Oral Health Knowledge and Practice Behaviors among Patients with Eating Disorders: A Pilot Study

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ABSTRACT

Jessica Catherine Peek
Oral Health Knowledge and Practice Behaviors among Patients with Eating Disorders
(Under the direction of Rebecca Wilder)

Oral manifestations of eating disorders (ED) have been well documented in the literature. However, the knowledge ED patients have about the effects of the disease on their oral health remains unknown. The purpose of this study is to determine oral health knowledge and oral homecare practice behaviors among ED patients. Oral health knowledge, homecare practice behaviors, and referral patterns of 41 patients currently or previously diagnosed with anorexia nervosa, bulimia nervosa, or eating disorder not otherwise specified were measured using an electronic survey. Univariate analysis revealed moderate to high knowledge of the oral manifestations of ED. However, there is a low level of knowledge regarding appropriate post-purging behaviors. Many participants reported brushing (79%) or doing nothing (42.1%) after purging. The rate of referral to a dentist among this population was (32.4%). The most commonly reported barrier to accessing dental care is embarrassment (50%).

ACKNOWLEDGEMENTS

I would like to thank my committee, Dr. Maria La Via, Dr. Michael Roberts, and Professor Rebecca Wilder for their expertise, time, and support of me in hopes of bringing the importance of dental care to so many individuals suffering from EDs.

Debbie Price and Dr. Ceib Phillips also deserve a special thank you for their statistical expertise. Without them none of this would have made sense!

I would also like to thank three very special friends, Lisa Barron, Nuha Ahmad, and Jonathan Owens, who have been there for me unconditionally and provided much needed insight through this endeavor. I love you all!

Last, but not least, I'd like to thank my family for listening when I was stressed to the max, calming me down, and reassuring me that I can do this!

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LIST OF ABBREVIATIONS

ED	**Eating Disorder(s)**
AN	**Anorexia Nervosa**
BN	**Bulimia Nervosa**
EDNOS	**Eating Disorder Not Otherwise Specified**
OHP	**Oral Healthcare Provider(s)**

INTRODUCTION

Eating disorders are serious psychiatric illnesses that can lead to death if untreated.[1] The American Psychiatric Association classifies Eating Disorders (ED) into three categories, Anorexia Nervosa (AN), Bulimia Nervosa (BN), and Eating Disorder Not Otherwise Specified (EDNOS), each having specific diagnostic criteria.[2] These disorders are characterized by acute disturbances in eating behavior resulting from an intense preoccupation with body image.[2] Consequently, many areas of the human body are negatively affected by EDs; the oral cavity being one. Published studies have investigated the oral manifestations that occur as a result of disordered eating. Mucosal lesions, glossitis, erythematous lesions on the soft palate, traumatized oral mucosal membranes and pharynx, dental erosion, sialoadenosis, hyposalivation, necrotizing sialometaplasia, oral burning sensation, glossodynia, xerostomia, angular cheilitis, and dental sensitivity have been reported.[3-6]

Early diagnosis, referral, and treatment of individuals with an ED can significantly increase the likelihood of recovery.[6]– A team approach is the recommended model of care including a psychiatrist, individual and/or family therapist, dietitian, and primary care provider.[1] Due to the nature of disordered eating, and the negative effects to the oral cavity, the oral healthcare provider plays a fundamental role in identification of patients with EDs and can also serve as a facilitator of intervention.

The literature reveals little in the area of healthcare providers' knowledge of the relationship of EDs to the oral condition. However, what is known reveals that the knowledge level of oral healthcare providers (OHP) about eating disorders is low. [7-9]

Patients with EDs should also be aware of the implications to oral care. Ultimately, they are responsible for their oral hygiene and their knowledge of how to protect their oral health is important. To date, there are no published studies addressing the oral health knowledge of individuals suffering from an ED.

The aim of this study is to investigate the oral health knowledge and oral homecare practice behaviors among individuals with an ED. Furthermore, this study aimed to assess dental referral patterns, willingness to get dental treatment, and possible barriers to dental treatment among this population.

REVIEW OF THE LITERATURE

Eating Disorders

An ED is a serious psychiatric illness with significant morbidity and mortality. AN has the highest mortality rate of any psychiatric disorder.[1] EDs are not limited to any particular sex, age, or race, but adolescent girls and young females are more commonly affected. [2,10,11] In the United States alone, as many as 10 million females and 1 million males are stricken with this disorder.[12] EDs are characterized by acute disturbances in eating behavior resulting from an intense preoccupation with body image.[2] The American Psychiatric Association classifies EDs into Anorexia Nervosa (AN), Bulimia Nervosa (BN), and Eating Disorders Not Otherwise Specified (EDNOS), each classification having specific diagnostic criteria.[2] The lifetime prevalence of AN and BN among adolescents is approximately 0.3% and 0.9 respectively.[13] Additionally, EDs more commonly affect Caucasian females and less commonly affect African American and Asian counterparts.[14,15] In more industrialized societies where being attractive is linked to being thin, AN and BN appears to be far more prevalent.[2] Furthermore, cultural factors[16] and sports place individuals at a greater risk for developing an ED.[17]—It has been suggested that sports such as dancing, gymnastics, figure skating, and distance running for females, and bodybuilding and wrestling in males place these athletes at a greater risk for developing an ED due to the emphasis on appearance and the need for weight control.[1]

AN is characterized by extreme weight loss due to a distorted perception of body image and a profound fear of gaining weight.[2] In contrast, BN is characterized by binge eating and inappropriate compensatory behaviors to prevent weight gain.[2]

Disordered eating can lead to complications in metabolic, morphological and functional alterations of multiple organs and systems and can consequently

result in life-threatening outcomes.[3] In addition, oral manifestations have been reported as a result of disordered eating.[4,18-20] These manifestations include mucosal lesions glossitis, erythematous lesions on the soft palate, traumatized oral mucosal membranes and pharynx, dental erosion, sialoadenosis, hyposalivation, necrotizing sialometaplasia, oral burning sensation, glossodynia, xerostomia, angular cheilitis, and dental sensitivity.[3-6] There are conflicting results in regards to the impact of EDs on dental caries.[4,19,20]

Early diagnosis, referral, and treatment of individuals with EDs can significantly increase the likelihood of recovery.[6] There has been an increased risk of death, mainly suicide among individuals with EDs.[21] Treatment modalities to be implemented are dependent on the type of ED and the age of the individual.[1] Psychiatrists often assume the leadership role, but collaborate with other physicians, psychologists, registered dietitians, social workers, other medical specialists, and dentists in the treatment of the individual that suffers from an ED.[1]

Anorexia Nervosa (AN)

The age of onset for AN is typically mid to late adolescence, usually ages 14-18 .[2,11] Due to extreme weight loss and profound fear of gaining weight, these individuals characteristically appear emaciated and malnourished.[2] AN has severe consequences to overall health, and is increasingly prevalent in cultures and societies where attractiveness is coupled to being thin.[2]

Diagnostic criteria for AN include refusal to maintain body weight at or above a minimal normal weight for age and height, marked fear of gaining weight or becoming fat, a deranged perception of one's body image, and amenorrhea, the loss of three consecutive menstrual cycles, in postmenarcheal females. AN appears in two subtypes: restricting and binge-eating/purging.[2] The restricting type employs dieting, fasting, or excessive exercise to achieve weight loss whereas, the binge-eating/purging type regularly engages in binge eating or purging. Purging in these individuals can occur through self-induced vomiting and/or the misuse of laxatives, diuretics, and enemas.[2]

Bulimia Nervosa (BN)

The age of onset for BN ranges from 13 to 35 years of age.[10] In contrast to AN, individuals with BN typically appear to be of normal weight[2], thus making bulimia more difficult to recognize and diagnose. Bulimia too, can lead to severe health and medical problems. [2]

Diagnostic criteria for BN include recurrent episodes of binge eating, recurrent inappropriate compensatory behaviors to prevent weight gain (vomiting, misuse of diuretics/laxatives, fasting, enemas, other medications, or excessive exercise), both of these behaviors must occur twice a week for 3 months.[2] BN appears in two subtypes: purging and non-purging. The latter of the two employs other methods to compensate for their binge eating such as excessive exercise or fasting.[2]

Shame and guilt are typical feelings associated with individuals with BN due to their want/need to hide their eating behaviors. Typically secrecy is involved when a binge occurs and can be triggered by many different stressors.[2]

Eating Disorder Not Otherwise Specified (EDNOS)

EDNOS is a category for disordered eating that doesn't meet the criteria for AN or BN.[2] Some examples include, but are not limited to, the following: 1) repeatedly chewing and spitting out, but not swallowing, large amounts of food; 2) binge-ED in which the individual will go through recurrent episodes of binge eating, but will abstain from purging; and, 3) all of the criteria for anorexia are met except the individual may have menstrual cycles or the individual's current weight is in the normal range.[2]

Although there are different diagnostic criteria for each ED, there are times when crossover between EDs can occur.[22,23] Research suggests that the crossover rate was higher for AN to BN than for BN to AN.[23]

Psychiatric Comorbidities

Substance abuse disorders, mood and anxiety disorders, as well as personality disorders have been well documented co-morbidities among patients with EDs. Other disorders include alcohol abuse[2,13,24], depression[13], panic disorder[2,13], attention-deficit/hyperactivity disorders[13], social phobia [13], obsessive-

compulsive disorder[2], body dismorphic disorder[2], oppositional defiant disorder[13], posttraumatic stress disorder[13], and conduct disorder.[13]

Oral Manifestations of Eating Disorders

Oral manifestations of EDs are primarily caused by nutritional deficiencies, metabolic impairment, lack of attention to hygiene/care, modified nutritional habits, assumption of certain drugs, and erosion of enamel resulting from self-induced vomiting and differ depending on the specific behaviors associated with each disorder.[3,19] Chronic ingestion of highly acidic carbonated beverages or fruit juices and habitual sucking on lemons or other citrus fruits can also lead to erosion of teeth.[19] The oral manifestations are dependent on the type of ED present. According to Little and colleagues[19], xerostomia, enlarged parotid glands and atrophic mucosa are the most commonly reported oral manifestations of AN. The most frequently observed oral manifestations seen in BN are labial tooth erosion, tooth sensitivity, xerostomia, dental caries, periodontal disease, enlarged parotid glands, and poor oral hygiene.[19]

Dental Management of Patients with Eating Disorders

A thorough medical, dental, and nutritional history should be taken on each patient; however research suggests a low incidence of assessment for EDs by oral health care professionals (OCHP).[7,25,26] If an ED is suspected, the OHCP may need to confront the patient, or the patient's parents if under the age of 18, and address the dental, medical, and psychological complications of the disorder.[19] The OHCP should refer the patient to a psychologist or physician for the evaluation of an ED. In the dental office, management of the patient with an ED consists of oral hygiene instruction and topical fluoride applications and appropriate restorative care of affected teeth.[19, 27] It is important to note that restoration of affected teeth should not be restored until the disease is controlled.[27]

Healthcare Providers' and Oral Healthcare Providers Knowledge of the Influence of Eating Disorders on Oral Health

The literature reveals little in the area of healthcare providers' knowledge of the relationship of EDs to the oral condition.[7-9] It is the responsibility of dental healthcare providers to collaborate with physicians and other providers who care for patients with EDs. Often times, OHCP's see their patients more frequently (≥ 2 times a year) than their medical or psychiatric counterparts. Therefore they play a fundamental role in the identification of patients with EDs and can also serve as the facilitator of an intervention.

DeBate and colleagues found that inadequate training, fear of misdiagnosis, fear of offending patients, lack of interdisciplinary communication, and or a combination of the above contribute to the low level of knowledge and lack of secondary prevention among OHCP's.[26] A subsequent study performed by DeBate and colleagues found that this lack of knowledge among OHP's may be due in part to the deficiency of information provided in the oral health curricula.[28] Only thirty-two minutes of didactic instruction on EDs in the oral health curriculum was reported.[28] In response to some of the aforementioned barriers DeBate and colleagues developed and evaluated a pilot web-based training program of four modules for OHP's on the secondary prevention of EDs. A pre-/post-test evaluation was given to dental and dental hygiene students. Overall, the short-term findings found the training to be effective in regards to knowledge gained among dental and dental hygiene students with respect to EDs and oral health. [29]

Patients' with Eating Disorders Knowledge about Oral Health

Patients with EDs should also be aware of the implications to oral health. However, there are no published studies addressing the oral health knowledge of individuals suffering from an ED.

Purpose of the Study

The purpose of this study is to investigate the oral health knowledge and oral homecare practice behaviors among individuals with EDs. Furthermore, this

study will assess dental referral patterns, willingness to get dental treatment, and possible barriers to dental treatment among this population.

INTRODUCTION AND LITERATURE REVIEW

An eating disorder (ED) is a serious psychiatric illness with the highest mortality rate of any psychiatric disorder.[1] EDs are not limited to any particular sex, age, or race, but can affect anyone worldwide; however, adolescent girls and young females are more commonly affected.[2,10,11] In the United States alone, as many as 10 million females and 1 million males are stricken with this disorder.[12] EDs are characterized by acute disturbances in eating behavior resulting from an intense preoccupation with body image.[2] The American Psychiatric Association classifies EDs into Anorexia Nervosa (AN), Bulimia Nervosa (BN), and Eating Disorders Not Otherwise Specified (EDNOS), each classification having specific diagnostic criteria. The lifetime prevalence of AN and BN among adolescents is approximately 0.3% and 0.9% respectively.[13]

AN is characterized by extreme weight loss due to a distorted perception of body image and a profound fear of gaining weight.[2] In contrast, BN is characterized by binge eating and inappropriate compensatory behaviors to prevent weight gain.[2] Disordered eating that does not meet the criteria for AN or BN falls under the category of EDNOS.[2] Although there are different diagnostic criteria for each ED, there are times when crossover between EDs can occur.[22,23]

Disordered eating can lead to complications in metabolic, morphological and functional alterations of multiple organs and systems and can consequently result in life-threatening outcomes.[3] Oral manifestations have also been reported as a result of an eating disorder. [4,18-20] These manifestations include: mucosal lesions glossitis, erythematous lesions on the soft palate, traumatized oral mucosal membranes and pharynx, dental erosion, sialoadenosis, hyposalivation, necrotizing sialometaplasia, oral burning sensation, glossodynia, xerostomia, angular cheilosis, and thermal sensitivity to name a few.[3-6] There are conflicting results in regard to the impact of EDs on dental caries. [4,19,20]

Early diagnosis, referral, and treatment of individuals with EDs can increase the likelihood of recovery from the disease.[6] AN has the highest mortality rate of any psychiatric disorder, in addition there is significant morbidity and mortality related to the eating disorders.[21] Treatment modalities utilized are dependent on the type of ED present, ideal management of the individual with an ED must take on a multidisciplinary approach including psychiatrists, psychologists, social workers, dietitian and primary care providers.[1] This team should also include a dentist.

Oral manifestations of EDs have been well documented and are dependent on the type of eating disorder and symptoms present. These manifestations are primarily caused by nutritional deficiencies, metabolic impairment, lack of attention to hygiene/care, modified nutritional habits, use of certain drugs, and erosion of enamel resulting from self-induced vomiting. These symptoms differ depending on the specific behaviors associated with each disorder.[3,19] Chronic ingestion of highly acidic carbonated beverages or fruit juices and habitual sucking on lemons or other citrus fruits can also lead to erosion of teeth.[19] According to Little and colleagues[19], xerostomia, enlarged parotid glands and atrophic mucosa are the most commonly reported oral manifestations of AN.[19] The most frequently observed oral manifestations seen in BN are labial tooth erosion, tooth sensitivity, xerostomia, dental caries, periodontal disease, enlarged parotid glands, and poor oral hygiene.[19]

A thorough medical, dental, and nutritional history should be obtained on each patient; however research suggests a low incidence of assessment for EDs among oral health care professionals (OCHP).[7,25,26] If an ED is suspected, the OHCP may need to educate the patient, or the patient's parents if under the age of 18, and discuss the dental, medical, and psychological complications of the disorder.[19] The OHCP is also responsible for referring the patient to a psychologist or physician for the evaluation of a suspected ED. In the dental office, management of the patient with an ED consists of oral hygiene instruction and topical fluoride applications and appropriate restorative care of affected teeth .[19,27]

The literature reveals little in the area of healthcare providers' knowledge of the relationship of EDs to the oral condition. It is the responsibility of dental healthcare providers to collaborate with physicians and other providers who care for patients with EDs. Often times, OHCP's see their patients more frequently (≥ 2 times a year) than their medical or psychiatric counterparts. Therefore they play a fundamental role in the identification of patients with EDs and can also serve as the facilitator of an intervention.

The literature suggests that the OHPs level of knowledge concerning the oral manifestations of EDs is low.[7-9] DeBate and colleagues[26] found that inadequate training, fear of misdiagnosis, fear of offending patients, lack of interdisciplinary communication, and/or a combination of the above are issues that contribute to the low level of knowledge and lack of secondary prevention among OHCP's.[26] Moreover, a subsequent study performed by DeBate and colleagues, found that this lack of knowledge among OHP's may be due in part to the deficiency of information provided in the oral health curricula.[28] Only thirty-two minutes of didactic instruction on EDs in the oral health curriculum has been reported.[28] In response to some of the aforementioned barriers DeBate and colleagues developed and evaluated a pilot web-based training program of four modules for OHP's on the secondary prevention of EDs. A pre-/post-test evaluation was given to dental and dental hygiene students. Overall, the short-term findings found the training to be effective in regards to knowledge gained among dental and dental hygiene students with respect to EDs and oral health. [29]

Patients with EDs should also be aware of the implications to oral health. However, there are no published studies addressing the oral health knowledge of individuals suffering from an ED.

The purpose of this study is to investigate the oral health knowledge and oral homecare practice behaviors among individuals with EDs. Furthermore, this study will assess dental referral patterns, willingness to get dental treatment, and possible barriers to dental treatment among this population.

METHODS AND MATERIALS

Survey Design

A self-administered online survey was created to assess oral health knowledge, oral practice behaviors, and referral patterns among patients with EDs (Appendix F). Initial approval was obtained from the University of North Carolina Institutional Review Board, pilot tested, revised, and resubmitted for final IRB approval.

Participants

Participants were females who voluntarily completed the online survey. They were recruited from various ED clinics/programs across the United States, listservs, social networking sites, and through respondent driven sampling. To be included in the study, participants were: (1) previously or currently diagnosed with an ED according to the Diagnostic and Statistical Manual of Mental Disorders, IV Edition; (2) 12 years of age or older; (3) female; and (4) able to speak and read English. Total participants were 41 ranging in age from 19-62 years.

Procedure

Emails containing a link to the data gathering website, *Qualtrics,* (www.qualtrics.com) were sent to (1) program directors at 83 ED programs throughout the United States; (2) listservs; and, (3) social networking sites. Program directors of ED clinics were instructed to forward the emails to their patients. In an attempt to increase the response rate, follow up emails were sent to program directors and listservs every two to three weeks until data collection ended.

Prior to accessing the survey, the participants were required to give informed consent. For participants aged 12-17, parents were required to give informed consent before obtaining consent from the child. The process of

obtaining consent within this study was approved by the University of North Carolina at Chapel Hill Institutional Review Board.

To encourage participation and completion, the survey did not ask for identifying information.

Assessments and Measures

Demographic information provided by the participants was age and ED diagnosis. Participants were also asked if they participated in purging behaviors and if so, how often purging occurred.

All questions asked were assembled based on a review of the existing literature related to the effect of EDs on oral health. The oral health knowledge items measured consequences of EDs on oral health (such as, dental erosion, salivary gland enlargement, dry mouth, angular cheilosis, and tooth sensitivity), oral homecare practices such as how many times per day tooth brushing should occur, and foods that may negatively affect oral health. Closed and open ended questions were used.

Oral health practice behaviors were assessed by asking participants how often they brush their teeth, and what type of procedures they participate in after purging (such as, brushing, rinsing with a fluoride rinse, rinsing with water, chewing on a Tums®, doing nothing, rinsing with a baking soda and water, and/or other). The response options for these questions were open ended and "check ALL that apply", respectively.

Referral patterns were assessed by asking if they had ever been told to see a dentist in reference to their ED and if so, by whom (including mental health professional, primary care physician, family member, friend, pastor, or other), whether or not they sought treatment and if not, why. The response options for these questions were "yes/no" and "check ALL that apply", respectively.

Statistical Analysis

Data was analyzed using Statistical Analysis Software (SAS), and univariate analyses were performed. No p-values were reported since this was a convenience sample.

RESULTS

Of the 41 participants, the median age range was 28 years. Nineteen subjects had AN, 12 had BN, and 10 had EDNOS. Reported median range of being diagnosed with an ED by a healthcare provider was 19 years (AN), 20 years (BN), and 25 years (EDNOS). Demographic data are presented in Figures 1 and 2.

Of the 41 participants, 22 participated in purging behaviors. The majority reported purging 1-2 times per day (55.6%) or 3-4 times per week (75.0%) as depicted in Table 1.

Table 2 describes the distribution of responses regarding post-purging behaviors. The majority of participants, 79%, reported brushing their teeth after purging while 36.8% rinse with a fluoride rinse. Forty two percent reported doing nothing after purging.

Tables 3 and 4 describe the distribution of responses regarding oral health knowledge. The majority of participants reported the most common oral effect resulting from purging is dental erosion (71.4%). In response to where dental erosion most commonly occurs in the mouth, 40% reported they didn't know, only 28.1% correctly answered dental erosion occurs most commonly on top teeth, tongue side. There was 100% agreement to the statement that tooth brushing should occur at least 2 times per day. The bulk of the participants agreed that acidic fruits and food high in carbohydrates can negatively affect oral health (65.6%). In addition, only 23.5% correctly agreed that brushing should NOT occur after vomiting.

In response to being referred to a dentist, only a third (32.4%) reported they had been referred. The most commonly reported person to refer was a family member (54.5%). Only one participant reported receiving dental treatment as a result of their ED. Ten participants reported wanting to receive dental

treatment due to problems of their ED (30.3%). Reported barriers to dental treatment were no insurance/financial reasons (40%) and fear/embarrassment (60%) as seen in Table 5. Almost half of the participants reported being interested in obtaining more information about good oral health habits (48.5%) with ED programs/clinics being the most commonly reported place they would like to receive the information (56.3%).

DISCUSSION

The current study investigated oral health knowledge, practice behaviors, and referral patterns among patients with EDs. Although the data suggested that subjects had a relatively high knowledge of the oral manifestations of EDs on oral health such as dental erosion, angular cheilitis, dry mouth, and sensitivity, it is of particular importance that many subjects reported brushing after purging. This indicates a low level of knowledge in respect to understanding how dental erosion occurs; namely from the acid produced by vomiting and the subsequent act of brushing the "acid" off of the teeth.

With regards to dental referral patterns, more participants reported they have never been referred to a dental professional, however, of the eleven that were referred, only one was referred by their primary care physician. This is of concern because the current recommended model of care suggests a multidisciplinary approach[2] which is clearly not represented in this sample. In addition, many participants were opposed to receiving treatment from a dental professional due to her ED. Future research may be needed to determine the reasons for this. Could it be shame or guilt as many would assume, or just not caring about themselves enough to pursue treatment?

It is important to note the current study's limitations with regard to interpretation of results. The small number of participants and lack of adolescent volunteers make it hard to generalize the results to all individuals with EDs. As reported in the literature EDs typically present initially in the adolescent years.[2,10] Therefore, the lack of adolescent participants may limit the validity of the results. Additionally, the entire survey was not completed by all participants.

Additional research is needed to determine better recruitment methods and ways to increase response rate. Additionally, oral/systemic links have been established in many different disciplines with a multidisciplinary approach being

the best method for comprehensive treatment. Future research may be needed to determine mental health professional's knowledge of the oral manifestations of EDs and their willingness to refer patients to the OHP.

CONCLUSION

Although most survey participants had basic knowledge concerning the oral manifestations of EDs, there was significantly less knowledge regarding the importance of not brushing after purging. The majority of respondents reported brushing directly after purging. Reported referral to a dental professional was low among this group as well, suggesting that many of these individuals are not receiving comprehensive care in regards to their ED. Of those who were referred, the most commonly reported barrier to receiving care was fear and embarrassment. The information gained from this survey will serve as the basis for the continuing need of interdisciplinary/comprehensive treatment of individuals suffering from an ED as well as bridging the gap in knowledge amongst all parties involved.

Table 1. Purging Characteristics (n = 41)

	n	(%)
Do/did you purge?		
Yes	22	53.7
No	19	46.3
How many times per day do/did you purge?		
1-2	5	55.6
3-4	4	44.4
If you do/did not purge daily, how many times per week do/did you purge?		
≤3	5	62.5
≥4	3	37.5

Frequency Missing = 5

Table 2. Distribution of responses to post-purging behaviors (n = 22)

	n	(%)
After purging, do/did you: (Choose ALL that apply)		
Brush teeth	15	79.0
Do nothing	8	42.1
Rinse with a fluoride rinse	7	36.8
Rinse with water	6	31.6
Rinse with baking soda and water	2	10.5
Chew Tums ®	1	5.3
Other	1	5.3
Frequency Missing = 3		

Table 3. Distribution of responses to oral health knowledge questions (n = 41)

	(n)	% Subjects
The oral effects of eating disorders are: (check ALL that apply)		
Dental erosion	25	71.4
Saliva gland enlargement	21	60.0
Dry mouth	17	48.6
Tooth sensitivity	17	48.6
Cracking in the corners of the mouth	13	37.1
Oral cancer	9	25.7
Frequency Missing = 6		
The most common oral effect that happens from purging is: (choose only ONE answer)		
Dental erosion	31	88.6
Cavities	2	5.7
Gum disease	1	2.3
Don't know	1	2.3
Frequency Missing = 6		
Where does dental erosion (wearing down of the teeth) most commonly happen in the mouth? (Choose ONE answer only)		
Top teeth, tongue side	9	28.1
Bottom teeth, tongue side	7	21.9
Bottom teeth, cheek side	1	3.1
Don't know	13	40.6
Frequency Missing = 9		

Table 4. Distribution of responses to Likert scale items regarding oral health knowledge (n = 41)

	Agree (%)	Don't Know (%)	Disagree (%)
You should brush your teeth at least 2 times per day. *Frequency Missing = 6*	100	0	0
Acidic fruits and foods high in carbohydrates can negatively affect the health of your mouth. *Frequency Missing = 7*	64.7	20.1	14.7
You are NOT supposed to brush your teeth after you vomit. *Frequency Missing = 7*	23.5	32.4	44.1

Table 5. Distribution of responses to dental referral questions (n = 41)

	n	(%)
Have you ever been referred to a dentist?		
Yes	11	32.4
No	23	67.6
Frequency Missing = 7		
Who referred you to a dentist?		
Primary care physician	1	9.1
Family member	6	54.5
Friend	1	9.1
Other	3	27.3
Have you ever received dental treatment because of your eating disorder?		
Yes	1	2.3
No	33	97.1
Frequency Missing = 7		
Have you ever wanted to get treatment from a dentist due to problems from your eating disorder?		
Yes	10	30.3
No	23	69.7
Frequency Missing = 8		
Why didn't you get treatment?		
No insurance/Financial reasons	4	40.0
Fear/Embarrassment	6	60.0
Frequency Missing = 1		
Are you interested in obtaining more information about good oral health habits?		
Yes	16	48.5
No	17	51.5
Frequency Missing = 8		
From who would you like to get the information?		
Dental Office	6	37.5
Eating Disorder Clinic/Programs	9	56.3
Other	1	6.2

Figure1: Distribution of Eating Disorder Types

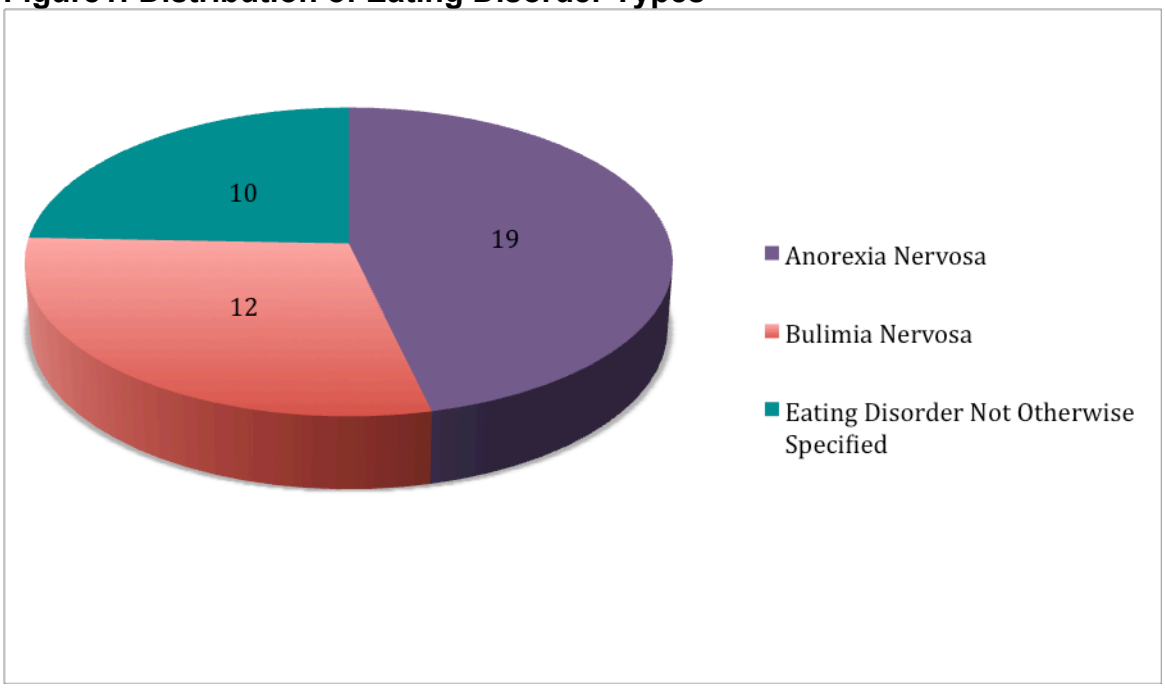
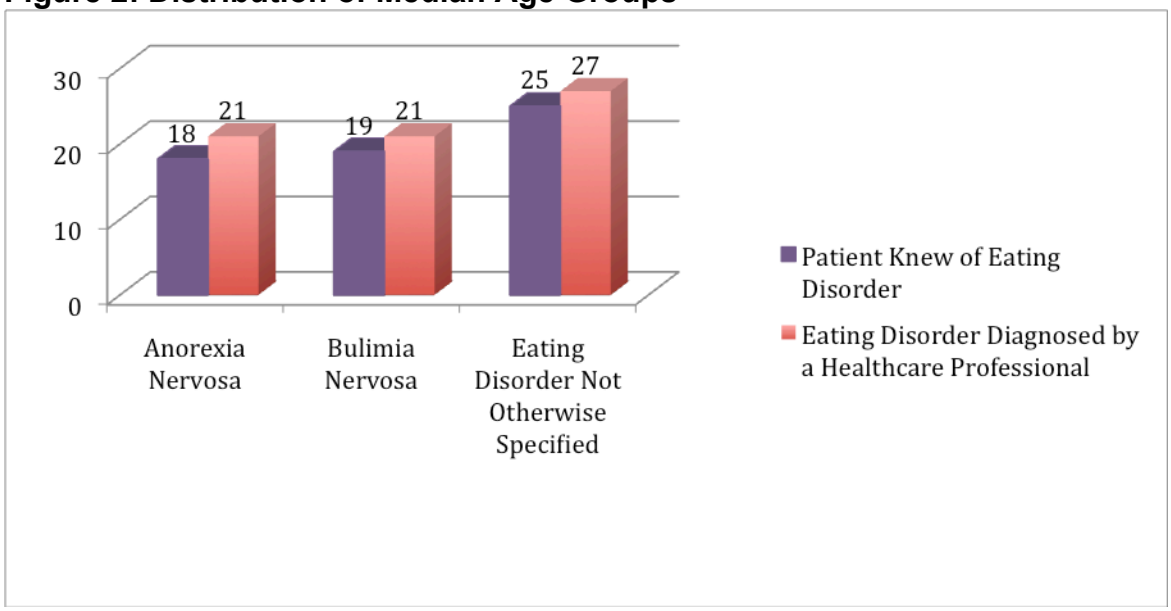


Figure 2: Distribution of Median Age Groups



APPENDIX A:

ADULT CONSENT

Oral Health Knowledge and Behaviors among Patients with Eating Disorders (IRB# 10-1398)

To Potential Participant:

Because we are quite concerned with the patient's knowledge, or lack thereof, regarding the oral problems associated with eating disorders, we are conducting a research study focused on determining the patient's knowledge of their disease on their oral health. We are also interested in learning the current oral homecare procedures being practiced by those with an eating disorder. A total of 500 patients have been randomly selected to participate in this study. Your participation in this study is completely voluntary.

You will be asked to complete a survey composed of questions addressing your knowledge of the oral problems associated with eating disorders, your current oral homecare practices, and whether or not you have ever been referred to a dental practitioner. Completion of the questionnaire should take 15-20 minutes. You are free to answer or not answer any particular question and have no obligation to finish the survey once you begin. Submitting your questionnaire connotes your consent to be a participant in this study.

Your participation is anonymous. You are asked not to put any identifying information on the questionnaire. All data obtained in this study will be reported as group data. No individual can be or will be identified. We plan on publishing the results of this research. The only persons who will have access to these data are the researchers involved in this study.

There are no risks anticipated should you participate in this study nor any anticipated benefits from being involved with it. There is no cost to you or financial benefit for your participation.

You may contact us with any questions at (919) 966-2800 or by email (peek@dentistry.unc.edu, Rebecca_wilder@dentistry.unc.edu)

All research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have questions or concerns about your rights as a research subject you may contact, anonymously if you wish, the Institutional Review Board at 919-966-3113 or by email to IRB_subjects@unc.edu.

Thank you for considering participation in this study!

Sincerely,

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Thesis Research Committee Members

Rebecca Wilder, BSDH, MS
Professor, UNC School of Dentistry

Michael Roberts, DDS, MScD
Professor, UNC School of Dentistry

I have read the information provided above. I voluntarily agree to participate in this research study.

Yes
No

APPENDIX B:

PARENT CONSENT

Oral Health Knowledge and Behaviors among Patients with Eating Disorders (IRB# 10-1398)

To the Parent of a Potential Participant:

Because we are quite concerned with the patient's knowledge, or lack thereof, regarding the oral problems associated with eating disorders, we are conducting a research study focused on determining the patient's knowledge of their disease on their oral health. We are also interested in learning the current oral homecare procedures being practiced by those with an eating disorder. A total of 500 patients have been randomly selected to participate in this study. Your child's participation in this study is completely voluntary.

Your child will be asked to complete a survey composed of questions addressing her knowledge of the oral problems associated with eating disorders, her current oral homecare practices, and whether or not she has ever been referred to a dental practitioner. Completion of the questionnaire should take 15-20 minutes. Your child is free to answer or not answer any particular question and have no obligation to finish the survey once she begins.

Your child's participation is anonymous. She will not be asked to put any identifying information on the questionnaire. All data obtained in this study will be reported as group data. No individual can be or will be identified. We plan on publishing the results of this research. The only persons who will have access to these data are the researchers involved in this study.

There are no risks anticipated should your child participate in this study nor any anticipated benefits from being involved with it. There is no cost to you or your child, or financial benefit for her participation.

You may contact us with any questions at (919) 966-2800 or by email (peek@dentistry.unc.edu, Rebecca_wilder@dentistry.unc.edu)

All research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have questions or concerns about your rights as a research subject you may contact, anonymously if you wish, the Institutional Review Board at 919-966-3113 or by email to IRB_subjects@unc.edu.

Thank you for considering participation in this study!

Sincerely,

Jessica Peek, RDH, BS
Master of Science Degree Candidate
Dental Hygiene Education
3210 Old Dental Bldg., CB#7450
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Thesis Research Committee Members

Rebecca Wilder, BSDH, MS
Professor, UNC School of Dentistry

Michael Roberts, DDS, MScD
Professor, UNC School of Dentistry

I have read the information provided above. I voluntarily agree for my child to participate in this research study.

Yes
No

APPENDIX C:

CHILD CONSENT

Oral Health Knowledge and Behaviors among Patients with Eating Disorders (IRB# 10-1398)

To Potential Participant:

We are doing a study to find out how much patients with eating disorders know about the oral problems that may happen because of their eating disorder. We also want to know what these patients do at home to take care of their teeth. And last, we want to know if patients with eating disorders have ever been told to see a dentist.

You will be asked to complete a survey with questions addressing how much you know about what eating disorders can do to your mouth, what types of things you do at home to take care of your teeth, and if anyone has ever told you to see a dentist. It should only take you 15-20 minutes to complete the survey. You don't have to answer any questions that you don't want to.

Your participation is anonymous which means that no one will know it is you that has completed the survey. You are not asked to put any identifying information, like your name and birthday, on the survey. All the answers will be reported as a group. We plan on publishing the results of this research in a journal, which may help others when they read it. The only persons who will be able to see your answers will be the researchers involved in this study.

There are no risks or benefits if you decide to participate in this study. It will not cost you anything to participate, nor will you receive anything for participating.

You may contact us with any questions at (919) 966-2800 or by email (peek@dentistry.unc.edu, Rebecca_Wilder@dentistry.unc.edu).

All research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have questions or concerns about your rights as a research subject you may contact, anonymously if you wish, the Institutional Review Board at 919-966-3113 or by email to IRB_subjects@unc.edu.

Thank you for considering participation in this study!

Sincerely,

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I have read the information provided above. I voluntarily agree to participate in this research study.

Yes

No

APPENDIX D:

ADULT FLYER

UNC DENTISTRY

Oral Health & Eating Disorder Research Study

We are quite concerned with the patient's knowledge, or lack thereof, regarding the oral problems associated with eating disorders. We are conducting a research study focused on determining the patient's knowledge of their disease on their oral health. We are also interested in learning the current oral homecare procedures being practiced by those with an eating disorder.

<u>You may be eligible to participate in a research study if you are:</u>

- Female
- Age 18-80
- Currently or previously diagnosed with an eating disorder

The online survey will take 10-15 minutes to complete.
Please visit the link below.

https://uncdentistry.qualtrics.com/SE/?SID=SV_cCRj8pUPBi7DLX6

https://uncdentistry.qualtrics.com/SE/?SID=SV_cCRj8pUPBi7DLX6

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APPENDIX E:

ADOLESCENT FLYER

UNC DENTISTRY

Oral Health & Eating Disorder Research Study

We are quite concerned with the patient's knowledge, or lack thereof, regarding the oral problems associated with eating disorders. We are conducting a research study focused on determining the patient's knowledge of their disease on their oral health. We are also interested in learning the current oral homecare procedures being practiced by those with an eating disorder.

<u>You may be eligible to participate in a research study if you are:</u>

- Parent of a female age 12-17 that is currently or previously diagnosed with an eating disorder

The online survey will take 10-15 minutes to complete.
Please visit the link below.

https://uncdentistry.qualtrics.com/SE/?SID=SV_0OKpNWRqFGPwvxG

Jessica Peek, RDH, BS: 704-400-2238

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APPENDIX F:

SURVEY

Oral Health Knowledge and Practice Behaviors among Patients with Eating Disorders

Q1 I have read the information provided above. I voluntarily agree to participate in this research study. (Consent form)

- ❍ Yes (1)
- ❍ No (2)

Answer If Yes Is Selected

Q2 How old are you?

Answer If Yes Is Selected

Q3 How old were you when YOU knew you had an eating disorder?

Answer If Yes Is Selected

Q4 How old were you when you were diagnosed with and eating disorder by a HEALTHCARE PROFESSIONAL?

Answer If Yes Is Selected

Q5 The type of eating disorder you have is:

- ❍ Anorexia nervosa (1)
- ❍ Bulimia nervosa (2)
- ❍ ED not otherwise specified (3)

Answer If Oral Health Knowledge and Behaviors among Patients with E... Yes Is Selected

Q6 Do/Did you purge?

- ❍ Yes (1)
- ❍ No (2)

Answer If Do/Did you purge? Yes Is Selected And Oral Health Knowledge and Behaviors among Patients with E... Yes Is Selected

Q7 How many times a day do/did you purge?

Answer If Do/Did you purge? Yes Is Selected And Oral Health Knowledge and Behaviors among Patients with E... Yes Is Selected

Q8 If you do/did not purge every day, how many times per week do/did you purge?

Answer If Do/Did you purge? Yes Is Selected And Oral Health Knowledge and Behaviors among Patients with E... Yes Is Selected

Q9 After purging, do/did you: (Choose ALL that apply.)

- ❑ Brush your teeth (1)
- ❑ Rinse with a fluoride rinse (2)
- ❑ Chew on a tums (3)
- ❑ Other (please specify) (4) _____
- ❑ Rinse with baking soda and water (5)
- ❑ Rinse with water (6)
- ❑ Do nothing (7)

Answer If Oral Health Knowledge and Behaviors among Patients with E... Yes Is Selected

Q10 The oral effects of eating disorders are: (Choose ALL that apply.)

- ❑ Dental erosion (wearing down of teeth) (1)
- ❑ Saliva (spit) gland enlargement (2)
- ❑ Cracking in the corners of the mouth (3)
- ❑ Dry mouth (4)
- ❑ Tooth sensitivity (5)
- ❑ Oral cancer (6)

Answer If Yes Is Selected

Q11 The most common oral effect that happens from purging is: (Choose ONE answer only.)

- ❍ Dry mouth (1)
- ❍ Gum disease (2)
- ❍ Dental erosion (wearing down of teeth) (3)
- ❍ Cavities (4)
- ❍ I don't know (5)

Answer If Oral Health Knowledge and Behaviors among Patients with E... Yes Is Selected

Q12 Where does dental erosion (wearing down of the teeth) most commonly happen in the mouth? (Choose ONE answer only.)

- ❍ On the top teeth, tongue side (1)
- ❍ On the bottom teeth, tongue side (2)
- ❍ On the top teeth, cheek side (3)
- ❍ On the bottom teeth, cheek side (4)
- ❍ I don't know (5)

Answer If Yes Is Selected

Q13 Please indicate your level of agreement with the following three statements.

	Strongly Agree (1)	Somewhat Agree (2)	Don't Know (3)	Somewhat Disagree (4)	Strongly Disagree (5)
You should brush your teeth at least 2 times per day. (1)	❍	❍	❍	❍	❍
Acidic fruits and foods high in carbohydrates can negatively affect the health of your mouth. (2)	❍	❍	❍	❍	❍
You are NOT supposed to brush your teeth after you vomit. (3)	❍	❍	❍	❍	❍

Answer If Yes Is Selected

Q14 How many times per day do you brush your teeth?

Answer If How many times per day do you brush your teeth? Text Response Is Equal to 0 And Yes Is Selected

Q15 If you do not brush your teeth every day, how many times do you brush your teeth per week?

Answer If Yes Is Selected

Q16 Have you ever been referred to a dentist?

- ❍ Yes (1)
- ❍ No (2)

Answer If Have you ever been referred to a dentist? Yes Is Selected And Yes Is Selected

Q17 Who referred you to a dentist?

- ❍ Mental health professional (1)
- ❍ Pastor (2)
- ❍ Primary care physician (doctor) (3)
- ❍ Family member (4)
- ❍ Friend (5)
- ❍ Other (please specify) (6) _____

Answer If Oral Health Knowledge and Behaviors among Patients with E... Yes Is Selected

Q18 Have you ever received dental treatment because of your eating disorder?

- ❍ Yes (1)
- ❍ No (2)

Answer If Have you ever received dental treatment because of your e... No Is Selected And Yes Is Selected

Q19 Have you ever wanted to get treatment from a dentist due to problems from your eating disorder?

- ❍ Yes (1)
- ❍ No (2)

Answer If Have you ever received dental treatment because of your e... No Is Selected And Yes Is Selected

Q20 Why didn't you get treatment?

- ❍ No insurance (1)
- ❍ Financial reasons (2)
- ❍ Fear (3)
- ❍ Embarrassment (4)
- ❍ Lack of transportation (5)
- ❍ Other (please specify) (6) _____

Answer If Yes Is Selected

Q21 Are you interested in getting more information about good oral health habits?

- ❍ Yes (1)
- ❍ No (2)

Answer If Are you interested in getting more information about good... Yes Is Selected And Yes Is Selected

Q22 From whom would you like to get the information?

- ❍ Dental office (1)
- ❍ Eating Disorder Clinics/Programs (2)
- ❍ Other (please specify) (3) _____

Answer If Yes Is Selected

Q23 Please identify how you received this survey.

- ❍ Link sent to you by an eating disorder program (1)
- ❍ Email from a friend or family member (2)
- ❍ Social networking site (3)

Answer If Yes Is Selected

Q24 If you have any comments you would like to add, please type below.

Answer If No Is Selected

Q25 Thank you for your time. Please exit the survey and have a great day.

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