted of a copy of the participant information sheet and poster which has details of the address of the website. A copy

of the ethical approval from the NRES committee was also made available to all support groups.

Support groups who agreed to be involved in the recruitment of participants were:

First Steps, Derby

Link –ED, Lincoln

Men get eating disorders too, Brighton

SEED –Eating disorder support services, Hull

Cornerhouse, Woking

Eating Disorders Support, Buckingham

I*eat, Bournemouth

Women's Health Information and Support Centre (WHISC), Liverpool

Student Run Self Help, Oxford

South Yorkshire Eating Disorders Association (SYEDA), Sheffield

BalancED MK, Milton Keynes

Finally, participants were recruited from specialist eating disorder services in Lincoln and Derbyshire. Participants were given information about the study by the clinician involved in their care; this included a participant information sheet as well as the address of the website. Care was taken to ensure that regardless of the method of recruitment, participants were aware that participation was voluntary and that all the information collected was confidential and anonymous.

3.6 Procedure

As previously mentioned participants were recruited in a number of ways. Once participants had made the decision that they were interested in participating in the research, or wanted further information about the study, they accessed the online survey. Information regarding the study was re-presented online, and participants were asked to acknowledge this information by pressing 'Next' to move forward to the questionnaires.

The five questionnaires and questions relating to demographic information were then presented (one per page), which participants completed until they reached the final page of the survey. This final page thanked them for their participation and included a link to the B-eat website, as well as a link to another survey page where they could input their e-mail address if they wanted receive a summary of the results of the study.

3.7 Measures

As there were a number of factors that the researcher hypothesised may influence the types of websites individuals with an eating disorder may visit, it was necessary to use a questionnaire for each. The researcher was aware that there was evidence to suggest that participants are more likely to return postal questionnaires that are shorter in length (Edwards et al., 2002). Whilst this did not directly relate to the current study, the researcher felt it was reasonable to assume that this effect may also be seen in online-based questionnaires. When choosing questionnaires, the length of questionnaire was considered along with the psychometric properties of the measures.

3.7.1 The Eating Disorder Examination Questionnaire (EDE-Q)

As mentioned in the journal article, the Eating Disorder Examination Questionnaire by Beglin & Fairburn (1992) was used to screen for eating disorder symptoms. Given that pro-ED websites are designed to trigger eating disorder behaviour, the researcher hypothesised that those who accessed pro-ED websites exclusively may score differently on a scale related to eating disorder attitudes and behaviours. On this questionnaire, eating disorder attitudes are measured using a 7-point scale, with a higher number representing a more severe attitude or symptom than a lower number. The measure is broken down into four individual subscales; restraint, eating concern, shape concern and weight concern, which are then summed together and divided by four to give the global score.

The EDE-Q has been used in many studies, and in individuals with a confirmed diagnosis of an eating disorder (Carter, Aimé, & Mills, 2001), as well as in primary care and community-based prevalence studies (Mond et al., 2008; Mond, Hay, Rodgers, Owen, & Beumont, 2004). This allowed for participants who did not have an eating disorder diagnosis to be screened for eating disorder symptoms, as global score of 2.80 or above indicates a likely eating disorder (Mond et al., 2004). The EDE-Q also allows for an analysis regarding severity of eating disorder symptoms to be conducted if appropriate.

3.7.2 University of Rhode Island Change Assessment (McConnaughy, Prochaska, & Velicer, 1983)

As motivation for change appears to be a key factor in the successful recovery from an eating disorder (Castro-Fornieles et al., 2007, 2011), it was hypothesised that those who access pro-recovery websites may be at a different stage of change to those who access Pro-ED sites. As stated in the journal article the University of Rhode Island Change Assessment Scale(URICA) was used. The measure asks people responding to the questionnaire to rate how much they agree or disagree (scored between 1 and 5) with 32 statements such as "I am actively working on my problem". In the case of this study, the problem was pre-defined as a person's eating disorder.

Although there are a number of eating disorder specific stage of change questionnaires such as the anorexia nervosa stages of change questionnaire (ANSOCQ; Rieger et al., 2000) or the motivational stages of change for adolescents recovering from an eating disorder (MSCARED; Gusella, Butler, Nichols, & Bird, 2003), these questionnaires tended to focus on a specific diagnosis or had been developed for use in an adolescent population. As there were no restrictions on diagnosis in this study, and it has previously been used in eating disorder populations (Feld, Woodside, Kaplan, Olmsted, & Carter, 2001; Treasure et al., 1999), it was felt that this measure was the most appropriate to use.

3.7.3 The Eating Disorder Recovery Self Efficacy Questionnaire (Pinto, Guarda, Heinberg, & DiClemente, 2006)

As stated in the journal article, the Eating Disorder Recovery Self Efficacy Questionnaire (EDRSQ) is a brief measure of self-efficacy in recovery. The measure has two subscales; normative eating and body image. It can also be scored to give a mean global score of one to five, where higher scores suggest higher levels of self-efficacy in recovery. A search of the literature suggested that this was the only questionnaire that measured self-efficacy regarding recovery across individuals with a range of eating disorder diagnoses and it is currently the only measure of this type that has been validated for anorexia nervosa, bulimia nervosa and eating disorder not otherwise specified (Pinto et al., 2008). It has also recently been validated in a number of languages (Couture, Lecours, Beaulieu-Pelletier, Philippe, & Strychar, 2010), further highlighting the increasing use of the EDRSQ in eating disorder research.

3.7.4 The Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet, Dahlem, Zimet, & Farley, 1988)

As previously mentioned, it was hypothesised that perceived social support may be linked to the type of website a person may access in relation to their eating disorder. The MSPSS was used, as it provided a measure of perceived social support: this was felt to be important as, whilst a person with an eating disorder may have a number of individuals such as family and friends surrounding them, this may not correspond with how supported they actually feel. The MSPSS was

chosen, not only as it has been used in a number of clinical populations (Clara, Cox, Enns, Murray, & Torgrudc, 2003; Eker & Arkar, 1995), but also as it is a very brief scale consisting of only 12 questions.

Participants are asked to rate how strongly they agree or disagree with statements relating to three subscales of perceived social support; family, friends and significant other. Responses are scored between one and seven, with higher scores suggesting higher levels of perceived social support. The measure can also provide an overall score of perceived social support, as well as scores on each of the three subscales. As a number of questionnaires were used in this study, it was felt that it was important to try to ensure that the measures were not only valid and reliable, but that they were also relatively brief. Other scales of social support that were available to use tended to be significantly longer that the MSPSS, and were therefore not used.

3.8 The Development of a Questionnaire of Internet Use in People with Eating Disorders

As touched on in the journal paper, this questionnaire was based upon the questionnaire developed by Wilson et al. (2006) in their study of internet use in children and adolescents with an eating disorder. Whilst attempts were made to contact the authors to see if a copy of this questionnaire was available for use, there was unfortunately no response from the authors. The researcher therefore developed a questionnaire based upon the information provided in the published paper. This was then sent to three people who did not have an eating disorder diagnosis, and their feedback was gained with regard to ease of use and

understanding. This feedback suggested that minimal changes needed to be made to ensure that the questionnaire was clear. See Appendix E for the final version of the questionnaire used.

3.9 Sample Size Calculation

Previous research investigating website use in people with an eating disorder, such as that by Wilson et al. (2006) has not use any validated measures. Furthermore, at the time of designing the study there were no published studies investigating the use of websites and variables relating to self-efficacy in recovery, social support and stage of change in adults with an eating disorder. Due to this it was not possible to calculate an effect size from previous research. Therefore, a medium effect size and a power of 90% was chosen in order to complete a sample size calculation.

Using G*Power software, it was calculated that for a MANOVA with 4 groups and 9 variables (the maximum number of variables that would be used in this analysis in this study) a minimum of 72 participants would be needed to detect a difference (5% level of significance) at the power and effect size chosen.

4 Extended Results

4.1 Section Introduction

The results section in the journal article briefly presented the main results of the study, which showed that there were no significant differences between participants when analysed by type of website used. The extended results will include a brief discussion of the planned analysis, as well as the results of normality of the distribution of scores in full. This section will also include the results of the analysis of the outcome

measures in full, before presenting an analysis of the groups by sub scale scores.

4.2 Planned Analyses

The analyses of the data were to be completed using chi square for categorical data, and multivariate analyses (MANOVA) for interval data. There was to be a further analysis using a multivariate analysis of covariance (MANCOVA) to adjust for duration of illness. The MANCOVA would be performed if the initial MANOVA had suggested that duration of illness (or any other interval variable not related to social support, self-efficacy or eating disorder severity) was significantly different between groups. The researcher hypothesised that this may be the case as Wilson et al. (2006) had found that duration of illness was linked to website use in relation to eating disorders (see Table 13 for more details of the planned analysis).

Table 13

Planned Analysis by Statistic, Measure and Coding

Chi Square (two group analysis – website use/no website use and four group analysis – Pro-recovery, Pro-ED, both and none)		MANOVA (four group analysis)		MANCOVA (four group analysis controlling for duration of illness)	
Gender	Male Female	Age	Years	EDE-Q	Global score
Diagnosis	Anorexia Bulimia EDNOS Other	Length of treatment	Months	Self-efficacy in recovery	Total score
Ethnicity	White British Mixed ethnicity Black/African/Caribbean Other	Duration of illness	Months	Perceived social support	Total score

Table 13

Planned Analysis by Statistic, Measure and Coding

Chi Square (two group analysis – website use/no website use and four group analysis – Pro-recovery, Pro-ED, both and none)		MANOVA (four group analysis)		MANCOVA (four group analysis controlling for duration of illness)
Stage of change	Pre-contemplation Contemplation Action Maintenance	Hospital Admission	Number	
Treatment Status	In treatment Not in treatment	EDE-Q	Global score	

Table 13

Planned Analysis by Statistic, Measure and Coding

Chi Square (two group analysis – website use/no website use and four group analysis – Pro-recovery, Pro-ED, both and none)		MANOVA (four group analysis)		MANCOVA (four group analysis controlling for duration of illness)
Time spent on the internet	1-5 hrs 6-10 hrs 11-15 hrs 16-20 hrs 21-25 hrs 26-30 hrs 31-35 hrs 36+ hrs	Perceived social support	Total score	

4.3 Analyses

As mentioned in the journal article, the interval data were tested for normality using Kolmogorov-Smirnov tests. Only perceived social support as measured by the MSPSS was normally distributed. Although MANOVA and MANCOVA tests are considered to be robust tests where the assumption of normality can be violated in large samples (Dimitrov & Rumrill, 2005), the researcher was aware that this was not the case in this study. Although transforming the data was considered, this was rejected as the group sizes were also small. As there were seven dependent variables in this analysis, each cell needed a minimum of seven cases. This was not the case and therefore it was not possible to run the analyses as planned. Due to this, Kruskal-Wallis tests were used to see whether the groups were significantly different on the interval measures (see 5.4 for the rationale and discussion of this).

4.4 Results

As mentioned in the journal article 45 participants completed the questionnaires in full. Of these 38% (*n=17*) accessed the link via the B-eat website, 31% (*n=14*) came via another referrer such as a link sent in an email, and 31% (*n=14*) did not come through a specific referrer. This means that they most likely typed the website address into their browser and were given a printed copy of the participant information sheet detailing the study.

Table 14

Outcome of Kolmogorov-Smirnov Test (df = 45) including Subscale Scores

	D	*p*
EDE-Q global score	.14	.030
MSPSS score	.11	.200
EDRSQ score	.14	.025
Age	.19	.000
Length of treatment	.30	.000
Duration of illness	.13	.062
Number of times hospitalised	.29	.000
Restraint[1]	.20	.000
Eating concern[1]	.12	.092
Shape concern[1]	.20	.000
Weight concern[1]	.14	.023
Body self-efficacy[2]	.19	.000
Eating self-efficacy[2]	.17	.003
Family[3]	.18	.001
Friends[3]	.15	.012
Significant other[3]	.15	.019

EDE-Q = Eating Disorder Examination Questionnaire, EDRSQ= Eating Disorder Recovery Self Efficacy Questionnaire, MSPSS= Multidimensional Scale of Perceived Social Support, [1] = on the Eating Disorder Examination Questionnaire, [2] = on the Eating Disorder Recovery Self Efficacy Questionnaire, [3] = on the Multidimensional Scale of Perceived Social Support

The interval data were tested for normality using the Kolmogorov-Smirnov test; as Table 14 shows the majority of this data were non-normally distributed. As previously mentioned, the only scale scores normally distributed were on the MSPSS. In addition, illness duration in months was found to be normally distributed. The subscale scores were also tested for normality using the same test (see Table 14). In this case the only normally distributed sub scale was the eating concern sub scale on the EDE-Q. In consequence, it was not possible to perform the planned analysis and therefore Kruskal-Wallis tests were performed on the interval data instead. As mentioned in the journal article, no significant differences were found between groups on the EDE-Q, EDRSQ and the MSPSS (see Table 15) and it was not possible to analyse the differences between groups on the categorical data due to small cell sizes.

Table 15

Outcome of the Kruskal-Wallis Tests for Scales and Other Interval Data (df=3)

	H	*P*
EDE-Q global score	5.53	.137
MSPSS score	0.13	.988
EDRSQ score	3.14	.371
Age	0.98	.087
Length of treatment	3.14	.371
Duration of illness	3.74	.291
Number of times hospitalised	5.53	.137

EDE-Q = Eating Disorder Examination Questionnaire, EDRSQ= Eating Disorder Recovery Self Efficacy Questionnaire, MSPSS= Multidimensional Scale of Perceived Social Support

4.4.1 Subscale Scores

As mentioned in section 3.7, three of the measures used in the study also provide sub scale scores. Due to this, a further analysis was completed to see if there were any group differences on sub scale scores. The means and standard deviations for these sub scales are reported below (see Table 16). As for the main analysis Kruskal-Wallis tests were used as a consequence of the data being non-normally distributed (see Table 14 for further information).

Table 16

Median and Interquartile Range on the Sub Scale Scores

	Pro-Recovery (*n=28*)		Pro-ED (*n=9*)		Both (*n=5*)		None (*n=3*)	
	Median	IRQ	Median	IRQ	Median	IRQ	Median	IRQ
Restraint[1]	3.70	2.60-4.80	4.40	3.1-5.00	4.80	4.70-4.90	4.80	NP
Eating concern[1]	3.80	3.80-4.75	3.40	2.70-4.90	4.40	4.20-5.10	3.60	NP
Shape concern[1]	5.05	4.46-6.00	5.40	4.30-6.00	6.00	5.43-6.00	4.86	NP
Weight concern[1]	4.33	3.75-5.33	5.00	4.17-5.50	6.00	5.67-6.00	4.70	NP
Body self-efficacy[2]	1.39	1.00-1.67	1.33	1.06-1.50	1.11	1.00-1.39	1.78	NP
Eating self-efficacy[2]	1.42	1.23-2.33	1.85	1.21-2.80	1.50	1.28-2.80	2.35	NP
Family[3]	3.50	1.75-5.50	1.75	1.38-5.25	4.00	1.25-4.63	5.00	NP
Friends[3]	4.50	2.63-5.63	5.25	5.00-6.25	4.50	1.38-5.13	4.25	NP
Significant other[3]	4.87	2.56-5.69	4.75	2.38-6.13	5.50	2.25-6.38	4.00	NP

[1] = on the Eating Disorder Examination Questionnaire, [2] = on the Eating Disorder Recovery Self Efficacy Questionnaire, [3] = on the Multidimensional Scale of Perceived Social Support, NP = not possible to calculate due small group size

The analysis of the sub scale scores showed that the scores between groups were only significantly different on the weight concern subscale on the EDE-Q, $H(3) = 8.24$, $p = .041$ (the outcome of all of the Kruskal-Wallis tests are shown in Table

17).[1] Mann-Whitney tests were used to follow up this finding, and comparisons were only made between participants who accessed websites in relation to their eating disorder.[2] A Bonferroni correction was applied and so all effects are reported at a .0167 level of significance. It appears that there was no significant difference between those who accessed pro-recovery websites and those who accessed pro-ED sites (U=104.5, *r* = -.13). However the group who accessed both pro-recovery and pro-ED sites had significantly higher weight concern scores than those who only accessed pro-recovery (U=17.00, *r* =-.47) or pro-ED websites (U=4.50, *r* = -.66).

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[1] The researcher is aware that there an argument to apply a Bonferroni correction at this point. However, the study was designed with multiple comparisons in mind, and the effect sizes found during the post hoc Mann-Whitney tests represent a medium to large effect (Cohen, 1992) .

[2]The researcher decided to only apply post-hoc tests to groups who accessed the internet in relation to their eating disorder. This was primarily due to the focus of the study, but also in part due to the small number of people who did not access websites in relation to their eating disorder.

Table 17

Outcome of Kruskal-Wallis Tests on Sub Scale Scores (df = 3)

	H	*P*
Restraint[1]	2.21	.531
Eating concern[1]	2.59	.460
Shape concern[1]	4.36	.226
Weight concern[1]	8.24	.041*
Body self-efficacy[2]	4.74	.192
Eating self-efficacy[2]	1.35	.717
Family[3]	3.09	.373
Friends[3]	4.88	.181
Significant other[3]	0.47	.924

[1] = on the Eating Disorder Examination Questionnaire, [2] = on the Eating Disorder Recovery Self Efficacy Questionnaire, [3] = on the Multidimensional Scale of Perceived Social Support

5 Extended Discussion

5.1 Section Introduction

Within this extended discussion I will summarise the results of the study, before exploring the results in the context of previous research. I will then discuss the strengths and limitations of the research, before considering the results in the context of future research and clinical implications.

5.2 Summary of Results

The aim of the study was to explore the use of the internet in adults with an eating disorder, with the hypothesis that scores on measures of stage of change, self-efficacy for recovery and social support may be different depending upon the website

visited in relation to eating disorder (pro-recovery, pro-ED, both sites, no sites). The results of the study suggest that the vast majority of people with an eating disorder will access websites that are associated with their disorder. Although many access pro-recovery websites, some will access pro-ED sites, and a small proportion will access both types of sites. In this sample 40% of those who accessed pro-ED or both types of website (pro-ED and pro-recovery) were also accessing treatment for their eating disorder.

No significant differences were found on the main scales of the EDE-Q, EDRSQ and the MSPSS. Due to small cell sizes, the results from the Stages of Change scale could not be analysed. Further analysis suggested that people who visited both types of website (pro-ED and pro-recovery) had significantly higher scores on the weight concern subscale of the EDE-Q than those who visited pro-recovery websites or pro-ED websites exclusively.

5.3 Results in the Context of Previous Research and Theory, and Clinical Implications

5.3.1 Accessing information on eating disorders online

As mentioned in the journal article, most participants (approximately 93%) accessed websites in relation to their eating disorder. Furthermore, the majority (60%) of those who were not currently in treatment for their eating disorder, gathered most of their information about eating disorders from the internet. A number of studies have questioned the quality of health based information on the internet; a systematic review of such studies suggested that not only is quality questionable, but in some cases the information presented is also factually incorrect (Eysenbach, Powell, Kuss, & Eun-

Ryoung, 2002). Furthermore, there have been reports of actual harm associated with seeking health information and advice from the internet (Crocco, Villasis-Keever, & Jadad, 2002).

In addition to these findings, recent research by Guardiola-Wanden-Berghe, Sanz-Valero, & Wanden-Berghe (2010) gives reason to believe that the quality of information about eating disorders on the internet may also be poor. They searched for blogs offering information about eating disorders, and found that nearly 40% of them presented information that was inappropriate for those with an eating disorder. Furthermore, a small percentage of blogs (6.43%) had advertising that was misleading or encouraged bad practices with regards to weight loss and dieting.

Given that there is some evidence for harm associated with health-related information from the internet, and that most of those in this study who used the internet to gain information were not in treatment, it is possible that these people may be at greater harm. Whilst it is currently not clear what factors may make someone more likely to use advice and information they have gained from the internet, it is evident that some do. This study suggests that health professionals may need to be mindful of where someone with an eating disorder is gaining information about their eating disorder, especially if they are not in specialist treatment.

5.3.2 Learning and using new eating disorder techniques online

The results of this study show that over half of the participants who completed the questionnaires had learned a new eating disorder technique from the sites they had visited. As

mentioned in the journal article this supports the work of Wilson et al. (2006) who found a similar proportion of their participants had also learned new methods online. Whilst the Wilson et al. (2006) study focused on children and adolescents, the current study shows that this is also the case in adults with an eating disorder. Both studies also found that not only did participants learn new strategies, but some also went on to try them.

However, this research suggests that this behaviour may be more prevalent in adult populations; 50% of the sample in this study had tried new strategies, whereas the Wilson et al. (2006) study found that 39% of their sample had tried new methods after learning about them online. In addition, both studies found that the participants had learned new techniques on *both* pro-ED and pro-recovery websites. This suggests that the role of pro-recovery and pro-ED websites may not be as clear cut as it first appears. It can be argued that pro-ED sites have been developed with the intention of triggering people and their eating disordered behaviour, and it is not surprising that people learn new techniques from such sites. However, this is not the case with pro-recovery sites which have been developed to help and support to people who wish to recover.

Nonetheless, people with an eating disorder are well known for their competitive nature and there is evidence to suggest that they can, and do learn new strategies to maintain their eating disorder during treatment (Colton & Pistrang, 2004). It should therefore come as no surprise that this also happens online and on pro-recovery websites. Given that 75% of those who accessed pro-recovery websites exclusively had them recommended by a professional, it may be useful for clinicians treating those with an eating disorder being mindful that

clients may learn and use new techniques from websites recommended by clinicians.

Not only does the research show that adults with an eating disorder have learned and used tips and tricks on pro-ED sites, it also shows that this is not exclusive to these sites. However, given that eating disorder severity scores are not significantly higher in people who access pro-ED websites exclusively, it could instead be argued that pro-ED websites are not affecting the behaviours of people who already have an eating disorder and therefore are not the threat they have been assumed to be. An alternative explanation for these results could be that both Pro-ED and recovery websites are having a similar effect on the behaviour of those who visit them.

5.3.3 Social support

As discussed in section 2.10 people with an eating disorder tend to report lower levels of social support than those without (Tiller et al., 1997), the current study supports this previous research. The participants in this study tended to report lower levels of social support than what would be expected in the general population (Clara et al., 2003). Furthermore, there appeared to be a tendency for participants who accessed pro-ED websites to report lower levels of social support from family members than from friends or significant others.

One reason for this could be that the experience of having a family member with an eating disorder is difficult and distressing. This can lead to disintegration within the family (Hillege, Beale, & McMaster, 2006), and could lead to less support being available from the family. Those accessing pro-ED websites may be more aware of the differences between

themselves and their family, and further distance themselves through their use of the internet. However, it may be related to the fact adults are less likely to live with their families, and may be able to physically isolate themselves, preferring to spend time online.

Previous research into the use of pro-ED websites has suggested that one of the reasons for the popularity of such sites is related to the need for support and acceptance by people with eating disorders who are not yet ready for recovery (Csipke & Horne, 2007; Gavin et al., 2008). This study supports this assertion; all of those who accessed pro-ED websites stated they did so in order to gain social support. However, less than half of the participants who access pro-ED sites in this study stated that they were either very supportive or supportive. This suggests that the many of those accessing pro-ED websites do not find the sites particularly supportive despite this being one of the reasons given for accessing them.

This may be due to the way in which the boundaries in pro-ED sites are policed by site admins. As mentioned in the extended background, pro-ED sites are at risk of being removed by service providers for violating terms of service. Members of these sites tend to be hyper vigilant to signs that suggest someone may not be as they seem. Outsiders and wannarexics are not tolerated, and new members often have to 'prove' they have an eating disorder and they are 'pro-ana' (Giles, 2006). Due to this, pro-ED sites can contain high levels of conflict between members, which may explain why some participants did not describe the pro-ED they visited as particularly supportive.

In the case of those who accessed pro-recovery websites, the majority (nearly 80%) used the sites as a means of gaining support from others. However, as discussed in the journal article, scores on the MSPSS suggest no differences between groups. Whilst people accessing pro-recovery websites do so for support, and claim that they find them supportive this does not translate into increased levels of perceived social support on this measure.

The lack of increased social support could be explained by Crandall's (1988) work on social contagion and eating disorders. Crandall (1988) found that women who displayed similar binging behaviour to those they lived with were more popular than those who did not, supporting the assumption that deviating from group norms is likely to lead to rejection through a reduction in popularity. The majority of those accessing pro-recovery websites do so in order to gain social support (possibly due to lacking such support in real life) and many of these groups represent a tight-knit community. Changes in behaviour such as beginning to successfully recover from an eating disorder could move that person further away from the group norm, leading to reduced online support.

Conversely, accessing support online is likely to be a very different experience from receiving it in person from family and friends. Although a person may feel that the pro-recovery sites they access are supportive and provide support whilst they are accessing them, this support may not translate successfully. It may be that the support a person receives online on pro-recovery websites, does not match the support that is required (Cutrona, 1990). This potential mis-match highlights the importance of (re)developing social support

networks in real life. Research on the process of recovery suggests that the (re)development of social networks is an important part of successful recovery (Linville et al., 2012). The current study suggests that the use of online website and forums is unlikely to fulfil this role.

5.3.4 Differences in weight concern scores between those who access pro-recovery, pro-ED, and both types of websites

The only differences found between those who access pro-recovery, pro-ED and both types of website was found on the weight concern sub scale on the EDE-Q. As previously mentioned, those who accessed both pro-ED and pro-recovery websites had significantly higher scores on this sub scale than those who accessed pro-ED or pro-recovery sites exclusively. They also tended to have higher global EDE-Q scores and more hospitalisations (although this was not significantly different from other groups). This finding is similar to the finding of Wilson et al. (2006) that this group tended to have been hospitalised more often as a consequence of their eating disorder than any other group. In addition, only 20% were accessing treatment in comparison to 33% of those accessing pro-ED sites and 75% accessing pro-recovery.

A possible explanation for this difference could be that those who access both websites are more involved in their eating disorder, suggested by a higher EDE-Q score and more incidents of hospitalisation in this group. Whilst weight is of high concern to anyone with an eating disorder, it is likely that those in treatment are developing new ways of evaluating themselves that are not based on how much they weigh. As people in this group are less likely to be accessing treatment, they may be more concerned about weight than those who are

in treatment. However, it is not clear from these results whether this is related to the type of website being accessed, or whether it is solely treatment related.

5.4 Strengths and Limitations

The main strength of this study is the contribution to the current literature surrounding internet use in eating disorders. As far as the researcher is aware, this is the first study looking at website use in adults with eating disorders that specifically focuses on the relationship between type of website accessed and self-efficacy for recovery, social support, severity of eating disorder, and stage of change. It is also the first study to investigate the severity of eating disorder symptoms in relation to pro-ED and pro-recovery website use. It further adds to the growing literature about pro-ED and pro-ana website use in those with eating disorders.

This study used a number of recruitment methods in order to increase access to potential participants and was open to anyone with an eating disorder. The unrestrictive inclusion criteria meant that all eating disorder diagnoses were represented, and participants were not excluded if they were not accessing specialist treatment, all of which increases the validity and generalisability of the study. However, the results of this study are based on a small sample size as, despite the range of recruitment methods and the researcher's best efforts, the intended sample size was not reached. Due to this the study was underpowered.

Owing to the nature of the project, the recruitment period was only nine months in length. In addition, it was not always possible to remind potential participants about the study. For example, the charity B-eat who helped with recruitment will

only inform members of their research database once about each study. Research suggests that response rates to questionnaires in those with an eating disorder is likely to increase if at least one reminder about the study is sent to potential participants (Mond, Rodgers, Hay, Owen, & Beumont, 2004). If this had been possible during the recruitment period in this study, the sample may have been larger.

Another way to increase the sample size could have been to try to recruit through other specialist eating disorder services in the area, although at the time of gaining ethical approval at least one service did not feel able to help with recruitment to this study due to their other research commitments. This highlights another potential difficulty in recruiting participants with an eating disorder. Currently there are in excess of 35 studies listed on the B-eat website, with potentially many more being carried out at various universities across the country. Given the small percentage of the population with an eating disorder, it is possible that people in this client group are frequently asked to participate in research. This may make this client group one that is potentially difficult to recruit to a study when carrying out research such as this that is of no immediate benefit to participants.

As the distribution of scores on the measures was non-normally distributed, it was not possible to perform all the planned analyses. In consequence, Kruskal-Wallis tests were used. This test can only examine the univariate differences between variables. This means that there is the potential that the analysis that was completed could have missed interactions between variables that a MANOVA or a MANCOVA may have uncovered. However, due to the distribution of scores being non-normal and having small group sizes

(Dimitrov & Rumrill, 2005), the researcher did not feel it was appropriate to violate the assumptions of a MANOVA or MANCOVA regardless of the generally accepted robust nature of these statistical tests.

Nonetheless, the sample is likely to be representative in terms of gender and ethnicity, and all of those who completed the study had a diagnosis of an eating disorder made by a healthcare professional and/or a global score of over 2.8 on the EDE-Q. A score of over 2.8 suggests that the participant would fulfil the criteria for an eating disorder diagnosis (Mond et al., 2008). However, as mentioned in the journal article, those with a diagnosis of AN did appear to be overrepresented in this sample; this may be because people with this type of diagnosis are more likely to be involved in research, or because AN can be seen as a more desirable diagnosis in those with an eating disorder (Giles, 2006). Like all studies which rely on self-report and disclosure there is always the possibility that some of the data collected my not be entirely accurate. Whilst this may limit the generalisability of some of the results, the clinical implications of this study are wide-ranging, and may be relevant to diverse groups including GPs, clinical psychologists and other healthcare professionals working in specialist services.

5.5 Recommendations for Future Research

As mentioned in the journal article, the current study warrants extending in order to increase the size of the sample. This may allow for the use of multivariate analysis such as MANOVA or MANCOVA, and it would also allow for an alternative analysis such as a multiple regression to be used to investigate whether social support, stage of change, and self-efficacy for recovery predict website use. Changing the order

of the presentation of the questionnaires on the website so that the demographic information is collected prior to the other measures would also mean that the differences between those who responded in full and those who did not complete the full set of questionnaires could be analysed in more detail. This would give further detail regarding the application of the results of the study and who the results are most applicable to.

The results of the study also suggest a number of other lines of enquiry in relation to internet use in adults with an eating disorder. Due to the high proportion of people accessing websites in relation to their eating disorder who were also accessing treatment, it would be pertinent to explore any effects that accessing these websites may have on treatment outcome. Given that there is evidence to suggest that pro-recovery websites may delay recovery in later stages of change (Keski-Rahkonen & Tozzi, 2005), and that it would be reasonable to believe that the philosophy of pro-ED websites would not be compatible with recovery; it is possible that website use may affect treatment outcome. As eating disorders, especially AN, can be resistant to treatment, the exploration of factors that may hinder or help recovery that have previously been overlooked is particularly important.

Additionally, all of the participants who visited pro-ED websites stated that one of the reasons they did so was for support. However, less than half of these participants felt that the websites were either very supportive or supportive. This discrepancy between reason for use and outcome warrants further investigation. As suggested in the discussion a possible explanation for this may be the high levels of conflict found on these sites. However, there may be other reasons

that these sites are failing to be supportive such as the change in the nature of pro-ED sites from traditional websites to groups hosted on Facebook and content hosted on Tumblr.

Finally, this study suggests that those who access both pro-recovery and pro-ED websites may be significantly different to those who access pro-recovery or pro-ED sites exclusively. Further research with people who access both types of websites, rather than one or the other, may lead to a better understanding of this difference. It may also show whether this difference is related to accessing both types of websites, or whether it is an artefact of not being in treatment.

6 Reflection

6.1 Section Introduction

In this section I will reflect on the conflict between my personal philosophy and epistemology of my research. It will also touch on the position of clinical psychology within the medical model, before looking at the potential advantages of working within a positivist epistemology and some final thoughts on the process of research.

6.2 Personal Thoughts on Epistemology

As stated in the extended method this research is situated in a positivist model; one that believes that science is essentially observation and eventual prediction. However, throughout this research I have become more conscious of, and grappled with the awareness that my personal philosophy and the philosophy I accepted as part of my research are at odds.

Much of my research background is situated within a positivist epistemology and therefore quantitative methods of research. My higher education has occurred almost exclusively at the

University of Nottingham, a university with a history of traditional research. My undergraduate degree in psychology was taught within a school whose research tended to focus on cognitive psychology, and embraced neuropsychological methods. I barely recall any qualitative methodology being taught during my undergraduate degree, and the research teaching during my postgraduate degree also focused primarily on quantitative methodology. My role as a research associate was also working on studies that were situated within a positivist epistemology, using quantitative methodology.

Consequently, my knowledge and understanding of qualitative methods and other philosophical positions within research are not as deeply embedded as the positivist position. Therefore, my first thoughts with regards to research tend to be situated within a positivist understanding of the world, knowledge and truth. Due to this, the questions I ask tend to be best answered with quantitative methodology. Using these methods, and by situating myself within a positivist epistemology as a researcher; I take for granted that 'truth' exists, and that it can be pursued using the scientific method.

I was intrigued by other philosophical positions and methodologies when beginning to design this research. However, at the time of designing the study, the thought of leaving the safety of numbers and certainty, of moving away from a methodology of research that I had firm grounding in when already in a context (that of beginning a clinical psychology training course, and becoming a clinical psychologist) that was new and often daunting, did not seem achievable. Qualitative research seemed complex, and at times undecipherable; using language which I had no

experience of. At that time, it seemed more sensible to situate my work within a framework that I had experience in, rather than learning yet another new skill, and risk feeling entirely overwhelmed.

However, as I have developed as a clinical psychologist and a researcher, my thoughts on the world, the idea of 'truth' and politics have become more important to me. My personal philosophy and standpoint, whilst not social constructionist is certainly allied to this position. Much of the clinical work I do comes from trying to interpret, understand and make meaning from experience through language. I have therefore, begun to question the role of my research. I have found myself at times becoming frustrated with the lack of depth, as well as lack of connection to the participants in my study.

Although using the internet to administer my questionnaire was appropriate, and meant that my research was accessible to many people. I was aware that by not people being able to meet people face to face, and discuss their answers with them, I was potentially missing a layer of understanding that may have been interesting to explore. Due to this, there were times when I wondered whether a mixed methodology may have been more appropriate for me and this study. Being able to ask participants what it was about pro-ED websites that meant that they did not gain the support that they were looking for, would have been particularly interesting. This additional layer could have supplemented not only the results of the study, but also to the pro-ED literature as a whole.

However, that is not to say that I do not see a place for my research as it currently stands, and whilst reflecting on research I think that it is important to recognise the position of

clinical psychology within the medical model and the NHS. Access to the profession is often through the gateway of a medical referral; our clients do not have the power to self-refer directly to us. Even within increasing access to psychological therapy services (IAPT), where self-referral is often possible, the stepped care model tends to preclude direct access to clinical psychology until after an assessment.

The medical model is powerful, and tells us that there is a hierarchy of evidence (Brysbaert & Rastle, 2009), that meta-analysis from randomised controlled trials produce evidence and results that are valid and reliable. It also tells us that this type of evidence is what we should base our practice on. NICE guidance is based upon such research and leaves little room for the experience of the particular client group the guidance is focusing on.

Whilst the experience and the understanding of the individual is undeniably important, in an organisation like the NHS which is expected to provide for the nation as a whole, it is understandable that research based upon quantitative methods and the positivist model is held in high regard. It's notions of reliability, validity, generalisability, and of a 'truth' that can be discovered allow for decisions to be made about the provision of care and the funding of services. In times of economic difficulties such as these, it is comforting to be able to justify decisions based upon research that provides evidence of efficacy.

As it stands, my research is positioned to add to the evidence base in a way that is currently accepted by the medical model. My work being situated within this dominant model of research allows access to journals and publications that qualitative

research can be excluded from. It also potentially allows my work to be accessible to a wider audience and have a greater range of influence. Most people have an understanding of positivist methodology. I as can confirm through my own experiences, it is comforting and familiar. It can also be easily understood, and boiled down into a take home message. Whilst at times I may have become frustrated with the process of research, I still think that the choices I made were right for me at that time.

However, given the increasing confidence I have in my own abilities both as a clinician and a researcher. I do think that if I were to begin this research now, I would be more likely to choose a methodology more in-line with my personal and political beliefs. Nonetheless, the experience of designing and completing my own research has been an enjoyable one. Whilst I generally like the process of research, it can be a lonely endeavour and it can be very easy to find the meaning that you are looking for, rather than what the data is actually telling you. Although, the positivist position of the research is that of being objective. In reality this is a difficult position to maintain, and it has only been through the use of supervision that this has been possible.

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Appendices

Appendix A: Thin Commandments

From
http://anabones.wetpaint.com/page/Thin+Commandments
(accessed 5/9/2012)

1. If you aren't thin you aren't attractive.
2. Being thin is more important than being healthy.
3. You must buy clothes, cut your hair, take laxatives, starve yourself, do anything to make yourself look thinner.
4. Thou shall not eat without feeling guilty.
5. Thou shall not eat fattening food without punishing oneself afterwards.
6. Thou shall count calories and restrict intake accordingly.
7. What the scale says is the most important thing.
8. Losing weight is good/ gaining weight is bad.
9. You can never be too thin.
10. Being thin and not eating are signs of true will power and success.

Appendix B: Ana Creed

From
http://anabones.wetpaint.com/page/Thin+Commandments
(accessed 5/9/2012)

Thin is beauty; therefore I must be thin, and remain thin, If I wish to be loved. Food is my ultimate enemy. I may look, and I may smell, but I may not touch!

I must think about food every second of every minute of every hour of every day... and ways to avoid eating it.

I must weigh myself, first thing, every morning, and keep that number in mind throughout the remainder of that day. Should that number be greater than it was the day before, I must fast that entire day.

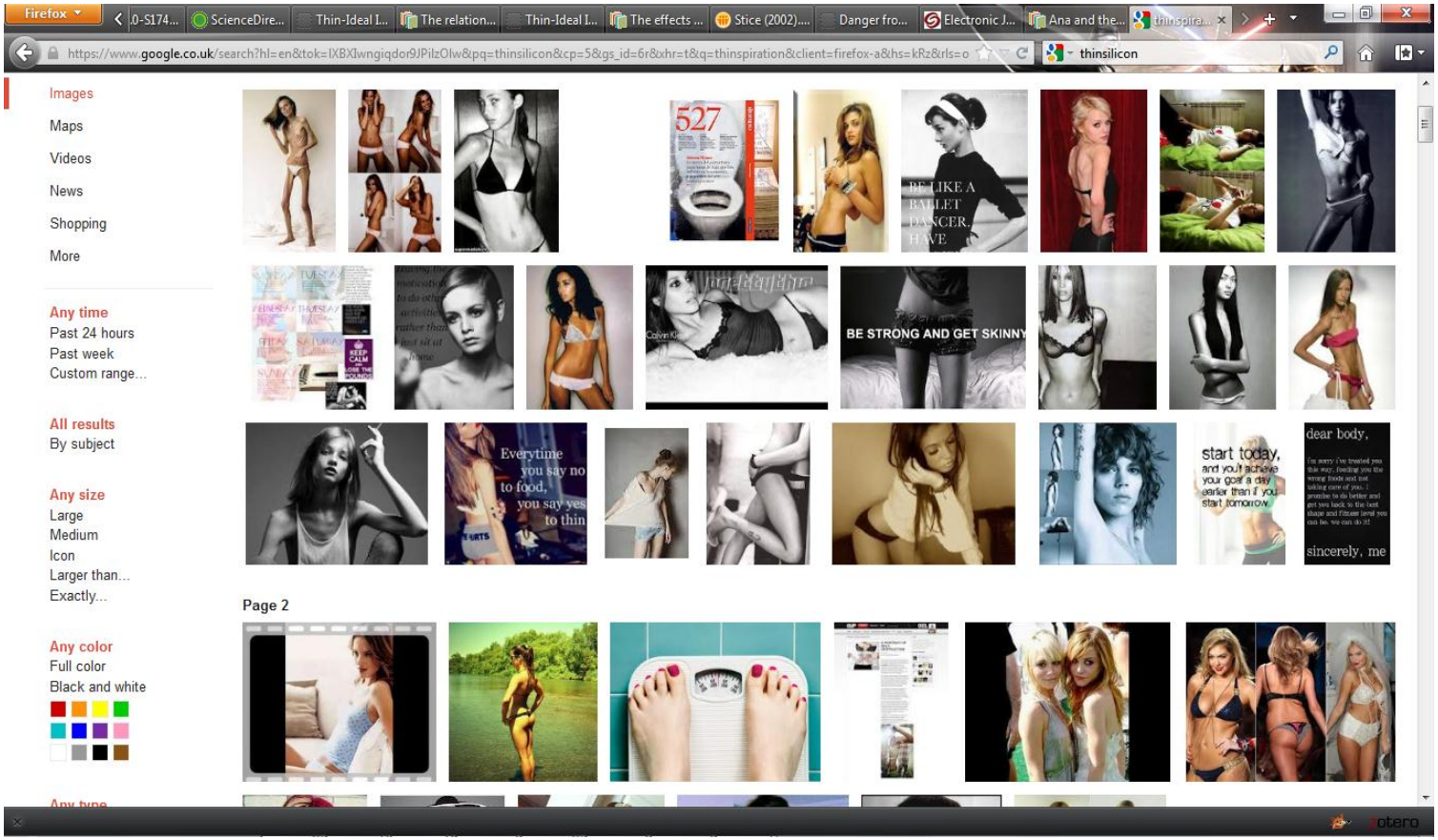
I shall not be tempted by the enemy (food), and I shall not give into temptation should it arise. Should I be in such a weakened state and I should cave, I will feel guilty and punish myself accordingly, for I have failed her.

I will be thin, at all costs. It is the most important thing; nothing else matters.

I will devote myself to Ana. She will be with me where ever I go, keeping me in line. No one else matters; she is the only one who cares about me and who understands me. I will honour Her and make Her proud. To the end of my ....."life"

Appendix C: Examples of Thinspiration

Google image search ‘thinspiration’ accessed 5/9/2012



Appendix D: Questionnaire on Internet Use

Questionnaire on internet use

(Final version 1.0:18.11.11)

Approximately how many hours have you spent on the internet over the last 7 days?

1-5 hrs

6-10hrs

11-15hrs

16-20hrs

21-25hrs

26-30hrs

31-35hrs

36+hrs

Please list any websites you visit in relation to your eating disorder

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

Why do you visit them?

For information about eating disorders

To gain support

Other (please state)

_____

What you do on them?

Read posts

Look at diaries

Post on forums

Read information

Other (please state)

_____

How did you find the websites you visit in relation to your eating disorder?

Recommended by a professional

Recommended by a friend

Other recommendation (please state who)

_____

Search engine

Other (please state) _____

How supportive do you feel the websites you visit are?

Very supportive

Supportive

Neither supportive or unsupportive

Unsupportive

Very unsupportive

Have you ever learned any tips and tricks on maintaining or controlling your eating disorder from a website?

Yes (if so please state the website)
_____

No

Have you ever used any new tips and tricks after visiting a website?

Yes (if so please state the website)
_____

No

Appendix E: Participant Information Sheet

Participant Information Sheet
Final version 2.0: 08.01.12

Title of Study: **An exploratory study of internet use in adults with eating disorders**

Name of Researcher(s): **Faye Yuill, Dr. Michael Rennoldson, Dr. Joanna Miatt & Prof. Nadina Lincoln**

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

This is an online study, and we would like to explore how people use the internet in relation to their eating disorder, and how this may be affected by what stage of treatment they are in, their social support and their confidence in their own recovery.

Why have I been invited?

You are being invited to take part because you have an eating disorder and access services related to your eating disorder. We are inviting 72 participants like you to take part.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep. If you decide to take part you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights.

What will happen to me if I take part?

On the website are five short questionnaires that you will be asked to complete. The instructions for each questionnaire are on the top of each page. Please read the instructions carefully as the questionnaires relate to different aspects of your eating disorder, internet use or how you may feel about treatment.

Once you have completed the questionnaires, you can then decide if you would like to receive the results of the study. If you would like a copy you can submit your e-mail address and the researcher will send you a copy once the study is finished. Your e-mail address will not be linked to the questionnaires that you fill in.

Completing the questionnaires should take between 15-20 minutes, and overall participation time should be less than one hour.

As the questionnaires you will be completely anonymous, the researcher will not be able to remove your results from the study once they have been submitted.

Any treatment you may be receiving will not be affected regardless of whether you decide to participate in this study or not.

Expenses and payments

Participants will not be paid to participate in the study.

What are the possible disadvantages and risks of taking part?

There are no particular risks involved in taking part in the study, although you will be asked to answer some questionnaires.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study may help us to understand the use of the internet in people with eating disorders and how this may be applied to treatment.

What happens when the research study stops?

The results of the study will be analysed and written up.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting the Derbyshire Healthcare NHS Foundation Trust Patient Advice and Liaison Service (PALS).

PALS Office
Derbyshire Healthcare NHS Foundation Trust
Bramble house
Kingsway site
Derby
DE22 3LZ

Telephone number: 0800 0272128
Email: PALS@derbyshcft.nhs.uk

Will my taking part in the study be kept confidential?

All information that is collected about you during the course of the research will be kept strictly confidential and is entirely anonymous.

We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, the data collected for the study will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database.

Your personal data (e-mail address, if given) will be kept for up to 3 months after the end of the study so that we are able to contact you about the findings of the study (unless you advise us that you do not wish to be contacted). All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your

confidentiality, only members of the research team will have access to your personal data.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw, though information collected so far cannot be erased and this information may still be used in the project analysis.

What will happen to the results of the research study

The results of the study will make up a research portfolio as part of a Doctorate in Clinical Psychology. We also plan to publish the results in a scientific journal. You will not be identified in any report/publication. If you would like to receive a summary of results, please enter your e-mail address at the end of the study. The e-mail address you enter will not be linked to your answers on the questionnaire.

Who is organising and funding the research?

This research is being organised by the University of Nottingham, conducted by Faye Yuill a Trainee Clinical Psychologist and is being funded by the University of Nottingham.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by NRES Committee East Midlands – Nottingham.

Further information and contact details

Ms Faye Yuill

Trainee Clinical Psychologist

Institute of Work, Health and Organisations

University of Nottingham

International House

Jubilee Campus

Wollaton Road

Nottingham

NG8 1BB

Email: lwxfly@nottingham.ac.uk

Nadina Lincoln

Professor of Clinical Psychology

Institute of Work, Health and Organisations

University of Nottingham

International House

Jubilee Campus

Wollaton Road

Nottingham

NG8 1BB

Email: Nadina.lincoln@nottingham.ac.uk

Appendix F: Recruitment Poster

The University of Nottingham

An exploratory study of internet use in adults with eating disorders

We would like to explore the use of the internet by adults with eating disorders.

What do I have to do?

You will be asked to visit a website and answer some questionnaires about your eating disorder, the websites that you visit and how you feel about treatment.

Completing the questionnaires should take between 15-20 minutes.

Will my taking part in this study be kept confidential?

All information that is collected about you during the course of the research will be kept strictly confidential and is entirely anonymous.

If you are interested please visit our website for more information

http://tinyurl.com/eatingdisordersinternet

(http://edu.surveygismo.com/s3/757156/An-exploratory-study-of-internet-use-in-adults-with-eating-disorders)

Appendix G: Letter Template for Lead Clinicians

service header

service address

date

Dear

An exploratory study of internet use in adults with eating disorders

Patients in contact with eating disorders services are being invited to take part in a study being conducted by researchers at the University of Nottingham on internet use.

The study would involve visiting a website and answering some questionnaires about your eating disorder, the websites that you visit and how you feel about treatment. Completing the questionnaires should take between 15-20 minutes, and no more than one hour.

All the information that is collected about you during the course of the research will be kept strictly confidential and is entirely anonymous.

If you are interesting in taking part or would like to know more information about the study please visit:

http://tinyurl.com/eatingdisordersinternet

(http://edu.surveygismo.com/s3/757156/An-exploratory-study-of-internet-use-in-adults-with-eating-disorders)

Thank you for your time and effort

Yours sincerely

Name of clinician

Position

Appendix H: Ethical Approval Letter

NRES Committee East Midlands - Nottingham 1

The Old Chapel

Royal Standard Place

Nottingham

NG1 6FS

Telephone: 0115 8839390 (Direct Line)

Facsimile: 0115 9123300

28 December 2011

Professor Nadina Lincoln

Professor of Clinical Psychology

University of Nottingham

Institute of Work, Health and Organisations

University of Nottingham, International House

Jubilee Campus

Wollaton Rd

Nottingham NG8 1BB

Dear Professor Lincoln

Study title:	**Ana and the web: An exploratory study of internet use in adults with eating disorders**
REC reference:	**11/EM/0445**

The Research Ethics Committee reviewed the above application at the meeting held on 13 December 2011.

Ethical opinion

- The Committee noted that actual consent is undertaken electronically before completion of the questionnaire. Participants are prompted to print off a copy of the Consent Form for their records. Consent is also implied by completion of the questionnaire. The Committee questioned the need for formal consent using the electronic form, and agreed that it is not necessary.

- The Lead Reviewer asked the Committee whether it would be possible for the Researcher or anyone else to change any data submitted via SurveyGizmo. The Committee confirmed that any data will be locked, therefore no alterations can be made.

- With regard to withdrawing from the study, in point number 2. of the Consent Form it states 'I understand that to do this I should navigate away from the website before submitting my results'. The Committee questioned whether participants will understand 'navigate away', and agreed that it should be simplified. However, after further discussion the Committee had agreed that the Consent Form need not be used. Therefore, changes to the Consent Form are not relevant.

- There are minor typographical and grammatical errors in supporting documents.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Additional conditions:-

1. The Committee agreed that there is no need for a formal Consent Form to be completed electronically. Therefore, the Consent Form submitted for review is not required. Consent is implied by completion of the questionnaire. Any reference to consenting online should be removed from the Participant Information Sheet.

2. In the Poster, a word in the introductory sentence should be changed i.e.

the word 'in' should be replaced with 'by' to read 'We would like to explore the use of the internet by adults with eating disorders'.

3. Under the heading 'What do I have to do?' in the poster, the word 'would' in the 1st sentence should be replaced with 'will' to read 'You will be asked to visit a website and answer some questionnaires….'.

4. In the 1st sentence of the 2nd paragraph in the Letter to Participants, the word 'would' should be replaced with 'will' to read 'The study will involve visiting a website and answering some questionnaires….'.

5. In the 1st sentence of the 3rd paragraph on page 2 of the Participant Information Sheet, the words 'you will be asked to complete' should be removed. The 1st sentence should then read 'As the questionnaires will be completely anonymous….'.

6. In the 2nd sentence of the paragraph under the heading 'What will happen if I don't want to carry on with the study?', the word 'then' should be replaced with 'though' to read 'If you withdraw, though information collected so far cannot be erased….'

7. Under the heading 'What if there is a problem?' in the Participant Information Sheet, there is no specific contact details for complaints identified i.e. a named department or telephone number. The Committee recommend that the Trust's Patient Advice and Liaison Service (PALS) details are inserted.

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Advertisement		18 November 2011
Evidence of insurance or indemnity		26 July 2011
Investigator CV	Nadina Lincoln	18 November 2011
Investigator CV	Michael Rennoldson	21 November 2011
Investigator CV	Ms Faye Yuill	18 November 2011
Letter from Sponsor		18 November 2011
Letter of invitation to participant	1	18 November 2011
Other: Demographic Information	1.0	18 November 2011
Participant Consent Form	1.0	18 November 2011
Participant Information Sheet	1.0	18 November 2011
Protocol	1.0	18 November 2011
Questionnaire: Stages of Change Scale	1	18 November 2011
Questionnaire: Multidimensional Scale of Perceived Social Support	1	18 November 2011
Questionnaire: Eating Disorder Recovery Self-efficacy Questionnaire		
Questionnaire: EDE-Q	1	18 November 2011
Questionnaire: Questionnaire on Internet Use	1.0	18 November 2011
REC application	77242/267754/1/316	18 November 2011

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

11/EM/0445	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

Reverend Keith Lackenby

Vice-Chair

Email: trish.wheat@nottspct.nhs.uk

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*

"After ethical review – guidance for researchers"

Copy to: *Miss Faye Yuill – Student*

Mr Paul Cartledge – University of Nottingham

Rubina Reza - Derbyshire Healthcare NHS Foundation Trust

Appendix I: R&D Approval from Derbyshire Healthcare Foundation Trust

Fergie Harrison Hall

Derbyshire Healthcare NHS
NHS Foundation Trust

NRCd 28.2.12

Mental Health Research Unit
Kingsway House
Kingsway
Derby
DE22 3LZ

Tel: (01332) 623579
Fax: (01332) 623576
Email: Rubina.Reza@Derbyshcft.nhs.uk

20th February 2012

Professor Nadina Lincoln
B19 International House
Jubilee Campus
University of Nottingham
Wollaton Road
Nottingham
NG8 1BB

Dear Professor Lincoln

I am writing to inform you that the Derbyshire Healthcare NHS Foundation Trust Clinical Research Committee has reviewed and approved the following study:

Title: An exploratory study of internet use in adults with eating disorders

REC Reference 11/EM/0445

Area: Eating Disorders Service, North Mill, Belper DE56 1YD

Start date: 27th February 2012 **End date:** 1st September 2012

As part of our monitoring requirements, we will ask you for a progress report six months after the start of your study, and every six months as applicable. We will also ask you for a short summary of your research findings once the study is complete to assist in the dissemination process within the Trust.

You can now proceed with your study in accordance with the agreed protocol and the Research Governance Framework. Please notify us immediately of any adverse events or changes to the protocol.

If you require any further information please do not hesitate to contact me.

Yours sincerely

RReza

Rubina Reza
Research and Clinical Audit Manager

On behalf of Dr John Sykes and the Clinical Research Committee

Appendix J: R&D Approval from Lincolnshire Partnership NHS Foundation Trust

Lincolnshire Partnership NHS
NHS Foundation Trust

Ref:

Date: 28 February 2012

Faye Harrison Yuill

Institute of Work, Health & Organisations

International House

Jubilee Campus

University of Nottingham

NOTTINGHAM

NG8 1BB

Research and Effectiveness Team

Trust Headquarters

Unit 9, The Point

Lions Way

SLEAFORD

Lincolnshire

NG34 8GG

Tel: 01529 222206

Fax: 01529 222226

Dear Faye

Study title: Ana and the web: an exploratory study of internet use in adults with eating disorders

Chief investigator name: Professor Nadina Lincoln

Sponsor name: University of Nottingham

REC number: 11/EM/0445

Date of permission: 28 February 2012

List of all site(s) for which NHS permission for research is given: **Lincolnshire Partnership NHS Foundation Trust, Eating Disorder Service**

List of all PIC(s) for which agreement is given: **N/A**

NHS permission for the above research has been granted by Lincolnshire Partnership NHS Foundation Trust on the basis described in the application form, protocol and supporting documentation.

Permission is granted on the understanding that the study is conducted in accordance with the Research Governance Framework, ICH GCP and NHS Trust policies and procedures (available at http://www.lpt.nhs.uk/).

Permission is only granted for the activities for which a favourable opinion has been given by the REC [and which have been authorised by the MHRA]

List of any conditions of approval: **none**

The research sponsor or the Chief Investigator, or the local Principal Investigator at a research site, may take appropriate urgent safety measures in order to protect research participants against any immediate hazard to their health or safety.

The Research and Effectiveness office should be notified, at the address above, that such measures have been taken. The notification should also include the reasons why the measures were taken and the plan for further action. The Research and Effectiveness Office should be notified within the same time frame of notifying the REC and any other regulatory bodies.

Any research carried out by a Trust employee with the knowledge and permission of the employing organisation will be subject to NHS indemnity. NHS indemnity provides indemnity against clinical risk arising from negligence through the Clinical Negligence Scheme for Trusts (CNST). Further details can be found at Research in the NHS: Indemnity arrangements (Department of Health 2005).

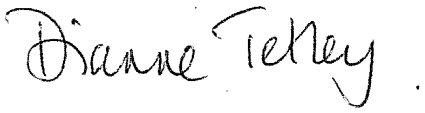
All amendments (including changes to the local research team) need to be submitted in accordance with guidance in IRAS.

Please inform the Research and Effectiveness department of any changes to study status.

Please note that the NHS organisation is required to monitor research to ensure compliance with the Research Governance Framework and other legal and regulatory requirements. This is achieved by random audit of research.

We are pleased to inform you that you may now commence your research. Please retain this letter to verify that you have Trust permission to proceed. We wish you every success with your work.

Yours sincerely



Dianne Tetley

Associate Director Research and Effectiveness

Lincolnshire Partnership NHS Foundation Trust

Cc Chief Investigator **Professor Nadina Lincoln, University of Nottingham**

Sponsor **Mr Paul Cartledge, University of Nottingham**

Local collaborator **Ingrid Whitaker, Consultant Clinical Psychologist, LPFT**

Enc: Data Protection Guidance on the transportation of personal identifiable data

Appendix K: Letter of Access from Lincolnshire Partnership NHS Foundation Trust

Lincolnshire Partnership NHS
NHS Foundation Trust

Ref

Date: 28 February 2012

Faye Harrison Yuill
Institute of Work, Health & Organisations
International House
Jubilee Campus
University of Nottingham
NOTTINGHAM
NG8 1BB

Research and Effectiveness Team
Trust Headquarters
Unit 9, The Point
Lions Way
SLEAFORD
Lincolnshire, NG34 8GG

Tel: 01529 222206
Fax: 01529 222226

Dear Faye

Letter of access for research:

Ana and the web: an exploratory study of internet use in adults with eating disorders

As an existing NHS employee you do not require an additional honorary research contract with this NHS organisation. We are satisfied that the research activities that you will undertake in this NHS organisation are commensurate with the activities you undertake for your employer. Your employer is fully responsible

for ensuring such checks as are necessary have been carried out. Your employer has confirmed in writing to this NHS organisation that the necessary pre-engagement check are in place in accordance with the role you plan to carry out in this organisation. This letter confirms your right of access to conduct research through **Lincolnshire Partnership NHS Foundation Trust (LPFT)** for the purpose and on the terms and conditions set out below. This right of access commences on **28 February 2012** and ends on **30 September 2013** unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

You are considered to be a legal visitor to Lincolnshire Partnership NHS Foundation Trust premises. You are not entitled to any form of payment or access to other benefits provided by this organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through Lincolnshire Partnership NHS Foundation Trust, you will remain accountable to your employer **Derbyshire Healthcare NHS Foundation Trust** but you are required to follow the reasonable instructions of your nominated manager **Dianne Tetley Associate Director of Research and Effectiveness** in this NHS organisation or those given on her/his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with Lincolnshire Partnership NHS Foundation Trust policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with Lincolnshire Partnership NHS Foundation Trust in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on Lincolnshire Partnership NHS Foundation Trust premises. Although you are not a contract holder, you must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of a contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

Lincolnshire Partnership NHS Foundation Trust will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions

described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Where applicable, your substantive employer will initiate your Independent Safeguarding Authority (ISA) registration in-line with the phasing strategy adopted within the NHS (as from 26th July 2010 at the earliest). Once you are ISA-registered, your employer will continue to monitor your ISA registration status via the on-line ISA service. Should you cease to be ISA-registered, this letter of access is immediately terminated. Your substantive employer will immediately withdraw you from undertaking this or any other regulated activity and you MUST stop undertaking any regulated activity.

Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

If your circumstances change in relation to your health, criminal record, professional registration or ISA registration, or any other aspect that may impact on your suitability to conduct research, or your role in research changes, you must inform the NHS organisation that employs you through its normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely

Dianne Tetley

Dianne Tetley
Associate Director Research and Effectiveness
On behalf of HR Department
Lincolnshire Partnership NHS Foundation Trust

cc:

Susan Purser, Workforce and OD, Derbyshire Healthcare NHS Foundation Trust, Bramble House, Kingsway Site, Kingsway, DERBY, DE22 3LZ