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A Storybook for Children with Celiac Disease

Heather A. Hope
University of Northern Iowa

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A Storybook for Children with Celiac Disease

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Abstract

The purpose of this research project was to create a children's story cookbook that addresses the dietary adaptations to avoid gluten and wheat for children diagnosed with celiac. Children's literature has a need for a cookbook that will have recipes appealing to children and have pictures that will make the recipes/ food more visually attractive. The book also included child friendly directions so that a parent can assist a child in preparing the food. The story cookbook also told the story of a young child who has celiac, who is learning to eat differently and to adapt to her disease. Children can learn how to cook easy gluten-free recipes and learn about their disease from the personal story of a child with celiac. The author's niece, was the "story-teller" of the book. This can help children put a face and success story to their own disease.

A STORY COOKBOOK FOR CHILDREN WITH CELIAC DISEASE

A Graduate Research Project
Submitted to the
Division of School Library Studies
Department of Curriculum and Instruction
In Partial Fulfillment
Of the Requirements for the Degree
Master of Arts
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by
Heather A. Hope
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Titled: A Story Cookbook for Children with Celiac

has been approved as meeting the research requirement for the
Degree of Master of Arts.

Jean Donham

7/24/2012
Date Approved

[Signature]
Graduate Faculty Reader

Karla Krueger

7/26/2012
Date Approved

[Signature]
Graduate Faculty Reader

Jill Uhlenberg

8-6-12
Date Approved

[Signature]
Head, Department of Curriculum and Instruction

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CHAPTER 1

INTRODUCTION

Imagine a doctor telling you that you can no longer eat cookies, toast, macaroni and cheese, spaghetti, and chicken nuggets. This is the reality of a person diagnosed with celiac disease. The National Institutes of Health (2009) estimates that two million people in the United States are diagnosed with celiac disease. These individuals have to adapt their diet to avoid any food which contains wheat, gluten, and barley. According to the National Digestive Diseases Information Clearinghouse (2008), Celiac is a disease that affects digestion and damages the small intestine. Celiac also prevents nutrients from being absorbed into the body. Celiac is caused by an individual's inability to tolerate gluten, which is a protein in wheat, rye, and barley. Gluten can also be found in medicines, vitamins, sunscreen and many everyday products (Celiac.com, 2008).

If a person with celiac consumes wheat or gluten, the symptoms they suffer from are varied, but severe. According to the MAYO Clinic (2011), the symptoms of celiac disease include diarrhea, abdominal pain, and weight loss. Individuals with celiac may also experience irritability, depression, anemia, stomach upset, joint pain, muscle cramps, skin rash, mouth sores, dental and bone disorders, and a tingling in the legs and feet. In particular, the MAYO Clinic (2011), also states that children with celiac can experience stunted growth.

The effects of celiac disease can become life threatening. According to Celiac.com (2008), A person with celiac who consumes gluten has increased chances of gastrointestinal cancer. It is important that a person with Celiac be quickly and correctly diagnosed so he or she can be immediately treated. When treated the effects of celiac disease can be reversed and controlled. According to the National Digestive Diseases Information Clearinghouse (2008), eating a gluten-

free diet causes the symptoms to go away, begins to heal the existing intestinal damage and prevents further damage. The National Digestive Diseases Information Clearinghouse (2008), also states that a child's small intestine heals within three to six months of eating gluten-free allowing the absorption of nutrients from food into her body.

The treatment for celiac disease is preventative. People with celiac must avoid consuming any product that has wheat or gluten. According to the National Digestive Diseases Information Clearinghouse (2008), for a person with celiac to stay well, it takes a life-long commitment to eating gluten-free. Children have a particularly difficult time adjusting to a gluten-free diet. The foods that are considered children's favorite foods usually contain some form of wheat or gluten. On the website, allrecipes.com (2011), the list of kid favorite foods include: macaroni and cheese, chicken nuggets, cupcakes, pizza, pancakes, peanut butter sandwiches, bagels, corn dogs and hotdogs. All of these foods have wheat and gluten.

Problem

The books published for children with celiac can be divided into two categories, informational about the disease and how to eat wheat and gluten-free. The informational books provide a story that helps a child and parent understand celiac disease. The informational books have accurate information and an interesting story that appeals to a child. The first informational book is *No More Cupcakes and Tummy Aches: A Story for Parents and Their Celiac Children to Share* by Jax Peters Lowell and Jane Kirkwood. This book is a children's picture book to help them understand their disease. It is written from the perspective of a seven-year old child. It does not include recipes for a child with celiac because the purpose is to help a child understand his disease.

The second picture book, *Mommy, What is Celiac Disease?* by Katie Chalmers is written for children and parents. It is told from the perspective of a mother explaining celiac to her daughter. This book is beautifully illustrated with drawn illustrations placed on top of photographs. The illustrations engage the reader and create an emotional reaction for the reader. The text of the book does not focus on what a child with celiac can't do, but what the child can do. For example, the child can find new recipes and try new foods. The book has a positive message about having celiac. This book has many positive reviews from parents on Celiac.org, (the website of the Celiac Disease Foundation), and it is excellent to help a child understand his / her disease. This book recommends foods that a child can eat, but no recipes. This book also has a companion website that is very informative.

Beyond informational resources are cookbooks to help children and families learn to live with the disease. One is *Special Foods for Special Kids: Practical Solutions and Great Recipes for Children* by Todd Adelman and Jodi Behrend. This cookbook includes information about how to cook foods for children with egg, milk and wheat allergies. This book also suggests ways to help a child adjust to eating differently. This book is written for a parent of a child with celiac. This book does an excellent job of providing valuable recipes and information for parents to understand how to help a child emotionally and physically.

A second cookbook is *Incredible Edible Gluten-free Food for Kids: 150 Family Tested Recipes* by Sheri L. Sanderson. This book is also written for a parent to be able to cook for their celiac child. This book provides substitutions for baking and cooking wheat and gluten-free.

The above four books are a representative sample of the books available to children and parents about celiac and eating wheat and gluten-free. A subject search using the terms *celiac* and *children* limited to juvenile audience in the OCL Worldcat.org database resulted in 9

informational texts. An advanced WorldCat subject search for *cookbooks* and *celiac* and *children* resulted in 7 books. However, no cookbooks are written for children to learn to cook for themselves. Further, there were no books that combine a storyline and a cookbook. The illustrations in each of the cookbooks are not visually appealing to a child. The cookbooks do not have pictures of the major steps taken to cook or make the recipe.

The ability of children with celiac disease to access kid-friendly recipes that have appealing information and visuals is limited. Also, the cookbooks written for children who have celiac do not have step by step appealing photographs of a child cooking with an adult. When assessing the books available to children with celiac, it became apparent that a cookbook written for children to help them cook gluten-free recipes and tell a story of a child with celiac would fill a void.

Purpose and Audience

The purpose of this research project was to create a children's story cookbook that addresses the dietary adaptations to avoid gluten and wheat for children diagnosed with celiac. Children's literature has a need for a cookbook that will have recipes appealing to children and have pictures that will make the recipes / food more visually attractive. The book also included child friendly directions so that a parent can assist a child in preparing the food. The story cookbook also told the story of a young child who has celiac, who is learning to eat differently and to adapt to her disease. Children can learn how to cook easy gluten-free recipes and learn about their disease from the personal story of a child with celiac. The author's niece, was the "story-teller" of the book. This can help children put a face and success story to their own disease.

Justification

The most difficult aspect for a child with celiac disease is to transition to eating wheat and gluten-free. It is important for a child with celiac to understand that she is making a lifetime eating change, that she is not the only child who copes with finding new foods to eat, and that there are good wheat and gluten-free foods that she can transition to eating. According to the National Digestive Diseases Information Clearinghouse (2008) treating celiac disease requires the individual to eliminate all gluten from his diet for a lifetime. Even a small amount of gluten can cause adverse symptoms to occur. This is why a change in diet is a lifetime commitment. A story cookbook would focus on making lifetime eating changes while exploring the emotional issues that a child with celiac experiences. The story cookbook would help the child find recipes and foods that replace the traditional kid-friendly foods they crave. These types of recipes will help the child to feel as if their life has been affected minimally. Parents need help to find gluten-free recipes that allow the child to feel they have agency. According to Cureton and Sharret (2007), finding recipes that are gluten-free substitutes for the foods that a child usually eats is a difficult task for a parent. An important part of transitioning to eating gluten, is finding recipes that appeal to children. The cookbook will help children find gluten-free foods and recipes that they can access immediately. The story cookbook will help children find those recipes to replace what they used to eat. Once the child feels comfortable with a changing diet, self-efficacy about eating is likely to rise.

A diagnosis of celiac is a challenge, but one that a parent and child can overcome by learning how to read labels, and ask questions about the ingredients in foods (Nemours). The process of looking for gluten-free alternatives develops knowledge about the disease and the

foods that are safe to eat (Nemours). The cookbook part of the story cookbook seeks to help children understand the food choices they have and give them the knowledge that they can find foods that will appeal to them. The cookbook will also help children feel as if they have control over their choices and disease. As supported by Cureton and Sharret (2007), adults and children need to learn about their disease and learn how to control their disease by managing their dietary choices.

Recent studies indicate that the number of people living with celiac could be as high as one in eighty, and celiac is the most common lifelong disease found in children (Cureton & Sharret, 2007). The story cookbook will help children with celiac see themselves in the story and to help the child transition to eating gluten-free.

Research Questions

This project addressed the following questions:

1. What should be the text structure employed in a children's book that combines a story and recipes?
2. What are the psychological and emotional aspects of eating gluten-free?

CHAPTER 2

LITERATURE REVIEW

Introduction

The structure of text and the organization of content in a children's storybook is an important factor in readability. The author needs to consider the type of informational text to be used and the various genres that will be placed in the text. The literature develops an understanding of how the text will be used and the impact the information has on children. The emotional and social effects are explored to help the author develop a storyline and information to support the reader.

Understanding Non-fiction and Genre

Informational texts are important to the aesthetic and academic needs of children. Compared to fiction, informational texts are used less in the classroom because teachers are more comfortable with fiction (Williams, 2009). Children are familiar with informational texts and use them at home and at school. The genres at home and at school differ, but children are able to distinguish between how to use each genre. The genre and structure of a text can support and enhance reader understanding. There is an inconsistency in the definition of informational text, but there are themes within how each text is structured. Authors need to understand the best organization for their topic.

Research conducted by Williams (2009) highlighted the problems in identifying a singular definition of children's non-fiction. This research was a meta-analysis of twenty-six studies about non-fiction. The purpose of the meta-analysis was to determine how each study defined non-fiction texts. The author emphasized the importance of reading non-fiction, along with why teachers and practitioners preferred to use fiction in the classroom. Williams submitted

that teachers are not familiar with the various forms of non-fiction, believe that young readers find non-fiction uninteresting and believe that non-fiction is too difficult for young readers. Williams identified the importance of non-fiction reading in developing student interest in reading and improving writing skills. Williams contended that children enjoy non-fiction because it allows them to pursue their own interests.

Williams (2009) conducted a meta-analysis to address the inconsistency in how non-fiction is defined in recent literature. Williams stated, "I believe there are three major issues emerging from this literature: (a) definitional inconsistency, (b) needlessly narrow boundaries set for nonfiction, and (c) the avoidance of defining nonfiction at all." (p. 249). Williams found that non-fiction is categorized as expository, non-narrative, informational text, and trade book. The definitions of each of these categories varied per author. Williams suggested that there is not a consistent categorization or definition of non-fiction text.

Williams (2009) proposed a framework for understanding the placement of non-fiction into three structural formats and six media modalities. Williams categorized non-fiction into narrative, expository and hybrid texts. Williams defined narrative non-fiction as, "(narrative texts) have a story-like quality with a clear beginning and end. The main purpose of these texts is to tell a factual story" (p. 252). Williams defined expository non-fiction as a text that is able to inform the reader about a particular topic and the structure is non-linear. Expository texts are arranged by introducing a topic and describing a topic and summarizing a topic. Williams described hybrid non-fiction as a combination of expository and narrative texts. Williams stated that, "(hybrid texts) include features that are characteristic of both narrative and expository texts, such as linear, continuous storyline along with related information that can be accessed in a nonlinear manner" (p. 253).

Williams (2009) cross-referenced the structural definitions with the media modalities in which the text was presented, including: books, periodicals, websites, digital books and periodicals. The article includes a chart of the various types of books that are included in each structural format and media modalities. For example, Williams categorized informational storybooks as a narrative structural format and as a book for the media modalities.

Williams (2009) found that no particular type of non-fiction is better than another, each had benefits and limitations. In particular, hybrid nonfiction books, “often contain multiple genres and storylines. A common approach employed by authors is to embed expository factual information within a continuous, sometimes fictional, storyline” (p. 255). Williams concluded that by providing a framework of the formatting of non-fiction, we encourage teachers to use it within their classrooms.

Encouraging teachers to use non-fiction in their classrooms is important to developing reading skills in children. It is also important to understand the types of genres children experience at home and school. Duke and Purcell-Gates (2003) examined the need of teachers to understand the genres of written work that children see at home compared to what children see at school. Duke et al. (2003) defined genre as, “(genre) refers to patterns in the way language is used; that is it refers to patterns in the situations in which a text is used and patterns in the features of that text—its language, format, structure, and content” (p. 31). Duke and Purcell-Gates completed a meta-analysis of two studies by Purcell-Gates and Duke. In both studies the participants were first grade, low socioeconomic children between the ages of four to six years old. The first study by Purcell-Gates in 1996 observed the types of genres children used in their home. The second study by Duke and Purcell-Gates in 2000 observed student use of informational texts in the classroom. In both studies, researchers documented when the children

read any type of written language. Examples of genres used in the home are labels, newspapers, cookbooks, game-related print, letters, and Biblical text. Examples of genres used in the classroom are worksheets, journals, charts and poems. Examples of the genres in both settings are lists, individual letters, individual words, and children's books. Duke and Purcell-Gates (2003) suggested that merging the types of genres at school with the genres seen in the home can help children with understanding and comprehension. In short, Duke et al. submitted that teachers should try to combine the genres students see at home with lessons and genres that are used in the classroom. They stated, "In essence, teachers can build a cumulative literacy culture in the classroom that draws on each child's home experiences with print while simultaneously expanding the two worlds" (p. 35). Duke and Purcell-Gates submitted several examples of how teachers can combine the genres seen in the home and at school. One example was of a kindergarten class using the book *Chicken Soup With Rice: A Book of Months* by Sendak and comparing it to a can of chicken soup label. In this way, they suggested, "Children related print in one genre to the other, locating the word chicken in both contexts" (p. 36). The authors also stated, "it appears that children benefited from the two genres in this phonemic awareness and phonics lesson" (p. 36). Duke and Purcell-Gates concluded, "Encountering genres in school that are common in their homes may help children to see the connections between the literacies they observe and participate in at home and what they engage in at school" (p. 35).

The ability of students to learn from various genres can help students increase their comprehension. Read, Reutzel & Fawson (2008) examined the importance using informational texts to develop reading skills. Read et al. explained the types of text structures commonly used in organizing informational texts, and described current books that are good examples of each of those text structures.

Read et al. (2008) highlighted the importance of adding expository text into the classroom setting. The authors stated that children find informational texts appealing. Also, high quality informational texts are available in a wide range of topics. Read et al. compiled evidence to support the importance of teaching comprehension strategies. Read et al. examined data collected from studies by Williams in 2005, Hall, Sabey and McClellan in 2005 and Reutzel, Smith and Fawson in 2005. These three studies found that students benefit from reading expository texts. These studies also found that comprehension increases when students are taught expository text structures. All of the studies incorporated training for reading text structures and reading for content. Read et al. explained, “that teaching young children the text structures found in expository texts is not only possible, but also quite effective in improving comprehension as measured by answering questions, summarizing, and retelling” (p. 214).

Including expository text in the classroom requires the ability to understand the organization of these texts. Read et al. (2008) highlighted the types of expository text structures most commonly used and gave examples of high quality trade books. The structures included are description / list structure, cause and effect structure, comparison / contrast structure, and order / sequence structure (p. 214). Read et al. defined the description / list structure as, “books that use sections with main ideas followed by elaborations on those main ideas, which are sometimes divided into subsections” (p. 215). The cause and effect structure was defined as, “the author presents the results of an event and the reasons that the event occurred” (p. 215). The comparison / contrast structure was defined as, “two or more objects, events, people, or places described in terms of their similarities or differences” (p. 215). The order / sequence structure was defined as, “text that explain the steps of a process or the order of a sequence of events” (p. 216). Read et al. concludes by highlighting the importance of including expository texts into the classroom.

The development of non-fiction lessons in a classroom is more effective when the instructor understands the capabilities of students to process non-fiction writing. Filipenko (2004) found that children in pre-school have the ability to understand the text features of non-fiction, comprehend the content, and inquire about the aspects of the text they do not understand. Filipenko studied children ages 3-5 in a Canadian preschool. The teachers in the preschool were well versed in children's non-fiction and provided the children with access to quality non-fiction, along with support for spoken and written literacies. Filipenko conducted a naturalistic study by watching the preschoolers as they read and talked about the non-fiction reading. The researchers monitored children in small and large groups and when working on non-fiction text one on one.

Filipenko (2004) found that, "children as young as 4 and 5 years of age can demonstrate an impressive understanding of informational texts" (p. 33). The children in the study were beginning readers, yet they were able to attain meaning from the text features and text structure of informational texts. Preschoolers in Filipenko's study were able to ask questions based upon the information they don't know in the informational texts. The children were able to understand that the informational text would provide information over a particular topic, and they were able to analyze the information within that text. The children were also able to make connections between what they knew and what they were reading. Filipenko found that "young children can and do enthusiastically engage with informational texts" (p. 34). Filipenko concluded that teachers and teacher-librarians can help students understand informational text by teaching students to talk about what they are reading in a non-fiction text.

In conclusion, informational texts have many definitions, and a writer needs to be intentional about text types to be created. A children's story cookbook is a hybrid informational text, organized in an expository and a narrative structure. A writer of an informational text

should understand that children as young as preschool can understand different genres of non-fiction, can comprehend what they read and know the difference between the purpose of non-fiction and fiction reading. The need for the appropriate text structure in a children's cookbook parallel's the need for the appropriate content. The emotional and social needs of children with celiac disease should be the focus of the content of the story and the recipes included should address those needs as well.

The Emotional and Social Effects of Celiac

Individuals with celiac disease face a life time eating transition that is required to keep healthy. This transition affects their lives emotionally, socially and psychologically. The transition also affects the family and friends of a person with celiac. Identifying the needs of a person with celiac as they adapt to a gluten-free diet can help the individual to feel less social isolation.

Sverker, Ostlund, Hallert, and Hensing (2009) studied the impact of people with celiac disease eating gluten-free. They found that the effects of celiac were more than just a change in diet. Celiac affects a person's relationships and mental health. Sverker et al. studied individuals diagnosed with celiac disease and their family members. The individuals were identified as diagnosed with celiac from four hospitals in Sweden. The researchers conducted an interview and a questionnaire with each of the participants. The questions in the interview focused on open-ended answers of the experiences and dilemmas of living gluten-free. The questions in the questionnaire were specific, such as who purchases the food items for your household.

Sverker et al. (2009) found that people living with celiac experienced four major dilemmas on a daily basis: cognitive, social, emotional and physical. According to Sverker et al., cognitive consequences included constantly thinking about buying, preparing and avoiding

accidentally consuming gluten or wheat. The social consequences included feeling left out or excluded due to the amount of social interactions that include food. For example eating out at a restaurant was not possible, if the restaurant did not have a gluten-free menu. The emotional consequences included feeling sad about not being accepted or being different and having anxiety about possibly eating gluten or wheat. The physical consequences were linked to not having access to nourishing or appealing gluten-free food when eating out at a restaurant. Sverker et al. concluded that a person with celiac has larger effects than just changing their eating habits. Celiac affects all aspects of their lives.

The effect of living with celiac can cause victims to feel controlled by the food that they eat. Sverker, Hensing and Hallert (2005) found that a person with celiac is impacted emotionally, in their relationships and in the management of their life. The participants in this study were between the ages of 20-40 and identified with celiac from four local hospitals in Sweden. The individuals were selected from different ages, genders, and in various stages of their diagnosis. Sverker et al. conducted interviews of the participants that focused on the effect of celiac in their daily lives. Researchers analyzed the interviews for critical incidents or situations where celiac interfered with the person's life. Sverker et al. found that participants were affected while at home, at work, traveling, and shopping. The researchers described emotional effects as "feeling isolation, shame, fear of becoming contaminated by gluten, and worrying about being a bother to others" (p. 175). Sverker et al. offered examples of the emotional effect, such as when the participants could not eat the food that was offered at potlucks or at coffee breaks and not being able to eat the same food items at dinner. Another emotional affect was the fear of contamination and the need to constantly check the contents of food. They described problems in relationships as "unwanted visibility, neglect, being forgotten, having to disclose avoidance, and risk taking"

(p. 175). The researchers also offered examples of how relationships are affected by celiac. The participants stated that they were sometimes the center of conversation and had to describe celiac. In other circumstances, participants felt not wanted because their family members did not want to cook a separate food item. Participants also took risks in what they ate due to social pressures. Sverker et al. (2005) described a situation where an individual ate a piece of cake without asking if it was gluten-free because she did not want to be seen as different. Participants reported that managing daily life became tedious and monotonous. The ability to access gluten-free food was difficult and over time became bland.

Sverker et al. (2005) concludes that the effects of living with celiac disease vary per person, but are more severe than what was first expected. In diagnosing an individual with celiac disease, doctors need to consider the physical aspects alongside the social and psychological aspects.

Common psychological effects of celiac disease are depression and anxiety. Addolaroto, De Lorenzi, Abenavoli, Leggio, Capristo and Gasbarrini (2004) examined the impact that counseling had on individuals with celiac. The sixty-six participants in this study were identified to have celiac disease, but also had a diagnosis of anxiety and depression. The individuals participated in bi-weekly counseling sessions for six months to help deal with the emotional and personal issues associated with celiac disease. Individuals were assessed with an anxiety inventory and a self-rating depression scale.

This study was conducted in Italy, where communing over food is an important aspect of social relationships. Addolaroto et al. (2004) stated, “not being able to eat the same food as one’s companions can lead to a reduced social life and the onset of a feeling of inadequacy and being different” (p. 779). Addolaroto et al. found that individuals with celiac experience a decrease in a

feeling of well-being from a lack of proper nutrition. Participants also experienced “a reduction in the quality of life related to dietary restrictions that lead to difficulties in daily social relationships” (p. 781). Addolaroto et al. concluded that through the counseling sessions patients experienced an improvement in their psychological issues, but also had higher rates of complying with a gluten-free diet. The latter could be the cause of a better feeling of well-being due to physically feeling better.

The emotional experiences of adults mirror the experiences of children who are trying to eat a gluten-free diet. Helping children find foods that they enjoy and not have a burden of trying to find foods that are gluten-free were the goals of a gluten-free camp for kids researched by Simon-Bongiovanni, Clark, Garnett, Wojcicki and Heyman (2010). The camp was established in California for children diagnosed with celiac. The children were able to enjoy camp without having to worry about the food they ate or feeling different from others. Simon-Bongiovanni et al. studied the life experiences of the children at camp. A survey was administered at the beginning and at the end of camp to assess the quality of life experiences. The survey was fourteen questions that asked the children to rate their life experiences at camp based on a four-point Likert Scale. The participants ranged in ages from seven to seventeen and were in different stages of diagnosis. Simon-Bongiovanni et al. found that, “celiac camp enables children with CD to enjoy the camp experience freely without concern for and preoccupation with the foods that they are eating or the stigma of their underlying disease” (p. 527). Simon-Bongiovanni et al. also found differences between children who had been on a gluten-free diet for four years or more and children who have been on a gluten-free diet for less than four years. According to Bongiovanni et al., “camp had a positive effect on all children in almost all quality of life categories. The effect was more prominent for children who more recently had started a GFD (gluten-free diet)”

(p. 528). The camp provided the opportunity for all children to feel better about themselves and have less problems with feeling left out.

Summary

The experiences of people living with a gluten-free diet bring an understanding of the stigma and anxiety that accompany any disease. The effects of celiac disease are not just in treating or managing the disease. Substituting what one eats causes individuals to feel different and isolated in their home, work and social relationships. Celiac disease can also cause a person to become overly worried and experience excess fear. The ability to accept changes in diet and to feel less stigmatized occurs when an individual has a positive view of what they can eat and the support of family and friends.

A narrative non-fiction text offers a story of an individual successfully eating a gluten-free diet. The ability of a child to see his experience with celiac reflected positively in a story may help the child to overcome anxiety and isolation.

CHAPTER 3

METHODOLOGY

A diagnosis of celiac requires a child to learn the effects of the disease and how to manage her diet. The literature available to children with celiac is limited and does not include a hybrid text that combines a narrative and a cookbook. The combination of a story and a cookbook can help children to understand themselves, but to also provide kid-friendly, gluten-free recipes. A difficult aspect of maintaining a gluten-free diet is finding appealing food substitutes. The first goal of the story cookbook was to help children find recipes that they want to eat and to present these recipes in visually appealing photographs. This can help the child feel a sense control over the foods available to her. The second goal of the story cookbook was to provide children with a story of a child who has celiac, and to follow her life from diagnosis to diet management.

Project Description

The story cookbook has two components: the narrative and the recipes. The narrative was from the perspective of the author's nine year-old niece, Jacie, dealing with a diagnosis of celiac. The story followed Jacie as she had symptoms of the disease, was diagnosed with the disease and learned to change her diet to manage her disease. The second component was visually appealing recipes. The first step in writing the book was researching the gluten-free recipes that children would like to eat. The author cooked all of the recipes and took photographs of the final products and gluten-free ingredients. The author also took pictures of Jacie that were included in the book. The book was divided into two sections, the story and the recipes. The story was told from Jacie's voice as she described how she felt before diagnosis, her experience at the doctor's office, learning about celiac and learning to eat gluten-free. The focus of the story is to help the

reader understand that the only way to control celiac, is to not eat gluten. Within the story there are pictures of Jacie and her family. Jacie is a gifted artist, she is currently in the Talented and Gifted Program for art. Some of her artwork was used in the book as well. The text and illustrative material was integrated throughout the book. There was a 60 / 40 ratio of text to illustrative material. The audience for this book is parents and children who are experiencing a diagnosis of celiac. The story appeals to children from age seven to twelve, but the recipes appeal to all ages. The reading level was written at a 600 to 625 on the Lexile Score, which equaled a 3.5 grade level. The book was be forty-one pages.

Project Procedures

The author began the project by researching the disease of celiac, and chose the information that was a best fit for a children's book and the story of her niece. The author chose the parts of Jacie's story to include in the book. Jacie lived with the author when the diagnosis occurred, so the author had an understanding of what needed to be in the story. However the author consulted with Jacie about what it was like to be diagnosed with celiac. The author consulted with Anita Gordon on IRB approval. IRB approval is not required due to it being a journalistic project and not a study. However the author informed Jacie and her mother of the purpose of the book and the process of creating the book, and had them sign a permission slip. The permission slip was listed in Appendix A. Next, the author researched and decided what recipes to use in the cookbook. The author experimented with recipes and took pictures of the final product, and products used to create the recipes. The goal was to have at least twenty recipes and the book includes twenty-two recipes. The recipes included kid-friendly recipes that are main dishes, side dishes, desserts and muffins. The author consulted with Tome Hope, the

author of the cooking blog *Bonbons and Books*, about how to take pictures for the cookbook.

Tome showed the author how to take pictures of food. Next the author had Jacie create pieces of artwork. Jacie chose to use paint for her pieces for the book. The author consulted with Tom Murphy, Tori Devries and Carl Sunderman. They all suggested using Adobe InDesign. As Ms. Devries and the author looked at this program, it became clear that it required knowledge of graphic design. The author and Ms. Devries researched other programs and mixbook.com was the online program that had the best options. The author then formatted and arranged the information into the mixbook. The author chose the photographs, artwork, text layout, font, and text features. The author had the book printed and bound. The resources that the author used to research celiac, gluten-free recipes, and the format that she wanted to use are listed below:

Book Resources:

- 1) Celiac disease: A guide to living with gluten intolerance by Sylvia Llewelyn Bower with Mary Kay Sharrett and Steve Plogsted (2007).
- 2) The doctor's guide to gastrointestinal health: Preventing and treating acid reflux, ulcers, irritable bowel syndrome, diverticulitis, celiac disease, colon cancer, pancreatitis, cirrhosis, hernias and more by Paul Miskovitz and Marian Betancourt (2005).
- 3) Netter's internal medicine edited by Marschall Runge and M. Andrew Grganti (2009).
- 4) Coeliac disease: Nursing care and management by Helen Griffiths (2008).
- 5) Mayo clinic on digestive health edited by John E. King (2000).
- 6) Health-related disorders in children and adolescents: A guidebook for understanding and educating edited by LeAdelle Phelps (1998).
- 7) The pioneer woman cooks: Recipes from an accidental country girl by Ree Drummond (2009)

Web Resources:

- 1) The National Institute of Health (www.nih.gov)

- 2) www.Celiac.org
- 3) ww.allrecipes.com
- 4) www.foodnetwork.com
- 5) www.bonbonsandbooks.typepad.com
- 6) www.glutenfreely.com

CHAPTER 4
CHILDREN'S BOOK

See attached children's book titled "I love the gluten-free me: My journey with celiac.'

CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

Problem and Purpose

The ability of a child to understand celiac and have access to easily made recipes is crucial after a diagnosis of celiac. A child needs to feel they understand their disease, but also that she can take control of her disease. Children need to also understand that the only way to treat celiac is to eliminate gluten from their diet. This children's book gives children a description of the symptoms of celiac, the process of being diagnosed with celiac, and how to eat gluten free. The children's book includes easily made recipes to help the family access gluten free foods immediately. One major focus of the book is the commitment to eating gluten free. The reader needs to understand that this is the only way a celiac will be healthy and control her disease.

Content Summary and Adjustments

The beginning of the book is the story of Jacie and her diagnosis. The book highlights the emotional impact of having to eat gluten free. The second half of the book is a recipe book. The book has visually appealing pictures of the recipes, in order to show the child recipes that look tasty. Initially, the book was going to have pictures of the step by step process of making the recipes. In order to keep the book shorter, the author chose to eliminate that aspect.

Conclusions

This book will be helpful for children and their families in learning to adjust to eating gluten free. Parents will be able to immediately access foods that their children will want to eat, and through the story will be able to prepare their children emotionally for a diagnosis of celiac. This book will help children understand that they are the same person, they have family who loves them and their talents remain the same, but they have to eat differently to be healthy. The

reader will learn through Jacie's story that it feels difficult at first, but it gets easier. The storyline of a child with a disease and the organization of the recipes could serve as a model for other types of diseases, such as childhood diabetes.

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APPENDIX A**PERMISSION SLIPS****Permission Slip for Adult**

I, Alisha Stewart, give my permission for my daughter, Jacie Stewart, to serve as a central character in a children's book about celiac disease being created by Heather Hope in partial fulfillment of her Master's degree requirements at the University of Northern Iowa. I also give permission for Heather Hope to include photographs of my daughter in her children's book.

Alisha Stewart Signature

Date

Permission Slip for Child

I, Jacie Stewart, understand that Heather Hope will write a children's story about celiac where I am the central character. I also understand that Heather Hope will take use photographs of me and my artwork in her children's book.

Jacie Stewart Signature

Date