# SURVEY OF REGISTERED DIETITIANS' PROFICIENCY OF CELIAC DISEASE AND USE OF TWITTER, FACEBOOK, SMART PHONE APP, AND INTERNET FOR CELIAC DISEASE MANAGEMENT

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### **Title** SURVEY OF REGISTERED DIETITIANS' PROFICIENCY OF CELIAC DISEASE AND USE OF TWITTER, FACEBOOK, SMART PHONE APP, AND INTERNET FOR CELIAC DISEASE MANAGEMENT

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#### ABSTRACT

The Registered Dietitian (RD) plays an integral role in helping patients manage their celiac disease (CD). This study explored how proficient RDs are with CD management in addition to determining how RDs use technology to educate themselves and CD patients. RDs (N=405) participated in this 35 item internet-based survey to measure self-reported CD proficiency, CD knowledge, preferences for CD resources for self-education and patient education, and use of Twitter, Facebook, smart phone apps, and internet for CD management. RDs reported either moderate or high levels of proficiency for all seven of the seven selfreported proficiency topics. Professional and academic publications were the most commonly used resources by the RD for self-education whereas handouts were the most commonly used resource by the RD for patient education. RD's reported using Twitter the least for self-education and the Internet the most for patient education.

Keywords: Celiac Disease, Registered Dietitian, Twitter, Facebook, Internet

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~"I know God won't give me anything I can't handle. I just wish he didn't trust me so much."~ Mother Teresa

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#### **CHAPTER 1. INTRODUCTION**

Approximately one to two percent of individuals worldwide are affected by celiac disease (CD) with an increased prevalence among whites (Autodore, Verma, & Gupta, 2012; Niewinski, 2008). Adhering to a strict gluten-free diet (GFD) is the only treatment for CD (Mubarak, Houwen, & Wolters, 2012; Autodore, Verma, & Gupta, 2012; Case, 2005), and strict adherence to the GFD in adults has been reported to range between 36% and 96% (Hall, 2009). The National Institutes of Health Consensus Development Panel acknowledged six key essentials in managing CD: education about the disease, consultation with a skilled Registered Dietitian (RD), lifelong adherence to a GFD, identification and treatment of nutritional deficiencies, access to an advocacy group, and continuous long-term follow-up by a multidisciplinary team (2004).

Information regarding CD can be obtained from numerous technology sources including Internet web sites, smart phone applications (apps), and social media such as Facebook or Twitter. Despite the abundance of information, not all of the information is accurate. An evaluation of 98 CD websites revealed that 47 (48%) of the websites provided information that was less than 95% accurate (McNally et al., 2012). The Academy of Nutrition and Dietetics (AND) reviewed 10 free iPhone apps for gluten-free eating on a scale of one to five stars (five stars being the best). Of these apps one received one star, five received two stars, two received three stars, one received four stars, and one received four and one half stars (Crandall, 2012). Since following a GFD is the only treatment for CD as even trace amounts of gluten ingestion can result in small intestine damage (Lahdeaho, Maki, Laurila, Huhtala, & Kaukinen, 2011), and disease education and a visit with a skilled RD are identified as key essentials in CD management, it is imperative that the RD is able to provide the patient with accurate and updated information.

#### **Statement of the Problem**

There is evidence that some of the CD information available is not accurate. As mentioned, CD patients may be using smart phone apps or websites that are providing incorrect information which could potentially result in ingesting a gluten-containing food which could potentially result in small intestinal damage. Little is known about the RD's proficiency and use of technology to obtain and disseminate information regarding CD which is of interest, since they play a role in educating the patient following a GFD.

#### **Purpose of the Study**

The first purpose of this study was to measure the RD's CD proficiency and knowledge. The second purpose was to determine the RD's use of technology in practice (e.g. smart phone apps, Facebook, Twitter, Internet), especially regarding CD management.

#### Hypotheses

The first hypothesis was that >90% of RDs have high CD self-reported proficiency and knowledge. The second hypothesis was that >90% of RDs use technology in practice.

#### Limitations

There are several limitations to the current study. For example, 63% of the population reported seeing zero CD patients a week, so the majority of participants seldom work with the CD patient, thus limiting how much we are able to determine about the RD who works with the CD patient. Additionally, if the RD worked in one of the settings in which CD exposure is low, she or he might not have been interested in fully completing the survey given its CD self-reported proficiency and knowledge nature. In regards to time, the informed consent described the time commitment to be roughly 10 minutes which could have been an obstacle for participation.

### **Definitions**<sup>1</sup>

*Celiac Disease (CD):* Also referred to as gluten-sensitive enteropathy; small intestine inflammatory disorder resulting from an inappropriate T cell-mediate autoimmune response to the ingestion of gluten by genetically predisposed people.

*Gluten:* Specific peptide fraction of proteins found in rye, barley, and wheat which are resistant to complete digestion by gastrointestinal enzymes.

*Gluten-free diet (GFD):* A diet excluding the gluten peptides.

- *Laparoscopy:* Visual examination of the abdomen by means of a laparoscope (fiberoptic instrument used to examine visually the interior of the peritoneal cavity)
- *Social media*: Forms of electronic communication (e.g. Web sites for social networking and microblogging) through which users create online communities (e.g. Facebook and Twitter) to share personal messages, ideas, information, and other content

Steatorrhea: Excessive amounts of fat in the feces, common in malabsorption syndromes.

<sup>1</sup>Definitions obtained from Celiac Disease Foundation. (2014). What is celiac disease? Retrieved from <u>http://celiac.org/</u>.

#### **CHAPTER 2. LITERATURE REVIEW**

#### **Clinical Description of Celiac Disease**

Aretaeus the Cappodocian is thought to be one of the first to describe celiac disease (CD). His second century AD writings were translated from Greek to English by Francis Adams in 1856 (Pavely 1988; Dowd & Walker-Smith, 1974). Aretaeus noted "labours in digestion" (Pavely, 1988) in patients afflicted with "coeliac diathesis" (Dowd & Smith, 1974). In 1887, Samuel Gee, MD, described CD as "a kind of chronic indigestion which is met with in patients of all ages." He noted that an error in diet could be a reason for the manifestation of the observed symptoms of diarrhea and cachexia (Gee, 1888).Wheat, barley, and rye were later identified as CD triggers in 1953 by Willem Karl Dicke (Dicke, 1953). His study demonstrated that CD could be reversed by eliminating those food sources from the diet.

In 1954 Paulley identified abnormalities via biopsy specimens obtained by laparoscopy in the small intestinal mucosa of four patients who had been experiencing steatorrhea. All four specimens revealed chronic inflammation of the lymph nodes and jejunum (Pauley, 1954). Additional symptoms of CD can include abdominal pain, iron deficiency, and bone disease (Shemesh, 2009; Barney, Paul, & Taylor, 2010). It is estimated that 32% of patients with CD are asymptomatic or experience minimal symptoms (Shemesh, 2009).

#### **Prevalence and Diagnosis of Celiac Disease**

In the United States prevalence is less than one percent, and CD affects about one percent of non-Hispanic whites (Rubio-Tapia, Ludvigsson, Brantner, Murray, & Everhart, 2012). The European population has been found to have up to one and a half percent prevalence (Ress, 2007).

Diagnostic tests for CD include serological antibody testing and examining the small intestine by biopsy. The immunoglobulin A (IgA) – class endomysial antibody (EMA) is the most sensitive antibody test (Lindfors, 2011). Despite its close to 100% association with CD, though, about 10-20% of patients still test negative for serum EMA (Salmi, 2006).

Physician awareness of CD symptoms varies. In a survey of 132 California Primary Care Physicians, only 32% were aware that adulthood onset of CD is common. Ninety percent were aware that diarrhea was a symptom, but other common symptoms such as chronic abdominal pain (67%), depression and irritability (24%), anemia (45%), and fatigue (54%) were less well known (Zipser, Farid, Baisch, Patel, & Patel, 2005).

#### Treatment

As previously stated, adherence to the GFD is the only treatment for CD, and a visit with a skilled RD is considered an essential aspect of managing the disease (NIH, 2004; Niewinski, 2008; Case, 2005). Gluten, which is found in wheat, barley, and rye products, is resistant to digestion by human digestive enzymes, but it has been found to be degraded by bacterial endopeptidases. Some studies have demonstrated these bacterial endopeptidases can prevent the immunologic response seen with CD, but these enzymes are not yet available from exogenous sources (Mahan & Stump, 2008).

Trace amounts of gluten in the diet can induce small-bowel damage as a study on 25 previously diagnosed CD patients demonstrated. These 25 volunteers, aged 18-75 years, met the following criteria to participate in the study: biopsy-proven CD, adhering to a strict GFD for at least two years, clinical remission as based on an interview, clinical examination, and on-site rapid celiac autoantibody testing. The volunteers were divided into two groups, those consuming a moderate (3-5 g) amount of gluten and those consuming a low (1-3 g) amount of gluten daily.

The patients agreed to continue to follow their previous GFDs, so gluten intake came from the researcher in the form of a daily biscuit containing 1.25-5 grams of gluten.

Participants were instructed to follow their GFD in addition to their daily assigned amount of gluten, and at four weeks and eight weeks into the intervention, serological (Serum IgA class transglutaminase 2) and clinical assessments (upper gastrointestinal endoscopy) were repeated. Three patients in the moderate-dose group withdrew early from the study because they developed abdominal symptoms like vomiting, abdominal pain, and diarrhea while all patients in the low-dose group completed the study. Overall, those in the moderate-dose group experienced a significant decrease in small bowel villous height and crypt depth (Vh/CrD) ratios, a measure that shows mucosal morphological changes. Twenty-two percent of the participants who developed significant small-intestinal damage did not experience symptoms (Lahdeaho, Maki, Laurila, Huhtala, & Kaukinen, 2011) demonstrating the fact that CD can be presented in an asymptomatic manner.

#### **Complications of the GFD**

The GFD can be difficult to follow because of the increased cost and limited availability of gluten-free products, taste/texture of products, the complexity of the diet, and its restrictive nature (Hall, 2009). A survey of 2,265 CD adult members of the Dutch Coeliac Association revealed that depressive symptoms were present in about 39% of the population who followed the GFD. The survey involved questions that cover the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders criteria for past and current major depression such as impact of functioning in the areas of quality of sleep or appetite (van Hees, 2013).

Dilemmas experienced by close family members of a CD patient have also been identified including stressors related to "disease-related worries," "management of daily life,"

and "disturbances in social life." These dilemmas were experienced "within the family," "in social relations with relatives and friends," and "in interactions with service professionals in shops and restaurants" (Sverker, 2007). Because of these complications, adherence to the diet may be impacted as a CD patient may not want be a source of stress for his or her family members.

#### **The Registered Dietitian**

A Registered Dietitian (RD) is a food and nutrition expert who has fulfilled the necessary professional and academic requirements (AND, n.d.) to practice medical nutrition therapy. These include the following: earning a bachelor's degree with course work approved by the Academy of Nutrition and Dietetics; completing a supervised, accredited practice program, passing a national examination administered by the Commission on Dietetic Registration (CDR); and completing continuing professional educational requirements to maintain registration (AND, n.d.).

An estimated 50% of RDs have advanced degrees, and some have additional certifications in areas of practice such as nutrition support or diabetes education (AND, n.d.). In working with CD patients, the RD assesses dietary intake and provides nutrition interventions and education. Education topics can include learning how to read the nutrition label and ingredient declaration panel, identifying the nutritional quality of the GFD, and preventing contamination with gluten-containing foods (Simpson, 2012). Additionally, as the National Institutes of Health (NIH) has identified having knowledge of potential nutrient deficiencies and awareness of local advocacy groups, the RD may be able to assist the CD patient by providing him or her with this information.

In an survey of family physicians and RDs in the outpatient setting, 80% of RDS (of 389 respondents) reported that they always assess a patient's lifestyle and educational level before choosing an educational approach, and 69% send the nutrition plan to the referring family physician. Among physicians, 49% of family physicians (235 respondents) reported they often or always found the RD's interactions with clients to be useful (Kuppersmith & Wheeler, 2002).

To assess the CD patient's perception of the RD with regard to knowledge of CD, a University of Mississippi study surveyed 160 people diagnosed with CD. Diagnostic criteria were based on procedures such as blood tests, biopsies, and absorption tests. About 54% of the participants reported that the RD did not seem to be knowledgeable about CD. Nearly 39% of participants reported that the RD seemed knowledgeable, and about seven percent were unsure. Approximately 47% of patients perceived the RD's interaction as very helpful as opposed to the 53% who did not find the RD to be helpful (Tidwell & Bomba, 2001). These results demonstrate a need for identifying the RD's proficiency of CD management.

#### **Internet Use**

Information pertaining to CD can be obtained by using the Internet. According to the 2010 census, 75.9% of those ages three and over have access to the Internet in their own home (United States Census Bureau, 2010). Fifty-five percent of those over the age of 18 look to the Internet as a source of health or medical information (United States Census Bureau, 2011).

Since a considerable amount of Internet users look to the Internet as a source of health or medical information, it is important to consider the accuracy of the source. An evaluation of CD websites was conducted to assess their comprehensiveness, transparency, accuracy, and reading grade level. The term "Celiac Disease" was searched and 100 of the top searched Englishlanguage websites published by commercial, academic, nonprofit, and other professional (nonacademic) sources were reviewed. Three reviewers independently reviewed each site to determine comprehensiveness, transparency, accuracy, and reading grade level. This study revealed that 47 (48%) of the websites provided information that was less than 95% accurate (McNally et al., 2012). If an RD is aware of credible websites, he or she may be able to provide the patient with recommendations for where to look for more reliable information.

#### **Cell Phone Use**

Smartphones are mobile devices that have computing capabilities in addition to Internet access (Smith, 2011; Franko & Tirrell, 2012) serving as a possible source of information for those with CD. According to a study conducted by the Pew Research Center's Internet & American Life Project, as of May 2011, two in five cell phone owners (42%) owned a smartphone (Smith, 2011). Consumer software applications, or apps, that run on smartphones represent the fastest growing consumer product segment in merchandising (Datta et al., 2013). Since December, 2010, the monthly app market growth rates for Apple and Android have been about four percent and seven percent, respectively (Datta et al., 2013).

The Food and Drug Administration (FDA) does not control the content of most apps, but when apps cross the line of providing direct medical advice the FDA makes approval mandatory (Ozdalga, 2012). There are over 225,000 app developers globally, and over 900,000 apps between Apple and Android systems (Datta et al., 2013).

In a study of medical providers working in Accreditation Council for Graduate Degree Medical Education training programs, 85% of the 3,306 respondents reported using some sort of a smartphone with iPhones being the most popular followed by Android and Blackberry operating systems. Additionally, 56% of respondents reported they use apps in their clinical

practice, and there was a trend towards decreased app use with an increased level of training (Franko; Tirrell, 2012).

A review of GFD iPhone apps on the AND website noted the following weaknesses in various apps: "Can have issues scanning the bar code," "Membership fee required," "Has spelling errors," and "Limited reviews." With regards to the "can have issues in scanning the bar code" comment, phones that have scanning capabilities are able to read barcodes to determine nutrition information with select Apps. Pros included: "Contains local and chain restaurants," "The restaurant database is fairly comprehensive," and "Lists dining locations by category, ratings, and review" (Crandall, 2012).

#### **Social Media**

CD information can also be acquired from social media. A cross-sectional survey was conducted to determine health professionals' use of social media and their attitudes about the value of using social media to enhance Continuing Medical Education (CME). Three hundred twenty-seven health professionals (of 539) responded to the Social Media Use and Perception Instrument which consisted of 10 items (5-point Likert scales) and response options. The results revealed that 89% of respondents used social media with Facebook and Twitter being the most commonly used. Favorable attitudes toward social media were associated with younger age (Wang et al., 2012). Facebook reached an estimated one billion users on September 14, 2012 (Fowler, 2012).

#### **Registered Dietitians and Technology**

There is limited research regarding how RDs use technology. In a study of Pennsylvania Academy of Nutrition and Dietetics members, 90.3% of participants reported that their ability to function efficiently within the nutrition profession is improved by their technology skills.

Additionally, 86.3% of those surveyed predicted making future efforts to strengthen their technology skills (Davis, Taylor-Davis, & Barker, 2004).

A survey of British American Dietetic Association members questioned how frequently patients discussed information that they found on the Internet with them. Of the 149 members who responded, 48% said rarely, 28% answered about once a month, 13% replied about once per week, and one stated daily (Kirk, Cade, & Greenhalgh, 2001). This demonstrates that technology appears to play a significant role in the nutrition and dietetics profession.

In summary, following a GFD is essential for a person with CD. There is an abundance of CD information available on the Internet, smart phone applications, and social media, but as stated, some of this information is inaccurate. The RD's responsibility is to provide accurate information to the patient with CD, and so it is of interest to measure the RD's CD proficiency, knowledge, and use of technology in practice.

#### **CHAPTER 3. METHODS**

#### **Experimental Design**

Approval from the North Dakota State University Institutional Review Board was obtained before this study began. A cross-sectional research design was used to conduct an exploratory study of the Registered Dietitian's self-reported proficiency and knowledge of celiac disease and technology use (e.g. smart phone apps, Facebook, Twitter, and Internet) for celiac disease education.

#### Recruitment

Researchers contacted statewide Academy of Nutrition and Dietetics (AND) groups to distribute recruitment materials via listservs in order to reach the Registered Dietitians. The recruitment letters, survey instruments, informed consent, and reminder email are illustrated in appendices B, C, and D. The RDs were recruited by an e-mail sent from his or her respective statewide AND listserv. State affiliates that participated include the following: Colorado, Delaware, Montana, North Dakota, Connecticut, Nebraska, and Alaska (7 states).

#### Procedure

In the summer of 2013, an e-mail (Appendix B) was sent from the respective state affiliate inviting individuals to complete the online survey (Appendix C). If they chose to participate, they clicked on the link that brought them to the SurveyMonkey link where they found the Informed consent (Appendix D) and survey (Appendix C). SurveyMonkey is a webbased survey site which allows the participants to respond on-line and researcher to gather and view results. Participants were informed that choosing to complete the online survey meant that they would read and understand the Informed Consent and agreed to participate in the study.

#### Survey

The participants completed a survey with 35 items. Survey topics included: demographics, proficiency of CD, CD knowledge, and use of technology for CD management. For example, RDs were asked to rate their self-reported proficiency of various CD topics from "high" to "not at all," with the numbers one to four being associated with those values. CD topics were related to the six key essentials for managing CD as identified by the NIH (2004).

#### **Statistical Analysis**

The collected data were analyzed using SAS (version 9.3; SAS Institute Inc., Cary, NC). Age, education level, years of practice, and number of CD patients seen per week were divided into categories when analyzing the results. Age was divided into the following categories: 20-29, 30-39, 40-49, and over 50 years. Education level was divided into the following categories: bachelor's and >master's degree. Years of practice was divided into the following: 0-11, and over 11 years. Number of CD patients seen per week was divided into the following: 0 and greater than 1 CD patient per week.

Pearson correlation coefficients were calculated to determine the correlation of the independent variables (age, education level, years of practice, and number of celiac disease patients seen per week) on the dependent variables, RD's self-reported proficiency of CD, CD knowledge, CD resources used for self-education and patient education, and Twitter, Facebook, smart phone, and Internet use for CD management.

Chi squares were also used to determine frequencies and differences in responses per variable. The significance level used for each statistical analysis was p<0.05. Categories were aggregated for selected variables to avoid problems with underlying assumptions of the chi-square tests of independence. Not all respondents answered all the survey questions, resulting in

varying number of responses for each question. Thus, differences in the sample sizes of the data occurred.

#### **CHAPTER 4. MANUSCRIPT**

#### Abstract

The Registered Dietitian (RD) plays an integral role in helping patients manage their celiac disease (CD). This study explored how proficient RDs are with CD management in addition to determining how RDs use technology to educate themselves and CD patients. RDs (N=405) participated in this 35 item internet-based survey to measure self-reported CD proficiency, CD knowledge, preferences for CD resources for self-education and patient education, and use of Twitter, Facebook, smart phone apps, and internet for CD management. RDs reported either moderate or high levels of proficiency for all seven of the seven selfreported proficiency topics. Topics where the RD indicated a moderate level of proficiency were identifying potential nutritional deficiencies related to celiac disease and having knowledge of local gluten-free support groups or area restaurants. Professional and academic publications were the most commonly used resources by the RD for self-education whereas handouts were the most commonly used resource by the RD for patient education. With regards to using Twitter, Facebook, smart phone apps, or the Internet for self-education, RD's reported using Twitter the least and with regards to patient education the Internet the most.

Keywords: Celiac Disease, Registered Dietitian, Twitter, Facebook, Internet Introduction

Approximately one to two percent of individuals worldwide are affected by Celiac Disease (CD) with an increased prevalence among whites (Autodore, Verma, & Gupta, 2012; Niewinski, 2008). Adherence to the gluten-free diet (GFD) is the only treatment for CD as ingestion of even trace amounts of gluten can induce small-bowel damage (Lähdeaho, 2011). The GFD can be difficult to follow because of the increased cost and limited availability of

gluten-free products, taste/texture of products, the complexity of the diet, and its restrictive nature (Hall, 2009). Therefore, a visit with a skilled Registered Dietitian (RD) is considered an essential aspect of managing the disease (Niewinski, 2008; National Institute of Health, 2004; Case, 2005).

Although a visit with a skilled RD is identified as a key to managing the disease, information regarding CD and the GFD can be obtained from numerous technology sources including Internet web sites, smart phone applications (apps), and social media such as Facebook or Twitter. Previous research has shown that not all websites which share CD and GFD information are accurate (McNally, 2012).

There is limited recent research regarding how proficient RDs are with CD management and how they are using technology in their practice to provide education of CD. For example, in a survey of CD patients who worked with an RD, about 54% of participants reported that the RD did not seem to be knowledgeable about CD and 53% did not find the RD to be helpful (Tidwell & Bomba, 2001). With regards to RD's technology use, a study of Pennsylvania Academy of Nutrition and Dietetics members reported that 90.3% of members improved their ability to function efficiently within the nutrition profession by their technology skills, and 86.3% predicted making future efforts to strengthen their skills (Davis, 2004). Therefore, it is of interest to determine if these numbers are similar today.

As mentioned, there is evidence that some of the CD information available to patients is not accurate, and little is known regarding the RD's proficiency in regards to CD management and technology use. Because of this reason, the purposes of this study were 1) to measure the RD's CD proficiency and CD knowledge; and 2) determine the RD's use of technology in practice (e.g. smart phone apps, Facebook, Twitter, and Internet). These purposes are important

to see if there are areas in which RDs need to be more educated to assist CD patients who need to follow the GFD.

#### Methods

#### **Experimental Design**

Approval from the University Institutional Review Board was obtained before this study began.A cross-sectional research design was used to conduct an exploratory study of the Registered Dietitian's self-reported proficiency and knowledge of celiac disease and technology use (e.g. smart phone apps, Facebook, Twitter, and Internet) for celiac disease education.

#### Participant Recruitment

Researchers contacted statewide Academy of Nutrition and Dietetics (AND) groups to request their assistance in distributing recruitment emails via respective listservs to contact the RDs. The RDs were recruited by an e-mail sent from his or her respective statewide AND listserv. State affiliates that participated include the following: Colorado, Delaware, Montana, North Dakota, Connecticut, Nebraska, and Alaska (seven states). Some states were excluded from this study because of restrictions with their listservs in assisting with collegiate research or if fees were associated with distributing information via respective listservs.

#### Procedure

In the summer of 2013, a researcher scripted message was sent by the state affiliate inviting RDs to complete the online survey. If they chose to participate, they clicked on the link that brought them to the Survey Monkey, a web-based survey site (Palo Alto, CA), link where they found the Informed Consent and explanation. Participants were informed that choosing to complete the online survey meant that they would read and understand the Informed Consent and agreed to participate in the study.

#### Survey

The participants completed a survey with 35 possible items. For example, answering "yes" to certain questions, e.g. "Do you use Twitter?" prompted further questions, so not all respondents answered all 35 questions. The tool was modeled after a survey used to measure self-reported proficiency of RDs and food allergy management (Groetch, 2010). Survey topics included: demographics, self-reported CD proficiency, CD knowledge, current CD management resources use, and technology use in CD management. The self-reported proficiency section asked the RD to rate his or her proficiency in seven CD topics using a 4-point scale ("high," "moderate," "low," and "not at all"). In the CD knowledge section, RDs were asked five objective CD questions. To determine which CD resources use by RDs, they were asked to identify the resources they use for self-education and for patient education. RDs were also asked questions regarding their current technology use for providing CD education including that of the Internet, Twitter, Facebook, and smart phones.

#### **Statistical Analysis**

The collected data were analyzed using SAS (version 9.3; SAS Institute Inc., Cary, NC). Pearson correlation analyses were performed to determine the correlation of the independent variables (age, education level, years of practice, and number of CD patients seen per week) on the dependent variables, CD self-reported proficiency, CD knowledge, and technology use.

Chi squares were also used to determine frequencies and differences in responses per variable. Categories were aggregated for selected variables to avoid problems with underlying assumptions of the chi-square tests of independence. The significance level used for each statistical analysis was p<0.05. Not all participants answered all the survey questions resulting in

varying number of responses for each question. Thus, differences in the sample sizes of the data occurred.

#### Results

#### Characteristics of the Participants

Of the 405 people who participated in the study, 98% (n=378) identified themselves as female and 2% (n=8) as male. As participants were not required to answer all questions of the survey, some of the questions had fewer than 405 responses. Fifty-eight percent (n=210) of the participants were younger than 50 years of age. In terms of education level completed, 53% (n=209) of participants had a bachelor's degree, 43% (n=169) of participants had a master's degree, and 4% (n=17) had a doctorate degree. The number of years of practice varied among the RDs with 30% (n=122) reporting 0-5 years of experience in comparison to the 44% (n=175) of RDs who had 15+ years of experience (Table 1).

The number of patients with CD seen per week also varied with 63% (n=251) of RDs reporting seeing no patients a week and less than 2% (n=3) of RDs seeing seven or more patients a week. In terms of practice setting, private practice was identified to be the setting with the fewest practicing RDs with 6% (n=30) compared to outpatient or other (please specify) which 31% (n=143) and 28% (n=130) of RDs reported, respectively (Table 1).

#### **Registered Dietitians' Self-Reported Proficiency**

The RD's self-reported proficiency in several areas of CD management is shown in Table 2. RDs primarily rated themselves "high" for understanding CD and gluten-free definitions, determining if a food contains gluten by reading nutrition label, and providing avoidance education (e.g., cross-contamination, ingredient identification). RDs primarily rated themselves "moderate" for being able to provide information regarding local gluten-free supports groups,

identifying potential nutrition risks associated with a gluten-free diet, and providing information

regarding local gluten-free restaurants or grocery stores (Table 2).

Table 1

Demographics of Participants

	%	n
Gender (n=386)		
Male	2	8
Female	98	378
Age (n=366)		
20-29 years	17	61
30-39 years	26	94
40-49 years	15	55
50-59 years	28	104
60-69 years	13	47
70+ years	1	5
Education level (n=395)		
Bachelor's degree	53	209
Master's degree	43	169
Doctorate degree	4	17
Very of practice (n-208)		
0.5 years	20	122
6 10 years	30 16	63
11 15 years	10	38
15 + years	10	175
15+ years	-+-+	175
Number of CD patients seen per week		
0	63	251
1-3	34	133
4-6	3	10
7-9	<1	1
10+	<1	2
Practice setting		
Outpatient	31	143
Inpatient	25	117
Private Practice	6	30
Food Service	11	47
Other	28	130

Registered Dietitians' Self-Reported Celiac Disease Proficiency of Celiac Disease Management Topics

Proficiency Area	Self-H	<b>Reported Prof</b>	iciency Level	% (n)
	High	Moderate	Low	Not at all
Understands gluten-free definition	65 (251)	33 (125)	2 (8)	0 (0)
Able to determine if food item contains gluten using nutrition label	61 (233)	36 (139)	3 (13)	0 (0)
Understands celiac disease definition	55 (213)	41 (157)	4 (16)	0 (0)
Able to provide avoidance education (e.g., cross-contamination, ingredient identification)	51 (197)	40 (158)	8 (29)	1 (3)
Able to provide information regarding local restaurants or grocery stores that provide gluten-free items	33 (128)	45(178)	20 (76)	2 (8)
Able to identify nutrients at risk for deficiency when following a gluten-free diet	32 (125)	50 (194)	17 (29)	1 (3)
Able to provide information regarding local gluten-free diet support groups	30 (117)	31 (121)	26 (100)	13 (47)

A significant negative correlation of RD's self-reported proficiency and number of CD patientsseen per week was found for each of the seven questions (Table 3). A significant negative correlation of RD's self-reported proficiency and years practice was found for two of the seven questions (able to provide avoidance education, r=-0.3209, P<0.0001; understands CD definition, r=-0.1456, p=0.0042) (Table 3). A significant negative correlation of RD's self-reported proficiency and age was found for three of the seven questions (understands celiac disease definition, r=-0.1377, p=0.0067; able to provide avoidance education, r=-0.3168, P<0.0001; able to provide information regarding local gluten-free establishments, r=-0.1011, p=0.0499) (Table 3). No significant correlation was found with RD's self-reported proficiency and education level.

	Age	Education	Practice Years	CD Pts./Week <sup>2</sup>
Understands gluten-	0.0889	0.03012	-0.0890	-0.1886
free definition	0.0815	0.5578	0.0816	0.0002*
	$385^{2}$	381	384	384
Able to determine if food	0.0279	-0.0389	0.0395	-0.1553
item contains gluten using	0.5852	0.4501	0.4407	0.0023*
nutrition label	384	380	383	382
Understands celiac	-0.1377	-0.0484	-0.1456	-0.2381
disease definition	0.0067*	0.3444	0.0042*	<.0001*
	387	383	386	385
Able to provide avoidance	-0.3168	0.0180	-0.3209	-0.2657
education	<.0001*	0.7257	<.0001*	<.0001*
	385	381	384	383
Able to provide	-0.1001	0.0041	-0.0658	-0.2170
information regarding	0.0499*	0.9372	0.1985	<.0001*
local restaurants or grocery stores <sup>3</sup>	384	380	383	382
Able to identify nutrients	-0.0240	-0.0401	-0.0409	-0.1567
at risk for deficiency	0.6387	0.4356	0.4243	0.0021*
	385	381	384	383
Able to provide	-0.0887	-0.0365	-0.0984	-0.1928
information regarding	0.0819	0.4774	0.0537	0.0001*
local gluten-free diet support groups	386	382	385	384

Correlation of Registered Dietitians' Self-Reported Proficiency and Variables<sup>1</sup>

<sup>1</sup>Each cell indicates r (r=Pearson Correlation Coefficient), p-value, and n; <sup>2</sup>Number of celiac disease patients seen per week; \*Indicates significance at p<0.05; <sup>3</sup>Able to provide information regarding local restaurants or grocery stores that provide glutenfree items

There was a significant difference in RD's self-reported proficiency and number of CD patients seen per week for each of the seven questions (Tables 4-10) according to chi-square testing. There was a significant difference in RD's self-reported proficiency and years of practice for two of the seven questions (able to provide information regarding local gluten-free diet support groups, p<0.001; able to provide avoidance education, p=0.0013) (Tables 7 and 10). A significant difference in RD's self-reported proficiency and age was found in two of the seven questions (able to identify nutrients at risk for deficiency, p=0.0186, Table 6; able to provide

information regarding gluten-free diet support groups, p<0.0001, Table 7). No significant

difference in RD's self-reported proficiency was found for the seven topics and education level.

Table 4

	High	Moderate	Low	P-Value
	% (n)	% (n)	% (n)	
Overall (N=385)	55 (213)	41 (157)	4 (15)	
Age (Years)				0.5149
20-29	11 (43)	12 (47)	1 (3)	
30-39	13 (50)	9 (36)	1 (4)	
40-49	8 (32)	5 (20)	<1 (2)	
50 and over	15 (56)	14 (54)	2 (6)	
Education				0.5844
Bachelor's degree	30 (116)	20 (78)	2 (9)	
Graduate Degree	25 (95)	20 (77)	2 (6)	
Years of Practice				0.3641
0-11	24 (94)	21 (81)	7 (2)	
11 and over	31 (119)	18 (76)	8 (2)	
CD Pts. /Week <sup>2</sup>				0.0002*
0	30 (117)	28 (108)	4 (15)	
1+	25 (96)	13 (49)	0 (0)	

Self-Reported Proficiency: Understands Celiac Disease Definition<sup>1</sup>

<sup>1</sup>None of participants responded "Not at all" for this question; therefore, it was not included in the table; <sup>2</sup>Number of celiac disease patients seen per week; \*Indicates significance at p<0.05

	High	Moderate	Low	<b>P-Value</b>
	% (n)	% (n)	% (n)	
Overall (N=384)	65 (251)	33 (125)	2 (8)	
Age (Years)				0.7244
20-29	16 (61)	8 (31)	<1(1)	
30-39	16 (60)	7 (28)	1 (2)	
40-49	10 (39)	3 (13)	1 (2)	
50 and over	24 (91)	14 (53)	3 (1)	
Education				0.3846
Bachelor's Degree	34 (128)	18 (68)	2 (6)	
Graduate Degree	32 (120)	15 (56)	1 (2)	
Years of Practice				0.5226
0-11	32 (124)	14 (55)	1 (3)	
11 and over	33 (127)	18 (70)	1 (5)	
CD Pts./Week <sup>2</sup>				0.0029*
0	38 (144)	23 (89)	2 (8)	
1+	28 (107)	9 (36)	0 (0)	

Self-Reported Proficiency: Understands Gluten-Free Definition<sup>1</sup>

<sup>1</sup>None of participants responded "Not at all" for this question; therefore, it was not included in the table 2 Number of celiac disease patients seen per week \*Indicates significance at p<0.05

#### Table 6

	High	Moderate	Low	<b>P-Value</b>
	% (n)	% (n)	% (n)	
Overall (N=387)	32 (124)	50 (194)	17 (67)	
Age (Years)				0.0186*
20-29	6 (23)	12 (46)	6 (22)	
30-39	5 (21)	14 (56)	3 (13)	
40-49	21 (5)	6 (24)	2 (9)	
50 and over	15 (59)	18 (68)	6 (23)	
Education				0.9103
Bachelor's Degree	16 (62)	27 (104)	10 (37)	
Graduate Degree	14 (54)	21 (80)	7 (28)	
Years of Practice				0.0538
0-11	17 (62)	27 (104)	10 (37)	
11 and over	16 (60)	23 89)	8 (29)	
CD Pts./Week <sup>2</sup>				< 0.0001*
0	16 (63)	31 (121)	15 (56)	
1+	16 (61)	19 (73)	3 (11)	

Self-Reported Proficiency: Able to Identify Nutrients at Risk for Deficiency When Following a Gluten-free Diet<sup>1</sup>

<sup>1</sup>n=2 participants indicated "Not at All"; <sup>2</sup>Number of celiac disease patients seen per week; \*Indicates significance at p<0.05

	High	Moderate	Low	P-Value
	% (n)	% (n)	% (n)	
Overall (N=365)	30 (117)	31 (121)	27 (100)	
Age (Years)				<0.0001*
20-29	4 (15)	6 (23)	8 (32)	
30-39	5 (18)	8 (32)	8 (29)	
40-49	4 (17)	4 (17)	4 (14)	
50 and over	17 (67)	13 (49)	6 (25)	
Education				0.2388
Bachelor's Degree	18 (69)	14 (55)	14 (55)	
Graduate Degree	12 (48)	16 (64)	11 (43)	
Years Practice				<0.0001*
0-11	9 (36)	13 (50)	16 (61)	
11 and over	21 (81)	18 (71)	10 (39)	
CD Pts./Week <sup>1</sup>				<0.0001*
0	14 (52)	21 (81)	17 (67)	
1+	17 (17)	10 (40)	9 (33)	

Self-Reported Proficiency: Able to Provide Information Regarding Local Support Groups<sup>1</sup>

 $^{1}$ n=47 participants indicated "Not at All"; <sup>2</sup>Number of celiac disease patients seen per week; \*Indicates significance at p<0.05

#### Table 8

	High	Moderate	Low	P-Value
	% (n)	% (n)	% (n)	
Overall (N=390)	33 (128)	45 (178)	20 (76)	
Age (Years)				0.4362
20-29	7 (26)	11 (43)	6 (21)	
30-39	8 (29)	11 (41)	5 (19)	
40-49	4 (16)	6 (24)	3 (11)	
50-59	15 (57)	17(64)	7 (25)	
Education				0.2084
Bachelor's Degree	20 (75)	22 (82)	11 (41)	
Graduate Degree	14 (53)	23 (87)	9 (34)	
Years Practice				0.5936
0-11	15 (58)	21 (80)	11 (41)	
11 and over	18 (70)	24 (92)	9 (35)	
CD Pts./Week <sup>2</sup>				0.0009*
0	17 (65)	29 (110)	15 (56)	
1+	16 (63)	16 (62)	5 (20)	

Self-Reported Proficiency: Able to Provide Information Regarding Local Restaurants or Grocery Stores that Provide Gluten-Free Items<sup>1</sup>

<sup>1</sup>n=8 participants indicated "Not at All" <sup>2</sup>Number of celiac disease patients seen per week \*Indicates significance at p<0.05

High	Moderate	Low	<b>P-Value</b>
% (n)	% (n)	% (n)	
61 (233)	36 (139)	3 (13)	
			0.7757
15 (56)	9 (35)	1 (2)	
13 (52)	9 (34)	1 (4)	
8 (29)	6 (23)	1 (2)	
41 (69)	12 (47)	1 (5)	
			0.6428
31 (118)	20 (76)	2 (8)	
29 (112)	16 (62)	1 (5)	
			0.7606
28(107)	18 (68)	2 (7)	
33(126)	18 (71)	2 (6)	
			0.0008*
34 (129)	27 (104)	2 (9)	
27 (104)	9 (35)	1 (4)	
	High % (n) 61 (233) 15 (56) 13 (52) 8 (29) 41 (69) 31 (118) 29 (112) 28(107) 33(126) 34 (129) 27 (104)	High $% (n)$ Moderate % $(n)$ 61 (233)36 (139)15 (56)9 (35)13 (52)9 (34)8 (29)6 (23)41 (69)12 (47)31 (118)20 (76)29 (112)16 (62)28(107)18 (68)33(126)18 (71)34 (129)27 (104)27 (104)9 (35)	High $% (n)$ Moderate $% (n)$ Low $% (n)$ 61 (233)36 (139)3 (13)15 (56)9 (35)1 (2)13 (52)9 (34)1 (4)8 (29)6 (23)1 (2)41 (69)12 (47)1 (5)31 (118)20 (76)2 (8)29 (112)16 (62)1 (5)28(107)18 (68)2 (7)33(126)18 (71)2 (6)34 (129)27 (104)2 (9)27 (104)9 (35)1 (4)

Self-Reported Proficiency: Able to Determine if Food Contains Gluten Using Nutrition Label<sup>1</sup>

<sup>1</sup>None of participants responded "Not at all" for this question; therefore, it was not included in the table <sup>2</sup>Number of celiac disease patients seen per week; \*Indicates significance at p<0.05

#### Table 10

Self-Reporte	d Proficiency:	Able to	Provide A	Avoidance	Education
./ /					

	High Moderate		Low	<b>P-Value</b>
	%(n)	%(n)	%(n)	
Overall (N=383)	51 (196)	41(158)	8 (29)	
Age (Years)				0.2300
20-29	10 (38)	12 (45)	3 (10)	
30-39	12 (45)	10 (40)	1 (5)	
40-49	7 (26)	5 (21)	1 (5)	
50 and over	23 (87)	13 (52)	2 (9)	
Education				0.7504
Bachelor's Degree	26 (98)	23 (88)	4 (15)	
Graduate Degree	25 (95)	18 (69)	4 (14)	
<b>Years Practice</b>				0.0249*
0-11	22(83)	21 (81)	3 (13)	
11 and over	29 (113)	7 (26)	1 (5)	
CD Pts./Week <sup>1</sup>				0.0013*
0	27 (104)	29 (112)	6 (23)	
1+	24 (92)	12 (46)	2 (6)	

<sup>1</sup>n=3 participants indicated "Not at All"; <sup>2</sup>Number of celiac disease patients seen per week; \*Indicates significance at p<0.05

#### **CD Knowledge**

There was a significant correlation for the RD's knowledge in only one question (length of time needed to follow gluten-free diet before CD diagnosis can be accepted) with their age (P=0.0047) and years of practice (P=0.0007) (Table 11). No significant correlation was found for RD's knowledge and education level or number of CD patients seen per week for any of the

questions (Table 11).

#### Table 11

*Correlation of Registered Dietitians' Celiac Disease Knowledge and Age, Years of Practice, Education Level, and the Number of Celiac Disease Patients Seen per Week*<sup>1</sup>

	Age	Education	Years of Practice	Pts./Week <sup>2</sup>
Which of the following	$-0.0372^2$	-0.0783	-0.0144	0.0818
indicates the presence of	0.4718	0.1311	0.7812	0.1138
gluten?	377	373	376	375
Which of the following would	-0.0579	-0.00670	-0.0445	0.0191
be considered gluten-free?	0.2618	0.8975	0.3895	0.7124
	377	373	376	375
A gluten-free diet may be low	0.0625	0.0105	0.0201	0.0463
in the following nutrients	0.2270	0.8395	0.6983	0.3725
	376	372	375	374
Supplements may contain	-0.0277	-0.0400	-0.0304	-0.0180
fillers from wheat or barley	0.5910	0.4404	0.5569	0.7275
	378	374	377	376
In order to be diagnosed,	0.1452	0.0003	0.1738	0.0055
gluten-free diet must be	0.0047*	0.9950	0.0007*	0.9151
maintained for two months	378	374	377	376

<sup>1</sup>Each cell indicates r (r=Pearson correlation coefficient), p-value, and n; <sup>2</sup>Indicates CD patients seen per week; \* Indicates significance at p<0.05

For the first multiple choice question, "Which of the following indicate the presence of gluten?" the correct answer was selected by 94% of participants (n=354) (Table 12). For the second question, "Which of the following ingredient lists would be considered gluten-free?" the correct answer was selected by 94% of respondents (n=355) (Table 13). For the third question, "A gluten-free diet may be low in the following nutrients: iron, calcium, fiber, B-vitamins," the correct answer was selected by 85% of participants (n=251) (Table 14). For the fourth question,

"Supplements and pharmaceuticals may contain fillers made from wheat or barley," the correct answer was selected by 98% of participants (n=372) (Table 15). For the fifth question, "In order to be diagnosed with CD, the patient must first be following a GFD for at least two months," the correct answer was selected by 90% of participants (n=339) (Table 16).

There was a significant difference in RD's knowledge and number of CD patients seen per week for one of the five questions (indicating which item contained gluten, p=0.0151, Table 12). There was a significant difference in RD's knowledge and years of practice for one of the five questions (length of time needed to follow gluten-free diet before CD diagnosis, p=0.0046, Table 16). There was a significant difference in RD's knowledge and age in the aforementioned question (length of time needed to follow gluten-free diet before CD diagnosis, p=0.0042, Table 16). There was no significant difference in RD's knowledge and education level.

Table 12

0	Correct	Incorrect	P-Value
	%(n)	%(n)	
Overall (N=377)	94 (354)	6 (23)	
Age (Years)			0.5920
20-29	23 (87)	1 (4)	
30-39	21 (80)	2 (7)	
40-49	14 (52)	1 (2)	
50 and over	36 (135)	3 (10)	
Education			0.2469
Bachelor's Degree	50 (188)	2 (9)	
Graduate Degree	44 (163)	3 (13)	
<b>Years Practice</b>			0.6219
0-11	45 (169)	3 (210)	
11 and over	49 (185)	3 (13)	
CD Pts./ Week <sup>1</sup>			0.0151*
0	57 (215)	5 (20)	
1+	36 (137)	1 (2)	

Registered Dietitians' Knowledge: Identifying Presence of Gluten

<sup>1</sup>Number of celiac disease patients seen per week; \*Indicates significance at p<0.05

	Correct	Incorrect	P-Value
	% (n)	% (n)	
Overall (N=377)	94 (355)	6 (17)	
Age (Years)			0.3664
20-29	23 (88)	1 (3)	
30-39	22 (82)	2 (6)	
40-49	14 (52)	1 (2)	
50 and over	35 (133)	3 (11)	
Education			0.7334
Bachelor's Degree	50 (186)	3 (10)	
Graduate Degree	45 (166)	3 (11)	
Years Practice			0.5510
0-11	45 (171)	2 (8)	
11 and over	49 (184)	4 (14)	
CD Pts./Week <sup>1</sup>			0.0596
0	58 (218)	5 (19)	
1+	36 (137)	1 (3)	

Registered Dietitians' Knowledge: Gluten-free Ingredient List

<sup>1</sup>Number of celiac disease patients seen per week

#### Table 14

Registered Dietitians' Knowledge: Gluten-free Diet Deficiencies

	Correct	Incorrect	<b>P-Value</b>
	% (n)	% (n)	
Overall (N=376)	85 (321)	15 (55)	
Age (Years)			0.0968
20-29	22 (82)	2 (9)	
30-39	19 (72)	4 (15)	
40-49	13 (50)	1 (4)	
50 and over	31 (117)	7 (27)	
Education			0.3849
Bachelor's Degree	46 (171)	7 (25)	
Graduate Degree	40 (148)	8 (28)	
Years of Practice			0.9913
0-11	40 (152)	7(26)	
11 and over	45 (169)	8(29)	
CD Pts./Week <sup>1</sup>			0.6461
0	54 (203)	31 (118)	
1+	9 (33)	6 (22)	

<sup>1</sup>Number of celiac disease patients seen per week
	Correct	Incorrect	<b>P-Value</b>
	% (n)	% (n)	
Overall (N=378)	98 (372)	2 (6)	
Age (Years)			0.3638
20-29	23 (88)	1 (3)	
30-39	23 (88)	0 (0)	
40-49	14 (53)	<1(1)	
50 and over	38 (143)	1 (2)	
Education			0.4889
Bachelor's	52 (193)	1 (4)	
Graduate Degree	47 (175)	1 (2)	
Years Practice			0.8959
0-11	47 (176)	1 (3)	
11 and over	52 (196)	1 (3)	
<b>CD Pts. Per Week</b> <sup>1</sup>			0.8498
0	62 (234)	1 (4)	
1+	37 (138)	1 (2)	

Registered Dietitians' Knowledge: Gluten in Supplements and Pharmaceuticals

<sup>1</sup>Number of celiac disease patients seen per week

## Table 16

<i>Registered Dietitians</i>	'Knowledge:	Gluten-free	Diet and	l Diagnosis
	11//0////201	0,0000000000000000000000000000000000000		DIGGIODID

	Correct	Incorrect	P-Value
	% (n)	% (n)	
Overall (N=378)	90 (339)	10 (39)	
Age (Years)			0.0042*
20-29	19 (73)	5 (18)	
30-39	21 (79)	2 (9)	
40-49	14 (52)	1 (2)	
50 and over	36 (135)	3 (10)	
Education			0.8541
Bachelor's	47 (177)	5 (20)	
Graduate Degree	42 (158)	5 (19)	
Years Practice			0.0046*
0-11	40 (152)	3 (12)	
11 and over	49 (187)	1 (5)	
CD Pts./Week <sup>1</sup>			0.6130
0	56 (212)	7 (26)	
1-3	34 (127)	3 (13)	

<sup>1</sup>CD patients per week;\* Indicates significance at p<0.05

### **Registered Dietitians' Celiac Disease Resources Preference**

As seen in Table 17, RDs were asked to select all resources that they have used in the past to receive information about CD in addition to selecting all resources that they have used to educate patients. Academic publications were the most frequently used resource to educate self (66%) (n=266) while handouts were the most frequently used resource to educate patients (78%) (n=316). Tables 18 and 19 reveal the breakdown of RD's resources use for CD management more closely.

Table 17

Current Resources Used by Registered I	Dietitians for Celiac Disease Management
<b>Resources Used to Self-Educate (N=405)</b>	<b>Responses %</b> $(n)^1$

Professional/Academic Articles	66 (266)	
Internet	57 (231)	
Self-taught	57 (231)	
Handouts	51 (206)	
Continuing Education	45 (182)	
Conferences	35 (140)	
Magazine	24 (98)	
Curricular	19 (77)	
Specialized CD Conference	13 (51)	
Facebook	3 (11)	
Twitter	<1 (1)	
Resources Used to Educate Celiac Disease Patient		
Handouts	78 (316)	
Internet	40 (163)	
Professional/Academic Articles	37 (148)	
Magazine	17 (70)	
Self-taught	17 (71)	
Conferences	15 (62)	
Continuing Education	13(52)	
Specialized CD Conference	7 (29)	
Curricular	4 (15)	
Facebook	2 (8)	
Twitter	<1 (3)	

<sup>1</sup>Respondents were able to select more than one answer

, , , , , , , , , , , , , , , , , , , ,	Conventional Resources <sup>1</sup>		Technology Resources <sup>2</sup>
	% (n)	N=1,251	% (n) <sup>3</sup> N=243
Age (Years)			
20-29	23 (289)		28 (68)
30-39	24 (296)		23 (57)
40-49	14 (169)		14 (33)
50 and over	40 (500)		35 (85)
Education			
Bachelor's Degree	53 (663)		52 (125)
Graduate Degree	46 (576)		48 (116)
Years Practice			
0-11	46 (571)		50 (122)
11 and over	54 (676)		50 (121)
<b>CD</b> patients/week <sup>4</sup>			
0	56 (695)		62 (150)
1+	44 (549)		38 (92)

Celiac Disease Resources Used by Registered Dietitians for Self-Education by Age, Education, Years of Practice, and the Number of Celiac Disease Patient Seen per Week

<sup>1</sup>Include self-taught, handouts, curricular, conference, continuing education, magazine, and academic publication; <sup>2</sup>Include Twitter, Facebook, and Internet; <sup>3</sup>Respondents were able to select more than one answer; <sup>4</sup>Number of CD patients seen per week;

#### Table 19

	Conventional Resources <sup>1</sup>		<b>Technology Resources<sup>2</sup></b>		
	$\% (n)^3$	N=763	% (n) <sup>3</sup>	N=174	
Age (Years)					
20-29	21 (158)		27 (47)		
30-39	21 (161)		21 (36)		
40-49	13 (103)		11 (19)		
50 and over	45 (340)		41 (71)		
Education					
Bachelor's	52 (395)		48 (84)		
Degree					
Graduate Degree	48 (359)		52 (88)		
Years of					
Practice					
0-10	42 (319)		44 (76)		
11 and over	54 (411)		56 (98)		
CD					
patients/week <sup>4</sup>					
0	53 (404)		55 (96)		
1+	47 (355)		45 (78)		

Education, Years of Practice, and the Number of Celiac Disease Patient Seen per Week	Celiac Disease Resources Used by Registered Dietitians for Patient E	Education by Age,
	Education, Years of Practice, and the Number of Celiac Disease Patie	ent Seen <u>p</u> er Week

<sup>1</sup>Include self-taught, handouts, curricular, conference, continuing education, magazine, and /academic publication; <sup>2</sup>Include Twitter, Facebook, and Internet; <sup>3</sup>Respondents were able to select more than one answer; <sup>4</sup>Number of CD patient seen per week

#### **Registered Dietitian's Personal Use of Technology**

Of the 17% (n=63) of RD's who reported using Twitter in the past for viewing or posting tweets (Table 20), <1% (n=3) reported having used Twitter to educate a CD patient. There was a significant negative correlation between the age of the RD and Twitter use (r=-0.1784, P<0.0005.), education level of the RD and Twitter use (r=-0.10770, p=0.0324), and the years of practice and Twitter use (r=-0.1024; P=0.0040) (Table 21). There was no correlation in the number of CD patients seen per week by the RD used Twitter and Twitter use (r=0.0485, p=0.3315).

In regards to Facebook use, 74% (n=279) of RDs reported that they use Facebook, and 26% (n=98) of RDs reported that they do not use Facebook (Table 20). There was a significant negative correlation between RD's age and Facebook use (r=-0.2978; p<0.0001) and years of practice and Facebook use (r=-0.0634; P<0.001). There was no correlation between the number of CD patients seen per week and RD's use of Facebook to educate the patient (Table 21).

In regards to smart phone ownership, 74% (n=279) of RDs reported that they have a smart phone and 26% (98) reported that they did not (n=377). When asked if the RD had used information obtained from a smart phone app to educate a patient, 22% (n=60) of RDs reported that they had (Table 24). There was a significant negative correlation of RD's age (r=-0.1868; P=0.0003), years of practice (r=-0.1455; P=0.0046), and smart phone use. There was also a negative correlation between the number of CD patients seen per week by the RD and whether or not the RD used a smart phone app to educate the patient (r=-0.2345; P<0.0001) (Table 21).

In regards to Internet use, 100% (n=375) of RDs reported that they use the internet. (Table 20). There was a significant negative correlation of number of CD patients seen per week (r=-0.2305; P<0.0001) and internet use for CD management (Table 21). There was no correlation

between age, education level, or years of practice for whether or not the RD used the Internet to

educate the patient.

Table 20

Personal Technology Use	Yes	No
	% (n)	% (n)
Do you use Twitter? (N=378)	17(63)	83 (315)
Do you use Facebook? (N=377)	74 (279)	26 (98)
Do you have a smart phone? (N=377)	74 (279)	26 (98)
Do you use the Internet? (N=375)	100 (375)	0 (0)

## **Registered Dietitians' Twitter Use to Educate a Celiac Disease Patient**

There was no significant difference in RD's Twitter use for CD management by age, education level, years practice, or number of CD patients seen per week (Table 22). There was also no significant difference in how often RDs use Twitter for CD management by age, education level, years practice, or number of CD patients seen per week (Table 22).

Correlation of Registered Dietitian's Use of Twitter, Facebook, Smart Phone Apps, and Internet and Age, Education, Years of Practice, and the Number of Celiac Disease Patients Seen per Week<sup>1</sup>

	Age (years)	Education	Years Practice	CD Pts./Week <sup>2</sup>
Do you use Twitter?	-0.1748	-0.1077	-0.1024	-0.0485
	0.0005*	0.0324*	0.0399*	0.3315
	399	395	403	403
Have you ever used	-0.0192	-0.0129	-0.0290	-0.1489
Twitter to educate a	0.8812	0.9212	0.8214	0.2441
CD patient?	63	61	63	63
Do you use Facebook?	-0.2976 <.0001* 399	-0.0627 0.2135 395	-0.2341 <.0001* 403	-0.0180 0.7186 403
Have you used	-0.0629	-0.0481	-0.0634	-0.0431
Facebook to educate a	0.2975	0.4284	0.2936	0.4763
CD patient?	276	273	276	276
Do you have a smart phone?	-0.1868	-0.0793	-0.1455	-0.0234
	0.0003*	0.1261	0.0046*	0.6505
	377	373	377	377
Do you use smart phone apps?	-0.2185	-0.0402	-0.1823	-0.01380
	<.0001*	0.4408	0.0004*	0.7904
	374	370	374	374
Have you ever used smart phone apps for patients?	-0.0668	-0.0611	-0.0072	-0.2345
	0.2681	0.3148	0.9056	<.0001*
	277	273	277	277
Do you use Internet?	**	**	**	**
	**	**	**	**
	275	271	271	272
Have you used	0.0617	0.0798	0.0327	-0.2305
Internet to educate a	0.2329	0.1245	0.5278	<.0001*
CD patient?	376	372	376	376

<sup>1</sup>Each cell indicates r (r=Pearson correlation coefficient), p-value, and n; <sup>2</sup>Number of celiac disease patients seen per week; \*Indicates significance at p<0.05; \*\*No r and p value for this question as all respondents selected answer "Yes"

Have you used Twitter to educate a Celiac Disease		How often have you used Twitter to				
patient?				educate a C	eliac Disease p	atient? <sup>1</sup>
	Yes	No	<b>P-Value</b>	<1x a mo. <sup>2</sup>	1+ a month <sup>3</sup>	P-Value
	% (n)	% (n)		% (n)	% (n)	
Overall	5 (3)	95 (60)		67 (2)	33 (1)	
Age (years)			0.4849			0.0833
20-29	3 (2)	38 (24)		67 (2)	0 (0)	
30-39	0 (0)	24 (15)		0 (0)	0 (0)	
40-49	0 (0)	19 (12)		0 (0)	0 (0)	
50 and over	2 (1)	14 (9)		0 (0)	33 (1)	
Education			0.9195			0.0833
BS	3 (2)	61 (37)		67 (2)	33 (1)	
MS	2(1)	34 (21)		0 (0)	0 (0)	
Years of Practice			0.8178			0.0833
0-11	3 (2)	57 (36)		67 (2)	0 0	
11 and over	2(1)	38 (24)		0 (0)	33(1)	
CD Pts./week <sup>4</sup>			0.2372			0.3865
0	2(1)	63 (40)		33 (1)	0 (0)	
1+	3 (2)	32 (20)		33 (1)	33 (1)	

Registered Dietitian's Twitter Use to Educate Celiac Disease Patient

<sup>1</sup>Limited to participants who answered 'yes' to "Have you used Twitter to educate a celiac disease patient?; <sup>2</sup>Less than one time a month; <sup>3</sup>At least once a month; <sup>4</sup>Number of celiac disease patients seen per week

#### **Registered Dietitians' Facebook Use to Educate a Celiac Disease Patient**

There was a significant difference in RD's Facebook use to educate patients with CD and number of CD patients seen per week (p=0.0053) No significant differences were found in RD's Facebook use for CD management by age, years practice, or education level (Table 23). There was a significant difference in how often an RD uses Facebook to educate a CD patient by age (p<0.0078) and number of CD patients seen per week (p<0.0009). There was no significant difference in how often an RD uses Facebook to educate a CD patient by age (p<0.0078) and number of CD patients seen per week (p<0.0009). There was no significant difference in how often an RD uses Facebook to educate a CD patient by education level or years of practice.

Have you used Facebook to educate a patient			How often have you used Facebook			
with Celiac Disease?			to educate a Celiac Disease patient? <sup>1</sup>			
	Yes	No	P-	<1x a mo. <sup>2</sup>	1+ a mo. <sup>3</sup>	Р-
	% (n)	% (n)	Value	% (n)	% (n)	Value
Overall	19 (60)	81 (258)		82 (18)	14 (3)	
Age (years)						
20-29	3 (8)	26 (71)	0.3924	41 (9)	0 (0)	0.0078*
30-39	1 (4)	26 (71)		18 (4)	0 (0)	
40-49	<1 (1)	14 (40)		14 (3)	0 (0)	
50 and over	2 (5)	28 (76)		9 (2)	5 (1)	
Education			0.4265			0.3575
BS	3 (8)	51 (138)		50 (11)	5 (1)	
MS	4 (10)	43 (117)		32 (7)	9 (2)	
Years practice			0.4221			0.2919
0-11	4 (12)	50 (139)		45 (10)	0 (0)	
11 and over	2 (6)	43 (119)		14 (3)	0 (0)	
CD Pts. <sup>4</sup>						
0	4 (10)	60 (165)	0.0053*	48 (10)	5 (1)	0.0009*
1+	3 (8)	34 (93)		24 (5)	10 (2)	

Registered Dietitian's Facebook Use to Educate Celiac Disease Patient

<sup>1</sup>Limited to participants who answered 'yes' to "Have you used Facebook to educate a celiac disease patient?; <sup>2</sup>Less than one time a month; <sup>3</sup>At least once a month; <sup>4</sup>Number of celiac disease patients seen per week

### **Registered Dietitians' Smart Phone App Use to Educate a Celiac Disease Patient**

There was a significant difference in RD's using smart phone apps to educate a patient with CD and number of CD patients seen per week (p<0.0001). No significant differences were found with RD's smart phone app use for CD management and age, years practice, or education level (Table 24).

Have you used smart phone apps to educate				How often have you used smart phone			
a patient with	celiac dise	ase?	apps to educate a celiac disease patient? <sup>1</sup>				
	Yes	No	Р-	<1x a mo. <sup>2</sup>	1+ a mo. <sup>3</sup>	Р-	
	% (n)	% (n)	Value	% (n)	% (n)	Value	
Overall	22 (60)	78 (217)		64 (39)	20 (12)		
Age (years)			0.2718			0.8048	
20-29	8 (22)	19 (53)		28 (17)	5 (3)		
30-39	5 (13)	22 (62)		15 (9)	3 (2)		
40-49	2 (6)	10 (29)		5 (3)	3 (2)		
50 and over	7 (19)	20 (55)		17 (10)	8 (5)		
Education			0.3131			0.3798	
BS	12 (34)	38 (105)		38 (23)	13 (8)		
MS	10 (26 )	40 (108)		27 (16)	7 (4)		
Years practice			0.9052			0.3876	
0-11	11 (31)	41 (114)		38 (23)	8 (5)		
11 and over	10 (29)	37 (103)		27 (16)	12 (7)		
CD Pts. <sup>4</sup>			< 0.0001*			0.0689	
0	9 (25)	54 (150)		35 (21)	3 (2)		
1+	13(35)	24 (67)		23 (14)	15 (9)		

Registered Dietitian's Smart Phone Use to Educate Celiac Disease Patient

<sup>1</sup>Limited to participants who answered 'yes' to "Have you used smart phone apps to educate a celiac disease patient?; <sup>2</sup>Less than one time a month; <sup>3</sup>At least once a month; <sup>4</sup>Number of celiac disease patients seen per week

#### **Registered Dietitians' Internet Use to Educate a Celiac Disease Patient**

In regards to internet use, 316 RDs (84%) reported that they have used information obtained from the internet to educate a patient with CD. When asked about how frequently they have used the internet to educate a patient with CD, 218 (69%) RDs reported less than once a month, and 75 (24%) reported more than one time a month (Table 25).

There was a difference in RD's internet use to educate a patient with CD and number of CD patients seen per week (p=0.0005). There were no differences in RD's internet use for CD management by age, years practice, or education level (Table 25). There was a significant difference in how often an RD uses the internet to educate a CD patient by education level (p=0.0227) and number of CD patients seen per week (p<0.0001). There was no significant difference in how often an RD uses the internet to educate a CD patient by age and years of practice (Table 25)

Have you used internet to educate CD patient?				How often have you used internet to educate CD patient? <sup>1</sup>		
	Yes	No	Р-	<1x a mo. <sup>2</sup>	1+ a mo. <sup>3</sup>	Р-
	% (n)	% (n)	Value	% (n)	% (n)	Value
Overall	84 (316)	16 (60)		68 (218)	24 (75)	
Age (years)			0.4788			0.3639
20-29	20 (77)	3 (13)		17 (55)	7 (21)	
30-39	20 (77)	3 (10)		16 (50)	6 (18)	
40-49	11 (43)	3 (10)		9 (29)	3 (10)	
50 and over	32 (119)	7 (27)		27 (84)	8 (26)	
Education			0.1411			0.0227*
BS	37 (116)	14 (44)		37 (116)	14 (10)	
MS	32 (99)	10 (30)		29 (91)	10 (30)	
Years practice			0.5265			0.2792
0-11	40 (151)	7 (26)		34 (108)	11 (35)	
11 and over	44 (165)	9 (34)		35 (110)	13 (40)	
CD Pts./week <sup>4</sup>			0.0005*			< 0.0001*
0	49 (182)	14 (53)		50 (160)	7 (21)	
1+	35 (133)	2 (7)		18 (58)	17 (54)	

Registered Dietitian's Internet Use to Educate Celiac Disease Patient

<sup>1</sup>Limited to participants who answered 'yes' to "Have you used the Internet to educate a celiac disease patient?; <sup>2</sup>Less than one time a month; <sup>3</sup>At least once a month; <sup>4</sup>Number of celiac disease patients seen per week

#### Discussion

Overall, this study sought to explore the relationship between the RD's self-reported CD proficiency, CD knowledge, current CD resource use, and Twitter, Facebook, smart phone app, and Internet use in CD management. We found that RDs rated themselves moderate or high proficiency for all seven of the seven topics with the highest percentage (65%) of RD's reporting a high level for understanding the CD definition, and the lowest percentage (30%) of RDs reporting a high level of understanding of local CD support groups. Previous research is somewhat limited regarding the RD's self-reported proficiency of CD, but in a survey of RDs who work with children with food allergies, most respondents (>50%) rated themselves less than high proficiency in all areas aside from understanding the definition of food allergies and food intolerance and very few respondents (<20%) rated their proficiency level high for understanding

the steps involved in a food allergy diagnosis, developing an elimination diet, and evaluating safe food items in a hospital or school setting (Groetch, 2010).

We found a significant negative correlation of RD's self-reported proficiency and number of CD patients per week for all self-reporting proficiency questions translating to a decrease in self-reported proficiency with an increase in the number of CD patients per week. This finding could be related to the sample's CD exposure, as 63% reported seeing 0 CD patients per week on average, while only 39% of our sample saw greater than 1 CD patient per week. Additionally, a significant negative correlation of RD's self-reported proficiency and years practice was found for two of the questions, and this again could be attributed to the fact that our sample's distribution for CD patients seen per week was somewhat unbalanced.

Since meeting with a skilled RD has been identified as an essential aspect of managing CD (NIH, 2004), our study also attempted to assess the RD's knowledge of CD by asking five closed-ended questions. According to Mahadev (2013), in a study of biopsy-diagnosed CD patients, 40% of patients (n=164) agreed with the statement that it is difficult to find an RD knowledgeable about the GFD. In a similar study which surveyed 160 biopsy-diagnosed CD patients, 54% of the participants (n=86) reported that the RD did not seem to be knowledgeable about CD, and 53% of patients (n=85) did not find the RD to be helpful (Tidwell & Bomba, 2001).

While our results indicate that the RD has a fairly good understanding of CD topics, ingestion of even trace amounts of gluten can induce intestinal damage, so it is imperative that the RD and medical team are able to provide the CD patient with as much reliable information as possible. Identification and treatment of nutritional deficiencies has been identified as one of the essential aspects of managing CD (NIH, 2004), and we found that the RD may need more

reinforcement of this topic based off of self-reported proficiency levels and knowledge question findings. Additionally, research has suggested that physicians might not be entirely knowledgeable of CD as a study of 132 California primary care providers demonstrated that only 32% of providers were aware of the possible onset of CD in adulthood (Zipser, Farid, Baisch, Patel, & Patel, 2005).

Handouts and academic publications were the conventional resources that the RDs used most frequently to educate patients with CD. In a similar study where RDs were surveyed regarding food allergies, handouts were also identified as the leading resource used to educate patients (Groetch, 2010). In terms of patient preference for methods of receiving CD education, a German study of 64 biopsy-diagnosed CD patients found that the use of a computer-based interactive training program significantly increased knowledge and sustainability of CD topics as compared to a conventional training for CD patients (Meyer, 2003), so future studies should explore the effectiveness of using such programs for CD education.

We found that the Internet was the RD's preferred technology resource for educating a patient with CD as well as the preferred tech resource for self-education. As mentioned our study also found a negative correlation of number of CD patients seen per week and RD internet use for patient education translating to decreased RD internet use for patient education with an increase in the number of CD patients seen per week. This may be related to the RD having less overall familiarity with CD topics, thus, requiring the Internet to assist with education topics. While our study did not determine specific website preferences of RDs, there are several resources available to the RD and general public to increase CD knowledge. For example, the Academy of Nutrition and Dietetics' website hosts information for academy members including its Evidence-Based Celiac Disease Practice Guidelines and Evidence Analysis Library.

Additionally, the website provides information to the public on various CD topics such as glutenfree app reviews (Crandall, 2012; Boyce, 2014).

Other websites such as the CD Foundation or National Institute of Health also provide information on CD topics which can improve the general public or RDs knowledge base of CD topics. According to a study in which researchers determined the accuracy, comprehensiveness, transparency, and readability of various celiac disease websites, only 4 of 98 (4%) websites were found to be trustworthy and reliable; of those, two were considered nonprofit websites (http://www.celiac.org and http://www.digestive.niddk.nih.gov/ddiseases/pubs/celiac), one academic (http://celiaccenter.uscd.edu), and one commercial (http://celiacdisease.about.com) (McNally, 2012).

It has been estimated that fifty-five percent of those over the age of 18 look to the Internet as a source of health or medical information (United States Census Bureau, 2011), and research has supported the notion of utilizing Internet-based programs for health interventions. The use of eHealth, which can be defined as using technology with an emphasis on the Internet to communicate and monitor health-related practices (Norman et al., 2007), has been found to be effective with delivering health interventions. For example, in a study in which thirty-six volunteers participated in a 12-week intervention which consisted of 36 healthy lifestyle-focused email messages, participants reported increased intake of fiber, decreased intake of fat, and increased physical activity levels. Additionally, overweight and obese participants lost an average of eight pounds during the intervention period. (Nyquist, Rhee, Brunt, & Garden-Robinson, 2011).

Medical professionals are also using the Internet to increase proficiency and knowledge of their areas of study by enrolling in online programs. For example, in a survey of occupational

therapists that completed an online post professional master's degree program, participants reported that their online education effectively increased their critical reasoning, leadership, and reflection abilities. (Richardson, Schwartz, Bankston, & Kosten, 2008). Though research is somewhat limited regarding dietitians and post professional education, an online master's degree would seemingly be effective in increasing dietitians' knowledge of various medical nutrition therapies. An example of such an online program is the Great Plains Interactive Distance Education Alliance M.S. Dietetics program in which students are able to enroll in online courses from eight different colleges. Electives offered in this program include courses with an emphasis in public health, food science, healthcare administration, and more (Great Plains Interactive Distance Education Alliance, 2014).

In regards to RD's social media use, our results were somewhat similar to a study (Wang, 2012) which surveyed medical professionals about their use of social media. In that study 89% of respondents reported using Facebook and Twitter, and in our study 74% reported using Facebook but only 17% reported using Twitter for leisure use. In terms of Facebook use, our study's results differed from a study of pharmacists who reported Facebook use to be at about 10%, but that the majority of that use was related to personal use (Grindrod, 2014).

Our study also demonstrated that there was a correlation between the RD's age and Twitter, Facebook, or smart phone use with the older RDs generally demonstrating decreased use of such technologies. In a study of younger adults (20-29 years old) and middle-aged adults (46-59 years old), it was found that differences in age impacted the participants' behaviors such rigidity of exploration, success of physical operation methods, and number of interaction steps with complicated electronic devices (portable multimedia players and MP3 players). Conversely,

frustration levels and trial-and-error behaviors were impacted by differences in background knowledge of electronic devices rather than by age (Neung, 2007).

As we found that the Internet is a preferred method of receiving self-education, perhaps RDs will be able to increase technology use by utilizing online modules of such information. Text messaging or Short Message Service (SMS) may be another avenue for RDs to explore as they gain familiarity with various technology health interventions. Text messaging-based programs have been found to be effective in treatment plans for obesity, smoking, diabetes, and asthma as patients receive personal messages from mobile coaches (Nundy, Dick, & Goddu, 2012).

There are several limitations to the current study. For example, 63% of the population reported seeing zero CD patients a week, so the majority of participants seldom work with the CD patient, thus limiting how much we are able to determine about the RD who works with the CD patient. Additionally, if the RD worked in one of the settings in which CD exposure is low, she or he might not have been interested in fully completing the survey. In regards to time, the informed consent described the time commitment to be roughly 10 minutes which could have been a difficulty for some.

Future studies might also be beneficial in determining the best way to provide CD education to RDs. Research has suggested that more medical programs are encouraging the use of apps, but the accuracy of some apps can range in accuracy from 48-55%, so it is important for the RD and medical team to be able to determine whether or not an app is reliable (Aungst, 2014).

In conclusion, RDs reported either moderate or high levels of proficiency for all seven of the seven self-reported proficiency topics. Topics where the RD indicated a moderate level of

proficiency were identifying potential nutritional deficiencies related to CD and having knowledge of local gluten-free support groups or area restaurants. The five knowledge based questions of the survey revealed some potential knowledge gaps as no question resulted in 100% correct answers from the RDs. As previously mentioned there are resources available to the RD to improve knowledge base of such topics such as the Celiac Disease Foundation or National Institute of Health's websites, and the Celiac Disease Foundation website also provides information regarding local gluten-free or celiac disease support groups. Professional and academic publications were the most commonly used resources by the RD for self-education whereas handouts were the most commonly used resource by the RD for patient education. Our study also demonstrated that there was a correlation between the RD's age and Twitter, Facebook, or smart phone use with the older RD's generally demonstrating decreased use of such technologies.

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#### **CHAPTER 5. SUMMARY**

This study aimed to measure RD's CD proficiency and to determine how they use technology in their practice. As it is well established, adherence to the GFD is the only treatment for CD, thus making the RD an essential member of the treatment team. Topics that the CD patient needs to be informed of are those such as the nutritional quality of the GFD, and preventing contamination with gluten-containing foods (Simpson, 2012). The five knowledge based questions of the survey revealed some potential knowledge gaps, as no question resulted in 100% correct responses from the participating RD's. While a goal of 100% accuracy is quite high, the research shows that even the smallest ingestion of gluten can induce intestinal damage (Lähdeaho, 2011), so it is imperative the patient receive accurate information from the RD.

There are several resources such as the CD Foundation or National Institute of Health websites which RDs could use to increase knowledge base of CD topics. According to a study in which researchers determined the accuracy, comprehensiveness, transparency, and readability of various celiac disease websites, only 4 of 98 (4%) websites were found to be trustworthy and reliable, and of those two were considered nonprofit websites (http://www.celiac.org and http://www.digestive.niddk.nih.gov/ddiseases/pubs/celiac), one academic (http://celiaccenter.uscd.edu), and one commercial (http://celiacdisease.about.com) (McNally, 2012).

In regards to the technology use for CD management found in this study, there were differences in technology use by variables such as age, education, years of practice as an RD, and number of CD patients seen per week. While technology is not essential to use as an education tool, past research has suggested that technology use can enhance the work of the RD. For example, in a study of Pennsylvania Academy of Nutrition and Dietetics members, 90.3% of

members reported that their ability to function efficiently within the nutrition profession was improved by their technology skills, and 86.3% predicted making future efforts to strengthen our skills (Davis, 2004). Our study found that RDs are using technology in their practice; however, this study was limited to use of Twitter, Facebook, smart phone, and Internet with excludes several additional technology sources.

The hypotheses of this study were that >90% of RDs have high CD self-reported proficiency and that >90% of RDs use technology in practice. The results of our study do not support our hypothesis that >90% of RDs have high CD self-reported proficiency and that >90% of RDs use technology for CD education. Though a majority of RDs reported levels of high proficiency for four of seven CD topics (understands CD definition (65%); able to determine if food contains gluten using nutrition label (61%); understands gluten-free definition (55%); able to provide avoidance education (51%), none of these topics resulted in >90% of RDs reporting high levels.

With regards to our hypothesis and RD knowledge, the five knowledge based questions of the survey revealed some potential knowledge gaps as no question resulted in 100% correct answers from the RDs, but four of the five questions resulted in >90% of RDs selecting the correct answer, and just one question resulted in <90% of RDs selecting the correct answer. With regards to our hypothesis and RD use of technology for CD education, only 5% of those who use Twitter report using Twitter for patient education, with similar results from Facebook use, smart phone app use, and Internet use (19% of those who use Facebook reported use for CD patient education; 22% of those who use smart phone apps reported use for CD patient education; 84% of those who use Internet reported use for CD patient education).

There are several limitations to the current study. For example, 63% of the population reported seeing zero CD patients a week, so the majority of participants seldom work with the CD patient, thus limiting how much we are able to determine about the RD who works with the CD patient. Additionally, if the RD worked in one of the settings in which CD exposure is low, she or he might not have been interested in fully completing the survey. In regards to time, the informed consent described the time commitment to be roughly 10 minutes which could have been a difficulty for some.

As professional publications, the Internet, and self-taught methods were the resources most frequently used by the RD to learn about CD, future research might be beneficial to determine the accuracy of such resources. Additionally, future studies regarding celiac disease patients learning preferences would be of interest.

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## APPENDIX A. IRB APPROVAL OF HUMAN RESEARCH PROJECT

#### NDSU NORTH DAKOTA STATE UNIVERSITY

Tuesday, May 21, 2013

FederalWide Assurance FWA00002439

Yeong Rhee Health, Nutrition & Exercise Science

Re: IRB Certification of Exempt Human Subjects Research: Protocol #HE13256, "Survey of Registered Dietitians' Proficiency of Celiac Disease and Their Use of Technology and Determination of Effectiveness of Twitter in Nutrition Education"

Co-investigator(s) and research team: Joan Nagel, Sherri Stastny, Ardity Brunt, Elizabeth Salafia

Certification Date: 5/21/13 Expiration Date: 5/20/16 Study site(s): varied Funding: n/a

The above referenced human subjects research project has been certified as exempt (category # 2) in accordance with federal regulations (Code of Federal Regulations, Title 45, Part 46, Protection of Human Subjects). This determination is based on protocol materials (received 5/17/2013).

Please also note the following:

- If you wish to continue the research after the expiration, submit a request for recertification several weeks prior to the expiration.
- Conduct the study as described in the approved protocol. If you wish to make changes, obtain
  approval from the IRB prior to initiating, unless the changes are necessary to eliminate an
  immediate hazard to subjects.
- Notify the IRB promptly of any adverse events, complaints, or unanticipated problems involving
  risks to subjects or others related to this project.
- Report any significant new findings that may affect the risks and benefits to the participants and the IRB.
- Research records may be subject to a random or directed audit at any time to verify compliance with IRB standard operating procedures.

Thank you for your cooperation with NDSU IRB procedures. Best wishes for a successful study. Sincerely,

Kosty Shinley

Kristy Shirley, CIP, Research Compliance Administrator

INSTITUTIONAL REVIEW BOARD NDSU Dept 4000 | PO Rox 6060 | Fargo HD Simole-6060 | 701231.8595 | Pox 701231.8098 | Indixaedu/vo Shipping addimate: Research 1, 1735 NDSU Research Park Drive, Pargo, ND 59102

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## **APPENDIX B. E-MAIL RECRUITMENT LETTER**

E-Mail Subject Box: Your Input is Requested on Survey for Dietetics Research

Dear Registered Dietitian,

As a Graduate Degree Degree student in the Health, Nutrition, and Exercise Sciences Department at North Dakota State University, I am seeking your input on my research regarding the Registered Dietitians' proficiency of celiac disease and use of technology in practice as part of the requirements for my master's degree.

The results of this study may be published. This will provide information to all stakeholders to identify the proficiency of Registered Dietitians' regarding celiac disease, and their use of technology in practice.

Participating in this study should take approximately 10 minutes. Your response will be anonymous and confidential. The data will be aggregated for analysis. The North Dakota State University Institutional Review Board approved this study. If you wish to take this survey, please click on this link <u>http://www.surveymonkey.com/</u> and complete by July 15, 2013.

Thank you.

Joan Nagel, RD Master's Candidate North Dakota State University Health, Nutrition, and Exercise Sciences Fargo, ND 58108-6050 joan.nagel.1@my.ndsu.edu 701.471.9505

Yeong Rhee, PhD., RD Health, Nutrition, and Exercise Sciences North Dakota State University Fargo, North Dakota 58108-6050

## APPENDIX C. SURVEY FOR REGISTERED DIETITIANS

## Please, only take this survey once.

## **Demographics**

*Instructions: Select the answer(s) that apply.* 

- 1. What is your gender?
  - o Male
  - o Female
- 2. What is your age?
  - o 20-29
  - o 30-39
  - o 40-49
  - o 50-59
  - o 60-69
  - o 70+
- 3. What is your highest achieved education level?
  - o BS
  - o Master's
  - o Doctorate
- 4. How many years have you been in practice as an RD?
  - o 0-5 years
  - 6-10 years
  - 11-15 years
  - $\circ$  > 15 years

- 5. How many patients do you see in an average week with celiac disease?
  - o 0
  - o 1-3
  - o **4-6**
  - o **7-9**
  - o 10+
- 6. Type of practice settings (respondent could choose more than 1)
  - □ Clinic/outpatient
  - □ Hospital inpatient
  - □ Private practice
  - $\Box$  Food service
  - □ Other \_\_\_\_\_
- 7. Have you been practicing as an RD in the past six months?
  - o Yes
  - o No
- 8. Do you belong to the Dietitians in Gluten Intolerance Diseases (DIGID) practice group of AND?
  - a. Yes
  - b. No

## Study Population's Self-Reported Celiac Disease Proficiency

Using a scale of 1-4 as described, please rate the following items.

(*High=1*, *Moderate=2*, *Low=3*, *Not at All=4*)

1. Understands celiac disease definition

*High=1, Moderate=2, Low=3, Not at All=4* 

2. Understands gluten-free diet definition

*High=1, Moderate=2, Low=3, Not at All=4* 

- 3. Able to identify nutrients at risk for deficiency when following a gluten-free diet *High=1*, *Moderate=2*, *Low=3*, *Not at All=4*
- 4. Able to provide information regarding local gluten-free diet support groups

*High=1, Moderate=2, Low=3, Not at All=4* 

 Able to provide information regarding local restaurants or grocery stores that provide gluten-free items

*High=1, Moderate=2, Low=3, Not at All=4* 

6. Able to determine if food item contains gluten using nutrition label

*High=1, Moderate=2, Low=3, Not at All=4* 

7. Able to provide avoidance education (e.g., cross-contamination, ingredient identification)

*High=1, Moderate=2, Low=3, Not at All=4* 

#### Study Population's Celiac Disease Knowledge

Select the answer/answers that apply.

- 1. Which of the following indicate the presence of gluten?
  - Wheat
  - Barley
  - o Rye
  - All of the above
- 2. Which of the following ingredient lists would be considered gluten-free?
  - Corn, Rye, Barley

- Amaranth, Corn, Quinoa
- o Buckwheat, Corn, Rye
- Quinoa, Flour, Wheat
- A gluten-free diet may be low in the following nutrients: iron, calcium, fiber, B-vitamins.
   True
  - o False
- 4. Supplements and pharmaceuticals may contain fillers made from wheat or barley.
  - False
- 5. In order to be diagnosed with celiac disease, the patient must first be following a glutenfree diet for at least two months.
  - o True
  - o False

### Current celiac disease resources used by study population

Which of the following answer (s) have you used in the past to receive information about celiac disease? Check all that apply.

- □ Self-taught
- □ Handouts
- □ Curricular course work
- □ Specialized CD conferen
- □ Continuing education courses
- □ Conferences
- Internet
- □ Magazines
- □ Professional/academic publications
- □ Twitter
- □ Facebook

Which of the following have you used to educate clients/patients regarding celiac disease? Check all that apply.

- □ Self-taught
- □ Handouts
- □ Curricular course work
- □ Specialized CD conference
- □ Continuing education course
- □ Conferences
- □ Internet
- □ Magazines
- □ Professional/academic publications
- □ Twitter
- □ Facebook

### Technology use in celiac disease management

Select the answer(s) that apply for the following questions.

- 1. Do you use Twitter?
  - Yes, I view and post tweets. (Go to #2)
  - Yes, I only view tweets. (Go to #2)
  - No, I have stopped using it. (Go to #4)
  - No, I have not used it before. (Go to #4)
- 2. Have you ever used or shared information obtained from Twitter to educate a patient who

has celiac disease?

- Yes (Go to #3)
- No (Go to #4)
- 3. How often have you shared information obtained from Twitter to educate a patient who has celiac disease?
  - $\circ$  Less than once a month
  - At least once a month

- At least once a week
- At least once a day
- 4. Do you use Facebook?
  - Yes, I view and post statuses. (Go to #5)
  - Yes, I only view status updates. (Go to #5)
  - No, I have stopped using it. (Go to #7)
  - No, I have not used it before. (Go to #7)
- 5. Have you ever used or shared information obtained from Facebook to educate a patient

who has celiac disease?

- Yes (Go to #6)
- No (Go to #7)
- 6. If yes to #3, then how often have you used or shared information obtained from Facebook to educate a patient who has celiac disease?
  - Less than once a month
  - At least once a month
  - At least once a week
  - At least once a day
- 7. Do you have a smart phone?
  - Yes (Go to #8)
  - No (Go to #11)
- 8. Do you use smart phone apps?
  - Yes (Go to #9)
  - No (Go to #11)

- 9. Have you ever used or shared information obtained from a smart phone app to educate a patient/client who has celiac disease?
  - Yes (Go to #10)
  - No (Go to #11)
- 10. How often have you used or shared information obtained from a smart phone app to educate a patient/client who has celiac disease?
  - Less than once a month
  - At least once a month
  - At least once a week
  - At least once a day
- 11. Do you use the Internet?
  - $\circ$  Yes (Go to #12)
  - No (Go to end)
- 12. Have you ever used information obtained from the Internet to educate a patient who has

celiac disease?

- Yes (Go to #13)
- No (Go to end)
- 13. How often have you used information obtained from the Internet to educate a

patient/client who has celiac disease?

- Less than once a month
- At least once a month
- At least once a week
- At least once a day

## APPENDIX D. INFORMED CONSENT FOR REGISTERED DIETITIANS

NDSU North Dakota State University Department of Health, Nutrition, and Exercise Sciences Campus Address NDSU Dept. 2620 PO Box 6050 Fargo, ND 58108-6050 701.231.7487

# Title of Research Study: SURVEY OF REGISTERED DIETITIANS' PROFICIENCY OF CELIAC DISEASE AND USE OF TWITTER, FACEBOOK, SMART PHONE APPS, AND INTERNET FOR CELIAC DISEASE MANAGEMENT

Dear Participant:

My name is Joan Nagel. I am a Graduate Degree Degree student in the Department of Health, Nutrition, and Exercise Science at North Dakota State University, and I am conducting a research project to assess Registered Dietitians' proficiency regarding Celiac Disease (CD) management, particularly their proficiency in utilizing technology. It is our hope, that with this research, we will learn more about how dietitians are using technology in their current practice and how proficient they are in educating patients with CD.

Because you belong to a statewide Academy of Nutrition and Dietetics (AND) affiliate and/or a member of the Dietitians in Gluten Intolerance Diseases DIGID sub-unit group of AND, you are invited to take part in this research project. Your participation is entirely your choice, and you may change your mind or quit participating at any time, with no penalty to you.

It is not possible to identify all potential risks in research procedures, but we have taken reasonable safeguards to minimize any known risks.

Benefits may include gaining a better understanding of the RD's comfort level with CD and may help to create learning opportunities based on the RD's preferred methods of learning.

We are asking you to consent to participate in this research study. By consenting you are agreeing to complete the online survey at https://www.surveymonkey.com. Please click on this link https://www.surveymonkey.com/ and complete the survey by July 15, 2013 You will not need to identify yourself to take this survey however we will ask you to acknowledge whether or not you belong to the DIGID sub-unit of AND and whether or not you are currently a practicing Registered Dietitian. It should take about 10 minutes to complete the questions regarding your current practice, general knowledge of CD, and use of technology. You will not receive any compensation for this study.
Participation in the initial survey will be anonymous. That means that no one, not even members of the research team, will know that the information you give comes from you.

If you have any questions about this project, please contact me at 701.471.9505 and joan.nagel.1@my.ndsu.edu\_or contact my advisor, Dr. Yeong Rhee at 701.231.7476 or yeong.rhee@ndsu.edu.

You have rights as a research participant. If you have questions about your rights or complaints about this research, you may talk to the researcher or contact the NDSU Human Research Protection Program at 701.231.8908, toll-free at 1-855-800-6717, by email at ndsu.irb@ndsu.edu, or by mail at: NDSU HRPP Office, NDSU Dept. 4000, P.O. Box 6050, Fargo, ND 58108-6050.

Thank you for your taking part in this research. If you wish to receive a copy of the results, please email the researchers requesting the results, and we can provide the results after the study is completed.