The growing realism that has emerged in children’s literature in the past several decades has made it possible for more complicated topics such as chronic illness to be considered. Despite the growing presence of illness in children’s literature, chronically ill characters are still vastly underrepresented and are often portrayed negatively or only partially. This remains true even as more children are diagnosed yearly with a chronic condition.

Research suggests that for children’s literature featuring chronically ill characters to be valuable to its young readers, it must be reflective of the realistic emotions and behaviors chronically ill people experience. The “illness experience” has been defined in this paper by medical, social, and emotional factors. The following content analysis considers whether twenty children’s picture books published since 2000 realistically present the illness experience of childhood chronic illness.

Headings:

Chronic Illness -- Children’s Literature

Chronic Illness -- Picture Books for Children

Disability -- Children’s Literature

Health Literacy -- Picture Books for Children
THE CHRONICALLY ILL CHILD: A CONTENT ANALYSIS ASSESSING THE REALISTIC PORTRAYAL OF THE “ILLNESS EXPERIENCE” FOR CHILD CHARACTERS IN 21ST CENTURY CHILDREN’S PICTURE BOOKS

by
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Approved by:

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Advisor
“An adequate exploration of chronic illness must begin with the lived experience”

~Toombs
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Introduction

A new kind of realism in children’s literature emerged in the late 1960’s and 70’s. Topics that were once considered taboo for children began to be openly discussed and presented in the literature written for them. This emergent climate made it possible and socially acceptable for writers to explore complicated, less easy to solve subjects such as divorce, death, bullying, racism and sex.¹ One such subject that gained attention in children’s literature during this period was disability. Though the relationship between disability and illness has, at times, been debated, for the purpose of this paper, illness will be considered as a component of disability. Despite an increased appearance of disabled and ill characters in children’s literature around this time, they are still vastly underrepresented even today. “Perhaps no group has been as overlooked and inaccurately presented in children’s books as individuals with disabilities.”²

This remains true even as more children are diagnosed yearly with a chronic illness or a medical condition of some kind. This increase is due to a multitude of different factors, the primary factor being the significant technological gains that have been made in the medical field in the past twenty to thirty years, resulting in increased diagnosis and also increased survival. Chronic illness is a long-term health problem, usually lasting three months or more. For children, chronic illnesses are normally long-term with no existing cure, and they often affect and disrupt a child’s daily activities and

involve frequent hospitalizations or extensive health and medical care.³ Epidemiologists suggest that as many as 1 out of 4 children in the U.S., or 15 to 18 million children age 17 years and younger, suffer from a chronic health problem.⁴

Consequently, as chronic childhood illness becomes more prevalent, there exists a lack of children’s literature available for these children to identify with and learn coping skills from. “Books serve as mirrors for children to see characters who look like themselves and have feelings and experiences similar to their own.”⁵ Yet, often, chronically ill characters in children’s literature are seen only as supporting minor characters or in health literature familiarizing children with an illness. This lack of literature also means that other, healthy children have fewer opportunities to learn about this population of people. While a lack of this type of literature provides obvious deficits for both ill and healthy children, the presence of literature giving negative images of people with illness is even more harmful. According to Saunders, much of the literature that does feature people with disabilities, illness or differences, gives negative or subliminal messages that can become ingrained into society without further discussion.⁶

Research shows that for children’s literature featuring chronically ill characters to be valuable to both ill and healthy readers, it must be reflective of the actual experience of a person living with chronic illness. “Realistic emotions and behaviors…can help readers identify with ill or well characters and generate understanding of a population of

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children who may often be misunderstood.” In order to determine whether the literature accurately reflects the experience of having a chronic illness, one must establish a picture of what it means to live with a chronic illness. Chronic childhood illness is fraught with periods of disease activity and disease remission. It is not a single event in a child’s life but rather a permanent reality that a child must learn to live with. “To live with chronic illness...is to live a certain kind of life.” Health research shows that illness easily spills over into all areas of life. “Illness affects the child’s interaction with the physical and social environment in which he or she lives, and aspects of the child’s environment such as parents, peers, or school systems are altered as a result of the illness.” Additionally, its effects on the physical and social environments elicit emotional responses that must be considered when looking at chronic illness.

Previous disability literature has, like health research, made distinctions between the medical and social models of disability and illness. The medical model considers a person’s corporeal condition, including their physical, sensory, intellectual, emotional and psychological functioning while the social model considers the way society limits or excludes disabled people from full participation. To gain a full understanding of chronic childhood illness, medical and social models of both health and disability literature research must be taken into account when considering this type of children’s literature, as well as the emotional response these models elicit.

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Childhood Chronic Illness

In order to be able to affectively assess the realistic portrayal of chronic illness in children’s literature, it is important to establish a clear understanding of what is meant by chronic illness. Though there exist varying definitions of chronic illness, it is commonly agreed upon that chronic illness is long-term in nature, is colored by periods of acute exacerbations and subsequent remissions, and that it is often a permanent fixture in one’s life with little chance of ever being completely cured. Chronic illness can be progressive or changeable. Chronic illness can be fatal or associated with a relatively normal life span, despite impaired physical or mental functioning. According to the Centers for Disease Control and Prevention, or CDC, “chronic diseases and conditions—such as heart disease, stroke, cancer, diabetes, obesity, and arthritis—are among the most common, costly, and preventable of all health problems.” However, it must be noted that chronic childhood illnesses are often not preventable or caused in any way by health neglect on the part of the child. “Adults face a relatively small number of chronic conditions whereas children face a relatively large number of rare conditions.”

Illnesses common in childhood include asthma, insulin dependent diabetes mellitus, epilepsy, congenital heart disease, juvenile rheumatoid arthritis, sickle cell disease, hemophilia, cystic fibrosis, cancer and AIDS.

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Several factors have contributed to the increase of chronic illnesses in children. First, improvements in medical knowledge, technology and treatments mean more children are surviving and living with illnesses that, though now considered chronic, would have once been considered fatal. For example, most children with cystic fibrosis and cancer, including leukemia, can now expect to live into adulthood. Months of children and adolescents in the United States are living with type 1 and type 2 diabetes, cancer, sickle cell disease, asthma, and chronic pain. In the United States, over 13,000 children are diagnosed with cancer each year: 13,000 are diagnosed with type 1 diabetes annually; and 9 million children suffer from asthma. Secondly, infants who might have once died due to prematurity or low birth weight are now able to be successfully born. Finally, infants with prenatal drug exposure or AIDS are more common. For people living with chronic illness, life is often a roller coaster of highs and lows, disease activity and remissions. Illness affects multiple facets of a person’s life and affects how they feel or act on a daily basis. When thinking about chronic illness, one might primarily think of its medical realities. What are an illness’ symptoms and what treatments are possible for it? For a chronically ill child the symptoms and treatments vary from disease to disease. Chronically ill children are often limited in the types of physical activities they are able to perform. Additionally, actions taken to treat an illness

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19 Ibid, p.3.
can often become part of the problem while acting as a solution to the problem. Medicines, for example, can have negative side effects the longer they are used. Hydroxychloroquine, often used in preventing swelling and pain due to arthritis in lupus patients, can drastically damage a person’s eyesight if used long-term. Given the protracted nature of chronic illness, the long-term effects of ongoing treatments can be just as physically, socially, and emotionally damaging as the illness itself. As Turner suggests, while the physical realities of chronic illness are telling of the experience, the social and emotional aspects of the illness experience should not be underestimated.

For children, chronic illness exaggerates the already existent challenges of growing up. Chronic illness spills over into non-illness related aspects of life, including the social. It can complicate familial relations or limit the number of existent opportunities to socialize with peers. “Chronic physical illness can potentially interfere with opportunities for normal socioemotional development by limiting age-appropriate independence from parents, exposure to same-age healthy peers, participation in childhood activities, and development of a sense of self-efficacy and self-determination.”

One of the ways that chronic childhood illness affects children and their families is by disrupting normal processes of child development and family functioning.

Chronic illness, especially in childhood, requires ongoing medical attention such as

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doctors’ visits, hospitalizations, time out of school, restrictive treatment regiments, painful medical procedures, social rejection and the resultant expenses for managing an illness. Hampel terms these effects of chronic illness as “illness-related stressors.”

Many of these stressors consequently translate to the family of a chronically ill child. Parents, for example, may have to take time off work to accommodate doctors’ appointments and hospitalizations. Siblings may feel as though they are less important to parents than their chronically ill sibling. Thus, the management of a chronic illness is shared with, and in the early childhood years, transferred to the family.

Chronic illness also affects the way children interact with their peers and how they view themselves in relation to those peers. Children, especially school-aged children, seek peer acceptance, even above parental approval. Health research studies have determined that chronically ill children are considered different by their healthy peers. Furthermore, research shows that children with chronic illnesses worry about how their peers will view them in relation to their illness. Grinyer (2007) proposed that “changes or differences in appearance directly threatens children and young people’s self-esteem, self-belief and confidence, which in turn affects their confidence to form relationships and feel socially accepted.” Thus, whether due to acknowledged

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differences by peers or to a chronically ill child’s perception of difference, ill children often find their social environment deeply affected by their illness.

All of these factors of the physical and social effects of illness are considered Hampel’s illness-related stressors. These stressors have a great impact on a child’s emotional response to his or her illness. “A much neglected aspect of physical illness is its affective dimension. We experience the world of life everyday not only in terms of physical interaction but in light of our emotions.” According to Snyder, emotions are a by-product of goal-directed thought – positive emotions reflect perceived success in the pursuit of goals, and negative emotions reflect perceived failures. The emotional responses of a chronically ill child come in relation to the directly effective medical realities and the indirectly, and sometimes only perceived, social responses to those medical realities. Thus, when fully considering how chronic illness can affect a child’s life, one must consider medical, social and emotional facets.

Disability and Illness in Children’s Literature

The depiction of chronic illness and disability in literature has changed over time. As most disability literature includes chronic illness, the following section will use the word “disability” with the understanding that it does include chronic illness in practice. Disability studies show that since the passage of the Americans with Disabilities Act in 1975 in the United States, American books featuring disabled characters have increasingly emphasized the reality of medical conditions as well as the influence of social attitudes on disabled persons’ ability for independence, social integration, equality

and pride.\textsuperscript{32} Much of this change has occurred in response to the emergent field of disability studies. Disability studies is the study of the sociological, political, historical, and cultural perspectives of disability, rather than the medical concerns.\textsuperscript{33} Representatives of disability studies have put forth medical and social models of disability. The medical model considers a person’s bodily condition and recognizes that, when compared to the majority of the population, a disabled person experiences differences in their physical, sensory, intellectual, emotional or psychological functioning. The social model considers how society incorporates or fails to incorporate the disabled into the mainstream of social activities.\textsuperscript{34} Disability literature critics have faulted many of the early depictions of disabled characters as focusing predominantly on the medicalization of disability while ignoring the impact of society on the disabled experience.

The changing portrayal of disability in literature has impacted children’s literature as well. Studies considering this literature suggest that literature for children and youth are increasingly depicting positive attitudes towards people with disabilities.\textsuperscript{35} Much of the existent research has analyzed children’s fiction quantitatively rather than qualitatively, assembled annotated lists, or offered criticism of the depiction of disabled characters in classic texts.\textsuperscript{36} In 1992 Blaska and Lynch conducted a study of 500 award-winning and highly recommended books for children ages birth through eight that were

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\item[\textsuperscript{34}] ibid, 2004.
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published between 1987 and 1991. In this study they reviewed the books for the inclusion and depiction of people with disabilities and illnesses. Of the 500 titles reviewed, only ten, or 2%, included people with disabilities or illness, and the characters were only integral to the storyline in 6 out of those 10 books. The results of this study exemplify the vast underrepresentation of disabled and ill characters in children’s literature.

The majority of the existent research has attempted to analyze how children’s fiction represents disability or illness. Unfortunately, there has been very little research done to assess how children respond to books that feature characters with disabilities. In her 1993 doctoral dissertation, Drennon examined, by content analysis methods, a selection of books about chronically ill, school-aged children, to determine whether the books realistically depicted the children, their illness and their circumstances. Drennon’s study drew input from both medical and education professionals in order to determine the quality of medical and literary realism. Although the majority of the sample literature was identified by medical professionals as presenting accurate medical information, they indicated that they would not recommend almost 40% of the literature to patients and families. The medical professionals cited that they would not recommend books that were “discouraging, depressing, those that present a negative impression of the illness or disturbing information about it, paint a bleak picture of a child’s life, or display negative emotions toward the child.” While Drennon’s study found that only 5.8% of readers thought that the sample books were slightly unrealistic, a 1996 doctoral dissertation by


Saad, which used a similar method, found that 72.9% of readers found books at least slightly unrealistic.\textsuperscript{39} The stark contrasts of these findings suggest that there currently exists no standard method by which to assess disability realism in children’s literature.

As previously noted, very little research has been done to assess how children respond to books that feature disabled or chronically ill characters. However, much postulating has been done about how literature featuring disabled and chronically ill characters can be used. As a subset of multicultural literature, children’s fictional literature featuring chronically ill and disabled characters, has the potential to acquaint ill and healthy children with a population of individuals that they may currently be unaware of. Arizpe and Styles found that children as young as four years old are capable of determining complex, subtle meanings and attitudes in texts.\textsuperscript{40} Thus, children’s literature depicting ill and disabled characters must realistically portray them so as not to encourage negative or unreal stereotypes. The most obvious setting for introducing this type of literature to well children is in the classroom. “It is important that children learn about disabilities and illness throughout the curriculum and throughout time so [that] when children have the opportunity to interact or be classmates with someone with a disability, they have some previous knowledge and understanding.”\textsuperscript{41}

Additionally, this literature has been cited as having the potential to help chronically ill children learn about their illness while helping them cope. “Children’s

\textsuperscript{40} Ibid, 2004.
literature can be used to educate patients about illness, surgery, and hospitalization." \(^{42}\)

As mentioned earlier, chronic illness presents people with a roller coaster of highs and lows, periods of disease activity and subsequent remissions. For children with chronic illness, these highs and lows of illness further complicate the process of growing up. Children’s literature can go a long way in helping chronically ill children. Bibliotherapy studies, especially, have discussed the ways by which physicians, nurses, and parents can introduce these books to chronically ill children. Bibliotherapy, for the purposes of its use with chronically ill children, is the “sharing of a book or books with the intent of helping the reader deal with a personal problem.” \(^{43}\) Part of aiding in the coping process involves the child being able to see themselves in the literature. “Literature can show chronically ill people that they are not alone, that others have similar problems and feelings.” \(^{44}\) Another part of this coping process involves including children in issues about their health, which can be encouraged by presenting them with children’s literature about chronically ill characters. Roter and Hall proposed that not fully engaging children in medical interactions leads them to being less likely to actively engage, manage, and cope with their own medical condition and care. \(^{45}\) Thus, children’s literature featuring chronically ill characters can have a significant impact on the way ill children feel about


themselves and their illness and can encourage their participation in issues about their health.

The literature used, however, must adhere to both the child’s traditional developmental needs and the additional needs of the chronically ill child. Children, especially school-aged children, want to know truths and facts, and children’s literature must be honest and believable for this age group. This holds true when considering illness and disability in children’s literature. “When presenting information about disabilities or illness to young children, it is important to be open and honest.”46 The truth, or medical realities, of chronic illness, however, can be too much for a chronically ill child to understand or manage psychologically and emotionally. “Children can usually accept a chronic problem only little by little, over a prolonged period. They need – and have the right – to be sustained by hope…therefore, to tell a child that he will have his problem ‘forever’ or ‘all your life’ may leave [him/her] feeling discouraged, hopeless, even overwhelmed.”47 Thus, it is not suggested that children be given the most technical information about their illness. Rather, it is suggested that the knowledge given be most pertinent to the child’s possible understanding of the explanation of conditions and treatments.48

Sharing illness knowledge with children can reduce their anxiety and encourage their ability to voice this information to other peers. “Knowing is a way of feeling in charge. It offers a basis for planning how to solve problems. It enables the ill child to make judgments that gradually help [him or her] toward independence in managing

medical needs.” Though there still remains a lack of representation of ill and disabled characters in children’s fiction, current evidence suggests that the literature that currently exists is targeted towards books for older readers. Texts for younger readers, on the other hand, are most often explanatory and portray disability mainly in terms of its biological and medical details. Studies have shown that, while it is important to present medical knowledge, both adult and children find less satisfaction in solely explanatory medical coverage. In a study done by Adomat, 2nd-5th graders were asked to consider children’s literature featuring disabled and ill characters. Adomat assessed how the children constructed their opinions, stereotypes and ideas about disabilities and people with disabilities. One thing she discovered was that the children had trouble moving beyond the medical definitions of disability, which reinforced a solely medical model of illness and disability.

It has been determined by both the multifaceted impact of illness and disability on a person’s life and by the separation of medical and social models of disability in disability studies that realistic portrayals of disability and illness must include discussion of both medical and social components. “Children with illness are physically, emotionally, mentally, and socially vulnerable. The medical model focuses on how an illness limits the child. The social model focuses on removing barriers within the physical and social environment that might limit children.”

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suggested, the large majority of current disability and illness literature for younger readers focuses on the medical details. As suggested by Gervay, it is perhaps more important to move away from this type of didactic teaching and into the realm of more meaningful human experience, focusing on the person and the story.”

This can be more greatly accomplished when the social model, in addition to the medical model, is applied to disability literature. “In examining how disability is socially constructed in literature, readers might look at how disability is defined, how disability affects the character’s interactions with family and the wider community, how people with disabilities are treated, and the problems that these characters face.”

The resultant product of combining the medical and social models in literature is better representation of the disabled experience. “We might say more accurately that the illness experience – as opposed to the brute facts of the disease process – is a story.”

Ill children can learn a great deal from a well-represented, accurately depicted protagonist character, especially if the overall outlook of the protagonist is positive and hopeful. To be hopeful, the truth must be presented, but not bleakness.”

Thus, there is a balancing act between hope and illness reality that must be achieved for this type of literature to be most effective for ill children. This is especially important because ill children are often faced with less than hopeful circumstances and realities. “When children read about others who are trying to make sense of an action similar to their own, it brings hope. Children learn their feelings are typical, which helps them understand that

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they are okay people even if they experience some negative feelings.”58 A connection must be made here between hope and emotions. As considered earlier, emotions are a by-product of hopeful thinking, or, according to Snyder, goal-directed thought – positive emotions reflect perceived success in the pursuit of goals, and negative emotions reflect perceived failures, hence the presence or absence of hope. Consequently, it stands to reason that the hope presented, or not presented, in disabled children’s literature will be reflected through the emotions of the ill or disabled character or characters. The resultant range of emotions the characters experience will, as Blaska suggested, help children realize the emotions they are experiencing are normal. “Through identifying with book characters, children can experience self-determination, independence and success.”59

**Picture Books and the Chronically Ill Child**

Picture books, as a distinct genre of children’s literature, allow children to experience a story through the combination of words and pictures, auditory and visual senses. Children are especially drawn in by the visual appeal of pictures.60 Pictures in picture books exist primarily to assist in the telling of stories.61 However, they have the ability to do much more than support the text. “Pictures make the verbal visible and extend the textual meaning; they permit the artist to add personal interpretation while

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staying within the story, but they do not overwhelm the text.”62 The sum total of this combination of words and pictures in relationship to each other creates a much richer experience for the reader than either part could achieve alone.

This is especially apparent given that picture books have been cited as being suitable for a wide range of ages. As Saunders has suggested, picture books have the capacity to present complex ideas and topics to readers of all ages.63 Though it is sometimes assumed that picture books for younger children require simpler composition than those for older readers, Rabey has concluded that even the youngest children can “interpret, comprehend and communicate the visual far beyond what they might be assumed to know.”64 Picture books, for example, can evoke emotions that words cannot. They can also mirror large societal issues. “Picture books are significant means by which we integrate young children into the ideology of our culture. Like most narratives, picture book stories most forcefully guide readers into culturally acceptable ideas about who they are through privileging the point of view from which they report on the events they describe.”65

In this way, picture books can greatly affect and shape the way a child sees his or her world. The belief that early exposure to picture books may contribute to children’s developing knowledge of the world around them is one of the main reasons why health care providers choose picture books as a method of patient education.66

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mentioned, children’s literature is often used with ill children as a way to help them cope with their illness. Existent children’s picture books that feature chronically ill characters often consider a range of different ways these characters cope with their illness. Some use creativity and imagination, others are shown receiving love and support from their families, a few are seen making connections with animals, and a fair amount depict the character affirming their strength and declaring that their disease does not define who they are.  

Additionally, as discussed earlier, much of the current disabled and ill literature relies heavily on the medical model of disability and illness. Given the visual nature of picture books, the presentation of medical information in picture books is thought to have an ever greater impact on a child’s ability to remember and later parrot these medical facts. Brookshire (2002) noted that, in describing medical information to children, “picture books are more appealing and therefore more likely to be engaged with than written text, and give access to dual coded information – information in written and pictorial formats which enhances comprehension and memory and improves retention.”

As mentioned earlier, studies have shown that children have trouble moving beyond the medical model of disability. Thus, it stands to reason that, given the enhanced potential of picture books, strictly medical portrayals of disability and illness in picture books can greatly deprive readers, ill and healthy children, of fully understanding the experience of chronic illness. Furthermore, this has the potential to be additionally harmful if the

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portrayal of disabled and ill characters is negative, stereotypical, or incomplete. For this reason, it is further suggested that picture books represent both the medical and social models of disability and illness. “Picture books that present ‘scientific’ and ‘factual’ material on illness and disability, and picture books that are essentially stories to encourage general reading skills but happen to have characters with disabilities in them, should and must be judged using criteria that uphold the social model of disability.”

Emotions, too, in response to medical and social factors must be considered as representative of chronic childhood illness.

**Research Questions**

Given the research presented, a few questions emerge that will direct the focus of the following content analysis. Previous research has been done to analyze the representation of disability and illness in children’s literature. However, much of this research occurred throughout the 1990’s and the early 2000’s and has approached the topic quantitatively rather than qualitatively. For these reasons, the following analysis will assess both quantitative and qualitative factors, with greater emphasis being placed on the qualitative, and the literature will focus on titles published since 2000. Furthermore, the bulk of research previously conducted has also considered the portrayal of ill characters throughout several genres of children’s literature, appearing in both primary and supporting roles. Given that little research has been devoted to qualitatively assessing the depiction of ill characters in the pictures of picture books, the following analysis will further consider how pictures support or contradict the text in the overall

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presentation of chronically ill characters. Additionally, given the previously mentioned research that suggests that “illness experience” should drive a story, rather than solely medical facts, the following analysis will only include children’s fiction featuring chronically ill main child or animal characters. The thought is that, literature featuring a chronically ill child as the primary character of a work will be more focused on exploring this illness experience and more easily identifiable for a child. Research has also proposed that peer modeling is more effective than adult modeling. Animals are included because they, too, are shown as effective protagonist models for children. Animals allow children to somewhat distance themselves from often difficult stories. For this reason, the literature will include ill child and animal characters. Consequently, the following analysis intends to assess the realistic portrayal of chronically ill main characters in children’s picture books published between 2000-present by exploring whether the “illness experience” is fully represented.

Though the books will be thoroughly analyzed for similarities, differences, and reoccurring themes, the driving questions used to assess the representation of “illness experience” in the literature will be the following:

1. Are both the medical and social models of disability and illness considered?
2. To what extent is the social model addressed and discussed?
3. To what extent are negative emotions explored and how do these emotions compare to the overall tone of each book?

All of these books will be assessed using the aforementioned questions, and quantitative and qualitative measurements will be taken in light of both text and pictures.

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Methodology

The method of content analysis has been defined various ways. Donohew stated in 1967 that there is no one way of conducting a content analysis. “Each content analysis is unique, presenting individual problems that require individual handling…each study must be defined primarily on the basis of its purpose and the types of content involved.”

Content analysis, as defined by W. Lawrence Neuman in 1994, has two parts: 1) identify a body of material to analyze 2) create a system to record aspects of the chosen material. The second part of the process requires a set of instructions or rules to categorize and classify observations. Traditionally, researchers have sought meaning in bits of data, such as words, sentences, or paragraphs. The following content analysis has attempted to follow these approaches to content analysis.

First, parameters were set in order to collect a representative body of literature. Books that did not adhere to these pre-defined limits were not considered.

1. The book was published in the U.S. between the years 2000-2014.
2. The book featured a main character with a chronic illness.
3. The main character was either a human child or an animal.
4. The book was in picture book format.
5. The book was fictional.
6. The book was readily available, either through an academic or public library system.

As previously mentioned, little research has been done looking at chronically ill characters in children’s picture books published in the past fourteen years. Additionally, given the intended focus on “illness experience,” it is assumed that a main character with a chronic illness will garner more attention and discussion than he or she would as a supporting character.

The process by which the books were chosen was multifaceted. Given that research shows this type of literature can be used in doctors’ offices and hospitals, schools, homes, and libraries, and with both ill and healthy children, it was assumed that the primary means these individuals would use for finding appropriate books would come from a combination of online searching and library catalogs. Consequently Amazon, Goodreads, NoveList, Boston Children’s Hospital, Seattle Children’s Hospital, The University of North Carolina at Chapel Hill, and Wake County Libraries were consulted. Additionally, A to Zoo was the starting point for the relevant literature. A combination of search terms was used, often by matching the name of a common childhood chronic condition with the terms ‘juvenile lit*’ or ‘children’s lit*.’ The illnesses included in the finalized book set were chosen based on their appearance and mention in the both medical and health and disability literature research. After extensive searching and subsequent elimination of inappropriate titles, twenty books were selected for inclusion in this analysis (Appendix A). These books represent 9 different chronic conditions: asthma, cancer, congenital heart disease, Crohn’s Disease, diabetes, epilepsy, juvenile rheumatoid arthritis, lupus, and renal failure. The bulk of books fall under the three most prevalent childhood chronic illnesses: asthma, cancer, and diabetes (Appendix F).
Next, a set of defined rules for categorization were put into place for the measurement of medical, social and emotional factors as seen in the literature. The following content analysis attempts to assess how representative the literature is of the “illness experience.” Thus, instances of medical and social issues were counted and compared to the total number of pages, with a final percentage of their representation given. Both text and pictures were considered. For example, if a book included textual information about treatments for diabetes, that page received one tally in the medical text column and was included in the final overall medical count for a book. If that same page also included a picture of those treatments, the page received one tally in the medical picture column and was included in the final medical count for the book. Since the two were on the same page, the page itself only got counted once. However, the number of individual instances was also tallied, which included the number of total medical text and medical picture combined. Based on the medical and social models of disability, the following were divided and counted as they appeared in either text or pictures:

**Medical Model**
- Illness symptoms
- Illness treatments (including any medicines, therapy, equipment, etc.)
- Equipment needed for illness (including those monitoring disease activity)
- Visits to doctor’s office and/or hospital
- Missed school days
- Illness management
- Diagrams used in explaining illness
- Explanations of how illness works or what causes it
- Mention of no cure

**Social Model**
- Others’ reaction to character’s illness
- Main character’s perception of others’ reaction to illness
- How relationships are altered or affected
- Presentation of stereotypes
- Acknowledged difference
- Limitations within society (perceived or actual, physical or social)
Having a chronic illness can cause a roller coaster of emotions as ill individuals face good and bad days. The following analysis intends to further investigate the range of negative emotions felt by the characters. Thus, negative emotions were tallied. However, while the appearance of social and medical models was tallied by text and pictures, negative emotions were only tallied if indicated by the text. This was done to eliminate any subjective speculation about what emotion a picture represented. However, further qualitative analysis does intend to discuss the pictures. The assessment of negative emotion serves to help further evaluate whether the “illness experience” is upheld in the literature. While there is an endless list of possible negative emotions, given the intended audience, it is assumed that most negative emotions cited will fall somewhere under the following three basic emotions, as established by Paul Ekman:

- Sadness
- Anger
- Fear

Additionally, the assessment of negative emotion in the literature will be compared to the overall tone of the book to better assess what role emotion plays or does not play in the literature.

**Preliminary Findings**

Based on the medical and social data generated from assessing the twenty books, the medical model of illness is addressed, on average, over twice as often as the social model of illness (Appendix D). Out of the twenty books, the social model occurred more often in only three books, and only by a small margin. Two books saw percentages within 6-7 points of each other. In one book, the social model did not appear at all. The
remaining 14 books saw significant difference between medical and social occurrence. The number of picture counts to text counts for both the medical and social models did not always match up, meaning that pictures did not always exist to support the text (Appendices B and C). Throughout the twenty books, negative emotions were mentioned 39 times, or less than 2 times per book (Appendix E). The ending of all twenty books was positive and the overall tone for all of the books was positive. Taken together, these findings suggest the tendency of this literature to focus on the medicalization of illness, rather than on socialization of illness. The low number of negative emotions cited suggests that the literature is either more neutral or positive in nature, though the presence of hopeful endings in each book suggests an overall slant towards the positive. This is comparable to Drennon’s findings where very few ill characters demonstrated prevailing negative behaviors and they tended towards perseverance. The books that saw a greater representation of social issues to medical issues, as well as those within 6-7 points of each other were those that tended to be more story driven, rather than illness driven. It is perhaps important to keep in mind that even qualitative data can, at times, be subjective. For this reason, the following qualitative assessment attempts to further flesh out literary details.

A few commonalities emerged throughout the books. Eleven out of twenty books, for example, were stories about characters being diagnosed with an illness. Seventeen books featured parents in either an active or passive role. Fourteen were from the third-person perspective and six were from the first person perspective. Several of the books were written by either a medical professional, parent of an ill child, or person

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with a chronic illness. Thirteen books included additional information on the illness such as glossaries, additional resources, precautionary measures, notes to parents, and so on. Eight out of twenty books acknowledged the reality of both good and bad days with a chronic illness. Seven books had an underlying “listen to your doctor” theme. Twelve featured the main character being active in the management of their illness, while the remaining eight were either managed by a parent or not seen doing either. Six books had characters that feared losing friends because of their illness and four featured characters concerned about how their disease would prevent them from doing the things they enjoyed. Two books discussed the illness as a secret to be kept. Female main characters represented 14 of the books and males represented the remaining six. Based on prescribed reading levels, these books targeted ages three through twelve years, with the greatest focus falling primarily on 5-9 year olds. These topics will be considered in greater detail in the next section. These characteristics and themes are important to keep in mind as the books are analyzed, because they contribute to the overall presentation of illness.

Detailed Analysis (by illness category)

Asthma

Asthma is the most common childhood chronic illness. According to CDC statistics from 2010, asthma affects 7 million people under the age of 17. Asthma has increased in prevalence from 3.1% in 1980 to 8.4% in 2010. Asthma affects the lungs and is triggered by attacks that cause breathing difficulties and inflamed airways. Certain

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triggers for asthma can include allergies, colds, exercise, cigarette smoke, pollen, pet dander, molds, viral infections and emotional stress. The cause of asthma is currently unknown and there is no cure. However, asthma can be successfully managed for the most part.

In *Abby’s Asthma and the Big Race*\(^\text{76}\), Abby’s main goal for the year is to win the big race at the fair. Abby shares this goal with her class, and the response is doubt. A couple of the children express disbelief that Abby can win the race because she has asthma and are seen whispering to one another in pictures. “But doesn’t she have asthma?” asked Hari. “How can she win the race?” The stigma that is attached to asthma is apparent here. Someone with asthma can’t possibly win a race! However, as the *Asthma and Exercise* note at the back of the book tells readers, asthma does not limit physical activity, with some exceptions. This is a social misconception that the book sets about to disprove. The whole book centers on Abby working towards her goal. She practices running outside and at the gym with her father to build up her speed. Abby, however, encounters several setbacks on her way to achieving her goal. Several times she has signs of an asthma attack and has to discontinue her exercise, but she never gives up. This is true despite the fact that several adult figures throughout the book suggest she try the pie eating contest instead. These characters, her father, her teacher, and the school nurse are all juxtaposed against her pediatrician who encourages her to run in the race, but still reminds her to take her medicine and warm up before running. “Go for it Abby! Just remember to keep taking your medicine every day and to warm up before the race.”

This juxtaposition highlights doctors as the authority figure on illness and rejects a social belief presented here that someone with asthma cannot participate in physical activity the

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same as someone without asthma. Thus, while the book gives a lot of medical representations of asthma throughout the book, the overall goal of this book is to challenge a societal belief about asthma, making this book largely social in nature, despite its low percentage of social representation.

Brianna in *Brianna Breathes Easy*\(^7\) is similarly attempting to accomplish something. Having gotten the lead in the school’s Thanksgiving play, Brianna wants to do her absolute best. Like Abby, Brianna faces several setbacks in attempting to achieve her goal. She has a severe coughing attack that prevents her from breathing properly and is sent to the hospital where she is diagnosed with asthma. The book is narrative, so the main focus is on how Brianna is able to achieve her goal despite setbacks, much like Abby. Still, the book gives a detailed picture of asthma’s symptoms, treatments, and causes. The main social component of the story comes from the response Brianna’s asthma receives. During her worst attack, Brianna is depicted on stage with her peers but separate from them as they look on her attack with disbelief and fear. This depiction clearly differentiates Brianna from her peers, though it is not stated in the text. A notable part of this book is the inclusion of two other kids with asthma. Two kids in Brianna’s class also have asthma, and the three of them bond over their asthma colors. “Brianna and Yasmin were on the same kind of medicine and had the same type of inhaler.” Instead of looking at how Brianna’s healthy classmates respond to her asthma, the author chose to include others like her. By doing so, the author does not attempt to normalize Brianna by further setting her against her well peers. Rather the author normalizes illness against illness standards by presenting more kids with asthma.

The main child character in *I Have Asthma* also gets diagnosed during the course of the book. Unlike Abby and Brianna, a huge factor in this story is fear of peer rejection. As discussed early, peers play an important role in a child’s life during childhood. While playing soccer with his teammates, the main character suddenly can’t catch his breath and is taken to the hospital, like Brianna. While having his attack, his teammates are shown in pictures standing apart from him and are looking on unsure of what to do. His parents rush him to the hospital and discover he has asthma. The doctor explains asthma to the child and gives him medicine to help control it. After leaving the hospital, the child’s parents take him back to the soccer field, assuming he will want to see his friends. However, he is worried that if his friends find out about his illness “they wouldn’t want to be friends with [him] anymore.” The positive reception the child receives from his teammates makes him temporarily forget that he has asthma. “I was just like other kids again.” The author makes clear the difference between the main character and healthy children by doing so. The author further distinguishes between the two groups when, similarly to *Brianna Breathes Easy*, she uses the presence of another child with the same illness to normalize illness. Still scared about how his friends will feel about his asthma, a highly perceptive teammate shares his asthma diagnosis with the main character. This sharing of “secret” information occurs in pictures while the two children with asthma are seen huddling far away from their same age teammates who seem to be completely oblivious to the information being exchanged. The main character’s response is surprise. “How could the fastest runner on our team have asthma?” Here we see the character’s own preconceptions that asthma limits a person’s physical activity. His teammate challenges this belief. As a final note of separation, the

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main character never does share his secret with his teammates during the duration of the book. This creates an us-versus-them mentality and does very little to show readers positive ways to either share or receive sensitive information about a child’s chronic illness. Of the four asthma books, *I Have Asthma* is the only one to have comparable medical and social model percentages. While the social components of this book are clear, one wonders if the social message being delivered is the best for children.

Unlike the other three, *Peter, the Knight with Asthma*\(^79\), is a story of diagnosis that occurs largely in isolation. No other peers or adults are seen outside of Peter’s mother, doctor, and a nurse. Peter’s story is fairly cut and dry. In the process of role playing fighting dragons, Peter has a coughing and wheezing fit. In response his mother decides to take him to the doctor where Peter is finally diagnosed with asthma. The doctor tells Peter about asthma and gives him medicines to “tame the beast.” On the next page Peter is shown in the picture using a nebulizer while a nurse gives him instructions for his health. “She says if I use the nebulizer every day, my lungs will get stronger – which means more time chasing dragons and less time reaching for Puffy.” Afterwards, Peter is seen fighting dragons again. This book included no social model elements and discusses asthma only in terms of the medical model. This book also does not include any easily identifiable emotions for Peter. Thus this book seems to suggest that asthma is merely an inconvenience that can be controlled by medication.

Taken together, these books paint a picture of how asthma is viewed by larger society. Given that asthma is the most common childhood chronic illness and is largely able to be controlled, asthma is viewed mainly in relation to how it disrupts a child’s physical activity, rather than the child’s larger place in society. In each of the books, an

asthma attack disrupts a physical activity the child is participating: soccer, running, jumping on stage, and fighting dragons. The children in each of the books are shown in pictures coughing, grabbing their chest, gasping for air, and wide-eyed. Adult characters in all of the books respond to the attacks with worry and concern and are seen taking the child away from the physical activity that has caused the attack. The emotions of the children in these books are overwhelmingly positive, with the representative negative emotions being fear and sadness. In two out of three of these cases, the negative emotion occurs in response to a physical manifestation of their illness, hence, reinforcing the medicalization of the illness. In one case, negative emotions occur in response to a fear of social rejection, reinforcing a social model of illness. At the end of each book, however, the outcome is positive, as all children are able to return to their original goals and activities.

**Cancer**

In 2011, the most common cancers diagnosed in children between 0-19 years were leukemia and brain and central nervous system cancers. The highest rate of incidence for both types was found among children between 1-4 years but the highest death rate for either occurred in older kids. As is noted here, cancer is a general term used to describe a group of diseases characterized by the uncontrolled growth and spread of abnormal cells in the body. There is no one cause of cancer and it is thought to occur both from internal and external factors. According to the United States Cancer Statistics for 2005, each year approximately 13,000 children and youth under the age of 20 years

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are diagnosed with cancer in the U.S.\textsuperscript{81} Cancer can now be considered a chronic illness given the increased survival rates. Five year survival estimates for childhood cancer survivors have increased from 59\% in 1975 to 80\% in 2002.\textsuperscript{82}

In \textit{The Great Katie Kate Tackles Questions About Cancer}\textsuperscript{83}, Suzy is sent to a special doctor to talk about a cancerous lump her pediatrician discovered. Her immediate emotion is worry as she thinks “what’s going to happen to me?” While the doctor takes Suzy’s concerned and clearly worried parents to fill out paperwork, the Great Katie Kate takes Suzy around the hospital to learn more about cancer. Thus, the book is largely informative in its attempts to dispel Suzy’s and other readers’ fears about cancer. Katie Kate tells Suzy about the ways doctors find and assess cancer, the possibility of surgery and hospital visits, and the possible treatments for cancer such as chemotherapy and radiation therapy. In the process, Suzy meets other children with cancer. All of the children in the book appear happy and unconcerned about their cancer. They are shown in pictures smiling, despite having just had surgery, chemotherapy, radiation therapy, and so on. Suzy, too, appears happy by the end of the book, though her original emotional state was one of fear and concern. With a big smile, Suzy says “Thanks Katie Kate. I won’t worry anymore.” Suzy’s change in emotion throughout the book is shown through the use of the Worry Wombat, a critter that is present when a child is worried but that shrinks and eventually disappears as a child becomes less worried. Pictures of the Worry Wombat becoming smaller and smaller mirror and exemplify Suzy’s shrinking fears.


\textsuperscript{83} DeLand, M.M. (2010). \textit{The great Katie Kate tackles questions about cancer}. Austin, TX: Greenleaf Book Group Press.
about having cancer. Suzy’s change in emotion also comes in response to the knowledge Katie Kate provides about cancer. For example, after Katie Kate tells Suzy about how radiation therapy helps the chemotherapy medicines make cancer go away, Suzy says “I am not worried about radiation therapy.” This suggests that the more medical information a child knows, the more accepting they are of their diagnosis. Much like two of the previously mentioned asthma books, this book uses the appearance of other similarly ill children as a means of normalizing illness and providing social inclusion for the main ill character. All of the other children that appear in pictures throughout the book are shown in the hospital setting and are seen going through routine cancer treatments. Still, this social inclusion comes in response to only those children in similar circumstances and does not consider how larger society such as peers and family will react to Suzy’s cancer. Thus, the book focuses largely on the medical model and does not portray realistic social elements.

_Taking Cancer to School_\(^{84}\) is also largely informative in nature. This book is part of series of books published for kids with various special needs and illnesses. As the title suggests, the main focus of this book is discussing cancer at school, thus introducing other kids to the illness. The main character, Max, is going to receive chemotherapy soon and is telling readers about his leukemia and what chemotherapy will do to his body. Though the book serves as an informative resource for healthy school kids it also intends to promote social inclusion of ill children. As the main character points out, “don’t treat me any differently just because I have cancer…I’m a lot like you in every other way.” In tandem with these words, Max is dressed in a baseball uniform and is on the baseball field, suggesting that he can participate in sports like other healthy children. These and

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other similar instructions to readers model the appropriate behavior for how a person should react to and treat a person with cancer. These subtle instructions are given from Max’s personal vantage point of what being treated differently feels like. His request that others “please don’t make fun of me if I lose my hair” indicates to readers that such behavior is inappropriate, for example. Max is seen in the book having friends that include and support him. One classmate, for example, asks if she can visit Max in the hospital. Consequently, social inclusion is another main focus of the book. Notably, this book also features the presence of another child with cancer that Max befriends. Finally, Max only mentions and depicts a negative emotion one time throughout the course of his story. This emotion is “scared.” In its picture, Max is shown sitting in his mother’s lap and frowning, a departure from his usually smiling face. For the rest of the book, Max is depicted as happy and hopeful, and he is always smiling. His assertion at the end of the book that he will be trying out for the baseball team ends the books on a positive, hopeful note, because it suggests to readers that he will be physically able to participate, despite the effects of chemotherapy.

*The Lemonade Club*85 is more narrative in format largely because its intention is to tell a fictionalized version of events that occurred in real life. The book features three main characters, one of which becomes diagnosed with leukemia during the course of the story. The events of the story occur largely at home and in the school, allowing both the personal and social aspects of struggling with cancer to be explored. Marilyn, the child with leukemia, has both good and bad days with cancer. Her best friend, Traci, is pictured walking in on Marilyn brushing her hair one day after her chemotherapy sessions have begun. An upset Marilyn is shown trying to put the hair she has lost back

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on her head while Traci watches, concerned. “My hair…it’s falling out! I even made a
wish on a star last night that I wouldn’t lose my hair!” Traci and their teacher provide
positive forces for Marilyn as she struggles with her cancer. Their presence in the book
suggests the importance of having a strong network of people, possibly friends and
family, which an ill person can talk to about their illness. The initial response of
Marilyn’s classmates to her diagnosis is sadness and tearful. “Everyone in that room
knew that this was something very serious.” The children are pictured sitting around or
at the foot of their teacher. Some children are shown covering their eyes or mouths and
others are shown bowing their heads. One of the children even notes that people die from
cancer. “But Miss Wichelman, people die when they get cancer, don’t they?” The class’
reaction to Marilyn’s diagnosis suggests the serious stigma attached to cancer. Unlike a
largely manageable asthma, cancer is often associated with death, making its diagnosis
much more acute. The difference in significance of illness between asthma and cancer,
however, does not seem to greatly change the representation of the medical to social
model. However, of the three books featuring cancer, *The Lemonade Club* does have the
most balanced representation of medical and social representation.

A common theme that does seem to occur in these books is the presence of other
ill characters. Their appearance is used by main characters in the book as a means of
adjusting to their own illness. In *The Great Katie Kate Tackles Cancer*, for example,
Suzy becomes less and less worried by watching other children go through the things that
Katie Kate tells her about cancer. In *Taking Cancer to School*, Max makes a new friend,
Jeremy, who has brain cancer and gets radiation treatments. As Max points out,
“Jeremy’s hair is already gone! He said it’s no big deal, though. I think it looks kind of
cool!” Max’s adjustment to losing his hair is positive in response to Jeremy’s positive attitude. Finally, Miss Wichelman, Marilyn’s and Traci’s teacher also is going through cancer. In *The Lemonade Club*, Marilyn’s diagnosis is revealed before Miss Wichelman’s diagnosis. Upon finding out about her teacher’s breast cancer, Marilyn uses her own cancer experiences to encourage Miss Wichelman to fight it. The presence of another ill character in each of these books serves to show ill readers that they are not alone and that other people are facing the same illness. Unfortunately, the reality is that chronically ill children may not always have the presence of other “like individuals” to normalize themselves against.

**Congenital Heart Defect (CHD)**

Congenital heart defects exist at birth and occur when the heart or blood vessels don’t develop normally before a baby is born. There are several different types of congenital heart defects including holes in the heart, obstructed blood flow, abnormal blood vessels, and heart valve abnormalities. Congenital Heart Defects (CHDs) are the most common birth defect in America, affecting approximately one in one hundred, or 40,000 newborns each year. CHDs are responsible for one third of all birth defect-related deaths and twenty percent of children who make it through birth will not survive past their first birthday.

In *Riley’s Heart Machine*, Riley has a secret that she does not want anyone to know. This secret is that she has a pacemaker for her heart defect. Riley worries that her friends will not like her anymore if she shares her secret. “She worried if she told the

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other kids, they would laugh at her. She worried if she told her friends she was different, they might not like her anymore.” In the accompanying picture, Riley is wearing a black trench coat, hat, and sunglasses, and she is clinging to a briefcase that reads ‘Top Secret!!.’ Here we see that Riley is assuming that others will perceive her as different because she perceives her own self as different. When Riley finally tells her secret, her classmates are very accepting and, even more, they are extremely interested in learning about her illness. Their enthusiasm for the subject is seen in their hand raises during show and tell, as seen in pictures, and the quick fire of questions they aim at Riley. “No one laughed, they only clapped and clapped.” In the final picture of the book, Riley is seen in a group huddle with a few other friends, all of whom are smiling. This suggests a happy ending for Riley who has finally achieved the social inclusion she worried she would not receive if her condition were shared.

The positive reception of Riley’s secret shows a theme of social inclusion. Despite her fears of rejection, Riley’s classmates applaud her for sharing. This seems to present a two-fold message to both ill and healthy readers. One message is that sharing illness information with others is good and will be well-received. The other message is that readers can learn very interesting things from people that have different experiences. Overall, Riley’s Heart Machine is fairly representative of medical components, social components, and emotional responses.

**Crohn’s Disease**

Crohn’s Disease is a type of inflammatory bowel disease (IBD) and affects the gastrointestinal tract. Crohn’s is similar to ulcerative colitis, another type of IBD, but they affect different parts of the gastrointestinal tract. Crohn’s most commonly affects
the end of the small bowel and the beginning of the colon, but it may affect any part of the gastrointestinal (GI) tract, from the mouth to the anus. Ulcerative colitis is limited to the colon, also called the large intestine. According to the Crohn’s and Colitis Foundation, ten percent or 140,000 of an estimated 1.4 million Americans who suffer from IBD are under the age of eighteen. The cause of Crohn’s is currently unknown and the symptoms can range from mild to severe and, at times, life threatening.

*Toilet Paper Flowers* is one of the three books that averaged a higher percentage of social representation than medical representation. This is probably due to the fact that the author, a licensed psychologist that specializes in working with chronically ill children and adolescents, says he tries to promote a “realistic attitude” or “fighting attitude” toward the illness, rather than simply a positive attitude. “Children need to learn to integrate all feelings in order for them to grow and change as people…[The] fighting attitude teaches children that there will be both good and bad days of living with their illness and to find out as much information as they can.” This message from the author encompasses the whole of his book. Julia has a new friend, Nikki, coming to her house. Throughout their interactions, Nikki begins to notice differences between herself and Julia and asks Julia to explain them. The majority of the book is then spent having Julia both textually and pictorially explaining Crohn’s to Nikki.

Nikki listens intently to Julia’s explanations and repeatedly asks follow-up questions. This is seen as the girls are depicted lounging on Julia’s bed talking for the majority of the book. Nikki’s attentiveness suggest social acceptance of Julia. Rather

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than judge Julia for having Crohn’s or making fun of her for her repeated trips to the
bathroom, Nikki expresses concern for and camaraderie with Julia. This is best seen and
expressed in the exchanges between the girls toward the end of the book. In response to
Julia’s assertion that she will “fight this disease” and “always have hope,” Nikki gives
her a high five. A few pages later, Nikki tells Julia she is “smart and brave” and gives
her a hug. On the final two pages, Julia gives Nikki a toilet paper flower, her symbol for
hope, because Nikki wants to “have hope with [Julia].” The two are pictured walking out
of Julia’s room, with arms around one another and with white toilet paper flowers behind
their ears. This ending is positive and shows Julia’s social inclusion with her healthy
friend Nikki.

Thus, this book obviously promotes social inclusion of the chronically ill. Nikki
represents that inclusion. Julia represents the medical model most frequently in her
attempts to inform Nikki about her illness. In response to Nikki’s enthusiastic statement
that Julia knows a lot about her illness, Julia puts forth the idea that knowledge is power.
“Knowing and learning about my disease helps me feel more in control of it.” Julia also
tells Nikki that talking with friends and family helps her manage her emotions. Thus, the
book is not only encouraging the sharing of illness information as a form of social
inclusion but also as a coping mechanism for ill children.

Julia does share that she is not always in a good mood. Sometimes she feels sad,
mad, scared, and confused and other times happy. The acknowledgment of good and bad
days and the subsequent range of emotions those days illicit are important. It introduces
a more realistic and balanced representation of emotions that not all of the books include.

A final notable scene in this book comes from the following statement from Nikki:
“When I met you at school, I would have never known you had Crohn’s disease.” In the picture Julia is standing in front of a mirror with Nikki waving in the background. This further emphasizes that Crohn’s is not an illness that you notice in a person’s physical appearance. The large bulk of illnesses considered here are non-visible illnesses. Health and disability research has cited this as a social issue because it affects the way a member of society perceives or does not perceive the seriousness of a chronic illness. “People who are chronically ill with [non-visible illnesses] are likely to have trouble getting recognition of their illness – if not by the medical profession, then by friends, relatives, acquaintance, employers, insurers, and others who believe that they should have recovered from their [illnesses] long ago.”  

This, much like the stigma in the aforementioned books featuring cancer that cancer patients are likely to die, exists in the minds of healthy individuals and creates doubt about the seriousness of an illness. Such a mentality can be harmful to chronically ill persons throughout their lives. The author attempts to counter this by having Nikki point it out.

**Diabetes**

Diabetes is a disorder in which the body is unable to properly convert food into energy or control its production of glucose. The result is a deficiency of insulin, a hormone that helps the body metabolize carbohydrates. There are two types of diabetes: insulin dependent and non-insulin dependent. Though we now know that adults can get type 1 diabetes as well, it is commonly known as juvenile diabetes. “Type 1 diabetes is one of the most common severe chronic childhood illnesses, affecting 1 in every 400 individuals under the age of 20, and recent research suggests that the incidence is

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rising.” A diagnosis with diabetes leads to a lifelong monitoring of blood glucose levels, administering insulin, dietary and exercise restrictions, and with the likelihood of significant physical complications.

Of the four books featuring characters with diabetes, *Lara Takes Charge* had the lowest percentage of medical and social representation. This is possibly due to the fact that the book seems to be geared towards younger preschool and early elementary children, unlike the large bulk of books considered in this analysis. The book is presented from Lara’s perspective as she tells readers what she can do. After listing a series of things she can do like running, swimming, playing, and thinking, Lara tells readers that there is one thing she does that most kids don’t have to do. “That is, I watch my blood sugar. I have diabetes.” In the accompanying picture Lara is seen standing on the outside of a group of children. This picture reinforces difference. The book begins and ends with Lara’s assertion that she is a “normal kid.” This juxtaposes those kids with diabetes against those without an illness, setting well children as the standard for normal. Diabetes is then simplified to being a process of blood checks and insulin management, thus resulting in its medicalization. A fault of the book that should be pointed out occurs in the following sentence: “because I take care of myself, I will always be able to do anything I want.” The word ‘anything’ is presented in exactly the same manner in the book, being emphasized by being underlined. There will be cases where this is not necessarily true. The real flaw occurs in the implication that’s Lara’s ability to do anything is dependent upon whether she takes care of herself. This statement fails to

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acknowledge those times Lara’s health will be compromised due to no fault of her own and lays all of the responsibility on the child. This has the potential to lead to damaging psychological and emotional consequences for a chronically ill child, especially considering the uncontrollable nature of chronic illnesses. Beyond the inclusion of “normality,” the book does not consider the social consequences of having diabetes. Lara holds a positive attitude throughout the book and only acknowledges negative emotions once when she explains that sometimes she gets frustrated and mad. At the book’s ending, Lara reinforces that she is a normal kid. “Yes, I am normal as normal can be. I love being me.” This ending is positive and suggests that Lara is not limited by her diabetes.

*Life with Diabetes*[^1], unlike *Lara Takes Charge*, promotes an overall theme of “diabetes does not have to limit you” while introducing the possibility of complications from diabetes. Thus, it provides hope while still tempering it with realism. This book also does a better job at considering a social perspective of diabetes. Lacie the Lizard is the main ill character in this story. Lacie’s goal in the book is to make friends with three other lizards, and her first action in the book is to ask these lizards if she can play with them. Here readers begin to see a social response of the lizards to Lacie’s diabetes. After telling Lacie she can play with them, Larry is pictured pointing at the “funny looking computer” on Lacie’s belt, and he says “but, umm, what is that?” At this point, Larry is acknowledging the difference between himself and Lacie. The phrasing of his question suggests that he is weighing whether or not this difference will change his answer about whether Lacie can play with them. Throughout the book we see the other lizards’ perception that diabetes limits a person and keeps them from doing the same things as

someone without diabetes. The lizards question whether Lacie can participate in running and swimming if she has diabetes. “Just because I have diabetes doesn’t mean that I can’t run or play. I can do everything you can do.” By the end of the book, Lacie has convinced the group that she is just like them. “We want you to know that when we first met you, we thought you were different because of the diabetes. But now we know that you are just like us and can do so many things even better than us.” Not only has Lacie proven that she can do the same things as the other lizards, despite her diabetes, she has also earned their respect by proving that she can do a lot of things even better than they can. Lacie remains a positive model for readers throughout the book, and she demonstrates the importance of sharing information about your illness with others. The only time Lacie begins to doubt herself occurs at the end of the book. After a nap, Lacie wakes up to find that her new friends are gone. She worries that they have left because they thought she was different and she becomes sad. While several of the books in this analysis show characters worrying about how their illness will affect their friendships, few of these books have the friends acknowledge their perceived difference. When the lizards tell Lacie that they did think she was different because of her diabetes, Lacie’s worries find value. However, after spending the day with Lacie, they decide she is not different at all. At the end of the book, all four of the lizards, Lacie included, are pictured standing together in a group, smiling. Thus, this book promotes social inclusion and ends on a positive note.

Unlike any of the other books in the set, *Sillwee Wobbert, Diabetes and Jose at School and Play* is told in rhyme. Similar to several of the other books in this analysis,

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this book focuses on giving readers medical information with the overall intention of the book being to promote coping for and social inclusion of kids with chronic illnesses. Sillwee Wobbert’s friend Jose has diabetes. Jose explains to Wobbert that he takes insulin and eats regular snacks to help manage his diabetes. Similar to Lacie in *Life with Diabetes*, we see the assertion that diabetes does not limit Jose. After explaining to Wobbert how he manages his illness, Jose challenges Wobbert to race him. “Now I eat better as you can see. I bet I’m even faster than you so you can’t catch me.” Later on in the day, Wobbert, Jose and their fellow classmates go outside to play baseball. This time readers see what happens when Jose’s blood sugar falls too low. “His vision began to blur; he started to shake.” In the accompanying picture, the back of Jose’s head is shown as he faces his friends whom all appear blurry. Sweat is seen rolling down his neck. In response to this, Jose’s classmates crowd around him with concern and ask what they can do. They send for the school nurse who gives Jose juice and a healthy snack, which makes Jose feel better. The nurse and, eventually, Jose’s parents take the primary role in explaining diabetes to Jose’s classmates in the book. This establishes adults as the experts on a child’s illness rather than the child. This is a deviation from most of the books in this analysis that feature the child being knowledgeable of and managing their own illness. However, the sharing of information to other, well children reinforces the idea that this sharing of information about a child’s illness will promote greater social inclusion of ill children. This seems to be the case for Jose who is applauded by his friends at the end of the book for just being himself. “Hooray for Jose! We’re all special in our own special way!” In a picture, Jose is shown being thrown into the air by his friends, and all of the children are smiling. Thus, Jose’s story ends positively with his
acceptance and social inclusion by peers. Jose’s emotional response to having diabetes, however, is never mentioned in the book. Rather, his diabetes is simplified to its physical effects on his life.

Unlike any of the other books in this study, Why Am I So Tired?\(^{98}\) features a child character that has the primary role of exemplifying what the narrator gives to readers in the text. The narrator of the book speaks directly to the reader and uses the images of the child to emphasis the speaker’s points or statements. For example, the author tells readers that “diabetes can make you feel very tired, shaky, and thirsty. It can also make you feel like you want to urinate all the time.” The female child depicted throughout the book is seen here holding her lower half as though she has to go to the bathroom. In another frame on the same page the child character is seen drinking water. It is unclear to readers whether the voice is male or female, adult or child. Still, the narrator, rather than the main child character, is seen as the main expert on diabetes. The narrator tells readers what it means to have diabetes and how children with diabetes must manage their illness. The narrator empathizes with the reader throughout the book, acting as both a friend and an authoritative voice. For example, the narrator recognizes the difficulty the reader might have with eating healthy when everyone around them is snacking on sweets and treats. The narrator also points out how readers may feel different from other children because of their diabetes but proposes that there may be other children in the school or neighborhood that also have it. Given that the narrator’s voice in this book takes the place of the voice of the chronically ill child, the book is not about telling a story. Rather, it’s about instructing readers, theoretically children with diabetes, about the medical, social, and emotional realities of having diabetes. Similar to the other three

diabetes books, this book emphasizes the importance of sharing information about an illness and your feelings with others. The books ends on a positive and hopeful note. The reader is told “Once you learn to [take care of yourself], you’ll find you can do all the same things other children do and have just as much fun.” The main character is pictured participating in physical activities outside with her friends. This reinforces the author’s message that diabetes does not limit you.

All of the books considered in this section focus on the effect diabetes has on a child’s ability to participate in physical activities with other children. This is similar to the previously discussed books featuring asthma. Perhaps this can be attributed back to disease significance. Diabetes has, like asthma, become a highly prevalent, yet still fairly manageable, chronic illness. Still, both illnesses involve a lifelong process of illness management including taking medicines, modifying physical activity, and the possibility of triggering illness activity by nutritional or environmental factors. Diabetes can also cause neurological complications over an extended period of time.99 The focus on the physical limitations caused by having diabetes is not fully representative of a child’s illness experience. Out of the four books considered here, the only one to point out how hard and frustrating this long-term management can be is Why Am I So Tired?. The other books seem to reduce diabetes management to the steps involved: taking insulin, eating healthy, monitoring blood sugar and so on. Additionally, two of the books here are intended to promote social inclusion and thus show characters being well received by their well peers.

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Epilepsy

Epilepsy is a disorder of the central nervous system in which the nerve activity in a person’s brain is disturbed. This causes seizures which manifest different ways in different people. Some people simply stare blankly while other experience repeated twitching of the arms and legs. “Epilepsy symptoms may appear frighteningly out of the blue, causing [an] individual not only to have to face a changed situation, but also the potentially stigmatizing reactions of others.”

Epilepsy can continue throughout a person’s life, but a child can also eventually grow out of his or her epilepsy. According to the Epilepsy Foundation, the incidence of epilepsy is higher in young children and older adults, and 48 out of 100,000 people develop epilepsy each year.

*The Great Katie Kate Explains Epilepsy* is the second book of this series that was included in this analysis. Similar to *The Great Katie Kate Tackles Questions About Cancer*, Katie Kate helps Jimmy learn about his epilepsy. As Jimmy learns more about epilepsy, he becomes less worried and shrinks the Worry Wombat. To help Jimmy learn about his illness Katie Kate shows Jimmy around the hospital and introduces him to other children with epilepsy. Thus, similar to its cancer counterpart, this book focuses on the transferal of medical information rather than social models of illness. The only form of social response considered in this book comes from children who all have epilepsy. Other children are seen in pictures telling Jimmy about their first epileptic seizures, each of which has a different experience. On one hand, the inclusion of other chronically ill characters has the potential to show readers there are other people experiencing this

illness. On the other hand, the focus on medical information and the social inclusion with similarly ill characters does not prepare readers for the stigmatizing reactions that epilepsy can elicit from others. This potential reaction is noted by Jimmy when he learns about the different kinds of seizures an epileptic can have. “I don’t want to have seizures. What if it happens at school? I’ll be so embarrassed.” Here Jimmy points out his own concerns that his epilepsy makes him different, and he predicts that this difference will be made obvious to others if he has a seizure at school. In response, Katie reassures Jimmy that there are lots of people with epilepsy, thus again normalizing the character against illness, rather than wellness, standards.

No adults are present as Jimmy learns about his illness, making him the agent in charge in the management of his epilepsy. The emotion readers witness Jimmy experience is worry. Mainly Jimmy is worried about what it means to have epilepsy, as he does not know anything about it at the beginning of the book. As Jimmy learns new information about epilepsy, this worry dissipates, thus promoting the theme that knowledge is power. Pictures showing the shrinking of the Worry Wombat further emphasize the point the more information means less worry. Overall, this book intends to educate readers about the medical realities of epilepsy and does little to acknowledge the effects that social model issues can have on someone with epilepsy. It further simplifies epilepsy to symptom management. This is best seen by assessing what Jimmy has learned by the end of the book. “I learned that if we take our medicine, get regular checkups, and get rest, we can do anything we want.” The dispelling of Jimmy’s fears and worries seems to suggest a positive and hopeful ending, as does his belief that he will still be able to do anything he wants.
In *Mommy, I Feel Funny*, Nel is diagnosed with epilepsy. Unlike the majority of books in this analysis, this book focuses on how Nel and her family process and learn about her epilepsy together. Nel’s parents and grandmother are her primary caregivers and they are seen managing most of the information about Nel’s epilepsy. This is important to the analysis because few of these books have considered the role parents play in a child’s illness or how the family is affected because of it. Nel’s family is both described and depicted as concerned and responsive to Nel’s epilepsy. They drop whatever they are doing to take care of Nel’s medical needs. For example, when Nel experiences a bad seizure, Nel’s mom is pictured rushing out of the house towards her. “She picked Nel up, put her in the car with her grandma, and drove her right to the doctor’s office.” Thus, while this book includes medical information about the symptoms, diagnosis, and treatments of epilepsy, the changing of family functioning in relation to a Nel’s illness is a social model issue.

Despite Nel’s diagnosis with epilepsy, Nel and her family are all depicted throughout the book with smiles on their faces. The exception to this is found at the beginning of the book when Nel sense’s a big, scary monster behind her. Nel becomes frightened and begins to cry. This is then shown in the picture as Nel runs away from the monster crying. Her mom and grandma are seen coming out of the house with worried expressions on their faces. However, throughout the rest of the book, Nel and her family are seen smiling even during their time at the hospital and in the doctor’s office when they are still not sure what is wrong with Nel. One could assume that the positivity that is portrayed through the pictures is intended to translate to the overall tone of the story, which is optimistic. In the last two frames of the book, Nel asks her doctor if she can still

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do all the things she likes to do including swinging, riding her bike, and playing with her friends. The doctor tells her she can as long as she takes her medicine and Nel is seen swinging in the backyard with her friends on the last page, “pumping and pushing herself higher than ever before!” Again we again see illness simplified to a matter of disease management through the use of medication. Thus, the overall tone of the book and its ending are positive.

Karen’s Epilepsy is the second book in this analysis that had a higher percentage of social model to medical model issues. In fact, this book included medical model information on only 2 out of 20 pages, or a mere 10% of the book. The large focus of the book is placed on Karen’s social inclusion, or lack thereof, in her new school. When Karen finds out that her dad has gotten a new job and her family will be moving, she begins to worry about how kids at her new school will treat her and her epilepsy. Karen’s fears are pictured in a thought bubble where a couple of kids are seen pointing and laughing at her. Thus, Karen imagines that her new classmates will not accept her. On her first day at her new school, Karen has a seizure during class. Despite her teacher’s explanations to the class that a seizure was “normal” for Karen, “the children treated her differently.” Several of the books in this analysis focus on promoting social inclusion for chronically ill children and/or have considered how a chronically ill character feels about being “different” from their peers. Yet, none of these books have shown a chronically ill main child character being ostracized by their peers or teased for their illness. This occurs in Karen’s Epilepsy. After having a seizure in class, nobody would eat with Karen at lunch, nobody would play with her at recess, and several of the

104 Baltaro, E. (2010). Karen’s epilepsy. Omaha, NE: WriteLife, LLC.
boys from her class pretended to have seizures. “They walked around her and made silly noises and spit on the ground.”

*Karen’s Epilepsy* also explores a wider range of negative emotions than any of the other books in this analysis have. Throughout the book, Karen is described as being scared, angry, or sad, and she is pictured crying, yelling, and frowning. These emotions come in direct response to her struggles of social inclusion with her peers. This greater inclusion of both social issues and negative emotional responses seems to suggest a more balanced portrayal of the illness experience. However, in order for this picture book to remain hopeful, there has to be a hopeful ending. By the end of the book, Karen has finally been included by her peers and has additionally gained their respect. She is shown in the pictures of the final pages surrounded by her classmates as she explains epilepsy and seizures. Karen achieved this inclusion by knowing exactly how to respond when their teacher had a seizure and fell to the floor. As similarly seen in several other books considered in this analysis, Karen’s epilepsy is normalized in response to another ill character. This approach to the normalization of illness seems to suggest that chronic illness is normal because other people experience it too. It is notable that her peers accept Karen only after they see another person have a seizure.

All three of the books considering epilepsy approach the story a different way. *The Great Katie Kate Explains Epilepsy* occurs in a hospital setting where all of the characters introduced to the main character also have epilepsy. Nel’s story occurs mainly within the home and at the hospital, involving only family and medical personnel. *Karen’s Epilepsy* focuses on how Karen’s classmates respond to her epilepsy. Despite their differing approaches, all three books point to seizures as the primary factor that
differentiates a person with epilepsy. Jimmy fears that having a seizure at school would be embarrassing. Nel worries that having seizures may limit her physical activities. Karen, like Jimmy, worries that people will make fun of her seizures. Karen’s Epilepsy, is the only book of the three that shows how other people, beyond the main character, perceive epilepsy. As mentioned previously, the sudden appearance of epilepsy symptoms can cause stigmatizing reactions from others. When their teacher has a seizure, “many of the children were afraid, and they didn’t know what to do.” Another child yelled out, “Don’t touch her. She might be contagious!” In the book the children are shown standing apart from their teacher with surprised and confused expressions. The appearance of seizures in epilepsy carries significance that asthma or diabetes do not have. While asthma and diabetes are stereotyped as limiting a child’s physical activities, epileptic seizures are often viewed with fear as most people do not know how to respond.

**Juvenile Rheumatoid Arthritis**

Juvenile Rheumatoid Arthritis (JRA) is the most common type of arthritis in children. The cause is unknown, but it is thought to be an autoimmune disorder. In autoimmune disorders, the immune system becomes confused and attacks healthy tissue by mistake. Most cases of JRA develop before the age of 16, but they can occur as young as six months old. JRA can cause a wide range of symptoms including red, swollen, painful joints, limited mobility, rash, and eye pain. Due to the fact that there are a number of different types of arthritis conditions that affect children, there is no definite estimate for how many children are affected by childhood arthritis.105 JRA can behave like recurring acute illnesses, with periods of debility and normal health or it can have

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constant and ongoing symptoms and be characterized by recurring acute episodes that result in permanent loss of function.\textsuperscript{106}

*Taking Arthritis to School\textsuperscript{107},* though written by a different author, is part of the same special kids series as *Taking Cancer to School*. Thus, the book is similarly driven by the provision of medical model information with the overall goal of the book being to promote social inclusion among healthy children. Eric, the main character, has JRA. Throughout the book he tells readers about the various ways having JRA affects his life. For example, Eric spends a lot of time soaking in the tub to make his joints feel better and works with a physical therapist in the water to stretch his joints out. Though its subsequent picture in the book does not include other children, Eric does mention that he does these exercises at a pool with other kids with arthritis. This points out to the reader that Eric is not alone in his condition and serves to normalize arthritis by their inclusion. Beyond affecting Eric physically, arthritis also disrupts his life socially. One of the greatest ways this is seen is when he is forced to miss school because his arthritis is bad. Eric laments the missing of school, because he hates to miss anything. “I do whatever it takes to get to school. Even if I have to limp or walk slowly, I don’t want to miss going to school and seeing my friends!” As the author notes, “sometimes kids with arthritis have unexpected problems.” Eric cites a time when he missed school for several weeks due to hip inflammation and subsequent hospitalization and surgery. He is pictured sitting in a wheelchair in his room with a smile on his face. Despite the severity of problem, his friends thought he was the “luckiest kid” for being able to miss school and receive lessons at home from his teacher. His friends focus on his tendency to miss


school due to JRA rather than to its medical severity takes away from the overall significance of Eric’s condition.

Still Eric’s friends are responsive to his condition which is notable. At school they help him carry his books and lunch tray. In an attempt to better explain his condition to others, Eric says he did a science project on arthritis to help the other kids at his school understand why he cannot always participate in activities the same way physically as his friends. “The kids learned that arthritis isn’t contagious. They can’t catch it from me, and it’s okay for them to play with me and be my friends.” In much the same way as *Taking Cancer to School*, *Taking Arthritis to School* exists primarily to promote social inclusion of chronically ill children among well children. As suggested by the title, this book is intended to be used with kids in a school, perhaps in the case where a chronically ill child is part of the class. Despite the presence of both good and bad days, Eric remains wholly positive about his condition. In fact, Eric says he wants to design things to help kids with arthritis when he grows up. His attitude about his illness is positive and he is always pictured in the book smiling, suggesting a hopeful tone for the book. Unlike Max in *Taking Cancer to School*, Eric never shares his emotions about his condition with readers. Mainly, he focuses on the medical realities of having JRA, including his tendency to miss school.

On the other hand, Jennifer experiences a wide range of emotions in response to her JRA in *Keeping a Secret*.108 This book is one of the three that saw more instances of the social model than the medical model. Jennifer, much like the children in the asthma books, has JRA disrupt her normal physical activity. While playing in a soccer game one day, Jennifer stumbles to the ground due to bad pain in her knee. Her teammates are seen

Jennifer’s diagnosis further prompts her to worry that she will not be able to play soccer anymore. Her worry is confirmed when her doctor tells her that soccer is an activity that is fairly hard on the joints and suggests she swim, walk or bike instead. Jennifer is next seen worrying about telling her classmates about her JRA. Pictured with her mother at a conference with Jennifer’s teacher, Jennifer is shown with her finger over her lips as she looks toward the partially open door where a few of her classmates are congregating. Instead of sharing her condition like her teacher suggests, Jennifer decides to keep her illness a secret from them because she fears how they will react. “They will think I’m weird or worse, like an old lady!” Again readers are presented with this misguided stereotype of arthritis. Over time, it becomes harder for Jennifer to hide her JRA from others and the worry her secret causes her is as stressful as the arthritis itself. “She felt sick to her stomach that she was not telling the truth to her friends. In a way,
keeping her secret was more painful than her arthritis.” By the end of the book, Jennifer decides to tell her friends her secret. They are seen crowding around her as pulls up her pant leg to show them the splint on her knee. Rather than turning away from Jennifer’s friendship, they all ask a few questions to learn more information and eventually reaffirm their friendship status. “Friends forever!”

Both the social and medical models of JRA are represented in this book. Jennifer learns what her limits are with JRA. This often means she cannot participate in the same physical activities that she did before. As a result, Jennifer is shown in pictures separating herself from her friends in order to keep her secret. Thus, the medical reality of JRA is seen in terms of how it can impact a child’s social development and opportunities to interact with other well peers. Jennifer’s negative emotional response to her new limitations and pains are also explored. Throughout the book, Jennifer experiences worry, surprise, fear, anger, frustration and sadness. For a child facing both the medical and social realities that Jennifer faces, this range of emotions is understandable and highly realistic. The balance of medical, social and emotional factors suggests that this book is highly representative of the “illness experience.” Though Jennifer does experience negative emotions, she is happy by the end of the book because she has shared her secret with friends. Even with these negative emotions, Jennifer remains determined and hopeful. “Even if I can’t play soccer or jump rope right now, there are tons of things I can do. And I’m going to find all of them!”

While Eric seems to act more as a model to showing well children how to respond to a person with JRA, Jennifer serves more as a model for ill children. Her inclusive medical and social struggles and the subsequent emotions she experiences give
chronically ill children the opportunity to see themselves in the story. As noted earlier, having characters to identify with can help children realize that just because they experience negative emotions, they are not bad people.

**Lupus**

Lupus is an autoimmune disorder, like JRA. Though there are several types, the most common is systemic lupus erythematosus. In a lupus patient, the immune system, which normally acts to attack foreign substances, becomes confused and causes it to attack healthy cells and tissue. This can cause damage to various parts of the body including the joints, skin, kidneys, heart, lungs, blood vessels, and the brain. Lupus is characterized by periods of disease activity and disease remission. Lupus flares, as the periods of activity are often called, can manifest in various ways including joint pain, fatigue, and the malar rash, a butterfly rash across that face. While lupus can affect anybody, it most commonly affects females.

In *Fly My Lupus Butterfly*, *Fly*[^109], the main ill character is a caterpillar. The illness experience is not explored in any great depth in this book and mainly follows the caterpillar through her diagnosis with lupus. Teah the caterpillar is a very active caterpillar that likes to sports with her friends. One day, she becomes very sick, too sick to play with her friends. Despite persistent symptoms her doctors cannot figure out what is wrong with her. It is not until her symptoms become severe enough to hospitalize her that the doctors discover Teah has lupus. Teah’s emotions are not explored and her recovery occurs with one turn of a page. She goes from being extremely sick in one picture to being all better and turned into a butterfly by the next morning. Her lupus is

limited to symptoms and medicine. “The doctors tell Teah, as long as she takes her medication and gets the proper rest, she was free to fly.” The ending gives Teah and readers and overly hopeful ending, oversimplifying lupus and boiling it down to being something that can be easily solved with medicine.

In reality, it can take several years to get better with lupus and a great deal of damage can happen to your body before that time. As suggested in the literature review section of this paper, it is not advised that children be given all the bleak facts about an illness with no possibility of hope. However, this book gives very little information about what lupus is actually like. Instead of considering joint pain, fatigue, or sun sensitivity, Teah is simply said to be “sick.” Instead of considering a reasonable amount of time over which Teah’s health improves, she gets better overnight. This is a highly damaging representation for both ill and healthy child readers. For ill children it can give the false impression that one can easily recover from lupus, as with a cold or stomach virus, resulting in damaging results when reality does not match the literature. For healthy children it can deny the significance of the illness and misinform their understanding of lupus. Neither of these possibilities is wanted in literature featuring chronically ill children.

**Renal Failure**

Kidney, or renal, failure occurs when the kidneys slow down or stop working properly filtering wastes from the body. This can cause buildups of waste products and toxic substances in the blood.¹¹⁰ Chronic kidney failure involves a deterioration of

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kidney function over time and can result from acute kidney failure, birth defects, chronic kidney diseases, or chronic severe high blood pressure. If the kidney function continues to deteriorate over time, a kidney transplant is often necessary.

In Now Caitlin Can, Caitlin suffers from kidney failure due to a birth defect. Although the medical model has a greater occurrence in the book, the family dynamic in response to Caitlin’s illness plays a large role in the book as well. This is notable given that most of the books in this study have not explored the family dynamic, especially the impact of illness on the family, in any great detail. This contributes to the overall realistic depiction of illness in this book. The majority of the events in the book occur at home and most of the action centers on Caitlin’s illness. Given that this book is based on real events and people, it stands to reason that the work should, in fact, be representative of the “illness experience.” Surprisingly, however, Caitlin’s emotions are never considered throughout the book, and she acknowledges the difference between herself and other children only twice. In one of these instances, Caitlin is pictured sitting beside another young child pointing at his stomach. From her stomach protrudes a long tube. In the text Caitlin asks the other child where his “monkey-tail” is. In another instance, Caitlin is shown blowing the candles out on her formula for her birthday because she cannot eat cake. As she closes her eyes and blows out the candles, she whispers, “I wish I could be well like everybody else.” Though Caitlin’s emotions are never shared with readers, readers can assume that her wish to be well like other children is a response to existent negative emotions towards her illness.

Still, the focus of Caitlin’s limitations is mainly medical. She cannot eat the same as other children because her body cannot process food well. She cannot participate in

the same physical activities as other children because she becomes tired easier and because she has a feeding tube in her stomach. A large part of this is probably due to the illness significance associated with renal failure. Unlike other illnesses where medication can improve symptoms and overall health, the only way Caitlin can really get better is if she has a kidney transplant. The damage to Caitlin’s kidneys already exists and cannot be reversed. This brings significance to renal failure that isn’t seen to exist with an illness like asthma, for example. This is further seen in the book. For example, when Caitlin is younger, the first thing her brother does when he gets home from school is check to make sure she is still there. “Oh good! You’re okay!!” His expectation every day is that she may not be alive when he gets home. This is her brother’s social reaction to a medical reality of her illness. Despite the severity of Caitlin’s condition, the overall tone of the book is predominantly hopeful and the ending is positive. Before turning five, a kidney becomes available for Caitlin and her health improves so much that she is able to eat cake at her fifth birthday.

**Emergent Themes**

As determined by earlier qualitative data rendered in this study, medical information is represented more often than social model issues. This aligns with earlier disability literature research. However, rather than focus on the accuracy of the medical model information presented in the books, the main goal of this study is to establish whether and how social and emotional issues are handled in more modern literature. It is then important to note that, despite the high representation of the medical model in these books, many of the books included in this study have a social model purpose: to promote
social inclusion. This suggests that mere qualitative counts are not fully representative of this type literature. It further suggests that a book’s overall purpose should be considered when analyzing medical and social models of disability. A few other social model topics are considered, including the significance of an illness and how society responds, the effects of childhood illness on the family, and the child’s perception of their own illness. The negative emotional responses found throughout the books in this analysis contribute to the overall tone of each of the books but seem to have little bearing on its outcome.

Many of the books in this analysis attempt to promote social inclusion of chronically ill children among their peers. Given earlier research citing the importance of peers on the school-aged child, it is not surprising that this theme is adequately explored. Often, this social inclusion is achieved through the process of normalizing an illness. Characters are normalized in either of two ways in these books. One, they are normalized against the presence of healthy, non-ill children. Or secondly, they are normalized against other chronically ill children. When compared to a healthy child’s standard, the chronically ill main character’s physical differences due to illness are pointed out to readers. After these differences are pointed out, characters are then are shown and/or they tell readers that they are normal just like other kids in every other way. A definition of disability according to the medical model is based on the idea that to achieve normalcy, an individual must be made whole and healthy.112 Those books in this analysis which attempt to normalize a child’s chronic illness against a healthy standard are using the medical model. “There has been much criticism of the medical model of health and disability because it has been used to stigmatize and alienate individuals,

putting the emphasis on their need to change and adapt to the perceived norms of society.”

By setting healthy children as the “normal” standard, they are devaluing the chronically ill child as abnormal. This has the potential to be psychologically damaging to a chronically ill child reading this type of literature. At the same time, it has the ability to reinforce a healthy child’s belief that ill and disabled people are different.

On the opposite end of the spectrum, several of the books in this analysis attempt to use other ill characters to normalize the main child character. Part of this technique is an attempt on the part of the author to show ill children that they are not alone. There are other people, like them, dealing with a chronic illness. However, the flaw in this approach occurs when ill characters are the only ones for the main ill character to compare their self to. This does not adequately represent a reality where a child will not readily find people of the same age with their same illness. It oversimplifies the process of social inclusion with peers that chronically children often face.

While the social inclusion or exclusion of a person with chronic illness is highly important to the social model of disability and illness, it is not the only social issue that can or should be represented in the literature. As mentioned earlier, readers should also be able to see how disability is defined, how disability affects the character’s interactions with family and the wider community, how people with disabilities are treated and the problems these characters face. The representation of these other social factors was less prominent than the theme of social inclusion. Only two of the books, *Mommy I Feel Funny* and *Now Caitlin Can*, showed how a child’s illness can affect the whole family.

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few others such as *The Lemonade Club*, *Toilet Paper Flowers* and *Keeping a Secret*, consider stereotypes of the illnesses discussed. Only one book, *Karen’s Epilepsy*, showed other characters socially excluding a child because of their illness. In fact, the books that either showed or promoted the social inclusion of chronically ill children by their peers only presented the positive outcome of social inclusion. This suggests that, though the literature seems to be attempting to include the social model more frequently than in the literature written prior to 2000, it is still very limited in its scope of social issues.

The exploration of negative emotions in this literature is, likewise lacking and suggests an overwhelmingly positive portrayal of the illness experience. Based on qualitative counts, negative emotions are only seen, on average, twice in each of the twenty books included in this study. However, when looking at the actual data, it should be noted that some books do not even include any negative responses (Appendix E). Given the long-term and often unpredictable nature of chronic illness as well as the endless number of illness stressors, it is reasonable to assume that chronically ill children will periodically experience negative feelings towards their illness. The negative emotions that appear in this study most often come in response to the main character’s fear of being excluded by their healthy peers. This further shows the prevalence of social inclusion in the books. Though less prevalent in the literature, some of the books do consider anger and sadness as part of the emotional experience of a chronically ill child. In fact, it is notable that the books that have the highest number of textual mentions of negative emotions are also the three books that had a higher appearance of social to medical instances: *Toilet Paper Flowers*, *Karen’s Epilepsy*, and *Keeping a Secret*. It is
reasonable then to propose that these books have the most balanced and representative portrayals of the illness experience based on medical, social, and emotional instances. The lack of negative emotions included in these books must be weighed against the fact that every book includes a positive and hopeful ending. While previously mentioned research suggests that children’s literature about chronic illness must be factual but still hopeful, one must wonder whether this literature is hopeful to the point of being unrealistic. One must further question whether this abundance of positive portrayal of the chronic illness experience is also damaging to both ill and healthy readers who may form their assessments of illness based on these portrayals. “If we defend ourselves from life’s negatives by wrapping ourselves in positive illusions, how can we ever learn from bad experiences…What happens when distorted perceptions of reality are disproved by experience?”¹¹⁵ If overly positive illusions distort reality, one must ask what can be done to make these books more realistic while still hopeful.

In those instances where social and emotional factors are either not considered or are underrepresented, the chronic illness is simplified to disease management, normally through the regular use of illness-specific medications. A few books that seem to simplify illness this way are Peter, The Knight With Asthma, Lara Takes Charge, and Fly My Lupus Butterfly, Fly. In these books, the illness experience is summarized by its physical effects on a character, thus upholding the medical model of illness. Furthermore, we see the idea presented that, if characters take their medication, they can do anything they want. “In poor fiction, the protagonist’s problems may be solved in too pat a manner. Such fictional solutions are not only simplistic and sentimental, but also

lack reality and justice. In real life, difficulties are not solved quickly or easily. Readers who identify with the characters may find false hope for solutions to their own problems.\textsuperscript{116} Thus, this simplification of chronic illness can negatively impact readers. Ill children may find their illness misrepresented or believe their illness can be solved by taking medication. Healthy children too may be impacted by this simplification and thereby have a harder time understanding the experience of a chronically ill child.

It is notable to mention that several of the books considered do a good job encouraging ill readers to take charge of their own health. As seen in the qualitative analysis of the books, the main child characters have different ways of coping with their perceived or experienced feelings of difference. One of the ways several of the characters cope is by being open with and educating those around them about their illness. The education of others is also an attempt to promote the social inclusion of chronically ill children. In these cases, knowledge is often seen as power. In addition to promoting social exclusion, this type of sharing also encourages chronically ill readers to be knowledgeable about their own illness and to take charge in the management of their medical needs. For example, in \textit{Toilet Paper Flowers}, Julia tells Nikki that “knowing and learning about my disease helps me feel more in control of it.” Research shows that people – adults and children – feel less helpless and scared when there is an action they can take to cope with and manage a problem. “It can increase [a] child’s sense of mastery to realize that by taking medicine, following a diet and doing his therapy, he is taking action to control his illness.\textsuperscript{117} Thus, by modeling characters that share information about their illness with others, these books are promoting both social

\textsuperscript{117} McCollum, A.T. (1981). \textit{The chronically ill child}. New Haven: Yale University Press, p.120.
inclusion and encouraging chronically ill children to take responsibility and initiative in paying attention to and managing their health.

Overall, one must question the representation of the illness experience in the literature presented in this analysis. Medical, social and emotional factors are not always equally or fully considered in these books. Firstly, medical models of illness are still more frequently represented. Secondly, social models of illness that are included focus predominantly on the social inclusion of chronically ill characters by their healthy peers. Thirdly, the representation of negative emotional responses is lacking in the face of overwhelmingly positive emotions displayed by the books’ main characters. This is even more true when viewed in conjunction with the overwhelmingly positive and hopeful outcomes of the literature. Consequently, it must be concluded that the books are not fully representative of the illness experience.

**Conclusions and Further Research**

The previous content analysis has attempted to assess whether modern children’s picture books accurately and realistically represent childhood chronic illness. The realistic portrayal of chronic illness is defined in this paper by the inclusion of medical, social and emotional models. While these books do provide both factual illness-related information and, for the most part, positive and hopeful main protagonists, they still vastly underrepresent the social and emotional models of illness. By doing so, the literature often simplifies chronic illness to disease management. Furthermore, in those cases where social model components are considered, the primary focus is on social inclusion among peers, an inclusion which all of the characters in question eventually
receive by a book’s end. Thus, while they do include a greater presence of social and emotional representations than seen in earlier assessed literature, these books still do not create completely realistic portrayals of the illness experience of chronically ill children.

Research has shown that for this type of literature to be useful to young readers, ill and healthy, it must be true to the behaviors and emotions chronically ill children experience. Yet, this analysis suggests that the literature is not fully reflective of this experience. “The child with a chronic illness is like a pebble dropping into a still pond. That pebble sends rippling effects throughout the pond. The pond may include school, activities, and of course, the family.”\textsuperscript{118} Despite the multi-faceted effect illness has on a chronically ill child, the literature considered in this analysis most often limits itself to medical factors and the topic of social inclusion. The effect of illness on the family is largely omitted and the consideration of an illness’ negative effect on a child’s emotions is always overshadowed by positivity. Consequently, in order for future books to be more representative of the illness experience and thereby more useful to its readers, this literature needs to consider a wider range of character emotion and a greater inclusion of the social components of their lives.

Finally, much can and should be done in the future to assess this literature and its usefulness. Though detailed, this content analysis has focused on a relatively small sample of books. Future research should attempt to apply the research and methodology employed here on a larger scale to test whether the resultant conclusions are similar or different. Future research should also be conducted to assess how children, ill and healthy, respond to books featuring chronically ill characters. “The lack of investigation on the impact of disability in children’s material neglects the needs of huge numbers of

young readers whose ideas are formed by misrepresentations, many of whom will have to renegotiate their misunderstanding of the nature of disability at a later date.” As has been determined in this paper, children’s literature can be instrumental in creating and/or changing readers’ attitudes about existent stereotypes. In order for future literature featuring chronically ill characters to be more representative of illness experience, it is critical that children’s perceptions of current literature be evaluated in greater detail. Assessing children’s perceptions of the literature has the potential to generate input and feedback that authors can use in the future.

In conclusion, though much progress has been made in the last few decades, there is still much to be done in the way of improving children’s literature featuring chronically ill characters. It is hoped that, as more children are diagnosed yearly with a chronic condition, more children’s literature books will be written that respond to their medical, emotional, and social needs. Likewise, it is hoped that this literature will be more reflective of the experiences tantamount to a child experiencing chronic illness, so that ill and healthy children alike can learn and grow from it.

References


Appendix A:
Children’s Books Cited

Baltaro, E. (2010). Karen’s epilepsy. Omaha, NE: WriteLife, LLC.


## Appendix B: Medical Model Instances

<table>
<thead>
<tr>
<th>Title</th>
<th>Illness</th>
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<th>Total # Medical Instances</th>
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**Total:** 46.95%
# Appendix C:
## Social Model Instances

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**21.85%**
Appendix D:
Percentage of Medical and Social Model Instances

[Bar chart showing the percentage of medical and social model instances for various titles.]
Appendix E:
Instances of Negative Emotions
Appendix F:
Annotated Bibliography of Children’s Books Cited (by illness)

Asthma


Abby has asthma, but her goal for the year is to run in the big race at the fair that happens every year. Abby faces several setbacks involving her asthma in her preparation for the big race such as getting out of breath easily, coughing and wheezing, and having chest tightness. Despite several assertions by family and friends that she should join the pie-eating contest instead and armed with medical knowledge provided by her doctor, Abby finally gets to run in the race.


Brianna is excited to play the lead in her school’s upcoming Thanksgiving play and practices hard to get ready for opening night. The Friday before the play, Brianna has a bad coughing fit that causes her to have trouble breathing. Upon being rushed to the hospital, the doctor tells her she has asthma and shows her how she can control it. With this newfound knowledge, Brianna makes her stage debut.


Peter loves to fight dragons, bike through the jungle and build igloos, but his adventures are often sidetracked by fits of coughing and wheezing. After talking to his doctor, Peter finds out that he has asthma and that he must take medications to make his lungs stronger. Feeling better, he returns to defending the land against any and all monsters.


Reflecting on his experiences from the previous summer, the main child character, whose name is never given, tells readers about how he was diagnosed with asthma. During soccer practice on this hot day he began coughing, wheezing and having trouble breathing. His parents took him to the hospital and the doctor diagnosed him with asthma and gave him medication that he had to take. Despite fears that asthma would make him lose his friends and keep him from doing things he loves, he realizes by the end of the book that he can still have fun, even with asthma.
Cancer


Upon being told she might have cancer, Suzy begins to worry, which gives birth to a giant Worry Wombat. In order to get rid of her worry and make the wombat disappear, the Great Katie Kate teaches Suzy about biopsies, x-rays, CT scans, hospitalization, and other cancer-related information. The more Suzy learns, the less concerned she becomes until she makes the Worry Wombat completely disappear.


Max has Acute Lymphatic Leukemia. Throughout the book, Max tells readers about cancer and the chemotherapy treatments he will soon be starting. Despite an outlook of three years of chemo and periods of activity and remission, Max insists he is mostly like other kids his age. This book is informative for both recently diagnosed young cancer patients and school kids who could benefit from learning about cancer.


Best friends Traci and Marilyn love Miss Wichelman’s fifth grade class where they learn that when life hands you lemons, you make lemonade. When Marilyn is diagnosed with leukemia, Traci and Miss Wichelman support her as she struggles with chemotherapy, losing her hair, feeling tired and the further effects of her cancer. In a surprise twist, there is not just one, but two characters that have some type of cancer in this book.

Congenital Heart Defects


Riley has a secret: she has a pacemaker. Riley is worried that her peers will view her differently if they find out and will not want to be her friend anymore. After worrying all week about her secret, Riley finally decides to share the story of her pacemaker for show-and-tell. Her classmates are very receptive to this information and ask her a lot of questions.

Crohn’s Disease


Julia has a new friend, Nikki, coming over. While visiting Julia, Nikki notices that Julia is not eating the same things she is. Upon being questioned about this, Julia tells Nikki that she has something called Crohn’s Disease. In an attempt to explain her disease to her friend, Julia talks about her symptoms and doctor’s visits, shows Nikki a diagram of the digestive system, and explains that she still loves to do all the same things she did before her diagnosis. Julia’s toilet paper flowers that she makes during her extended trips to the bathroom remind her to have hope.
Diabetes


Targeted towards preschool and early elementary children, Lara tells readers about her diabetes. As a result of having diabetes, Lara has to use a special meter to check her blood sugar and she has a special pump to give her body the insulin she needs. Lara, however, says that she is “normal” like other kids in every way besides having diabetes. As long as she takes care of herself, she can always do anything she wants.


Sillwee Wobbert’s friend, Jose, has diabetes. Jose has to eat snacks more frequently than his classmates and take insulin regularly to control his illness. When the class gets to play baseball during gym, everyone learns what can happen if Jose’s blood sugar gets too low. With input from the school nurse and Jose’s parents, Jose is able to educate his peers about diabetes. In the end, his peers are all very supportive and happy to have learned this information about their friend.


Lacie the lizard wants to make friends with Lewis, Larry, and Lizzie. Throughout their day spent together running, swimming, and catching bugs, Lacie’s new friends learn about her diabetes and all the things she has to do to stay healthy. Rather than let her illness limit her, Lacie does just as much, if not more, as her friends. At the end of the day, Lewis, Larry and Lizzie tell Lacie how much they like her and think she is pretty cool. They give Lacie a friendship necklace.


Told from third person perspective, the main child character depicted throughout the book’s pictures demonstrates what the text is saying. The book gives readers an informative look at diabetes and what a child must do to stay healthy while living with it. The book emphasizes that though living with diabetes can be hard, you can still do the things you love and have fun.

Epilepsy

Baltaro, E. (2010). *Karen’s epilepsy*. Omaha, NE: WriteLife, LLC.

Karen has grown up in the same place her whole life. All her friends and teachers know and understand her epilepsy. When she finds out that her family will be moving to a new town, Karen becomes very upset and worries about explaining her epilepsy to new people. On her first day at her new school, Karen has a seizure during class. For several weeks, Karen is alienated by her peers until one day her teacher has a seizure too. Given her experience with seizures, Karen is able to handle the situation and gains the approval of her peers.

Jimmy has his first seizure one night and his mother rushes him to the hospital. The doctor talks with Jimmy and tells him he has epilepsy. While his mother and doctor are occupied, the Great Katie Kate takes Jimmy around the hospital introducing him to other kids who have epilepsy. Over the course of his tour, he learns about the different kinds of seizures, tests, and medicines epilepsy involves. In the process, his Worry Wombat gets smaller and smaller until he disappears.


One day while swinging, Nel sees a monster and suddenly can’t speak. Worried, her mother and grandmother take her to the doctor where Nel has to take MRI and EEG tests. Several days later the doctor confirms that Nel has epilepsy. Despite her concerns, Nel’s doctor says she can still do everything she likes to do, as long as she regularly takes her medications.

**Juvenile Rheumatoid Arthritis**


Eric tells readers that some days are better than others with his arthritis. Some days he jumps out of bed and others he has to have his parents carry him out. To make his arthritis feel better, Eric does a bunch of different things. He soaks in the bathtub, swims with his physical therapist, takes and uses special medications, and sometimes he stays home from school. Eric is many things. The fact that he has arthritis is only a small part of who he is.


During a soccer game, Jennifer suffers from extremely bad pains in her knee. Her worried mother takes her to the doctor and they discover Jennifer has juvenile rheumatoid arthritis. Fearful of what her friends will think, Jennifer insists that that they not be told about her recent diagnosis. After several weeks of keeping her secret, Jennifer decides that keeping her secret is more painful than her arthritis. Her friends support her and a glad that she told them.

**Lupus**


This story features a main character, portrayed by a caterpillar named Teah that becomes very sick. Teah becomes so sick that she can no longer play with her friends. The doctors cannot figure out what is wrong with her until she is rushed to the hospital one night. The doctors then discover that Teah has lupus. They help her get better and tell her that, as long as she takes her medication and gets rest, she is free to fly as a butterfly.
Renal Failure/Problems


Told from her brother’s perspective, readers learn that Caitlin was born kidney problems. Unlike most people’s kidneys which work to clean waste products from the body, Caitlin’s do not do this. Caitlin had to have a feeding tube inserted into her stomach when she was a baby to help her eat. Worried, her brother asks the doctor what would really help his sister get better. The doctor tells him that the only way to make Caitlin completely better is for her to have a kidney transplant. Caitlin stayed on the transplant list for a long time before a kidney became available.