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Exploring Factors of Non-Compliance for Adolescents with Celiac Disease

by

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MSW Clinical Research Paper

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Abstract

Individuals with celiac disease face many challenges when navigating the world around them. Adolescents with celiac disease must face the challenge of standing out in a world that is heavily influenced by peers and the pressure to fit in. The purpose of this project was to explore factors of non-compliance for adolescents with celiac disease. Using a qualitative design, two adolescent female volunteers participated in a focus group regarding factors in their lives that led them to not comply with the gluten-free diet. Data were analyzed and the focus group responses were then linked to previous related literature. The findings indicated that the respondents were in fact able to comply with the gluten-free diet based on the severity of their symptoms, support from others, knowledge of others about the gluten-free diet, and their own knowledge. These findings highlight the importance of support and knowledge and point out the need for a greater effort to offer continued support and research for celiac disease.

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Introduction

Restaurants and parties are places where many people find excitement and joy. However, many individuals with food allergies and food intolerances dread attending events where food will be served. There is a possibility that they will not be able to eat the food that has been provided by the host. In order to fit in with other guests they may have a few bites of food that contains ingredients that they are unable to tolerate. After consuming an intolerable food, they suffer from severe stomach pains and vomit. Many people would rather experience those symptoms than face the social ramifications of a dietary restriction. The immediate consequences of ingesting a food that they are not able to eat come and go with time but it is the long-term consequences that cause great concern for many individual's with food allergies and food intolerances such as celiac disease.

Celiac disease is an autoimmune disorder that is triggered by ingesting gluten, a protein found in wheat, barley, oats, and rye. When individuals with celiac disease ingest gluten the villi in their small intestines become damaged and they do not absorb the proper nutrients from foods. Mayo Clinic (2011), states that symptoms of celiac disease may include abdominal cramping, chronic diarrhea, anemia, and migraine headaches. There are over 200 symptoms of celiac disease (Sweeten and Schuhmacher, 2009). There are two main ways to diagnosis celiac disease including blood tests or a small bowel biopsy to assess damage (Celiac Sprue Association, 2012). The only treatment for celiac disease is adhering to a strict gluten-free diet for life. If celiac disease is left untreated there is an increased incidence of infertility, lymphomas, osteoporosis, cancers of the small bowel and the esophagus, as well as other ailments (Lee, n.d.). The National

Institutes of Health reports that one in every 133 people in the United States has celiac disease (as cited in Shelley, 2005).

It can be difficult to adjust to a gluten-free diet at any age but adolescents face greater challenges because they are not only trying to find their places as young adults in this world but they are doing so while trying to manage a disease that makes them different than most of their peers. Unlike teens without celiac disease, adolescents with celiac disease must constantly be aware of what kind of food will be available to them at school, at a friend's house, or at a restaurant. If gluten-free food is not available, they need to bring their own food along with them or make arrangements with the venue that they are dining at so that a food item can be made available for them. The extra precautions that adolescents need to take to remain healthy can lead to feelings of isolation. They may not be able to attend a birthday party or go out for treats after a ballgame because they cannot eat what is being provided for them. Those feelings of isolation may lead to non-compliance with the gluten-free diet (Sverker, Hensing, and Hallert, 2005). For the purpose of this research, non-compliance will be defined as the failure or refusal to comply with the gluten-free diet. Factors that may lead to non-compliance with the gluten-free diet include: psychological and social effects of celiac disease, lack of education about celiac disease, and lack of support available for those with celiac disease.

Literature Review

Psychological and Social Effects of Celiac Disease

Celiac disease is considerably under-diagnosed because it has been thought to be rare so physicians do not test for it (National Institutes of Health, 2004). It is often misdiagnosed as irritable bowel syndrome or acid reflux disease. For those reasons, the process that individuals must go through to receive a celiac disease diagnosis is sometimes long and drawn out. The initial reaction to the diagnosis is often relief because the individual has a confirmed condition (Lee, n.d.). The initial feeling is often followed by feelings of fear, anger, anxiety, and sadness (Lee, n.d.). These psychological responses that occur as a result of the initial diagnosis can affect the way that the adolescent reacts to the gluten-free diet. George et al. (2009), stated that high levels of depression and anxiety and low levels of self-discipline were factors associated with GFD compliance (as cited in Saqui, 2010).

Adolescents with celiac disease must take extra precautions when dining out, eating school lunch, and staying over at a friend’s house. Social situations can be frustrating for adolescents because many people do not understand what celiac disease is and how it affects them. An adolescent may have a difficult time explaining celiac disease to peers their own age, adults, and food service personnel. Green (2001) found that individuals would “cheat” on their diet when they were at functions outside of the home in order to fit in with those around them (as cited in Lee, n.d.). Doing so makes it easier for adolescents to avoid having all of the attention and curiosity focused on them when somebody realizes that their dietary needs are different than other adolescents.

Rosen, Ivarsson, Nordyle, Garlsson, Danielson, Hogberg, and Emmelin (2011) conducted a study on 117 adolescents with celiac disease regarding compliance with the gluten-free diet. Some respondents in this study expressed that they felt vulnerable, lonely, and without sufficient support (Rosen et al., 2011). Those respondents worried about asking for special food because they didn’t want to be a burden to others (Rosen et al., 2011). Those adolescents admitted that they would cover their celiac disease by claiming not to be hungry or by eating the food that was served even if it was not gluten-free (Rosen et al., 2011). Some of the respondents made a decision to not comply with the gluten-free diet because suffering from being different was perceived as worse than suffering from symptoms that were caused by celiac disease (Rosen et al., 2011).

Sverker et al. (2005) interviewed 43 individuals with celiac disease. The individuals were between 20 and 40 years of age. While they were not adolescents, several studies have eluded that many similar feelings regarding celiac disease occur across various age ranges. Sverker et al. (2005) found that some emotions regarding celiac disease include isolation, shame, and worries about being a bother to others. The feelings of isolation were triggered when the respondents could not eat the same food as others at parties, group dinners, and other social events (Sverker et al., 2005). Feelings of shame were induced when the respondents would go out to eat with friends or family and finding a restaurant that serves gluten-free food turns into a long ordeal (Sverker et al., 2005).

Olsson, Hornell, Ivarsson, and Sydner (2008), found that adolescents with celiac disease yearned to be like other individuals who do not have celiac disease. Individuals with celiac disease, no matter their age, are often questioned about their experience with celiac disease and the challenges of a gluten-free diet. Many times this is done out of curiosity but some adolescents feel that the questions are too demanding for them and they grow tired of informing others about their gluten-free diet (Olsson, Hornell, Ivarsson, and Sydner, 2008). Individuals with celiac disease may receive unwanted invisibility because they become the focus of others interests because of their celiac disease and the gluten-free diet (Sverker et al, 2005).

Knowledge and Education about Celiac disease

One factor that influences compliance with a gluten-free diet is the amount of education that the adolescent has received about celiac disease (Olsson et al, 2008). Some adolescents label celiac disease as just a food intolerance instead of a serious disease (Rosen, Ivarsson, Nordyle, Garlsson, Danielson, Hogberg, and Emmelin, 2011). The adolescent may not understand the long term effects that ingesting gluten can have on their bodies. If there are no significant symptoms that occur directly after ingesting gluten, the individual may think it is okay to do so because it did not cause a strong, immediate reaction.

In a study that surveyed 73 children with celiac disease, 42% said that they sometimes knowingly eat gluten-containing food (Roma, Roubani, Kolia, Panayiotou, Zellos, and Syriopoulou, 2010). The children were asked 15 questions to test their knowledge of celiac disease and the gluten-free diet. Of those 73 children, 57.5% answered incorrectly to more than two of the 15 questions (Roma et al., 2010). This means that over half of the children surveyed were not knowledgeable about celiac disease. It also means that there is room for improvement when it comes to educating individuals with celiac disease. The study suggested that better compliance was noticed when the child had information about celiac disease provided to them by a dietician (Roma et al., 2010). This information could include: how to read a food label and identify if a product is gluten-free.

The ability to read food labels is a great asset to managing celiac disease and the gluten-free diet. It can be a difficult skill to learn for some so receiving education from a health professional can be beneficial to adolescents. The ability to correctly read food labels to identify if the food is a gluten-free product can be difficult for adolescents with celiac disease, especially following a diagnosis because of the unfamiliarity that they may have with reading food labels. Of those 73 children, 65% of respondents in the study described above found it difficult to determine whether or not a food was gluten-free by reading the label (Roma et al., 2010). The Food Allergen Labeling and Consumer Protection Act of 2004 recognizes eight major foods or food groups that account for 90% of food allergies, including: milk, eggs, fish, crustacean shellfish, tree nuts, peanuts, wheat, and soybeans. This act requires food products to have a label that warns consumers if the product contains any of these eight food groups. However, gluten is found in wheat, barley, oats, and rye. Individuals with celiac disease need to be able to identify the ingredients that may contain barley, oats, and rye because they will not identified on the warning label. For example, if a food contains malt powder, which is a product that contains barley, the individual with celiac disease would need to be able to recognize that on their own. The Food Allergen Labeling and Consumer Protection Act of 2004, states "…the Secretary of Health and Human Services shall issue a final rule to define, and permit use of, the term 'gluten-free' on the labeling of foods". This is a common label that is seen in grocery stores today. It is helpful to quickly determine whether or not something is gluten-free without having to read all of the ingredients on the package. However, it is not required that food companies identify their products as gluten-free.

The amount of education is not only important for the adolescent with celiac disease but also for their family members, friends, teachers, and other support people. Roma et al (2010) found that parents of compliant adolescents were better educated about the disease and were more able to choose gluten-free items from a menu. Barlow, Wright, and Shaw (1998) found that parents who felt that they had too little information about celiac disease and the gluten-free diet were hindered in their ability to cope with their child's pain and diagnosis (as cited in Sallfors and Hallberg, 2003). Parents and other family members along with the adolescent can attend celiac disease support groups to gain information regarding the condition and maintaining the gluten-free diet (Allen, 2004). They can also speak with physicians and dietitians to gain more knowledge about the disease in general.

Some adolescent's express a concern that there is a lack of knowledge about celiac disease in society (Niewinski, 2008). The lack of knowledge of restaurant staff was a common source of frustration for adolescents (Rosen, et al., 2011). In one study of adolescents with celiac disease, 53 girls and 48 boys were surveyed about their experience with celiac disease. This study revealed that girls took on an active role in trying to educate friends, school personnel, and restaurant owners (Rosen, et al., 2011). On the other hand, boys asked for support in their efforts and did not take the initiative to advocate for themselves and others with celiac disease (Rosen, et al., 2011).

Both boys and girls in the study wished that the scientific community would make more of an effort to communicate about celiac disease in newspapers and television. Roma et al. (2010), found that education of health care professionals with regard to the detection and management of patients with celiac disease needs to be improved. A study conducted in San Bernardino County in California surveyed 132 primary care physicians to gauge the knowledge that each physician had about celiac disease as well as how many cases of celiac disease they have diagnosed (Zipser, Farid, Baisch, Patel, B., & Patel, D., 2005). Of those 132 physicians, 70% returned the surveys (Zipser et al., 2005). The average length of medical practice was 20 years and only 35% of the physicians had ever diagnosed a patient with celiac disease (Zipser et al., 2005). Seventy-one percent of the physicians were aware that individuals with celiac disease could display symptoms that resemble irritable bowel syndrome and 46% were aware that depression and irritability were symptoms of celiac disease (Zipser, 2005). Health care professionals should be educated about what celiac disease presents as in their patients because the symptoms can resemble other health problems. If they are not educated, their patients with celiac disease may be misdiagnosed and their symptoms only grow worse.

Education for health care professionals is crucial but it is also important for those health care professionals to be able to communicate that knowledge to patients with celiac disease, their parents, and society. Often times, communication between patients and doctors is lacking. Improving this communication can assist the doctors with understanding the patient and the problems that they are experiencing in relation to celiac disease (Strating, 2008). Some doctors may refer their newly diagnosed patients with celiac disease to a dietician so that they can learn more about the gluten-free diet. However, this is not always the case. If the patient is not referred to a dietician, they would need to initiate the contact themselves. This is problematic because patients and their families are not always aware that there is a professional that can guide them as they begin to learn about the gluten-free diet. A dietician may be aware of additional support outside of the clinic setting such as support groups for individuals with celiac disease and their families (Niewinski, 2008).

Amount of Support Available

Managing celiac disease and the gluten-free diet can be difficult for many adolescents because they often feel isolated and that they are different than those around them (Olsson et al., 2008). Adolescents are more likely to comply with the gluten-free diet if they have support from others (Olsson et al., 2008). For the purpose of this research, support will be defined as encouragement and assistance given to adolescent's with celiac disease. The amount of support will be defined as the length of time and the intensity of support available to the adolescent. Support can be given by parents, school personnel, peers, and any other important figures in the adolescent's life.

Rosen et al. (2011) found that parents play an important role in compliance with a gluten-free diet. Parents influence knowledge, ability, and strategies for handling life situations (Sallfors and Hallberg, 2003). Parental coping has a major influence on the coping of other members of the family, including the ill member (Sallfors and Hallberg, 2003). Parents must manage their own feelings of uncertainty and loss of control, as they face added responsibilities while caring for an adolescent with special dietary needs (Gerhardt, Vannatta, McKellop, Zeller, Taylor, Passo, & Noll, 2003). The most often used coping strategies reported by parents during a chronic illness are obtaining information and advocating and receiving support from hospital professionals (Sallfors and Hallberg, 2003).

Diabetes and celiac disease are comparable chronic diseases because they both require diet changes and monitoring of symptoms. Many of the information regarding parental support for those with diabetes can be applied to parental support for those with celiac disease. In a study relating to parent communication with adolescents who have diabetes, it was found that passing diabetes care responsibility onto the adolescent is an important developmental task during adolescence and achieving success is a significant challenge for parents (Dashiff, Hardemann, & McLain, 2008). Parents of celiac disease adolescents face this same transition as it may be difficult for those parents to allow their adolescent with celiac disease to take responsibility for their diet. The parent may worry about whether or not their adolescent was able to find a gluten-free snack to eat at a friend’s house or if their gluten-free food was accidentally contaminated by gluten in the school lunch line. It may be difficult for parents to let go of the control that they once had when their adolescents were children. If parents let go of all of their control over their adolescent’s diet, the adolescent may be at risk for increased non-compliance with the gluten-free diet. This may be accidental non-compliance because they may not understand food labels and they may eat something that indicated on the label that it contained gluten but they did not notice it.

Parental reminders to the adolescent about diabetes management are ways that parents can cope with their adolescents diabetes but those reminders can be associated with parent-adolescent conflict and negative feelings in the adolescent (Dashiff, Hardemann, & McLain, 2008). It is natural for adolescents to pull away from their parents in an effort to find their own identity and role in life (Schriver, 2004). Receiving constant reminders about diet management can be frustrating for adolescents. They may interpret the reminders as indications that their parents do not trust them to manage their diet on their own. These feelings of being controlled by their parents have been significantly associated with non-compliance to the prescribed diet (Dashiff, Hardemann, & McLain, 2008).

Another factor of non-compliance relating to the relationship between the parent and the adolescent is disagreement about diet management (Dashiff, Hardemann, & McLain, 2008). When a parent and an adolescent differ in their perspectives of diet management tasks, conflict between the two parties is often the result (Dashiff, Hardemann, & McLain, 2008). If an adolescent would like to "cheat" on their diet and the parent does not allow it, the adolescent may begin to resent their parent because they do not allow them to do what they would like to with their body. "Cheating" on their diet will be defined as intentionally ingesting gluten. Adolescents want to be able to find their own way through life (Schriver, 2004). They may act on this by "cheating" on their diet and finding out that they did not like how they felt afterwards. By experiencing that themselves they are able to decide if they want to "cheat" on the diet again or if they are going to try harder to comply with the diet. They are able to make their own decisions regarding their health instead of hearing how they should be handling their diet from their parents.

Bobrow et al. (1985) found that compliance was associated with open communication between the parent and the adolescent about expectations for diet management and allowing both parties to offer solutions to problems that might arise (as cited in Dashiff, Hardemann, & McLain, 2008). It is important for parents to be able to recognize the impact that their communication methods have on their adolescent (Dashiff, Hardemann, & McLain, 2008). Dashiff, Hardemann, & McLain (2008) state:

> Communicating a positive outlook, encouraging responsibility, asking questions that gain understanding of the adolescent's struggles and successes in management, asking questions that promote problem solving, and recognizing progress by giving feedback appear to be essential elements of support that is desired by adolescents with Type 1 Diabetes. (p. 159)

Parents can support their adolescent with celiac disease in the following ways: advocating for the adolescent, learning how to interact efficiently with the health care system, learning to persist to get the attention that is needed for the adolescent, negotiating with health care professionals so that opinions and requests are heard, and establishing a partnership with health care professionals to ensure the commitment to a common goal (Gibson, 1995). More importantly, parents can support their adolescent by teaching him/her to do all of the above for themselves. This allows them to gain independence from their parents and to prepare themselves for adulthood.

Parents can also support their adolescent with celiac disease by cooking gluten-free food at home and keeping gluten-free snacks on hand. They can also contact the school cafeteria personnel and their adolescent's teachers to inform them of the gluten-free diet that needs to be followed while at school. In order to increase the likelihood of compliance to the gluten-free diet long-term, it is important for the adolescent and their family to seek support and education as needed (Saqui, 2010).

Peer Support

While parental support is vital for adolescents, peer support is just as important (Pendley, Kasmen, Miller, Donze, Swenson, and Reeves, 2002). During the transition into adolescence, adolescents spend increasing amounts of time alone and with friends, and there is a dramatic drop in the amount of time that adolescents spend with their parents (Steinberg, Morris, 2001). An adolescent's fragile and developing self-image is influenced primarily by the adolescent's perceptions of how significant others see them (Stanton-Salazar and Spina, 2005). Adolescents in general, tend to depend heavily on their friends for multiple forms of social support and for staying psychologically healthy (Stanton-Salazar and Spina, 2005).

Some adolescents may feel uncomfortable about speaking openly about their diet needs, especially when they are first diagnosed. Self-disclosure involves honesty and risk-taking (Stanton-Salazar and Spina, 2005). There may be adolescents who have a peer group that is supportive and that shares personal problems and the feelings associated with those problems. There may also be adolescents who do not have a close peer group that they could feel comfortable speaking to about their diagnosis of celiac disease. For those adolescents, it may be more difficult to be compliant with the gluten-free diet because they do not want to appear to be different than other adolescents in the lunch line at school. If the adolescent was already feeling isolated prior to their celiac disease diagnosis, eating foods that are different than other students' at lunch can intensify that feeling.

When an adolescent received support from peers, teachers, coaches, and peers' parents, the support was appreciated and it was seen both as caring and as a form of positive control (Rosen et al, 2011). Olsson, Hornell, Ivarsson, and Sydner (2008), stated that difficulties arose from limited social support from teachers, school kitchen staff, friends, sports trainers, and grandparents. Nearly all of the groups in the Olsson et al.

(2008) study discussed school experiences where unsupportive attitudes exposed the adolescents in an embarrassing way.

Bongiovanni, Clark, Garnett, Wojcicki, and Heyman (2010), conducted a study to determine the effects of a 7-day GF camp in California on individuals ages 7-17. The campers were administered a questionnaire on the days of their arrival to the camp and departure from the camp. There were 104 campers present at the camp. Seventy-seven campers completed the survey: 21 male and 56 female. There were 14 questions on the questionnaire that were divided into 3 categories: general well-being, emotions, and perceptions of disease and self. The questionnaires demonstrated that camp had a positive effect on all children in almost all quality of life) categories. This was especially true for those had recently started a gluten-free diet less than 4 years prior to the administration of the questionnaires. It was found that children liked being able to learn from their peers about how to cope with celiac disease and its restrictions (Bongiovanni, et al., 2010). This study indicates that having support from peers with celiac disease is beneficial because those peers can offer an understanding of what the adolescent is going through that a peer without celiac disease cannot.

The literature reviewed for this research identified that there are many factors that may lead to non-compliance with the gluten-free diet including: psychological and social effects of celiac disease, lack of education about celiac disease, and lack of support available for those with celiac disease. These factors appeared to be common across the literature articles but of course vary in complexity from adolescent to adolescent.

Conceptual Framework

Erikson's Psychological Stages of Development.

Erikson's model of human development was included in this research because he was able to capture the needs of a human throughout his/her life span. Erikson's explanation of the developmental stage of adolescence seemed to be brought out in the factors of non-compliance that were found in the literature that was reviewed for this research. These factors include: the desire to fit in with peers and the desire to create their own identity in the world.

Erikson developed an eight-stage model that explains individual development through the life span (Schriver, 2004). Erikson theorized that "human development takes place according to a series of predetermined steps through which the person proceeds as he or she becomes psychologically, biologically, and socially ready" (Schriver, 2004). This development model assumes that the environment that development takes place provides the necessary resources and presents the necessary challenges at the proper times for the individual to move through each step. The individual cannot go on to another stage of development without meeting the needs of all previous stages.

The fifth stage of Erikson's stages of development is "Identity vs. Role Confusion". This stage occurs during ages 12-17. In this stage, the individual is at the cross-roads from childhood to adulthood. There are physiological changes occurring which may require some adjustment depending on the individual. The individual is in limbo between not being considered a child and not being expected to act like an adult. Individuals in this stage can experience an identity crisis because of the uncertainty of their future and their role in it. Adolescents may feel pressured to adopt an identity before they are ready to do so which can lead to this identity crisis (Schriver, 2004). During this stage adolescents become increasingly concerned with what they appear to be in the eyes of others. Gluten-free diet specifics often augment the “normal problems” of adolescent life with extra practical, emotional, and social burdens (Olsson, Hornell, Ivarsson, & Sydner, 2008).

Methods

Research Design

Qualitative research methods were used because certain experiences can only be captured by using words and not numbers (Berg & Lune, 2012). This research method allowed the researcher to explore those experiences deeper and with more meaning than quantitative research methods. This research method also allowed the data to be richer in content because it considered circumstances. For example, in quantitative research a respondent may answer “yes” to the questions “Have you ever felt uncomfortable around others in the lunch room?” but they don’t have the opportunity to explain why they felt that way. In qualitative research, explanations are encouraged in order to dig deeper into the responses.

In the past, topics related to non-compliance with celiac disease and adolescents’ experiences with celiac disease have been researched by using surveys as well as conducting interviews and focus groups. A focus group was chosen for this research project. One focus group was held for about one hour and included two respondents. The goal was to have seven to ten respondents but due to a lack of responses this was not possible. The focus group was originally open to only females ages 13-17. However, it was later expanded to include females ages 11-17. It was the hope that the female adolescents would be more willing to speak about their experiences if they participated in a group than if they participated in individual interviews. The researcher chose to include only females because the respondents may have felt more comfortable talking about social aspects of their lives if they were not in the presence of the opposite gender. The adolescents were to feed off of each other's comments to create more of a conversation about their experiences rather than a question and answer session.

Research Setting

A group of adolescents from an agency in a mid-western state were interviewed for this research project. The agency serves individuals from youth to early adulthood with celiac disease. The agency provides support for children with celiac disease and plans events for the clients to meet others with celiac disease. The agency provides support to over 200 families and has been around for over 10 years. Membership to this agency is free but there is a suggested yearly contribution for each family.

The focus group took place in a conference room at a public library in a metropolitan area in the Midwest. The specific library was chosen because it was a large enough venue to host all of the respondents and it was located nearby many of the larger towns in the area. The chairs were set up in a circle so that all of the group members could feel like they were an equal part of the group.

Sample

The researcher contacted a member of the agency board to recruit individuals to be a part of this research. The board member brought this proposal to the rest of the board for approval. The board approved the research and the board member agreed to assist with recruiting respondents. To recruit respondents, this researcher asked the board member to send out an email to a list of all of the group members inviting participation.

The researcher created the email so that the board member could copy and paste it to his contacts. Potential respondents were asked to contact the researcher by phone or email. The researcher planned to take the first individuals who contacted her and would not exceed 10 individuals. Given the fact that respondents were under 18, the researcher required a signed consent form (Appendix A) from the parent for each respondent. Each respondent signed an assent form (Appendix B). The researcher conducted a focus group that consisted of two female respondents ages 11-15 that were clients of the agency described above. The individuals that were chosen to participate in the focus group needed to be within that age range, gender, and needed to have a diagnosis of celiac disease. Any other demographics were welcomed.

Protection of Human Subjects

Protection of Human Subjects was ensured from approval of St. Catherine University's IRB committee. They reviewed all procedures and content of this study to protect those respondents.

Confidentiality was assured by omitting the names of the respondents. Numbers were be used instead to separate the experiences of each respondent. The focus group setting created an extra obstacle for assuring confidentiality. The researcher asked that each respondent and their guardian sign a confidentiality agreement (Appendix C) before the start of the focus group. This restricted the respondents from sharing the process outside of the group.

Given the fact that respondents were under 18, parental consent was obtained for each of the respondents prior to the focus group date. The consent form included a request for permission to use the information gained in this research report and in an oral presentation. Consent was also received to tape record the focus group session for transcription purposes. The consent form was emailed to the parent/guardian of the respondents about two weeks prior to the focus group. They were asked to bring it with them on the day of the focus group session. There were extra forms available that day in case a parent/guardian forgot one. Before the focus group began, the consent form was reviewed with the respondents. The blank consent form was approved by the Institutional Review Board (IRB). The respondents were given an assent form to sign just prior to the support group. Even if the parent has consented to the study, the adolescent may have decided she did not want to participate. They had that right. The form gave an explanation of confidentiality of the respondents during the research process. The respondent's names were omitted from the field notes, transcript, and this report. The audiotape will be destroyed on May 31, 2013.

Data Collection

The focus group lasted approximately one hour and was carried out in a semi-structured format. The focus group was recorded to ensure accurate data analysis. Prior to the focus group, the question guide used in the group (see Appendix D) was approved by the St. Catherine University's IRB. This was done to ensure that the questions met the SCU IRB and Protection of Human Subjects guidelines. The questions were open-ended in nature to provoke more detailed answers. The questions were guided by the overall research question and supported by literature related to the factors of non-compliance in adolescents with celiac disease. The agency board received a copy of the question guide prior to the interview for approval.

Data Analysis

Conventional content analysis (i.e., purpose of this is the generation of theories or explanations of the content of the document under analysis) structured the analysis of the data that was obtained through the interview (Berg & Lune, 2012). The data gathered through the focus group was listened to several times by the researcher using a recording device. Then the focus group was transcribed and re-read several times. The researcher took notes while reviewing the data and noted codes that emerged from the transcript. Coding refers to categorizing the data into a limited number of categories (Monette, Sullivan, & DeJong, 2011). The researcher created a theme for each code that occurred at least 4 times in the data. The researcher created a more structured note to keep all of the themes and codes organized and easily accessible.

Lens

There was a strong connection between the researcher and the topic of celiac disease. The researcher was diagnosed with celiac disease as a young adult a few years prior to beginning this project. The researcher had felt many of the feelings that were described in the literature review of this project. There was a chance that this lens may have hindered the project if it was not monitored. However, the researcher was aware of this lens and did monitor this on her own so that the research is not skewed.

The researcher recruited two individuals who served on a committee along with the chair of this research project to guide the research. The researcher utilized the committee in many ways including: reviewing the focus group questions, editing the research paper for any biased statements, and offering new insight on the topic of celiac disease and adolescents. The actions of the committee members described above ensured that this research did not present any biased information.

Strengths/Limitations

The topic of celiac disease has been receiving a lot of attention and it appears that people are taking it more seriously as more research is being done on it. A benefit to researching celiac disease is that there is already so much information available on celiac disease and adolescents in general. There has been research conducted specifically with celiac disease and adolescents in the past. Even though there is information that exists about this topic, there were few articles that were found that speak to noncompliance to the gluten-free diet in adolescents. The researcher was able to find resources to enrich the literature review and gain a perspective about the topic but she was also able to tread on newer ground and make some discoveries on her own.

A limitation of this research project is the perceived validity of qualitative research methods. Berg and Lune (2012) state "…Because qualitative research tends to assess the quality of things using words, images, and descriptions whereas most of quantitative research relies chiefly on numbers, many people erroneously regard quantitative strategies as more scientific than those employed in qualitative research" (p.4). Individuals who are more inclined to read about and pursue quantitative research projects may not believe the accuracy of the data that has been collected because it does not come in the form of numbers. For this reason, the researcher will need to be clear in the definitions that are used and general writing will need to be clear and precise (Berg & Lune, 2012).

Findings

After the researcher analyzed the data received from the focus group several themes emerged regarding non-compliance factors and the gluten-free diet. The respondents discussed the social impact of celiac disease, symptoms of celiac disease, and support for individuals with celiac disease. They discussed feelings of support and nonsupport in several areas including: restaurants, school, family, and friends.

Two adolescents participated in this focus group. The adolescents were both females and ranged in age from 11 to 15. One of the respondents had been diagnosed with celiac disease when she was four years old and the other respondent had been diagnosed about five months prior to the focus group. They both began the gluten-free diet immediately after diagnosis. Neither respondent has any family members diagnosed with celiac disease. One respondent has two friends that have been diagnosed with celiac disease while the other respondent does not have any. Through the sharing of their experiences, the respondents uncovered some factors that they face daily that impact their decision to comply with the gluten-free diet or not.

Social Impact of Celiac Disease

The respondents from the focus group spoke about the impact that social factors that play a role in the decision to comply with the gluten-free diet. Both respondents spoke of their experiences of mealtime with their peers. Respondent 1, a 15-year-old, who was diagnosed with celiac disease at four years-old, shared a recent experience that she had with peers that she did not know well.

"…I had a confirmation retreat and it involved a dinner…they had the people with dietary needs go up first and it was just really awkward standing up there in front of the

entire confirmation group getting my food while they just sat and watched me. It was just uncomfortable."

Respondent 2, an 11 year-old, who was diagnosed with celiac disease about five months ago, spoke about feeling different than her peers.

"…I think that it's mostly at birthday parties and I can't have pizza or cake. Then people say 'oh why aren't you eating that?' so I feel really weird trying to tell them."

Respondent 1 expressed that she isn't necessarily bothered by her diet restrictions but she notices that it makes others uncomfortable.

"I guess something that I don't really like about it [having celiac disease] would be when people don't remember and they don't have something that I can have and everyone else is eating something that I'm not eating. I mean I don't really mind that because I guess I'm used to it but like other people feel uncomfortable about it like about they're eating and I'm not and I don't really like making other people feel uncomfortable just because I have celiac."

Respondent 2 expressed that she feels like people feel badly or sympathetic towards her because she is not able to eat what they are eating.

"…when they [peers] are eating and they're like 'oh this is really good I'm so sorry you can't have this."

The respondents were asked about how they thought celiac disease would impact dating. One respondent responded with:

"I think it would be challenging in the beginning but I also feel like celiac is a pretty like once you figure it out it's also really easy to understand so I feel like it would just take some explaining and I also have friends who forget so some reminding probably."

Both respondents expressed that they have felt like their peers have failed to understand the impact that celiac disease can have on their body and the dedication that it takes to keep their bodies healthy. This is expressed in the following quotes:

"When I tell people I always just describe it as an allergy even though it is an intolerance. I feel like being an intolerance instead of an allergy downplays the seriousness of it."

"I always think it's funny when my friends are like 'oh I could on a gluten-free diet easy' but then they go ahead and eat their sandwich."

Symptoms of Celiac Disease

Each of the respondents in the research group expressed that the symptoms that they experience when they have eaten gluten is a large factor when deciding to comply with the gluten-free diet. For the purpose of this research the phrase "being glutened" will be defined as accidentally ingesting gluten. When asked to rate the effects of being glutened on a scale of 1 to 10 with 1 being no symptoms at all and 10 being the most pain that they have ever been in, Respondent 1 rated her symptoms at a 10 and Respondent 2 rated her symptoms at a 7-8. The following quotes represent the impact that the symptoms have on each respondent's life:

"…the idea of throwing up just isn't that appealing. …I've been following it [the gluten-free diet] since I was four4 so it's just kind of like I remember what it feels like not to [follow the diet] but it's just normal for me to."

"…I know that it damages my stomach and it's really dangerous."

Support for Individuals with Celiac Disease

The respondents both described the amount of support that they have experienced in restaurants, their schools, their families, and their friend groups. The following quotes from the respondents illustrate the various components of this theme:

Restaurant Support

Both respondents described going out to eat at restaurants as a challenge for them. Respondent 1 expressed her feelings of mistrust that she has with restaurants.

"…I throw up so fast [if glutened] I guess I'm a little bit paranoid that they're [the restaurant] is going to screw it [my food] up…I just feel like it would be so much easier if I could just order normally and not have to ask for gluten-free food and double check that it's gluten-free when I'm somewhere that I don't know…one time I used to get [chicken] and then one time it wasn't gluten-free anymore and then I threw up and I guess that just kinda reinforced the lack of trust that I have [with restaurants]."

Respondent 2 expressed her feelings of exclusion when eating at a restaurant that is not aware of celiac disease.

"…we're always super worried about cross-contamination since so many places don't have a gluten-free menu so they probably aren't as aware that some people just really can't have gluten and sometimes all I can get is just a salad. That makes me feel left out."

The respondents spoke about the amount of knowledge that they feel that restaurant staff have about the gluten-free diet. Respondent 1 was unsure about the amount of knowledge that staff have.

"I don't know, they all seem to have had experiences where some people have asked them about gluten but I don't know if they actually know what it is."

Respondent 2 spoke about some good experiences that she has had with staff at various restaurants. She has been pleased with her experiences thus far.

"I remember when probably the same month I was diagnosed we went to Mad Jacks and they have a gluten-free menu and the waitress there knew exactly what we were talking about like she check to see if they used the fryers for the same things gluten-free or not and like knew exactly what was gluten-free. Then at some other place one of the people there working in the kitchen used to be a nutritionist so she knew exactly what we were talking about."

The respondents shared their thoughts about what they would like to see happen to make restaurants and their customers more aware of celiac disease. The following quotes represent their thoughts:

"I feel like if restaurants…they should something next to it [billboard menu] that says gluten-free I feel like that would maybe get people interested and curious…"

"…I think that more places should have a gluten-free menu so then people who work there would know about it and be able to help us [people with celiac disease] easier."

School Support

Both respondents discussed the role of support that each of their schools play in relation to the gluten-free diet. They displayed mixed messages in that they expressed that each school was accommodating enough so that they could eat safely in the building but they were not accommodating so that they could go through the lunch line and eat a full meal like other students without celiac disease. The following quotes highlight that discrepancy:

"…last year I got salads a couple times but I didn't find that they were filling enough because I had first lunch…there's been a microwave available to me since elementary school. Generally I just bring home lunch just because I find that a lot easier."

"…the cafeteria doesn't really do anything but my teacher when we're going on field trips she always calls the place to make sure that I always have something good to eat."

"…my school has rules for people with peanut allergies and lactose intolerance but not about gluten."

Respondent 2 spoke about the changes that she would like her school to make so that she could dine more comfortably.

"I wish that they would open up the salad bar to students because then I could have salad and I like salad a lot."

Respondent 1 was not sure that she would eat lunch at the school if the cafeteria opened up more options to her.

"I don't know. I'm just so used to taking sack lunch that I'm a little freaked out by the lunch lines."

Each respondent had a different view of the amount of support that they received from their schools. While Respondent 2 would like more options, Respondent 1 was happy to handle lunches on her own in order to make sure that her food was safe.

Family Support

Both respondents in the focus group discussed the amount of support that they receive from their parents and their siblings. They expressed that they felt that their families were supportive however the way in which their family's showed support differed.

Respondent 1 spoke about the support that she receives from her family members. She did not wish to change anything about the amount of support that is shown or how it is shown.

"…if we're having pasta, my mom, my dad, and my sisters will have their pasta and I'll have my pasta but if it's something like meat loaf it'll be gluten-free…when it's easier to do it gluten-free they'll do it gluten-free but sometimes it's easier not to."

Respondent 2 also spoke about the amount of support that she receives from her family. The kind of support that she receives differs from Respondent 1's however she reported to be just as satisfied as Respondent 1 is.

"…my mom has gone completely gluten-free with me too and there's no gluten in my house but my dad and my sister eat gluten outside of the house."

"When we go out [to eat] it [the decision of where to eat] is not really put on me but where go eat we usually make sure they have gluten-free options."

Friend Support

Both respondents spoke about the amount of support that they receive from their close friends. They each described how their friends show support with the following quotes:

"…I had two really close friends that I would have sleepovers with and their family's both know me a lot so they wouldn't call [to ask what food to buy] they would just know to buy something [gluten-free]."

"…my friend really likes to cook and she's always super interested in cooking me gluten-free food and all my friends are also interested in trying what I can have."

"…they have a local celiac walk and my friends go on it with me and they seem interested in trying the food that they have there and they seem to really enjoy themselves there."

While each respondent had expressed feelings of positive support they also had experienced situations when they did not feel supported by their friends. The following quotes represent those feelings:

"…My friend was like 'can I try one of those [gluten-free animal crackers]' so I let her and she was like 'this tastes disgusting, this is so gross, it tastes like tar'. I thought they were fine but she just really hated them apparently…I kind of laughed it off but I guess I was a little bit offended that she so openly blunt about how much she hated my food."

"I'm not really sure about a time that they [my friends] didn't exactly support me but sometimes just flaunting their food that I can't have."

Respondent 1 expressed the difference between having friends with celiac disease versus having friends without celiac disease:

"…around Christmas time one of my friends [without celiac disease] just blanked and forgot that I can't have pretzels...she gave me a bag of them and I didn't want to be rude…so I just accepted them and put them in my locker. Later I was like 'oh that was really awkward' to my friend who has celiac and she's like 'yeah I hate those situations I never know what to do' so I guess it's good to have someone who understands that kind of thing."

Discussion

Researcher's Interpretation of Findings

The focus group for this research examined the factors for compliance with the gluten-free diet for two female adolescents. Each of the respondents discussed the social impact that celiac disease has on them. In their responses, the respondents shared their experiences with their peers at mealtimes and also the perceptions that others have about celiac disease. The respondents spoke of the symptoms that they have when they ingest gluten. They both experience negative symptoms and feel that they are costly. Both respondents spoke about the amount of support that they have received from restaurants, schools, family, and friends. The respondents expressed various experiences with all parties ranging from positive to negative. The information gathered from the females who participated in the focus group provides an insight to the factors of non-compliance for adolescents with celiac disease. However, the information that was gathered is limited by the small sample size and the lack of a broad demographic.

Psychological and Social Effects of Celiac Disease

Both of the respondents in the focus group spoke about the impact that celiac disease has on the social aspect of their lives. They talked about the challenges that they face when going to a birthday party, having a sleepover at a friend's house, and attending a confirmation retreat. The challenges occurred when they were with mere strangers as well as with close friends. Both respondents attended all events that are invited to but they choose to bring their own foods with them. One of the respondents parents call the host of the party prior to the date of the party in order to find out what they will be serving. This is so the respondent can bring a similar food so that she can fit in more with the group. Despite the challenges that the respondents face, they both shared that they have never knowingly "cheated" on the diet for any reason. Literature suggests that individuals "cheat" on their diets in the presence of others in order to fit in with those around them (Lee, n.d. and Rosen et al., 2001).

One of the respondents shared that she feels left out when she is not able to have the same food that those around her are having. Rosen et al. (2001) and Sverker et al. (2005) found that feelings of isolation were trigger when individuals are not able to eat the same food as others at events. While one of the respondents felt left out at times, neither respondent expressed feeling badly about themselves or saddened about being different than others. This is inconsistent with the data that was found by Stanton-Salazar and Spina (2005) which stated that an adolescent's self-image is primarily influenced by the adolescent's perceptions of how others see them. Both of the respondents are aware that others are curious about their diet but they did not express feeling incredibly influenced by the thoughts of others.

Erikson's stage of development titled "Identity vs. Role Confusion" was used as the conceptual framework with the expectation that the respondents would express feeling lost between physiological changes and the need to fit in with others. This was not the case with the respondents in this focus group. It may be that individuals with celiac disease reach this stage more quickly than others depending on the age of diagnosis and they need to face adult responsibilities such as diet control much sooner than those without celiac disease.

Both of the respondents were asked about their individual meals several times by their peers. One of the respondents felt "weird" telling others about the gluten-free diet while the other respondent said that she was “used to it”. Olsson, Hornell, Ivarsson, and Synder (2008) and Sverker et al. (2005) discussed that adolescents grow tired of informing others about the gluten-free diet and that they often receive unwanted attention because of others interests in the gluten-free diet.

The respondents expressed that they often feel uncomfortable because those around them worry about why they are not eating what the rest of the group is eating. They feel that others feel badly for them because they have diet restrictions. One respondent shared that she doesn’t like it when people feel badly if they forget what the respondent cannot eat. She doesn’t feel like it is their responsibility to remember her diet restrictions.

Support for Adolescents with Celiac Disease

Rosen et al. (2011) found that parents play an important role in compliance with a gluten –free diet. Both of the respondents shared the support that is offered in their homes and expressed satisfaction with the amount of support that they received from their parents. One of the respondents parents show support by cooking gluten-free meals in the home and by making sure that they make sure that gluten-free options are available if they dine out. This tactic was found to play an important role in compliance with a gluten-free diet (Saqui, 2010 and Dashiff, Hardemann, & McLain, 2008). The other respondent’s mother decided to start a gluten-free diet even though she does not have celiac disease. The other members of that family support the respondent by keeping all gluten outside of the home.

The respondents had differing experiences and feelings about the support that they receive from their schools. One respondent has had a microwave available to her since elementary school so she is able to bring a lunch from home to heat up her meals. She finds that bringing her lunches from home is easier for her. She got salads from the lunch line a few times but she never found them to be filling enough. She does not know if there is anything that the school could do differently to support her because she doesn't trust the lunch lines. She doesn't mind bringing her own lunches to school because she has been doing it for so long.

Another respondent did not feel that her school does anything in particular to support her diet needs. She brings her lunches from home but wishes that her school would open up the salad bar to the students so that she could eat salads from the lunch room. She explained that her teacher calls ahead to restaurants if the class is going on a field trip to make sure that there are gluten-free options available. The information found in the focus group was incongruent with a study that was completed by Olsson et al. (2008) which stated that nearly the entire group that participated in that study discussed school experiences where unsupportive attitudes exposed the adolescents in an embarrassing way. The respondents in the focus group did not express that they felt embarrassed at any time but were more concerned about the amount of options that were available to them at their schools. The study by Olsson et al. (2008) was however congruent with the story that Respondent 1 told of about her confirmation retreat in which all of the adolescents with diet restrictions were required to go through the line first in front of all of the other adolescents. Respondent 1 did express that she felt uncomfortable because everyone was staring at the group while they were getting their food and she was asked many questions about her diet afterwards.

Both of the respondents discussed the support that they receive from their friends and their friend's family's. One respondent explained that when she would stay overnight at another friend's house the parents would know what food she could have and they would buy it for her without asking. This was unexpected for her but appreciated. The other respondent's parents call her friends parents before she goes over to their home in order to brief them about her diet needs. That type of hands-on support was found to increase the likelihood of compliance to the gluten-free diet long-term (Saqui, 2010). The respondent brings her own food with her to her friends' homes and does not expect her friends to buy anything for her.

While parental support is important, Steinberg and Morris (2011) explained that during the transition into adolescence, adolescents spend increasing amounts of time with friends. The respondent's friends showed support by attending events that bring awareness to celiac disease as well as trying gluten-free foods and even attempting to cook food. The respondents felt the most unsupported by friends when they were blunt about not liking the taste of gluten-free food or by flaunting their food in front of the respondents when they knew they weren't able to eat it.

Only one respondent has a friend who also has celiac disease. She discussed the benefits of speaking with that friend versus friends who do not have celiac disease. She found that it is help to have someone who understands the challenges that they face every day regarding celiac disease. This is congruent with the study conducted by Bongiovanni et al. (2010) which stated that children liked being able to learn from their peers about how to cope with celiac disease and its restrictions. In that study the adolescent's found that the peers with celiac disease were able to understand the experiences with celiac disease to a greater degree than what peers without celiac disease could.

The respondents discussed the amount of support that they feel that they receive from restaurants. They feel most supported when restaurants are knowledgeable about celiac disease and go out of their way to make sure that the respondents receive gluten-free food. They expressed that they feel unsupported when restaurants don’t have many gluten-free options besides salads or when they are not aware of the seriousness of celiac disease.

Knowledge Regarding Celiac Disease

Both of the respondents knew many details about celiac disease and the importance of remaining compliant with the gluten-free diet. They were aware of not only the immediate physical effects of ingesting gluten but also the long-term effects if they were to ingest gluten on a regular basis. The knowledge that they have about the effects and the severity of their symptoms was a driving factor of compliance with the gluten-free diet.

One of the respondents expressed that the biggest challenge that comes with being on a gluten-free diet is the lack of knowledge that restaurants have. This is congruent with the literature by Rosen et al (2011) which stated that the lack of knowledge of restaurant staff was a common source of frustration for adolescents. The respondents shared their experiences with staff at restaurants. They discussed that most staff seemed to have had experiences with others asking about gluten-free options but one respondent wasn’t sure how much the staff actually knew about celiac disease other than they can’t have food that contains wheat. She was also unsure that they were aware of the danger of cross-contamination of the food and she mistrusted some restaurants because of that. Another respondent shared that she had experiences at a few restaurants where the staff was knowledgeable about the gluten-free menu and if they were unsure of something they asked the manager or the head chef.

While the respondents feel supported by their friends most of the time, they discussed the lack of knowledge that many of them have about celiac disease. The respondents expressed that others sometimes downplay the seriousness of celiac disease because they are unsure of what it entails. One respondent reflected on a situation when a friend asked her if she could have Wheat Thins. She pointed out that “wheat” is in the title and therefore couldn’t have the food. Another respondent shared that she sometimes gets upset with people who do not know what celiac disease is. She then feels badly for getting upset because she didn’t know what it was prior to being diagnosed with it either.

One of the respondents describes celiac disease as an allergy instead of an intolerance because she feels that the word “intolerance” allows a person to downplay the effect that it has on those diagnosed with it. This is quite different from the literature found by Rosen et al. (2001) which states that some adolescents label celiac disease as just a food intolerance instead of a serious disease.

The literature found by Niewinski (2008) stated that adolescent’s express a concern that there is a lack of knowledge about celiac disease in society. This concern was also discussed between the respondents of the focus group. Many people that do not have celiac disease or digestive troubles are using the gluten-free diet as a means to lose weight. The respondents expressed that they get angry when they see people who are using the gluten-free diet as a diet fad. This has led to some people downplaying the dedication that is needed to be a strict gluten-free diet that is needed for health purposes because those who are using it as a weight loss tool are able to “cheat” as often as they like without any symptomatic consequences.

Strengths and Limitations

There are several strengths and limitations to this study. The strengths are related to the perspectives that were shared by the respondents who were willing to share and participate openly throughout the focus group process. The questions for the focus group were created with the literature in mind but the respondents also led the conversation off topic which turned out to be beneficial to the study.

There were several limits to this study. The sample size was small and the perspectives of the respondents were often quite similar. There is a chance that in a group setting the respondents were matching their answers so that they did not seem out of place. The sample size was too small to allow for a large variety of perspectives.

There was a lack of variety in demographics in this focus group. The group consisted of two young, Caucasian, females who appeared to have well-kept appearances. Both of the respondents expressed that their friends and family were supportive and that may have made their decision to comply with the gluten-free diet easier and more accessible than those with unsupportive friends and family. The sample of two people is not representative of the entire population of adolescent’s with celiac disease.

The sampling method for this study was not optimal. The respondents were recruited from a list of individuals who had been in contact with an agency that supports adolescents with celiac disease. The agency contacts were emailed about the focus group. There may have been contacts that did not have email access that missed out on the opportunity to join the focus group. It would have been more beneficial to recruit respondents from various agencies in the area with the hopes that a larger, more diverse sample would be available.

Implications

The information that was gathered through the literature review and this qualitative research project uncovered data about non-compliance factors for adolescents with celiac disease. However, more information is needed to determine the impact that celiac disease has on non-compliance factors for individuals of various ethnic backgrounds, socioeconomic statuses, and religious backgrounds. The information gained from the focus group was aimed at young, Caucasian, females and much of the information gained from the literature review was aimed at adults and individuals from countries outside of the United States.

Social work research can assist adolescents with celiac disease with compliance concerns by conducting studies with a focus on compliance factors rather than non-compliance factors. It is more beneficial for individuals to manage their diet if they first identify the factors that are allowing them to be compliant and then working on identifying barriers to that compliance. Social workers can develop programs for adolescents in need of more assistance to remain compliance with the diet. There can also be programs for individuals who have concerns about the social and psychological impact of celiac disease. The focus of those programs would be to provide peer support as well as individual counseling.

Conclusion

The research that was found in the literature review and in the focus group suggests that adolescents are more likely to comply with the gluten-free diet if they have supportive friends and family, knowledge about celiac disease, and intense symptoms when ingesting gluten. While celiac disease has made great headway in the past few years, it is still unknown to many. Supporting awareness of celiac disease in the community is a way to foster more acceptance for individuals with celiac disease.

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Appendix A

Exploring Factors of Non-Compliance for Adolescents with Celiac Disease

INFORMATION AND CONSENT FORM

Introduction:

Your child has been invited to participate in a research study investigating the factors of non-compliance for adolescent with Celiac Disease. This study is being conducted by Alicia Darling, a graduate student at St. Catherine University under the supervision of Sarah Ferguson, PhD, a faculty member in the Department of Social Work. Your child is a possible respondent in this research because he/she has been identified as a child with Celiac Disease. Please read this form and ask questions before you agree to allow them to participate in the study.

Background Information:

The purpose of this study is to further understand factors of non-compliance to a gluten-free diet for adolescents with Celiac Disease. Approximately 7-10 adolescent girls are expected to participate in this research.

Procedures:

If you decide to allow your child to participate, you will be asked to sign this consent form. Your child will be asked to sign an assent form that would state their agreement to participate in the study after the researcher has gained your consent. Your child will participate in a focus group of about 7-10 adolescent girls ages 11-17 who have a diagnosis of Celiac Disease. Your child will be asked to answer a series of questions aimed at understanding how the gluten-free diet has or has not affected his/her life (i.e. activities, relationships, feelings about themselves). Your child will also be asked to complete a survey at the beginning of the group that allows me to know their age of diagnosis, length of diagnosis, and if there is a family history of celiac disease. This study will take approximately one hour for one focus group session. The session will be held at a public library to be determined based on availability. The focus group session will be tape recorded so that I can transcribe the session to insure that the data that I am using is accurate. Your child will be asked to provide feedback about the quality of the group after the session. A list containing resources related to celiac disease and the gluten-free diet will be provided after the sessions.

Risks and Benefits of being in the study:

The study has minimal risks. Other respondents in the study may learn about the reactions that your child had to the Celiac Disease diagnosis and the gluten-free diet. There is a risk of emotional reaction to the questions. We will be discussing your child’s feelings about their diagnosis and the reactions that they receive from others. The researcher will debrief with the respondents after the session, stay after the group for additional questions, and offer a resource list to all respondents.

There are no direct benefits to participation in this study. Your child may value the opportunity to speak to others about her experiences with Celiac disease, adjusting to the gluten-free diet, and how it has impacted her life.

Confidentiality:

Any information obtained in connection with this research study that can be identified with you or your child will be disclosed only with your permission; your results will be kept confidential. In any written reports or publications, no one will be identified or identifiable. In order to protect the confidentiality of all of the respondents, your child will be asked to sign a confidentiality form that requires that all information that is shared in the group remains with the group.

I will keep the research results and the tape recording disc in a locked file cabinet in my home and only I and my advisor will have access to the records while I work on this project. I will finish analyzing the data by May 30, 2013. I will then destroy all original reports and identifying information that can be linked back to you.

Voluntary nature of the study:

Participation in this research study is voluntary. Your decision whether or not to allow your child to participate will not affect your future relations with the support agency or St. Catherine University in any way. If you decide to allow your child to participate, you are free to stop at any time without affecting these relationships.

Contacts and questions:

If you have any questions, please feel free to contact me, Alicia Darling at 563-419-2592. You may ask questions now, or if you have any additional questions later, the faculty advisor, (Sarah Ferguson at 651-690-6296), will be happy to answer them. If you have other questions or concerns regarding the study and would like to talk to someone other than the researcher(s), you may also contact Dr. John Schmitt, Chair of the St. Catherine University Institutional Review Board, at (651) 690-7739.

You may keep a copy of this form for your records.

Statement of Consent:

You are making a decision whether or not to allow your child to participate. Your signature indicates that you have read this information and your questions have been answered. Even after signing this form, please know that your child may withdraw from the study at any time.

____
______

I consent to allow my child to participate in the study. I agree to allow my child to be audio-taped.

Signature of Parent, Legal Guardian Date

Signature of Researcher Date

Appendix B

Exploring Factors of Non-Compliance for Adolescents with Celiac Disease

Assent Form

My name is Alicia Darling. I am trying to learn about what has affected your decision to stick to or to not stick to a gluten-free diet and your experiences with trying to do so. If you would like, you can be in my study.

If you decide you want to be in my study, you will meet with me and 7 to 10 other teenage girls who have been diagnosed with celiac disease. I will ask you questions regarding your experience with celiac disease and the gluten-free diet. I will also ask you to complete a survey so I know when you were diagnosed and how long ago.

There is a risk with being in this study. The other teens in the group will be able to hear your responses to my questions. You will be able to choose how much you would like to share with the group. If you are not comfortable sharing a lot, that is OK. The benefits of this study include, you will get to speak with other teens that have celiac disease and you will get to share your experiences with them and gain feedback and tips on how to stick with the gluten-free diet.

Other people will not know if you are in my study. I will put things I learn about you together with things I learn about other teens, so no one can tell what things came from you. When I tell other people about my research, I will not use your name, so no one can tell who I am talking about. I will audio-tape the group session and type up our discussion. This is for my own notes and will not be available to anyone else.

Your parents or guardian have to say it’s OK for you to be in the study. After they decide, you get to choose if you want to do it too. If you don’t want to be in the study, no one will be mad at you. If you want to be in the study now and change your mind later, that’s OK. You can stop at any time. There are no direct benefits to participating in this study. You may however find that it is valuable to speak with others about your experiences with Celiac disease.

My telephone number is 563-419-2592. You can call me if you have questions about the study or if you decide you don’t want to be in the study any more.

I will give you a copy of this form in case you want to ask questions later.

Agreement

I have decided to be in the study even though I know that I don’t have to do it. Alicia Darling has answered all my questions.

Signature of Study Participant	Date
Signature of Researcher	Date

Appendix C

Confidentiality Statement

In order to maintain an atmosphere of trust and confidence in the focus group, I, __________________, agree to hold all participant discussions, comments, and information confidential and will not share any information to persons outside of this group. If I learn about any helpful food strategies or positive thoughts from other group members, I may share that with others that it may concern outside of the group. I will not share the name of anybody who shared that information with me.

____
Participant Signature Date

____
Parent/Guardian Signature Date

Appendix D

Focus Group Questions

What is challenging about being on a gluten-free diet?

Have you ever cheated on the gluten-free diet?
    Tell me about a time.
    How did you feel after that?
    What makes you feel like cheating?
    What stops you from cheating?

How involved are your parents with the gluten-free diet?
    What do your parents do to show their support?
    What would you like your parents to do differently?

Do you feel like your school is supportive of your diet needs?
    What steps have they taken to accommodate you?
    What do you wish they would do differently?

Tell me about a time when you felt different than others because of the gluten-free diet.
    How did you react to this?

Tell me about a time when you felt supported by friends.
    What did you like about what they did?

Tell me about a time when you did not feel supported by friends.
    What do wish they would have done differently?

Appendix E

Survey

How old were you when you were diagnosed with celiac disease?

How long have you been following a gluten-free diet?

Do any of your family members have celiac disease?

Rate the effects of being “glutened” on a scaled of 1 to 10 with 1 being no symptoms and 10 being the most pain you have ever been in.

Do you have any peers that have celiac disease? If so, how many?