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This study used content analysis to examine texts that depict characters with scoliosis for readers aged 10-14. The purpose of this study was to examine how scoliosis and characters with scoliosis are portrayed in literature available to adolescents. Specifically, this paper investigated what books are readily available to readers, whether or not scoliosis is described with medical accuracy, and how characters with scoliosis respond to and cope with their diagnosis and treatment. This study found twelve relevant titles, with only three available in public libraries. Overall, the books were found to be medically accurate; however, this study found many of the books to be overly focused on facts to the detriment of the story.

Headings:

Young adult literature

Children's literature

Scoliosis

Content analysis

THE PORTRAYAL OF SCOLIOSIS AND CHARACTERS WITH SCOLIOSIS IN YOUNG ADULT AND
CHILDREN'S LITERATURE

by
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Contents

Introduction	2
Literature Review	5
Scoliosis	5
Psychological Impact of Scoliosis and its treatment.....	8
Depiction of disabilities.....	9
Research Questions	13
Methodology.....	14
Collecting the Data.....	16
Findings and Results.....	19
Book Information	19
Depiction of Scoliosis	25
Phrases Used in Texts	29
Depiction of Characters with Scoliosis and Their Families & Friends	31
Discussion	40
Limitations	45
Future Research	46
Conclusion.....	47
Bibliography	49
Works Studied.....	51
Appendices.....	52
Appendix A: Code Used for Analysis.....	53
Appendix B: Synopses of Books	55

Introduction

As librarians, one of our roles is to provide the right book at the right time for our patrons. For adolescent readers, this can prove to be a challenge, since adolescents may want or need very different texts for a variety of reasons. Because of the breadth of our audience, we as professionals need to have an understanding of the myriad of literature available for our patrons to best make appropriate suggestions. In addition to having knowledge about the literature available to adolescents, it is equally important to understand adolescents themselves. What types of issues are they dealing with? What is important to them? And how does this knowledge influence the titles in our collection and our recommendations to patrons? In this paper, I will explore one specific challenge that adolescents may face – scoliosis - and how it is represented in juvenile and YA literature.

Studies have been done to determine if any type of literature is helpful to readers based on particular issues that they may be facing with mixed results. McGuire finds that adolescents who read books “characteristic of their stage of life” are better equipped to answer questions and solve problems that they may come across (McGuire cited in Taubenheim, p.519). This may include providing adolescents with books that portray characters at similar ages or who are experiencing similar struggles to give them a sense of belonging and to allow them to recognize that they are not the only people to encounter a particular experience. While some readers use reading as a way to escape the

real world, “all children like to see themselves in literature” (Campbell in Wopperer, 2011, p.26). Children want to know that their experiences are worth being recognized and that their viewpoints are worth being put on paper. Seeing themselves in literature not only provides validation, it allows readers to see someone like themselves doing different things. Reading also allows children and adolescents to explore things outside of their own experiences. Wilson (2012) states, “through literature, readers can learn about new experiences and live vicariously through characters that are vastly different from themselves, as well as reflect themselves with characters in which they may find similarities” (p. 1). As librarians, we need to ensure that we are providing a variety of materials for patrons that not only allow them to see themselves in the pages, but also allow them to explore new and different ideas and perspectives.

Scoliosis is a medical condition that can affect adolescents, and in fact, many students will face scoliosis screenings in school throughout junior high. Scoliosis is a lateral (side-to-side) curvature of the spine that can develop in adolescents as they go through puberty. A diagnosis of scoliosis can lead to treatment that includes wearing a back brace or even surgery, which will be described in greater detail below. Though some forms of scoliosis can be linked to genetics and congenital birth defects, the majority of cases of scoliosis have no known cause. Because of this, when students see their peers being diagnosed or treated, it may cause fear or concern that they could get it as well. Furthermore, those diagnosed with scoliosis may feel frightened or alone when facing their diagnosis or treatment. As librarians, we can provide access to and recommend stories that depict characters with scoliosis that can allow adolescents to see characters like them or like their peers. However, providing these books needs to be done

thoughtfully. As with any type of literature, “librarians need to be familiar with their collection so that they are not recommending books that they have not read themselves” (Wopperer, 2011, p.32). We cannot collect or recommend texts about characters with scoliosis if we do not know what exists. Beyond knowing what is out there, we must also be aware of how the books that do exist portray characters with scoliosis. According to Prater (2003), “Educators and researchers advocate using literature to teach others about disabilities and as bibliotherapy for those with disabilities. Yet few researchers have examined portrayals to ensure that they are accurate and appropriate” (p. 49). The purpose of this paper is to explore the literature that exists that depicts characters with scoliosis, though not necessarily to prescribe a certain set of texts for adolescents dealing with scoliosis. Little to no research has been done specifically in the area of the depiction of scoliosis in juvenile and YA literature, and this paper is meant to provide a thoughtful analysis of texts available in order to help inform collection development practices and provide an overview of the literature available as possible recommendations to patrons.

To begin, I will start with an overview of scoliosis, its treatment, and its effects on adolescents who are diagnosed and treated. I will then explore what research has been done on the portrayal of disabilities in juvenile and YA literature, as scoliosis can be characterized as a disability in some respects. I will then survey the literature available, analyze said literature, and discuss how the texts depict scoliosis, characters’ scoliosis, and what that may mean for librarians and our patrons.

Literature Review

Scoliosis

Scoliosis is a lateral (side-to-side) curvature of the spine in the shape of either a “C” or an “S”, with the “S” curve being more prevalent. Typically an initial curve will form, and a second sympathetic curve will form afterward in the body’s attempt to correct the initial curve. While the onset of scoliosis can vary from infancy to teen years, it is most frequently detected between the ages of 11 and 14 (or adolescence) and is thus referred to as adolescent scoliosis. While it has been found to run in families or can be related to a birth defect, the cause of scoliosis is largely unknown and because of this is referred to as idiopathic. For unknown reasons, girls are diagnosed with scoliosis more frequently than boys, and after diagnosis, girls face a larger likelihood of requiring treatment (Sapountzi-Krepia et al., 2001). Scoliosis is frequently detected through a bending test, in which the child bends to touch his or her toes so that an examiner can determine whether or not a curve is present. Following a positive identification of a curve, the child may be referred to a physician for an x-ray that can further aid in determining whether or not the child has scoliosis (Sapountzi-Krepia et al., 2001). The curvature of the spine is measured by a Cobb angle in degrees with different actions being required at different degree milestones (along with other factors).

There are three different courses of action to take when treating scoliosis: observation, bracing treatment, or surgery (Shaughnessy, 2007, p. 469). Studies have shown that bracing treatment is often effective for curves whose Cobb angle measures

between 20 and 40 degrees at the beginning of brace treatment; however, that effectiveness is directly related to a patient's compliance with brace treatment and supportiveness of family members (Shaughnessy, 2007 and Sponseller, 2011). Another factor of importance is the development of the bones themselves measured according to a Risser scale of 0-5 (with 5 being fully developed). If one or more of the curves reaches 20 degrees before the bones have developed to a stage 5, or before a girl has had her period, or before a major growth spurt, bracing treatment will often be prescribed (Shaughnessy, 2007 and Sponseller, 2011). If bracing is prescribed, the patient is often required to wear the brace full time - 23 hours a day; however, athletic activity is encouraged, and permission may be given to remove the brace for activities that cannot be performed in the brace, like swimming (Shaughnessy, 2007, p.470). There are three major brace types that are used in practice today: the Milwaukee brace, TLSO (thoracolumbar sacral orthosis) braces, and hypercorrective braces meant only to be worn at night like the Charleston Bending brace.

The Milwaukee brace is characterized by two rods running the length of the brace, with a ring for the chin to rest in. There are also several pads placed strategically around the body and connected by straps to put pressure on different areas in order to correct the spinal curve. Patients typically wear the Milwaukee brace for 23 hours a day. TLSO braces can come in many varieties. Some may be "off-the-shelf" - prefabricated braces selected after taking a patient's measurements. Pads are then added in key places to encourage correction of the curve, and other customizations may be made to make the brace more comfortable. TLSO braces may also be completely customized based on plaster moldings made of the patient's bodies. Typically, TLSO braces rest under the

armpit of the patient and can extend over the hips, though the extensiveness of the brace may depend on the type of curve the patient has. TLSO braces are also frequently worn 23 hours a day. The third and less common type of brace is the hypercorrective brace, or Charleston Bending Brace. This brace is only worn at night when the child is sleeping and is designed with the child bent to one side in order to provide more corrective pressure. While this brace has been found to be just as effective as the above two, it only works for patients whose spinal curves occur well below the shoulder blade. One benefit of this brace is that it is only worn at night, and so it does not interfere with the wearer's daily activities like the other two varieties. (McAfee, 2002; Shaughnessy, 2007; and Sponseller, 2011). The Milwaukee brace, though older, is still as effective as the other brace types, but according to Sponseller (2011), use of this brace type has decreased due to patient preference (p. S57). In addition to those described above, Sponseller (2011) mentions an additional type of scoliosis brace, "The SpineCor brace is a flexible derotational brace designed to produce dynamic detorsion. It is made with derotation straps attached to pelvic and shoulder harnesses" (p.S57). Being a newer brace, there is little research on its effectiveness.

According to Shaughnessy (2007), the goal of brace treatment is to avoid surgery. Furthermore, brace treatment continues until growth is completed. "This is determined by a variety of indicators: typically unchanged height measurements on two successive dates 6 months apart, 18-24 months postmenarchal, Risser 4 status, or skeletal maturity on bone-age determination" (Shaughnessy, 2007, p.470). However, if a curve progresses to 45 degrees even with bracing treatment, surgery is often the only course of action available. Other methods that have been tried but not proven to work for the treatment of

scoliosis include electrical stimulation, exercise, and manipulation (Shaughnessy, 2007, p.469).

Psychological Impact of Scoliosis and its treatment

The diagnosis of scoliosis can be frightening and emotionally disturbing for adolescents. According to Sapountzi-Krepia et al. (2001), “adolescence is a difficult psychological period in its own right, and when it is compounded with scoliosis and bracing, can produce immense psychological stress, resulting in altered body image” (p. 685). Beka et al. (2006) concur that scoliosis treatment may result in unpleasant psychosocial states, including problems with self-esteem.

Even though many schools perform scoliosis screenings, its diagnosis and treatment is not nearly as prevalent as other common corrective treatments (glasses, orthodontic braces, etc.), and so there may be uncertainty about what a diagnosis of scoliosis means and what treatment might feel like. Furthermore, scoliosis’ treatment with various brace types may be considered less normal than glasses or braces by peers and can cause anxiety among adolescents being treated who may worry what others may think about their new orthosis. By virtue of its purpose, the brace may limit the adolescent’s mobility, making brace-wearing more noticeable or uncomfortable. Despite these effects, research has shown that those being treated for scoliosis rarely have long-term psychological effects (Sponseller, 2011, p.S54), but the feelings of isolation and possible ridicule are still significant.

While the treatment for scoliosis typically only lasts for a few years during adolescence and other disabilities often have lifelong implications, the argument can be

made that scoliosis is a type of disability, if a temporary one. In fact, in research about disabilities in juvenile and adolescent fiction, scoliosis makes an occasional appearance (Andrews, 1998; Burns, 2009), but in both cases, the only book mentioned is Judy Blume's *Deenie*, published in 1974. While little to no research has been done on the representation of scoliosis specifically in juvenile and adolescent literature, a survey of research done about the portrayal of disabilities in literature can provide insights into how to evaluate books that depict characters with scoliosis.

Depiction of disabilities

According to Wilson (2012), "It is important to create a healthy awareness surrounding the subject of disabilities" (p.9). The research is fairly clear about how characters with disabilities should be portrayed in literature available to children and young adults. Characters with disabilities should not be shied away from or ignored, but they should be treated respectfully and accurately. The depiction of characters with disabilities in juvenile and young adult fiction has undergone changes in the last several years. In the past, children with disabilities were not necessarily considered as a target audience for books with characters who had disabilities. According to Burns (1997), this attitude has undergone a shift to one "that books should show disability in a positive light, and that children should be able to read stories about people like themselves" (p.40). Children and young adults with disabilities may feel alone and separate from their peers, and literature that features characters going through similar experiences may lessen their feelings of isolation and encourage them to see themselves differently and positively (Wopperer, 2011). However, children with disabilities and the families of those children should not be considered the only audiences for literature that features characters with

disabilities (Minaki, 2009, p.14). All children can benefit from reading about people different from themselves, and literature can provide a way for readers to discover “what another person’s world is like... [to] learn about something they have not themselves experienced” (Burns, 1997, p. 39).

In addition to changes in audience consideration, literature portraying characters with disabilities has undergone changes in recent decades in how those characters are portrayed. According to Wilson (2012), the changes in fictional literature available for adolescents often occurred after the passing of laws that mandated equal instruction and equal access to services and products to people with disabilities. In the last several decades, portrayals of characters with disabilities have shifted from being secondary “unfortunate” characters to being portrayed as protagonists and catalysts to the storyline. However, even with those changes and improvements in the portrayals of characters with disabilities, there still exist stereotypes and shortcomings that need to be recognized and avoided.

Most researchers agree that characters with disabilities need to be treated in much the same way that characters without disabilities are treated. They should be robust characters with multiple facets to their personalities, and they should not be defined solely by the fact that they have a disability. According to Wopperer (2011), “Like characters without disabilities, a character with disabilities should be portrayed as a whole person with feelings, emotions, ideas, and values” (p.29). There is some disagreement, however, on the role that a character’s disability should play within the plot of the story. “Some state that having the disability be a part of the plotline is important to show the impact of the disability on the characters’ lives. Others argue that

the character with the disability should see the disability as part of their identity, but not something that identifies them as a whole” (Wilson, 2012, p. 13). This seems related to the discussion about the intended audience for the book in question. If the intended reader is someone who has a disability, and the author’s intention is to show how another person/character with that disability has overcome obstacles in their path specifically related to that disability, then the disability is likely to play a central role in the storyline. However, if the author’s intent is to include a person with a disability within the sphere of characters of the story, the disability may play less of a prominent role and may just be a part of who the character is. With that said, there are conflicting opinions on which approach is better, and it may be that a combination of both approaches should be included in library collections. Wopperer (2011) seems to indicate that this may be the case when she states, “The difference between young adults without disabilities and young adults with disabilities is that they have these experiences while coming from very different perspectives. Librarians should have YA books written from many different perspectives available for their patrons to read and, in the process, to grow” (p.29).

With either approach to a character’s disability within a story, it is still important that the disability alone not define who the character is. When a character is solely identified by his or her disability, the story runs the risk of perpetuating myths about disabilities. Children (or characters) should be considered as individuals, not glossed together as a homogenous group based on one feature (Mellon, 1989, p.144). Several researchers have identified common themes and attitudes that surface in literature that focuses too heavily on the disability itself. These include condescension toward people with disabilities, a failure to tell a good story in the name of being informative,

romanticization of the character with disabilities, and perpetuating the idea that people with disabilities are separate from people who do not have disabilities (Burns, 1997; Mellon, 1989; and Minaki, 2009). Romanticization of the character with disabilities often involves ideas that having the disability somehow ennobles the character (Burns, 1997) or results in the clichés of the “heartwarming story,” an inspirational story to encourage others like the character, or references to the character as being a “brave little soul” or “poor little thing” (Mellon, 1989). Minaki (2009) concurs that “people/characters with disabilities should not be portrayed only to inspire, teach, or correct others. Stories should include people with disabilities because they are part of the world and lead lives within which interesting, powerful, fun, and thought-provoking things happen” (p.13). Other pitfalls of the portrayal of characters with disabilities are that characters are depicted as either “heroes or helpless” (Wilson, 2012, p. 11) and lack diversity (Prater, 2003 and Wilson, 2012).

In selecting books for the collection, Wopperer (2011) states that “books that portray characters with disabilities should be included naturally and not singled out because of the character with disabilities” (p. 33). Indeed, the books included in the collection should tell stories that matter to patrons and should be considered on merits of the book, not just the fact that it portrays a character with a disability. When looking specifically at books that do so, however, Mellon (1989) stresses the importance of the books accurately portraying the disability, stating that they need to be as factually accurate as informational books so as not to perpetuate stereotypes and misinformation (p.150). Librarians should avoid books with “mawkish sympathy” and should take care to select stories in which children with disabilities are not substantially different from their

peers though they may face additional obstacles (Burns, 1997, p. 43). Children with disabilities may face additional struggles in their daily lives, and it is appropriate for books to reflect that, though Wopperer suggests that making selection decisions about books that portray characters with disabilities may not be so different selecting any juvenile or YA book stating, “YA novels portray young adults trying to fit in, and they depict characters dealing with being different and dealing with bullying” (p. 29). In this framework, providing the perspective of characters with disabilities is just like including other stories from various perspectives to attempt to provide the diverse range of viewpoints that exist in the world.

Research Questions

The questions guiding this study are: What juvenile/YA literature exists that depicts characters with scoliosis? How are characters with scoliosis portrayed? How are scoliosis and its treatment portrayed?

Methodology

Content Analysis

In order to provide patrons with books that have characters like them, in this case characters with scoliosis, we must know what literature exists and how it portrays those characters. The best way to survey the literature available and measure how it depicts characters with scoliosis, scoliosis itself, and the treatment of scoliosis is to perform content analysis. According to Babbie (2010), “content analysis is the study of recorded human communications” (p. 333). Holsti (1969) adds to this by stating that content analysis is “any technique for making inferences by objectively and systematically identifying specified characteristics of messages.” (p. 14). This systematic identification of characteristics is achieved by developing a code, which will be discussed later.

Looking closely at the literature available can help identify qualities and characteristics that different books and characters may or may not share and themes and patterns that emerge within and between texts. Putting these together will provide a clearer picture of what is available and whether or not it is worth recommending. While content analysis has some drawbacks, one of the major advantages is the fact that it enables the study of literature over an extended period of time (Babbie, 2010, p. 344). Since the first book featuring a character with scoliosis (*Deenie*) was published in 1974, content analysis enables the examination of changes and developments in the literature over the last 30+ years.

There are varying schools of thought on how content analysis should be conducted. Babbie outlines two forms of content analysis: manifest and latent. Manifest content analysis looks at surface content and is primarily defined by the number of times certain words appear. While this method has the advantages of being easy to use and providing clear, measurable data, it may lack depth or nuance. Latent content analysis allows for more in-depth exploration of texts and looks at underlying meanings of texts in their entirety but can be difficult to measure and risks being unreliable due to coder bias, inconsistent definitions, etc. To take advantage of the pros and negate the cons of each type of analysis, Babbie suggests employing both methods in research studies (Babbie, 2010, p. 338-339).

Measuring the data can take place in two different ways, either through quantitative or qualitative content analysis. Quantitative analysis requires numerical coding and is useful for measuring the frequency of terms in particular documents to answer research questions (Babbie 2010). On the other hand, qualitative content analysis will not result in coding by numbers but will allow for descriptive analysis of data. Qualitative content analysis frequently begins with a reading of the literature to gain an understanding of what is present thematically and symbolically and to be prepared for any anomalies that may affect the study (Holsti, 1969, p. 11). These initial findings are akin to observations from which the researcher can determine patterns and relationships between variables, a process called analytic induction (Babbie, 2010, p. 341). Benaquisto (2008) and Julien (2008) suggest that during this initial reading phase, the researcher should take notes on qualities that stand out in each text so that clusters of similar information or themes may emerge. As the researcher proceeds through the literature, it

may become apparent that certain characteristics appear more frequently than others, that characteristics may appear in degrees rather than a simple presence, and that some characteristics may be notably absent from a particular text. All of these things are worth noting and comparing as part of the process for developing a code by which to measure all of the texts. The next step in building a code is to determine if certain characteristics should be fleshed out and explored more granularly by breaking them down into smaller parts or if they should be subsumed into broader characteristics.

Collecting the Data

The purpose of this study is to identify and analyze novels meant for adolescents that depicted characters with scoliosis. In order to gather these books, I started first with a search for “scoliosis” in Children’s Literature Comprehensive Database (CLCD). This initial search yielded results ranging from scoliosis fiction novels to case studies to sound recordings. Scoliosis-fiction appeared as a subject heading, so I used that to narrow the scope to fictional stories. This search only yielded 11 results not all of which were unique (for example, different publication dates of Judy Blume’s *Deenie* made multiple appearances on the list). I recorded unique incidents and then returned to the initial search results and browsed the list for other fictional novels with characters with scoliosis. I then recorded those results and began to secure copies of the novels from libraries, bookstores, and Amazon.com. In addition to searching the *CLCD*, I searched for “scoliosis” + “fiction” on Amazon.com and searched for books like *Deenie* to ensure that as many books as possible were listed. In addition to active searching, I also used the recommendation feature of Amazon - allowing the website to suggest texts for me until I

came full circle and was recommended *Deenie*. The use of this feature did result in the addition of one non-fiction text, a memoir-style account of one girl's experience with scoliosis called *When Life Throws You a Curve*. I included this book in the final data set as it was told in a style similar to some of the fictional texts. Copies of the books proved difficult to locate - many of them had not been printed in several years and were only available through used book sites like Amazon Marketplace. Of the final twelve novels used for the study, only three were available at the local public library: *Deenie*, *Madame Squidley and Beanie*, and *Just Like Always*.

Analyzing the Data

As outlined by Holsti and others above, to develop a comprehensive code, I first read through all of the books I located to gather recurring themes, differences, and an idea of the stages of scoliosis treatment that the book addressed. I also looked for overall coping messages and medical accuracy including terminology used and medical advice offered by various characters. I also took note of other issues the characters faced, how they were described, and whether or not they had any other defining features other than having scoliosis. After doing a first read and taking notes, I developed an initial code to describe and categorize all of the notes I took. I then revised that code by evaluating areas that overlapped, needed more definition, or could be considered subsets of other characteristics. Holsti recommends that the categories of a code should “reflect the purposes of the research, be exhaustive, be mutually exclusive, independent, and be derived from a single classification principle” (Holsti, 1969, p. 95). This ensures that categories do not overlap and that characteristics of one category do not impact other

categories. After finalizing the code to meet these standards as closely as possible, I re-read the books specifically looking to rate them against the code. This code appears in Appendix A of this paper. This process allowed me to identify and compare themes of characterization of scoliosis, adolescents with scoliosis, and other factors as illustrated in the following section.

Findings and Results

Book Information

All twelve books analyzed were published between 1973 and 2008. *Deenie*, by Judy Blume, is the oldest of the books, originally published in 1973, though new editions have been released as recently as 2010. Following the original publication date of *Deenie*, the next book to be published was *Just Like Always* by Elizabeth-Ann Sachs, published in 1981. Another book featuring a character with scoliosis was not published until 1992, *Patty's Last Dance*, a *Sweet Valley Twins & Friends* book by Francine Pascal. Three other books were published in the 1990s (*The Bravest Thing*, *Abby's Twin*, and *There's an "S" on My Back*) in 1995, 1997, and 1999 respectively. The next grouping of books were published in the 2000s, with *Stand Tall, Harry* in 2002, *Harry Scores a Hat Trick* in 2003, *Madame Squidley and Beanie* and *Josiah: Young Believer on Tour* both in 2004, *Plastic Back* in 2006, and *When Life Throws You a Curve* in 2008.

Of these books, three belonged to a series: *Patty's Last Dance* is #65 of the *Sweet Valley Twins and Friends* series, created by Francine Pascal; *Abby's Twin*, #104 of *The Baby-Sitters Club* series by Ann M. Martin; and *Josiah*, the first book in the *Young Believer on Tour* series by Stephen Arterburn. Though not an official series, Mary Mahony's *Harry Scores a Hat Trick* is a sequel to her earlier book, *Stand Tall, Harry*.

Of the twelve books analyzed, five were published through self-publishing companies. *There's an "S" on My Back*, *Stand Tall, Harry*, and *Harry Scores a Hat Trick* were all published under the author's own publication company, Redding Press. *When*

Life Throws You a Curve was published by Five Star Publications, owned and run by Linda Radke, and *Plastic Back* was published through iUniverse. *Josiah* was published by Tyndale, a company dedicated to publishing bibles, and Christian fiction, nonfiction, and other resources. The remaining novels were published by more well-known publishers like Dell, Bantam, Scholastic, etc.

Several of the books contained authors' notes, which often revealed the intent of the author in writing the book or provided a guide for readers to get more information. All five of the self-published novels contained an author's note indicating that either the author or someone close to the author had scoliosis and had undergone some form of treatment and that the book was being written to help others like themselves. In addition to these, *Abby's Twin* also contained an author's note, in which the author explained that readers do not need to fear scoliosis and can get more information about it from their family doctor or school nurse.

Of all twelve novels, only one cover featured a back brace (*Plastic Back*). The rest featured presumably the main character(s) of the story either participating in activities that occurred in the book or looking in the mirror or at the audience. Both *Deenie* and *When Life Throws You a Curve* have covers with characters looking out to the reader, while *Josiah*, *Patty's Last Dance*, and *Harry Scores a Hat Trick* have covers that indicate what type of person the book is about: a musician, a dancer, and a hockey player respectively. *Abby's Twin* features two characters (Abby and her twin sister, Anna) looking into a mirror. The remaining six covers feature events that happen within the novels. Cover art may have affected which books adolescents picked up and were comfortable carrying around. *Plastic Back*, which featured a back brace, indicated that

the primary focus of the book was on the brace itself, rather than on the character. The other books' covers may have been more accessible to readers by portraying characters that either looked like potential readers or was participating in an activity that readers also participated in, or they may have been designed to offer inspiration to readers who wanted to be like the characters on the covers of the books.

The average length of the novels was 143 pages, with most of the books falling between 130 and 150 pages. The outliers were *There's an "S" on My Back* at 197 pages, and *Plastic Back* at 85 pages. The books varied greatly in the amount of time covered in the book, ranging from a few weeks to two years. Those that covered only a few weeks included *Deenie*, *Madame Squidley and Beanie*, *Patty's Last Dance*, *Abby's Twin*, *Plastic Back*, and *Josiah*. Books that covered several months included *Just Like Always*, *Stand Tall*, *Harry*, and *Harry Scores a Hat Trick*. Those covering a year or more were *When Life Throws You a Curve*, *The Bravest Thing*, and *There's an "S" on My Back*.

Within these books, the main character was almost always the character with scoliosis. The exception to this was *Madame Squidley and Beanie*, in which the character with scoliosis was a secondary character (Charles) who was friends with the main character (Beanie). In *Patty's Last Dance*, *Abby's Twin*, and *Josiah*, the main character who had scoliosis was also somewhat of a featured character within the series. For example, Anna in *Abby's Twin* was not a regular character in *The Babysitter's Club* series, but she was in this particular story and was featured through the eyes of Abby, who was a regular series character. Meanwhile, *Josiah* was always a character in the *Young Believer on Tour* series, but in this book, his storyline was the focus. Patty, from *Patty's Last Dance*, may have had a recurring role in the *Sweet Valley Twins and Friends*

series, but she was not always featured as she was in this story, and she was not one of the official title characters of the series. Featured characters may have been an attempt on the part of the author to address an issue that they knew readers were facing without needing to incorporate those characters or issues into all future books. In all of the other books, the character with scoliosis was also the main character, though there may have also been other secondary characters who had scoliosis as well. These characters were occasionally friends or acquaintances of the main character, or they may have been mentioned in passing as a person that somebody knew but did not appear in the book.

The books that did not mention another character with scoliosis were *The Bravest Thing*, *Madame Squidley and Beanie*, *Plastic Back*, and *Josiah*. In *Deenie*, there was a support group for patients with scoliosis that Deenie mentioned going to where she could “ask the other girls how they sit at their desks and if they got rashes too...and rip their clothes...and worry about other people looking at them” (Blume, p.139). In *Abby’s Twin*, Abby’s friend Stacey mentioned knowing a girl who had scoliosis, noting that it “didn’t seem like a big deal for her” (Martin, p.34). In *Patty’s Last Dance*, a character mentioned knowing a girl who wore a brace who “said it was hard at first, but after a while she hardly noticed it” (Pascal, p. 96), and later Patty met another girl at the doctor’s office who reiterated that wearing a brace “was a real pain to get used to. But now I hardly notice it” and was swimming at the encouragement of their shared physician (Pascal, p.114). *When Life Throws You a Curve* featured Elizabeth whose aunt and grandmother both had scoliosis and were treated for it as teenagers. They were able to offer her encouragement that she would make it through her own treatment, emerge a better person, and that treatments had improved significantly since both of them were younger.

Maisey, from *There's an "S" on My Back*, learned that both her friend Jean and her father knew people who were treated for scoliosis, though Jean's focus was on her friend's inability to wear designer jeans with her brace, and Maisey's dad focused on how the girl he knew turned out to be okay after wearing the brace. Near the end of the novel, Maisey shared a hospital room with another girl who had undergone the same surgical procedure that Maisey was about to have, and she also learned that her friend Charlotte had scoliosis the entire time they knew each other, except that Charlotte's parents were apprehensive about treating her. In both of the *Harry* novels, Harry had several friends who had scoliosis. He learned that his older half-sister had scoliosis but never required treatment beyond observation. The revelation made him feel closer to his sister because "we had the same thing, because Consuela is my half-sister, and this would make her even more than half, at least to me" (Mahoney, 2002, p.85). He also befriended a chess opponent, Dawn, who wore a Milwaukee brace and later had surgery and Sam, a fellow hockey player who wore a brace and also later required surgery. *Just Like Always* was unique in that both main characters had scoliosis and became friends while sharing a hospital room, though Janie mentioned knowing "a whole bunch of kids at school who wore corrective braces" (Sachs, 1981, p.15).

Out of the twelve novels' primary characters with scoliosis, nine were female and four were male, and the characters' ages ranged from 10 to 13. Demographically, two characters were described as being Jewish (Elizabeth from *When Life Throws You a Curve* and Janie from *Just Like Always*), Patty was described as having "light brown" skin (Pascal, p.7), Harry was described as African-American, and the other characters

were not specified though Courtney from *Just Like Always* had blond hair, and all of the remaining covers indicated characters who were Caucasian.

Nearly all of the books featured or focused on scoliosis in some way with either the word scoliosis or some evidence of the character having scoliosis appearing within the first ten pages. The exceptions to this were *The Bravest Thing*, in which scoliosis was not the main topic and was not mentioned until page 58, *Stand Tall, Harry*, in which scoliosis was a major concern (though not the only concern) but did not appear until page 48, and *Patty's Last Dance*, where Patty's teacher noticed something strange on page 18, but scoliosis was not mentioned until page 57.

Table 1: Number of pages until appearance of scoliosis

Book Title	Page # that scoliosis appears
<i>Deenie</i>	evidence - p.11 scoliosis - p.50
<i>When Life Throws You a Curve</i>	p.1
<i>The Bravest Thing</i>	p.58
<i>Madame Squidley and Beanie</i>	p.7
<i>There's an "S" on My Back</i>	p. 4
<i>Just Like Always</i>	p. 7
<i>Patty's Last Dance</i>	evidence - p. 18 scoliosis - p. 57
<i>Abby's Twin</i>	p. 4
<i>Plastic Back</i>	p. 1
<i>Josiah</i>	p. 4
<i>Stand Tall, Harry</i>	p. 48
<i>Harry Scores a Hat Trick</i>	p. iv

Though scoliosis appeared early on in *Madame Squidley and Beanie*, scoliosis was not the main topic of the book but did play an important role in Beanie and Charles's friendship.

Depiction of Scoliosis

In four of the twelve novels, the character's scoliosis was detected through a school screening (*The Bravest Thing*, *There's an "S" on My Back*, *Abby's Twin*, and *Plastic Back*). The detection method was not discussed in four of the books (*Madame Squidley and Beanie*, *Just Like Always*, *Josiah*, and *Harry Scores a Hat Trick*). In the remaining four books, the character's scoliosis was detected in a variety of ways. In *Deenie*, the cheerleading coach noticed something off about the way that Deenie moved, performed a brief screening, and recommended that Deenie see her pediatrician for follow up. In *When Life Throws You a Curve*, Elizabeth's pediatrician detected a slight curve during a routine checkup. Like Deenie's cheerleading coach, Patty's dance teacher noticed that her movements in dance classes were slightly off and recommended she see a doctor to be sure in *Patty's Last Dance*. Harry's scoliosis was discovered through x-rays taken after a hockey injury.

Once the character's scoliosis was detected, they all seemed to follow some variation on the following progression: appointment with normal pediatrician or family physician → referral appointment with orthopedist → referral appointment with scoliosis specialist → a decision either to continue monitoring scoliosis or move forward with treatment (may repeat if monitoring is chosen) → appointment with orthotist to get measurements for brace → receive and begin wearing brace → continued appointments

with scoliosis specialist and orthotist → determination that bracing treatment is not working and surgery is necessary → surgery → recovery.

Both *When Life Throws You a Curve* and *There's an "S" on My Back* followed the progression above almost exactly, though *When Life Throws You a Curve* ended up skipping bracing treatment altogether because of the rapid progression of Elizabeth's curve. *Deenie* and *Plastic Back* followed this progression up to receiving a brace, but the novels both ended before it was revealed if bracing treatment had been successful. Both *Patty's Last Dance* and *Abby's Twin* skipped one of specialists, but followed the progression of detection → appointment with pediatrician → appointment with orthopedist → fitting for brace (and in the case of *Abby's Twin*) receiving the brace. *Patty's Last Dance* ended before the brace arrived. In *The Bravest Thing*, the pediatrician noticed a curve but suggested that it did not warrant action at the time and told Laurel to hang from a chin-up bar to help straighten her out (Napoli, p. 64). In *Josiah*, the process to receiving the brace was not discussed, nor was it discussed in *Madame Squidley and Beanie* or *Just Like Always*, though in both cases, the characters were undergoing some form of treatment (Charles wearing a brace, and Janie and Courtney facing surgery respectively). Harry's progression (through both *Stand Tall, Harry* and *Harry Scores a Hat Trick*) stopped at the monitoring phase, and he never required treatment.

Table 2: Success of Treatment by Book

Book Title	Initial treatment	Successful?	Secondary Treatment
<i>Deenie</i>	Brace	unknown	N/A
<i>When Life Throws You a Curve</i>	Observation	No	Surgery
<i>The Bravest Thing</i>	Observation, exercises	unknown	N/A
<i>Madame Squidley and Beanie</i>	Bracing (not full time)	No	Full time brace wearing
<i>There's an "S" on My Back</i>	Bracing	No	Surgery
<i>Just Like Always</i>	Unknown	No	Cast and surgery
<i>Patty's Last Dance</i>	Bracing	Unknown	N/A
<i>Abby's Twin</i>	Bracing	Unknown	N/A
<i>Plastic Back</i>	Bracing	Unknown	N/A
<i>Josiah</i>	Bracing	Unknown	N/A
<i>Stand Tall Harry</i>	Observation	Yes	N/A
<i>Harry Scores a Hat Trick</i>	Observation	Yes	N/A

In between doctor's visits, Elizabeth's family attempted several different types of alternative treatments including exercises, visits to a chiropractor, and visits to a massage therapist in *When Life Throws You a Curve*.

Table 3: Discussion and Use of Brace by Book

Books that discuss bracing	Brace types mentioned	Brace types used
<i>Deenie</i>	Milwaukee brace	Milwaukee brace
<i>When Life Throws You a Curve</i>	Milwaukee brace	None
<i>Madame Squidley and Beanie</i>	Unspecified TLSO, described as “buckled around his waist like a wide plastic belt” (p.34)	Unspecified TLSO
<i>There’s an “S” on my Back</i>	Milwaukee brace, underarm TLSO	TLSO
<i>Patty’s Last Dance</i>	Milwaukee Brace, Boston Brace	Milwaukee brace
<i>Abby’s Twin</i>	Milwaukee brace, low-profile (TLSO) brace	Low-profile brace
<i>Plastic Back</i>	TLSO (based on cover)	TLSO
<i>Josiah</i>	TLSO and also another “flexible brace”	TLSO, flexible brace used for performances
<i>Stand Tall Harry, Harry Scores a Hat Trick</i>	Milwaukee brace	none

Milwaukee and TLSO braces were the only brace types mentioned in the texts, except for at the end of *Josiah* when the band manager found a doctor to make a “flexible brace” for Josiah to wear during performances so that he could perform certain dance moves (Aterburn, 168), which could have possibly referred to a SpineCor brace, though it was not specified. Most of the TLSO braces were not identified as such, but were referred to by terms like Boston brace, low-profile brace, etc.

When brace treatment was prescribed in the texts, it was prescribed for full time wear except for possibly in the case of Charles in *Madame Squidley and Beanie*. Charles

did not wear his brace to school throughout much of the book, though near the end of the novel, his doctor recommended that he begin to wear it full time to combat some additional back pain that Charles was experiencing (Mead, 2004, p. 70).

Phrases Used in Texts

The novels repeated key medical phrases or situations related to a diagnosis of scoliosis. Nearly all of the books mentioned x-rays at various stages including before the initial diagnosis, right after receiving the brace, and at nearly every doctor's appointment following diagnosis. The only books that did not mention x-rays were *The Bravest Thing* and *Josiah*. In *Bravest*, the doctor decided based on observation that no further action was needed at that time, and the events in *Josiah* occurred after bracing treatment had begun and did not mention continuing doctor's appointments. Aside from x-rays, another common method of detecting and diagnosing scoliosis appeared across texts: bending over to touch one's toes, which appeared in all of the texts except for *Madame Squidley and Beanie*, *Just Like Always*, *Josiah*, and *Harry Scores a Hat Trick*. Less common were MRIs, in *When Life Throws You a Curve* and *Harry Scores a Hat Trick*, and measuring arms and legs to rule out other causes of a curved spine, in *Deenie*, *The Bravest Thing*, and *Harry Scores a Hat Trick*.

All of the texts talked about the curvature of the spine in some capacity, and many of them offered definitions of scoliosis, occasionally defining the term "idiopathic" as well. The majority of the texts also described the curve as an "S", though in *Deenie*, she questioned whether or not her curve was shaped like the letter "S" or the letter "C", indicating that an "S"-shaped curve was not the only possible shape.

Table 4: Definition of Terms

Book Title	Scoliosis	Idiopathic
<i>Deenie</i>	yes	yes
<i>When Life Throws...</i>	yes	no
<i>The Bravest Thing</i>	no	no
<i>Madame Squidley</i>	yes	no
<i>Just Like Always</i>	yes	no
<i>There's an "S"</i>	yes	yes
<i>Patty's Last Dance</i>	yes	no
<i>Abby's Twin</i>	yes	no
<i>Plastic Back</i>	yes	no
<i>Josiah</i>	yes	no
<i>Stand Tall, Harry</i>	yes	yes
<i>Harry Scores a Hat Trick</i>	yes	yes

Other aspects of scoliosis and scoliosis treatment that were mentioned were undershirts or bodystockings to help with comfort while wearing a brace (*Deenie*, *There's an "S"*, *Josiah*, *Plastic Back*), rounded or raised shoulder or rib cage (*When Life Throws You a Curve*, *Patty's Last Dance*, and *Plastic Back*), and concern about the growth spurt or bone maturity causing the scoliosis to worsen (*Deenie*, *The Bravest Thing*, *Madame Squidley and Beanie*, *There's an "S"*, *Patty's Last Dance*, *Abby's Twin*, *Josiah*, *Stand Tall, Harry* and *Harry Scores a Hat Trick*). In many cases, the novel provided the angle of curvature of the characters, listed in the table below.

Table 5: Angle of Character's Curve

Character	Curvature
Deenie (<i>Deenie</i>)	not given
Elizabeth (<i>When Life Throws You a Curve</i>)	started at 32, shifted to 42 & 45
Laurel (<i>The Bravest Thing</i>)	not given, measures a 4.5 with plastic device
Charles (<i>Madame Squidley</i>)	not given
Maisey (<i>There's an "S"</i>)	over 25 at bracing, 39 after bracing/before surgery
Janie and Courtney (<i>Just Like Always</i>)	not given
Patty (<i>Patty's Last Dance</i>)	35
Abby (<i>Abby's Twin</i>)	14
Anna (<i>Abby's Twin</i>)	25
AnnaBeth (<i>Plastic Back</i>)	20 (for each of the two curves)
Harry (<i>Stand Tall and Harry Scores a Hat Trick</i>)	20

Depiction of Characters with Scoliosis and Their Families & Friends

Except for Charles in *Madame Squidley* and Janie and Courtney in *Just Like Always*, all of the characters had an activity or aspiration that dominated their lives. Of these activities, the vast majority were physical and were thereby impacted by the scoliosis diagnosis. Athletics and physical beauty dominated the defining roles of the characters. Deenie was an aspiring model, Josiah a newly minted pop star, Patty an aspiring ballerina, and Elizabeth, Maisey, AnnaBeth, and Harry were all athletes. Only Laurel, who dedicated her time to caring for animals and was an aspiring veterinarian, and Anna, who was a violinist, had activities that were not dependent on the character's

physical abilities or appearance. Nearly all of the characters displayed concern and fear that they would have to give up their favorite activities, and while the diagnosis and treatment of scoliosis required that nearly all of the characters modify their behaviors, that modification did not necessarily mean giving up their preferred activities entirely. Harry's scoliosis was not necessarily the cause of his changed activities (he also suffered from a broken collarbone), but he did have to take a break from hockey and ended up honing his chess skills, which became his dominant activity throughout *Stand Tall, Harry* and its sequel, *Harry Scores a Hat Trick*. AnnaBeth, because of her brace, ended up spending less time on basketball and began to take piano lessons, because she "could play piano even with a shortened running stride. And it didn't matter that I had shoulder-pad arms" (Rakes, 2006 p. 60). Though the novel did not describe what Josiah's activities were before his bracing treatment, the brace caused him to struggle with the dance choreography for the band and eventually required modifications to the choreography and also to the brace itself. Maisey and Patty's physicians gave them permission to continue their activities while wearing the brace combined with limited time out of the brace. For the characters who underwent surgery (Elizabeth, Courtney, Janie), their activities were limited through recovery, but they were expected to be back at full activity levels after that period of time. In addition to limiting activities, some characters were encouraged to adopt new ones. The most common was swimming, which was recommended to Deenie and Patty. Laurel's physician recommended that she hang from a chinup bar for five minutes a day to encourage her back to straighten out.

Of the characters whose progression through detection, diagnosis, and treatment were represented in the books, some common themes emerged in their reactions to

various stages. Nearly all of the characters expressed concern, worry, or confusion at the first detection of scoliosis. Four of the characters (Deenie, Maisey, Patty, and Anna) looked up scoliosis in the encyclopedia to get more information about what was happening to them. Some characters attempted to ignore the initial concern. For example, Patty initially brushed off her teacher's concern about her posture out of fear that she would have to stop dancing if something was wrong (Pascal, 1992, p. 47). Laurel commented, "I didn't even know what scoliosis was, but I knew I didn't want it" (Napoli, 1995, p. 59). AnnaBeth reacted angrily toward the "stupid parent volunteer with nothing better to do than check kids' backs for some freak curve" (Rakes, 2006, p. 4), and her general attitude toward scoliosis was that "only freaks had twisted spines" (Rakes, 2006, p.2). As detection progressed into actual diagnosis, the characters' reactions began to vary slightly, though overall themes of worry, shock and hoping for a mistake were prevalent in *Deenie*, *When Life Throws You a Curve*, *There's an "S"*, *Patty's Last Dance*, *Abby's Twin*, and *Plastic Back*. Harry simply tried to put it out of his mind: "My parents are into this with me, but I don't want to think about it. I just want to move on for now" (Mahony, 2002, p. 99). Reactions to treatment included crying, anger, nervousness, and resignation. Elizabeth and Courtney, both facing surgery, cried upon learning that they will require surgery for their scoliosis, though Courtney learned she was facing multiple surgeries rather than just one. Deenie reacted angrily when she arrived home with her brace, yelling, "Damn you, damn you crooked spine" and impetuously chopping off all of her hair (Blume, 1973, p. 94). Both AnnaBeth and Maisey commented on how they hate their braces, though Maisey acknowledged to herself that "this was just something I was just going to have to do" (Mahony, 1999, p. 14). On the other hand, both Charles and

Anna expressed very different opinions saying of their brace treatments “My whole life isn’t messed up. Only a tiny unimportant part of it is” (Mead, 2004, p. 105) and “it’s not as bad as it looks...it doesn’t hurt. It’s a little weird though” (Martin, 1997, p.101). In addition to reactions to various stages, characters had a variety of ways to describe their braces, when applicable. These are recorded in the table below.

Table 6: Description of Brace by Characters

Book Title	Brace Type	Character’s Description
<i>Deenie</i>	Milwaukee	“weird looking thing” (p.70), “that thing” (p.71), “mostly of metal...some white plastic parts...two metal strips down the back...one down the front...a metal collar...a cage” (p. 91)
<i>Madame Squidley and Beanie</i>	TLSO	“car seat”
<i>There’s an “S” on My Back</i>	TLSO	“Armor” (p.25), “new cage” (p.27)
<i>Patty’s Last Dance</i>	Milwaukee	“big cage” (p. 69), “big, huge, horrible thing” (p. 81)
<i>Abby’s Twin</i>	TLSO	“thick belt going from under the armpit on one side to lower on her ribcage on the other...wrapped around brace held together by three Velcro straps” (p. 57)
<i>Plastic Back</i>	TLSO	“plastic curse” “shell” “plastic shield” (p. 41) “rippled butt” “linebacker shoulders” (p. 42)
<i>Josiah</i>	TLSO	“Vinyl case” (p. 64) “hard plastic case” (p. 88)

Across the novels, characters found different ways of coping with the diagnosis and treatment of scoliosis, though confiding in a close friend emerged as the most common coping strategy, appearing in *Madame Squidley and Beanie*, *There's an "S" on My Back*, *Just Like Always*, *Patty's Last Dance*, and *Stand Tall, Harry*. In addition to confiding in friends, many characters approached their parents or other family members to talk about what they were going through: *When Life Throws You a Curve*, *There's an "S" on My Back*, and *Stand Tall, Harry*. Other methods of coping included ignoring or trying to forget about the diagnosis (*The Bravest Thing*), withdrawing into private activities like music (*Abby's Twin*, *Plastic Back*), praying (*Josiah*), using humor (*When Life Throws You a Curve*), joining a support group (*Deenie*), and masturbating (*Deenie*).

Family and friends were supremely important to characters in nearly all of the novels. All of the books except *Madame Squidley and Beanie*, *Abby's Twin*, and *Just Like Always* depicted families with married parents and one or more siblings. Charles's family in *Madame Squidley* consisted of divorced parents who fought over his scoliosis treatment - "his mother believed the brace would help if he wore it enough, but his dad...thought the brace was useless and that playing sports was the way to straighten his spine" (Mead, 2004, p. 34). In *Abby's Twin*, Anna and Abby's father had died previous to the action in the novel, and they lived with their mother who was supportive of Anna's brace treatment and tried to help Abby understand that she was not a lesser twin sister because she did not require brace treatment (Martin, 1997). The families in *Just Like Always* were largely not present and did not seem to play an important role in the girls' treatment except for occasional visits to the hospital when the smuggled in food (Sachs, 1981). In addition to parents and siblings, both *There's an "S" on My Back* and the *Harry*

novels depict households that include a grandparent, and *When Life Throws You a Curve* highlighted the important relationship between Elizabeth and her aunt and grandmother.

Aside from exceptions mentioned above and *Deenie*, all of the remaining novels depicted families who were very concerned and supportive of the character's scoliosis diagnosis and treatment. Elizabeth's mother cried at the initial diagnosis of scoliosis but then encouraged her daughter that everything would be fine (Golden, 2008, p. 17). Her grandmother also offered support, telling her, "scoliosis has the power to bring out the best in you" (Golden, 2008, p. 1). Elizabeth herself commented that "as long as I had family there to support me, I would be fine" (Golden, 2008, p. 61). Laurel's mother expressed concern over her daughter's need to see a doctor for her back and both her mother and father were encouraging of her attempts to hang from a chinup bar for five minutes a day as the doctor ordered. Both of Maisey's parents offered support throughout *There's an "S" on My Back*, and Maisey's mother always had a plan in place for various situations that Maisey faced that presented issues for her brace wearing including camping outings, beach vacations, etc. Patty's parents accepted the doctor's recommendation for a brace but also ensured that she was ready to move forward with treatment, offering to postpone her brace fitting for a few weeks after a big dance event (Pascal, 1992, p. 101). AnnaBeth commented that her family was very supportive and helpful during her treatment, stating "I had shifted paths and was beginning a journey down a different road. But I had some very special people walking with me" (Rakes, 2006, p. 82). Harry commented about his family being supportive but not stifling: "They had that 'we're cool, we're not gonna ask any questions' look on their faces" (Mahony, 2002, p. 89), and throughout both books, they made the effort to be at important chess

and hockey matches and were involved in helping Harry understand the different perspectives and dynamics of his friends. The only family that was not entirely supportive of the character's treatment appeared in *Deenie*. Deenie's mother acted like her daughter's diagnosis was the end of her potential modeling career and thusly the end of her life, crying "Why Deenie?...I had such plans for her. I can't believe this is happening" (Blume, 1991, p. 55 & 59). Also, at Deenie's initial diagnosis, her mother blamed her for slouching and even when the doctor said that the scoliosis was not Deenie's fault, her mother said, "doctors make mistakes all the time" (Blume, 1991, p. 43). Her mother also encouraged friends and family not to talk about scoliosis with Deenie, though her sister approaches her about it anyway (Blume, 1991, p. 64). Deenie's father was supportive but firm with Deenie about wearing the brace, forcing her to wear it to parties and go to school even when she wanted to stay home, telling her "I promised myself I'd be firm...It's hard for me too, Deenie" (Blume, 1991, p. 141).

The diagnosis of scoliosis caused many of the characters to express concern about how their friends would react. AnnaBeth initially tried to keep her diagnosis and pending treatment a secret from her group of friends at school, fearing that she would lose her social status, saying "a physical change [like glasses or braces] spelled doom at junior high...a balancing act between being a freak and someone who was unique and cool" (Rakes, 2006, p. 17). She blurted out her whole story, however, when she saw that a friend was getting positive attention for a new pair of glasses. AnnaBeth was disappointed, however, when all of her friends reacted with pity, "they felt bad for me - kind of like how they felt sorry for the kids in Special Ed" (Rakes, 2006, p. 44). AnnaBeth did have one friend, Kristin, who supported her throughout the novel. Other

characters were also reluctant to share their news, but when they did, they were often met with kindness and support by their close friends. Josiah, in particular, feared revealing his brace to the band, because he thought it would lead to his expulsion, which it did not. Acquaintances, however, could be another story. A boy in *There's an "S"* told Maisey she "used to be perfect...then you got that jaw expander thing...and those glasses...and now you have scurvy" (Mahony, 1999, p. 60). Also, a clique at Charles and Beanie's school refused to associate with Beanie because she was friends with Charles, causing her to call him names and disassociate from him until she realized he was a true friend and worth more to her than the other girls (Mead, 2004). Occasionally, friendships changed because of the character's scoliosis. Close friends got closer, and distant friends grew less important. Also, in the cases of Maisey, Harry, Deenie, Patty, Courtney, and Janie, having scoliosis opened up new friendships with other people with scoliosis, people others considered outcasts, or people who were willing to help them deal with their diagnosis.

Occasionally the novels mentioned characters with disabilities other than scoliosis. In *Deenie*, she struggled to interact with Barbara Curtis who had eczema that Deenie referred to as "creeping crud", Old Lady Murray who had a hunchback, Gena Courtney and other students who were in the "Special Class" because they gave her a "creepy feeling" (Blume, 1991). As she began her treatment, Deenie tried to reach out to Old Lady Murray, developed a friendship with Barbara, and began to sympathize with students like Courtney, rather than fear them. AnnaBeth made several comments about the students in Special Ed including "kids with something wrong with them usually didn't fare well at school" (Rakes, 2006, p. 17) but made no indication that her views had

changed as she underwent her treatment. Patty also demonstrated some fear of disabilities, mentioning that “she had known a boy in her old school who had to wear a brace on one of his legs...if she wore a brace, she wouldn’t be able to dance anymore!” (Pascal, 1992, p. 58).

Discussion

In exploring the prevalence of characters with scoliosis, I was surprised to find that twelve books existed that depicted characters with scoliosis. Previous to this study, I had only heard of *Deenie*. I was also surprised to see that two fairly popular series of the 1990s (*The Babysitters Club* and *Sweet Valley Twins and Friends*) addressed scoliosis. Another unexpected result was the number of boys depicted with scoliosis. Statistically, scoliosis mostly affects girls, and it was surprising that one third of the fictional literature surveyed portrayed boys, especially boys wearing braces. The struggles that Charles faced with his parents highlights one of the biggest issues that physicians cite with boys wearing back braces: compliance. Charles's experience of his father pushing him to not wear the brace and his mother encouraging him to wear it more represents an undercurrent of the research done about brace treatments for scoliosis in boys. Josiah's experience of hiding the brace and trying not to wear it also speaks to the issue of compliance among boys wearing braces.

Despite being pleased that more books than *Deenie* had been published, I was largely disappointed with the quality. Admittedly, the most pleasing aspect of my results is the fact that overall, the books portrayed scoliosis and its treatments in a medically accurate manner, even if they sometimes left out details (about the degree of curvature, type of brace, etc.), the features included were often appropriate. The exceptions to this would be the flexible brace designed specifically for Josiah in *Josiah*, the suggestion that

Laurel help straighten her back by hanging from a chinup bar in *The Bravest Thing*, and the overall impression that *Just Like Always* was out of date with its two-month hospital stay previous to surgery and the general attitudes of the adults toward children in the novel. It is possible that Josiah's special performance brace is modeled after the existing SpinCor brace, but the idea that someone could obtain a flexible brace for certain activities does not seem to fit into common medical practice and may give false expectations to adolescents going through treatment who read the book and want an alternative. As far as the hanging exercises to straighten Laurel's back, medical research has shown that exercises are not effective in preventing or correcting scoliosis, though the belief that exercises could help could have been more prevalent in 1995 when the book was published. As a body of literature, however, the books did not indicate whether or not bracing treatment for scoliosis was effective, which is concerning as studies have shown that bracing treatment can be effective in preventing the need for surgery or for keeping curves from progressing (Sponseller, 2011). Though it could be argued that in the in the books that did not disclose whether or not bracing treatment was effective that the treatment was expected to be effective. The need for surgery in the texts overall, however, seemed exaggerated.

One of the alarming results that turned up was the number of books published through self-publishing companies and the number of books written by the same author. Three of the books were by Mary Mahony (both *Harry* books and *There's an "S"*), and the other two were autobiographical in nature, though Anna Rakes indicates some events may have been fictionalized and therefore her book should be considered fiction, and Elizabeth Golden does not mention any fictionalization to her story. Coming through a

self-publishing company raises some questions about their quality. Why did the author choose the self-publication route? Did they simply not have the funds to go through a standard publisher? Were publishers uninterested in their stories (and if so, why)? Also, what was editing process? The self-publishing route also raises some questions about current publishing practices. Why are these stories about scoliosis not coming through standard publishers? Is it simply not a topic that publishers think will sell? Or are the books being written not up to certain standards? In addition to questions that self-publishing causes, it also may have the effect of the books not being as well known because they lack marketing, notable reviews, etc. Therefore, even if the stories were of high quality, and I am not arguing that they are, they might never reach their audience.

Having one author writing a quarter of the books that depict characters with scoliosis also raises some concerns about authenticity of the characters' experiences. Mary Mahony notes in the backs of several of her books that she strives to write about scoliosis in nearly all of her books because of her experience with her daughter having scoliosis. She also makes a point to try to write about characters with different backgrounds than hers in order to expose readers to different types of people they may encounter in the real world. While this is admirable, her characters (Harry and Maisey) seem to be a little flat. Even though the family makeup of the two characters seems different on the surface, they end up being very similar. Harry lives with his mother, father, and grandfather and has an older half-sister, with whom he is relatively close. Maisey lives with her mother, father, and two brothers, but eventually her grandmother comes to live with them, making both households multi-generational homes. Furthermore, both families are extremely supportive of the characters with scoliosis, to

the point that the characters almost always go to their families to talk about their experiences and emotions. While she claims that her goal is to advance diversity in her writing, Mahony's characters seem very similar in how they cope with scoliosis and how they interact with their families. Furthermore, in both of her novels, there are several characters who have scoliosis and are in various stages of treatment for it. While it is possible that adolescents coping with scoliosis would have friends who also have scoliosis, the prevalence of characters in her stories comes across more as trying to teach readers about the different forms scoliosis can take rather than telling an interesting story.

While twelve books exist that depict characters with scoliosis, access to those books is significantly limited. Of the twelve, only three were available in the public library - *Deenie*, *Just Like Always*, and *Madame Squidley and Beanie* - and only *Deenie* was readily available on the shelf. The other two had to be retrieved from storage. In fact, in searching for the books, the remaining nine had to be obtained as used copies through Amazon Marketplace, as few of them were still in print. Additionally, three of the books obtained this way (*The Bravest Thing*, *Josiah*, and *Plastic Back*) had been library books that were apparently weeded for some reason and then sold. Some of the self-published books appeared to still be available on the publishers' websites. That being said, the fact that many were not out on the shelf would make serendipitous finding nearly impossible for someone just browsing and could impede the ability of someone to obtain a copy of the books even if they knew it existed.

In looking at the results above, I also questioned the depiction of characters as realistic and relatable. *Deenie*, originally published in 1973, seems to be the most realistic portrayal of an adolescent girl experiencing puberty in addition to wearing a brace for

scoliosis, and her character was sympathetic if sometimes melodramatic. For example, Deenie cuts off all of her hair in frustration of not having control of the things happening to her. While many readers may not have had the experience of cutting off their hair, nearly every adolescent has probably felt some level of frustration about not being able to control their bodies, their parents, etc. making her experience relatable. *Madame Squidley and Beanie* also addressed the complexities of growing up under difficult circumstances with realistic characters who were frequently compelling, if not always likeable.

AnnaBeth's character in *Plastic Back* is realistic with very honest descriptions of wearing a back brace and her fears and frustrations with it, but unfortunately the author's language and perspective decisions make the book difficult to read and make the character difficult to relate to. Both Deenie and AnnaBeth are the only characters to acknowledge their changing bodies, and Deenie is the only one to mention anything about changing or emerging sexuality. Elizabeth's story is based on her own experience, so presumably, her depiction is realistic, but overall the characters in the novels almost seemed too accepting of their diagnosis and treatment and more willing to talk to their parents than Erikson's Psychosocial Theory would suggest, although most of the books address the characters' concerns about friends' opinions, which does align with his fifth stage of development that addresses the increasing importance of peers over parents (Taubenheim, 1979). Furthermore, several of the authors indicated that their purpose in writing their stories was to encourage and inspire readers going through similar issues, which many researchers have said should not be the intent of books that portray characters with disabilities. The overall portrayal of characters with scoliosis indicates to me that several of the books (*There's an "S" on My Back, Stand Tall, Harry, Harry*

Scores a Hat Trick, When Life Throws You a Curve) would be ones that parents would like for their children to read and would like to believe their children will behave, while books like *Deenie* and *Plastic Back* are more indicative of actual adolescent thoughts and behaviors. Furthermore, the books from *The Babysitter's Club* and *Sweet Valley Twins and Friends* seem to do an accurate job of portraying scoliosis with characters that are relatable, at least to people who are already readers of those series. In fact, being embedded in popular series (though neither are as popular now as they once were) could be a really effective way to expose readers to scoliosis without making the books feel like they are only for kids with scoliosis.

Limitations

Some limitations to this study could be related to how I searched for books. I only included books that appeared under searches for scoliosis fiction, and while I did this in separate places, it is possible that books with characters with secondary or cursory characters were left out if the term scoliosis was not searchable as part of the book description. Further limitations involve the tool used to analyze the books. As I developed the tool and analyzed the books myself, it is possible that there were oversights or biases present. In the spirit of full disclosure, there may be some bias on my part toward the book *Deenie*, which I read frequently as an adolescent going through my own scoliosis bracing treatment

Future Research

Moving forward, it would be helpful to have reader reviews of the books included in this study (as well as any others that may have been left out). How do readers (both those with and without scoliosis) respond to the texts? Burns (1997) included *Deenie* in a series of texts read and reviewed by adolescent readers. Their reactions to the book were largely positive:

What do kids think? The Burns article has some insight into how people feel about *Deenie*: “Readers reactions to [*Deenie*] were positive: ...how a 12-year-old would act, they were realistic...funny...excellent...brilliant...a bit sad because of her spine...” (p.47). Further research like this for some of the other texts would be useful in gauging whether or not people would read them. Other factors that require further study including library collection holdings, availability of texts in book stores, circulation stats, sales, etc. Also it would be beneficial to get publishers’ perspectives on texts portraying characters with scoliosis to gain insight on whether they receive manuscripts regularly and if they see it as a market need.

Conclusion

While twelve books depicting characters with scoliosis is a start, it is not enough. *Deenie*, though it is a book that has withstood the test of time, is forty years old, and it seems wrong that it is the only book easily available for borrowing or purchase. Quantity, however, is not the highest aim, the quality of texts needs to improve. They cannot simply be books that are medically accurate, though that is important. They need to depict adolescents realistically as diverse and unique people who come from different types of families and represent a variety of experiences. *Deenie* is probably still the most relatable book for today's adolescents to read. *Anna's Twin* and *Patty's Last Dance*, while enjoyable, probably lack relevance with today's readers as they are both from series that are not as popular today. *Just Like Always* is also outdated, though some readers may enjoy the friendship that the two characters develop. While the remaining books may be inspiring and factually accurate, do not strike me as appealing unless the reader is specifically wanting to read about someone who is experiencing what they themselves are experience. The number of self-published novels gives cause to ask questions of the publishing industry about why books with characters with scoliosis are not more prevalent. In Wopperer (2011), Matthew and Clow encourage librarians to alert publishers to collection needs (p. 33), and we should do so if we believe our patrons' needs warrant it. With all of this knowledge about texts who portray characters with scoliosis, we as librarians must be careful not to assume that every reader with scoliosis will want these books, that these books should only be recommended to patrons with

scoliosis, or that books should be included in our collections solely because of their subject matter. However, in understanding the importance of medical accuracy and authenticity in these texts, we can ensure that our collections contain a variety of books that are relatable and useful for our patrons.

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Appendices

Appendix A: Code Used for Analysis

Generic Book Info	Context of Book
Publication Date	Number of pages until scoliosis appears
Publisher	Timespan covered (months/years)
Author's Note - if yes, what does it reveal?	Pop culture references (specific movies, music, clothing) (y/n) - if yes, what?
Cover characteristics	Is scoliosis main topic of book?
Series - if yes, what?	Point of View
Reading Level	
Number of Pages in book	
Presentation of Scoliosis	
Condition present at beginning of novel (y/n)	
Discovered through school screening? (y/n) - if no, then what	
Process from discovery to diagnosis to treatment (if applicable)	
Treatment options (nothing, brace, surgery)	
Brace types discussed	
Brace types used	
Bracing successful?	
Surgery (y/n) Key phrases used (ex. degree of curvature, diving position, raised shoulder/hip, rotation, idiopathic)	
Key phrases used (ex. degree of curvature, diving position, raised shoulder/hip, rotation, idiopathic)	
Age of character at diagnosis	
Words used by characters to describe brace	
Timeframe of treatment (immediately after diagnosis v. monitoring before treatment)	
Medically accurate	
Physician demeanor (kind vs. cold) - does physician offer help with understanding scoliosis?	
Character Traits	
Main or secondary?	
Gender	
Race/Ethnicity (if mentioned)	
Reaction to different stages	
- detection	
- diagnosis	
- treatment	
"type" of character (model, athlete, etc)	
impact of scoliosis on activities (stark before & after?)	
Attitude of character toward disabilities in general	
- does this attitude change?	
Attitude of character toward diagnosis/treatment	
Presence of other "correctives" (orthodonture, glasses, etc)	
Comparison of brace to glasses, etc.	
Is confusion present? (y/n)	
How does character resolve that confusion?	
Musings on how good things were before present?	

coping strategies
Friends and Family
Family structure (married, divorced, multiple siblings, only child)
Positive attitude on part of family? (different by family member?)
How do family members react? (parse out by relationship: mother, father, sibling)
Communication with family members?
Friendships/social circles before scoliosis
Change in friends/friendships after?
Importance of telling friends/social circle
Peers' reactions (pity, support, mockery)
Evidence of influence of family/friend opinions
Presence of other characters with scoliosis?
If yes, what is their role? (someone to talk to who has gone through it, just another character in passing, etc)
Significant quotes

Appendix B: Synopses of Books

Josiah: Young Believer on Tour. Aterburn, Stephen

Thirteen-year-old Josiah is thrilled when he learns that he will be joining the newest teen Christian band sensation, Y2B. Despite his excitement, he is also worried that the back brace he wears for scoliosis will cause problems for him in the band, so he tries to hide it from his fellow band members and manager. When his roommate notices the brace, however, Josiah realizes that he has to be honest with everyone, even if it could mean losing out on his dream.

Deenie. Blume, Judy.

After both a modeling agent and the high school cheerleading coach notice something off about the way Deenie moves, Deenie goes to her doctor where she learns that she has scoliosis and will have to wear a back brace. As if being a teenager wasn't hard enough, she is convinced that the brace will ruin her life. While Deenie struggles to adjust to the brace, she also learns to be more understanding of others who might be "different."

When Life Throws You a Curve: One Girls' Triumph Over Scoliosis. Golden, Elizabeth.

This story is based on Elizabeth's real life experience with scoliosis. As a popular thirteen-year-old squash player, Elizabeth can't imagine how much scoliosis will change her life until she learns that she not only has it but that she will require surgery to correct it. With the support of her family and friends, Elizabeth describes her journey from diagnosis to surgery to recovery.

There's an "S" on my Back: "S" is for Scoliosis. Mahony, Mary.

When the school nurse notices a curve to Maisey's spine during a school scoliosis screening, Maisey begins her journey through frequent doctors' appointments, brace treatment, and eventually surgery to treat her scoliosis. Through it all, Maisey realizes how important family and friends are and also learns that sometimes, a friendship is worth a second chance.

Stand Tall, Harry. Mahony, Mary.

When a hockey injury sidelines Harry and reveals a possible spinal curve, Harry takes up chess and discovers he is very good at it. Throughout the book, Harry's grandfather encourages him to "stand tall" as Harry navigates new friendships and activities. Along the way, he develops a closer relationship with his half-sister and a fellow chess competitor, both of whom also have scoliosis.

Harry Scores a Hat Trick: With Pawns, Pucks and Scoliosis. Mahony, Mary.

The sequel to *Stand Tall, Harry*, this book follows Harry's journey through a major chess tournament and his return to hockey. He also meets more people who have scoliosis and require brace treatments and surgery, while he continues to attend doctors' appointments to monitor his own spine's curve.

Abby's Twin. Martin, Ann M.

Abby, a member of the Babysitters Club, and her twin Anna both have curves detected during a routine scoliosis screening. When Anna requires a brace, and Abby doesn't, Abby worries that they won't be twins anymore and goes overboard trying to make Anna feel better. In the meantime, the BSC must find a way to break the monotony of winter, but lack of snow threatens to ruin their plans.

Madame Squidley and Beanie. Mead, Alice.

Beanie's mom is sick, but nobody seems to know what is wrong with her except that she is frequently tired and can hardly work. Beanie worries about her mother, but she also worries about how she can get into the popular crowd at school. Her best friend Charles is also struggling wearing a brace for scoliosis and dealing with his parents who have very different opinions on how his scoliosis should be treated. When his doctor recommends he wear the brace during school, he worries that everyone will think he's a freak. Together, Beanie and Charles learn the importance of true friendship.

The Bravest Thing. Napoli, Donna Jo.

Ten-year-old Laurel loves animals and wants to be a veterinarian, but when her rabbit refuses to take care of her babies, Laurel struggles to understand and fights to keep the bunnies alive. Meanwhile, Laurel's mother is preoccupied with her aunt's illness, and later, the possibility that Laurel has scoliosis.

Patty's Last Dance. Pascal, Francine.

Patty, a featured character in the *Sweet Valley Twins and Friends* series, is an aspiring ballerina more focused on dancing than making friends. When her dance teacher notices something off about her posture, Patty goes to the doctor and learns she has scoliosis and will have to wear a brace for several years. Worried that she won't be able to continue dancing, Patty confides in a fellow dancer and learns how important friendship can be.

Plastic Back. Rakes, Anna.

When AnnaBeth finds out that she will have to wear a back brace for scoliosis, she worries that she will lose her social standing and will not be able to play basketball as well. Through her treatment, she withstands some cruelty from classmates but learns that true friends and new activities like learning the piano can help her through this tough time.

Just Like Always. Sachs, Elizabeth-Ann.

Courtney and Janie have nothing in common except that they are sharing a hospital room as they await their body casts and surgery for scoliosis. Courtney is reserved and copes by retreating into a fantasy world, while Janie is a trickster and is constantly pulling pranks that land her in trouble. Despite these differences, the girls develop a close friendship that helps them to cope with their hospital stays and scoliosis treatments.