



Meeting the Needs of Parents of Children With Scoliosis: A Qualitative Descriptive Study

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Abstract

Needs of parents with children with scoliosis are complex and depend on their child's treatments. The purpose of this study was to identify needs of parents with children with scoliosis. This qualitative description involved interviews with parents of children at various stages of treatment. A convenience, then purposeful sample of 16 parents (12 mothers, two fathers, and two stepfathers) was interviewed; interviews were transcribed and analyzed using thematic analysis. Parents' needs included: Needing reliable medical information; Desiring information on complementary treatments; Wanting help in supporting and advocating for their child; Needing to protect the child and family; and Seeking connection and support. Although many parents' needs are being met, this study recommends a nursing role aimed at providing parents with reliable medical information, discussing alternative treatments, assisting parents in their role of supporting their child, helping parents in their advocacy efforts, and referring parents to appropriate connections.

Keywords

Scoliosis, parent support, scoliosis surgery, scoliosis bracing, qualitative description, Canada

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Introduction

Adolescent Idiopathic Scoliosis (AIS) is a 3-dimensional deformity of the spine, greater than 10° in an otherwise healthy child 10 years of age or older; the prevalence rate is 0.5–5.2% of children between the ages of 10–16 years (Konieczny et al., 2013). Current treatment recommendations include conservative treatment (observation, scoliosis-specific exercises and/or bracing) for mild/moderate curves and instrumentation surgery for severe curves. There are differing opinions on conservative treatment across the world with North American surgeons adopting more of a “wait and see” position on exercise treatment and European surgeons advocating scoliosis-specific exercises (Bettany-Saltikov et al., 2016, p. 1172). Curves over 30° have a ratio of 10 females to one male (Lonstein, 2006), and surgery to straighten the spine and halt progression of the curve is significantly more common in girls than boys, due to their

increased risk of progression (Negrimi et al., 2018). Parents are therefore faced with several treatment options that may change over time (Lysenko et al., 2016).

This study highlights the perspectives of parents of children with scoliosis. We reviewed the literature that included parents' perspectives for children receiving treatment for scoliosis, as well as literature on parental supports. Qualitative studies of parents of children with scoliosis were

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limited. Of five studies, four involved experiences relating to surgery (Bull and Grogan, 2010; Donnelly et al., 2004; Garrity et al., 2019; Young et al., 2007). One involved decision-making concerning bracing (Donnelly et al., 2004), and one involved experiences of the child participating in an exercise program (Toye et al., 2016). The vast majority of participants in the parent studies were mothers, with only a small number of fathers included in studies by Donnelly et al. (2004), Bull and Grogan (2010), and Young et al. (2007). As expected, given the higher prevalence of girls with AIS, 77–100% of patients in four studies were female (Bull and Grogan, 2010; Donnelly et al., 2004; Toye et al., 2016; Young et al., 2007). The exception was the study by Garrity et al. (2019), who reported that 44% of the patients were female.

Surgery

Most scoliosis research involving parent perspectives relates to their children undergoing spinal surgery. The decision to agree to surgery for their child is stressful for parents: spinal fusion surgery is extremely invasive with a demanding recovery for the patient and parents (LaMontagne et al., 2003). Parent concerns pre-surgery included pain, neurological injury, and return to physical activities (Chan et al., 2017). Parents' stressors and anxiety pre-surgery included parental role loss, post-surgical pain, and worries about poor surgical outcome (Salisbury et al., 2007). Theologis et al. (2016) noted that parents, pre-operatively, only moderately understood surgical risks such as neurological injury or hardware failure and did not understand mobility implications post-operatively.

In a mixed methods study including parent interviews, researchers found that parents of children undergoing scoliosis surgery needed information to help them in their parenting role to prepare their child for procedures and surgery, deal with concerns about the child's pain, address parental fear and stress, and deal with uncertainty (Bull and Grogan, 2010). Adolescent patients seek independence from their parents; thus, it is important that parents and medical professionals include patients in treatment planning to support buy in and improve adherence to treatment (Donnelly et al., 2004). Although parent anxiety decreased pre-to post-operatively, it remained moderately high after surgery (LaMontagne et al., 2003). Reducing parent stress is important not only for the emotional wellbeing of the parent, but also for the protection of the child as parental stress can affect the child's pain and emotional distress (Salisbury et al., 2007).

LaMontagne et al. (2003) identified several coping mechanisms employed by parents to help mediate their stress. The most frequently used emotion-focused method was positively reframing parent concerns by focusing on each step of the child's progress; the most often used problem-focused coping strategy was seeking social supports.

Conservative Treatment

There are limited studies on living with bracing from either a patient or parent perspective. Early studies involving bracing focused on parents' difficulties with adhering to bracing recommendations for their child (Hinrichsen et al., 1985). Tones et al. (2006) reviewed 30 studies prior to 2006 on health-related quality of life in patients with scoliosis, and reported patients having psychological and body image difficulties; only two studies included parent perspectives (Tones et al., 2006). These researchers noted that the health-related quality of life questionnaires that were most often used did not necessarily assess the psychological difficulties experienced by patients.

More recent research involved comparative studies between patient and parent on quality of life and spinal appearance (Misterska et al., 2014) or emotional stress (Misterska et al., 2012). Parents reported moderate stress which increased with their child's brace wearing.

Moramarco (2013), stated that "few ideal treatment protocols exist for scoliosis, especially from the perspective of the adolescent patient and his/her parents" (p. 1). The author advocated for conversations between health care providers, parents, and patients with the treatment goals being directed at minimizing harm and maximizing benefits.

Social Supports for Parents

Studies exploring living day to day with scoliosis are rare. In a study published 35 years ago, researchers noted that family relationships can be strained, and uncertainty over scoliosis treatment plans and prognosis weighs heavily on parents, especially if they are not prepared to manage these stressors (Hinrichsen et al., 1985). These authors examined the potential benefits of a scoliosis association self-help group attended by adolescents with scoliosis and their parents, and adults with scoliosis. Parents reported that they attended these groups to reduce their emotional distress, improve their relationship with their child, facilitate relationships with health care professionals and to help others. Adult-patients, parents, and adolescents all described high satisfaction in their respective groups. Tones et al., 2006, recommended self-help supports for patients and families dealing with scoliosis, and they noted that there were few studies that had explored the psychological impacts of scoliosis (Tones et al., 2006).

More recently, the internet is a source of information and support for parents, however little information exists regarding the level of internet use among parents of children with scoliosis. Baker et al. (2012), used a questionnaire to measure the prevalence of internet support used by parents attending a pediatric scoliosis outpatient clinic. The internet was used by 58% of respondents to search for information on scoliosis, and 94% used the internet to find local resources. The researchers found that corrective surgery was a predictor of internet use and concluded that the internet could be an

information source to augment the medical consultation (Baker et al., 2012). Telehealth has also been an effective source of support for patients and families after surgery, and aids in easing caregiver burden (Young, et al., 2007).

Schwieger et al. (2016) studied the presence and impact of online support groups, primarily through online public messaging accessed through the National Scoliosis Foundation (NSF) website. One message from each of 305 adolescents and 300 parents were analyzed. Most searches by both groups related to scoliosis diagnosis, causes and prognosis. Parents especially accessed the site at initial diagnosis.

Purpose of the Study

This research arose from a clinical question from nurse clinician-researchers involved in providing support to families of children with scoliosis. Parent and patient attendance in the support groups offered by the clinic was declining. The clinic nurses partnered with a university research team to explore the research questions: (1) What are the needs of parents of children with scoliosis at different stages of care? and (2) How are the parents' needs being met, and what supports could be implemented by the clinic or in the community? A related study explored the needs of patients. This article documents the results of the study of the needs of and supports for the parents.

Methods

Design

This Qualitative Description study involved semi-structured individual interviews with mothers or fathers of children with scoliosis, analyzed through thematic analysis. Qualitative Description is used in health care research to learn from perspectives of participants directly experiencing a phenomenon, is often used when little is known from the participants and is used to influence health care interventions (Bradshaw et al., 2017). This methodology fits well with the research question as the topic emerged from a clinical concern and the participants are those directly affected by the condition (Bradshaw et al., 2017). Our research team included perspectives from Nursing (scoliosis nurse practitioner Southon Hryniuk and advanced practice nurse Shearer), Psychology (Willson and Gingrich), and Rehabilitation Science (Rogers and Gingrich); four authors are also experienced researchers. The Interview Guide is appended as [Supplementary File 1](#).

Recruitment

All participants were recruited by the Scoliosis Research Coordinator at a spinal deformity clinic in a pediatric hospital in Western Canada. Participants were parents of patients

attending the clinic the days the interviewer attended clinic. Eligibility criteria required that the participant converse in English, and the patient/child of the participants be between 10 and 16 years and diagnosed with a spinal deformity with or without related syndromes or co-morbidities. The coordinator invited the parent(s) accompanying the child to participate in individual interviews. We started with convenience sampling; then to obtain further information from participants across stages of care and to obtain more fathers, we did purposeful sampling for the last six participants. This also provided more rich description about emerging themes especially relating surgical and holistic care and for more information from father perspectives (Coyne, 1997; Palinkas et al., 2015).

We obtained ethical approval from The King's University and University of Alberta Ethics Boards. Participants provided written consent, data were kept secure, and pseudonyms were assigned to participants.

Description of Participants

We completed sixteen semi-structured interviews (12 mothers, two fathers, and two stepfathers of 15 patients); in one case where both parents attended clinic, they were interviewed separately. Four parents were from rural communities and the rest were from urban centers. Of the 16 parents, all were Canadian but one, who was from the United States. One parent volunteered the information that they were Mexican Canadian. Our distribution between mothers and fathers as participants is similar to informal numbers obtained from the clinic which indicated that for 75% of the appointments the child is only accompanied by the mother. 13 participants were parents of children with idiopathic scoliosis and three were parents of children with additional comorbid conditions; these were Marfan syndrome, Chiari malformation, and autism spectrum disorder (ASD). Sixty percent of those diagnosed with Marfan syndrome have scoliosis (Child, 2017), and Chiari malformations are also associated with scoliosis (Kelly et al., 2015). A systematic review in 2019 addressing spinal deformities and ASD indicated that, although many children with ASD have postural disorders and there is some evidence in clinical settings that these conditions can co-exist, the association between these two disorders is understudied and prevalence is currently unknown (Trentin et al., 2019).

Note that since this article is about the parent perspective, we refer to the *adolescents* with scoliosis as the parents' *children*. The children were aged 10–16 years ($M = 13.1$ years), 12 girls and three boys. This sample of 80% girls closely approximates the prevalence rates of scoliosis at between 3:1 for girls (Konieczny et al., 2013) to 10:1 for girls (Lonstein, 2006), depending on the angle of the curve. Most children followed a trajectory of receiving the diagnosis, followed by a plan that may have included options of bracing, surgery, and/or periods of monitoring. Six children were in the initial fitting stages of bracing; three others were

undergoing bracing or had bracing in the past. Two were in the stage of monitoring. Two children were awaiting surgery and two were post-surgical.

Data Collection

The interview guide was co-developed by the nurse clinicians (authors Shearer and Southon Hryniuk) and researchers (authors Willson, Gingrich, and Rogers). We asked parents about their needs at different stages from diagnosis through to bracing, monitoring or pre/post-surgery, and ways in which supports and resources could meet their needs. All interviews were done by an experienced qualitative researcher (Rogers) or research trainee (Gingrich, following in-depth training). The interviewers and team members conducting the analysis were not part of the clinic and did not recruit or know the participants. Interviews were conducted from March 2017–January 2018; 14 parents were interviewed in person at the clinic, university, or at home and two were interviewed by phone. Interviews ranged from 20 to 60 minutes and were audio-recorded and transcribed.

Data Analysis

We did thematic analysis of the transcribed interview data (Braun and Clarke, 2006, 2019). This involved becoming familiar with the transcripts, doing initial coding, and inductively developing themes from the codes. Authors Gingrich and Rogers initially inductively coded two interviews, compared notes, and then coded two more interviews and established a coding structure agreed upon by Gingrich, Rogers, and Willson. Initial codes kept very close to the research data (Creswell, 2014; Saldana and Omasta, 2018). Rogers and Gingrich coded six interviews before proceeding with further interviews. Gingrich and Rogers then coded the remaining interviews and organized the coded data into themes. We further explored these themes as the interviews progressed and through construction of data code and theme charts. Themes emerged from the data rather than deductively obtaining them from pre-existing themes in the literature, and each theme reflected a trend within the data set (Braun and Clarke, 2006, 2019). Through an iterative process, we added new codes to the coding structure as they emerged in the analysis. Both interviewers did reflective memoing, post-interview field notes and kept an audit trail. We used NVivo11 to organize the data (QSR International, 2016).

Rigor

Based on the seminal work of Lincoln and Guba (1985), we established rigor or trustworthiness through building trust and rapport and showing empathy (credibility); use of an audit trail, reflective journaling and use of direct quotes (confirmability and dependability); and providing rich description, purposeful sampling and demographic information

(transferability) (Bradshaw et al., 2017; Finlay, 2006; Lincoln and Guba, 1985). The rigor of our findings was enhanced by the practice of coders working together to agree on the definition of codes, and the attainment of rich description through attending to the number and type of participants (Morse, 2015).

We started with convenience sampling and reviewed demographics after eight interviews; we then purposively sampled more parents of patients undergoing surgery. Code saturation was attained after interview 12. After review of emergent themes, demographic information, and the distribution of parents across stages (bracing, monitoring, pre-surgery, and post-surgery) of scoliosis, we completed four more interviews to further obtain rich description and depth in the interviews (Hennink et al., 2017). Rigor was also enhanced by congruence among research question, methods, and data analysis, and interpretation relates directly to the experiences of the participants (Bradshaw et al., 2017).

Results

Parents conveyed stories of their needs at different stages; these needs were grouped into five inter-related main themes: Needing reliable medical information; Desiring information on complementary treatments; Wanting help in supporting and advocating for their child; Needing to protect the child and family; and Seeking connection and support. The first four themes relate to parent expectations from the clinic and the last theme involves needs for support from other parents.

Needing Reliable Medical Information

This theme relates to the type and timing of reliable medical information that parents sought throughout all stages, from initial diagnosis to each change of the treatment plan. This includes the timing of information, and how parents weighed the information provided by medical professionals to make it specific to their own needs.

Twenty-five percent of patients in this study did not have a formal diagnosis of scoliosis until their first clinic visit. Before their initial visit, many parents experienced stress at the lack of information they felt was available to them. Most fear experienced by parents was associated with the initial shock of diagnosis and stemmed from uncertainty about the future. As one father stated, “just because you got a label doesn’t mean I know what to do with it.” Uncertainties, especially from fathers, included whether scoliosis would impact their child’s future and ability to participate in daily life activities both short and long term. One father summarized his concerns: “How is he going to be 10 years from now, 20 years from now? How is this going to affect his quality of life?”

Parents highly valued reliable medical information and education provided by doctors or the NP, which helped to inform them about their child’s treatment plan. Accessing

their child-specific medical information, such as the degree of their child's curve or reviewing x-rays with clinic staff helped to assuage fears. "I imagined it much worse than the actual x-rays... The NP made me feel better about it." At initial diagnosis the parents' information needs tended to outweigh a desire for anecdotal stories from other parents.

Despite having initial informational needs met through clinic, post-clinic they frequently turned to potentially less reliable information sources. However, all parents were clear that whatever information they sought needed to be from reputable sources. "I try and make sure I stick to the medical stuff that's on the Net, not the... secondary opinions section." Almost every parent reported doing some form of online research. Many parents described combining the information they received on their own with the clinic information. "I think it's good to get some information from Google, it's good to get some information from the doctor, and then go back to the doctor again." One mother reflected "I think the first response for everyone is to WEB MD and ask, what's the worst-case scenario?"

Parents were very explicit about what kinds of supports would work for them. Some sought information and connection primarily from online supports, mostly due to time and distance issues. They would prefer online resources such as a clinic website with reliable information (which the clinic does not provide), or an online monitored site for parents. Families of children with an atypical presentation of scoliosis found it challenging to find reliable information online and preferred information from the clinic specific to their child.

When it came to deciding on a plan of care for their child, some parents described a process of weighing the information obtained from different sources and then deciding on a plan that worked for their child and family and 1/3 of parents took on ownership of their role in managing their child's medical condition:

It was [the surgeon's] opinion that maybe we don't have to brace ... but slowly reading and getting more information from hospital and internet and all around... and we [mother, father and child] came to the conclusion that it would be maybe good that she has to get braced. ... We got [the surgeon's] blessing.

One father took this further, by appearing to trust his own information more than what the clinic provided.

I have no idea what scoliosis is. I'll find out when I get home, from the Internet. ... That's the best way to find out, 'cause I know what it is now, I can actually look it up and find out what it is. ... My wife was given [information from the clinic it] but I didn't really pay attention to that.

There was a small group of parents who sought their own information, but their reason appeared to be more related to not being comfortable with or agreeing with the clinic recommendations, especially if it involved long periods of

"doing nothing." One mother did not accept the prognosis her daughter was given to just wait until her child was older for surgery.

The main thing that I remember is basically they said, "we're going to stick her in a brace ... and you're looking at like rods down her spine by the time that she's 12". ... When I heard that I kinda went "mmm... I need to some research here". I did probably hundreds maybe thousands of hours.

Parents who had prior knowledge about scoliosis had fewer information needs than did those who were unfamiliar with the diagnosis. "I have scoliosis myself, and so does my older daughter, so it's not new to me."

New needs for information surfaced once bracing was recommended. A father said:

The only thing I know right now, is we need to have her into some kind of a program where it helps her to stay the way she is or it helps correct her, and if that's the brace, then that's what we need to do. They're going to give us somebody to talk to, which is good.

Some parents found relief from the clinic during the monitoring phase, like this parent of a child with a relatively minor curve. "I felt a sense of relief that it was going to be monitored. ... It's a sit and wait process. I'm confident just knowing we have that appointment in 6 months." Other parents were discouraged by waiting to see if the curve progressed without being proactive about doing something. A parent of a young child who had a curve that was progressing was discouraged with a plan to wait: "To me that was just like no hope. What do you mean she's in a brace now and there's nothing that we can do for 5 years except just watch it get worse?"

Parents had new concerns if it was decided that the child needed surgery. Parents wondered if their child's condition would worsen or fail to improve, and they feared surgical complications. They found comfort in the expert opinion and candid conversations regarding the necessity of risks, and future implications of spinal surgery. Knowing that the surgeon believed that surgery was the proper treatment brought some parents a sense of comfort and relief in moving forward. Trust with the surgeon was of paramount importance.

Once it was determined that the child needed surgery, parents felt optimism for their treatment plans: "(Scoliosis) is concerning but because I know there's going to be a solution to the problem; I'm not so worried about it." Treatment plans helped parents feel comfortable and confident that their child's condition would improve, and this trust afforded them the ability to say that they could comfortably take it one step at a time.

Parents felt that they received information about the surgery and the risks of surgery, but their issues were more about the timing of receiving more details about post-surgical needs. They wanted to know "more about after surgery. Can she go to the bathroom by herself?" Similarly, another parent

wanted to know “exactly what would happen, ...what he would be enduring afterward; if he needed physio...and we didn’t get that until the hospital [intake].” While this information was provided at the immediate pre-operative appointment, it was clear that parents wanted the information months earlier. When information was not available, parents sought out other parents to learn what to expect with surgery. “I was telling some ladies at a retreat what we were going through, and they [said] ‘We have somebody that we know that went through it,’ and they gave me that name.”

Rural families expressed information needs, especially around the time of the diagnosis and expressed frustration at the discrepancy between the perceived ease of medical access in urban centers compared to their rural communities. Post-surgical planning was particularly needed for rural families, who had to prepare for a several hour drive home.

Desiring Information on Complementary Treatments

This theme discusses some parents’ desire for the clinic to be open to a broader approach to care and discuss alternative treatments. One area of frustration for some parents was the lack of acceptance or discussion about more holistic and alternative treatments for scoliosis from the clinic. A few parents who wanted a more holistic approach to care did extensive research into complementary and alternative medicine and therapies, which led them to take charge and create more holistic plans for their children. Many families enrolled their children in back-strengthening activities such as Pilates, yoga, and swimming lessons. Parents understood that physicians were only able to support established therapies but were still frustrated when alternative approaches were not discussed. One parent commented:

I remember asking “there has to be something I can do?” ...There has to be a way that they could have said something like “this is not scientific, but you might want to look into this - we are not promoting this” or something like “we’re not standing behind any of this, but people have found success with ... whatever”.

Three mothers went to extensive lengths to develop teams of allied health care providers (such as osteopaths, physiotherapists, acupuncturists, or chiropractors) that they believed promoted spinal straightening and muscle strengthening of their child. Parents reported that through the alternative treatments, their children’s spines had either straightened significantly or had not worsened. This led them to believe that other families should have the chance to benefit from this knowledge, and they questioned the obligation of the clinic to share only “Western” medical information.

It appeared that for the small number of families that used these external supports, it was because the child was either in a long monitoring phase with no intervention, or their questions about complementary or alternative treatments and therapies had been dismissed by the surgeon. A mother said,

“we’re not going to sit and wait.” Parents consistently found it helpful to be told of practical ways they could support their child. This not only gave parents something concrete/tangible to focus on, but they reported it gave them a sense of empowerment. When community professionals discussed ways that families could be actively involved in treatment activities, it helped them feel that they had some control over their child’s state of health.

Wanting Help in Supporting and Advocating for their Child

Parents sought help from the clinic in how to support their child through the different stages of the child’s treatment. They described deeply connecting to what their child was going through. Parents also discussed their needs in advocating in different situations, and in helping their child with self-advocacy.

Some parents struggled to talk to their child about scoliosis and did not know how or what to tell their child, while others felt comfortable and confident including their child in treatment decisions and discussing the diagnostic implications with them. The ability of parents to talk to the child often depended on the child’s maturity and attitude, as some parents felt that their child did not want to talk about their condition. It seemed that parents who had open discussions, stated facts, and answered their child’s questions reported the most positive communication with their child.

Some parents found it challenging to enforce brace wearing fulltime, especially when their child was highly anxious about wearing it. The anguish in this parent is apparent as she tries to balance her child’s needs with the directions for wearing the brace. Encouraging their child to adhere to treatment plans could be stressful. “She’s crying and upset, and I have to lay a rule at some point and so that was a bit hard for both of us.” Although a father had expressed that his daughter took on some of the responsibility, he wanted to know “How do (other) kids deal with the brace?” For a mother with a child with a developmental disability who needed a brace, there were additional explanations needed, and normalizing of the brace through implementing necessary structure: “I would have to explain to her, especially with her (comorbidity), that it’s now her routine... it’s something she has to do.”

Parents reported that their children felt alone, as they usually did not know someone else who had scoliosis. However, one girl:

found a book called “Braced” was reading it at school, and her friends became interested in her book. ... The girls are taking turns reading the book, and now they’re all interested in what she is going through ... she’s finding that she’s getting a lot of support from her friends.

Parents reported varied confidence in discussing surgery with their child; some parents were comfortable talking to their child about surgery: “She’s 12 going on 30. I just tell her straight up what’s going to happen; ...I don’t think she’s really thinking that this is such a big deal. Or at least she hasn’t expressed any anxiety about it.” Other parents wished they had support and wanted to talk with someone else; “I have no idea, whatsoever, how to talk to her about surgery.”

Life stressors such as time constraints, finances, other children and family, and hectic schedules compounded the stress of their child’s condition. One mother believed that she was not as involved with her child’s care due to logistical constraints. “I almost feel like I’m not maybe as available as I should be for her because I’m a working parent and (my child) is struggling.”

Parents identified closely with their children and what they were going through. “I had a couple little minor like teary moments when I realized ‘oh my goodness he’s missing this, this and this and he’s always going to be braced.’” A father could place himself in his daughter’s position saying, “It’s going to be scary for her when she gets a full brace.” It was not unusual for them to personalize their child’s journey to self-reference as parents, such as “we got into clinic quite quickly... and we went through some MRIs.” One father, when his daughter was transitioning to needing a brace, caught himself saying, “it’s going to be—I need the brace—*Giselle* needs a brace...” A mother referred to herself when talking about her son’s anticipated surgery, saying “when we knew we were having surgery ...” Another mother also referenced herself, “Oh my goodness ... now what? Should I need surgery” (italics added). These examples showed the deep empathy parents felt for their children.

The biggest area of need for advocacy for the parents and their children was at school. Parents felt alone in trying to explain scoliosis to the school; their children were not believed when they requested accommodations, such as needing “to stand or move around a little bit during class” when it was painful to sit for prolonged periods of time. A parent reported that their child, while in pain and awaiting surgery, “felt that it was a bit silly that the phys. ed. teacher made him go to (the office), and they’re, like, ‘Why can’t you do (Phys Ed.)?’ And he’d just say, ‘Look at my back.’”

The most success with advocacy was with parents who already had a relationship with the teachers, were proactive in their efforts, and who spoke in person with the teachers. One parent second-guessed her decision not to talk to the school to “respect my child’s privacy, but now I’m realizing that the more she talks about it the more support she feels.”

Often parents found ways of empowering their child to self-manage and take responsibility for their treatment:

She was a little bit reserved about [the brace] in the beginning but after she read the books and mom showed her how many movie stars have scoliosis; she’s like “oh that’s cool stuff”. We’re letting

her more on her own to deal with it, ... and explain and motivate her to do her exercises regularly.

Children also recognized the need for information and advocacy; a father reported that his daughter was writing a book about scoliosis to help other children. Parents also helped their child to advocate for themselves.

[Daughter] said “the other day [teacher] asked me to referee.” I told [child], “you cannot go to gym because you get [hit by] a ball or somebody goes crazy then you’re back in the hospital” ... she’s only 12 so you don’t want to rock the boat and she has to be her own advocate at that age.

Needing to Protect the Child and Family

Unlike the other themes where parent needs were described as *needs for* something, this theme describes what the authors interpreted that parents *needed to* do. Parents tended to protect themselves and their child from negative or worrisome information from internet sources, other parents and even from medical professionals. In this protector role, they tried to appear strong throughout their child’s medical challenges. This included protecting their child from too much information about surgery:

I think I was probably keeping myself a bit, not uninformed, but I kept some distance... it was such a big surgery and I think for self-preservation... I didn’t want to be a wreck for her. I wanted to be strong. I don’t know if I actually talked to [daughter] about what the worst-case scenario would be.

Another parent did not want the child to be exposed to the possibility of a negative outcome.

[When] they said that we’re going to put her in the brace and hopefully it won’t get a lot worse ... I just thought, I don’t want that spoken over my child. ... Thank you for the information and I do need to know the severity ... but she didn’t need that in her head. ... I wanted her believing “hey, we can do something about this”.

Some parents expressed a concern about also protecting themselves and their family when seeking connection with other parents, especially online, unless the site was monitored by a professional. This included a desire to do brief background checks on individuals before adding them to a Facebook support group, avoiding forums due to a fear of psychologically “unbalanced” individuals, and awareness that some individuals hold different, or more negative and helpless attitudes towards their condition. “I just don’t like alarmist forums and being worried about things that I don’t have to worry about. I usually just stick with the doctors and the nurses and more official information rather than anecdotal.” Another parent echoed those same concerns about social media,

I was worried about social media. It gets a little bit carried away sometimes and maybe it's not always good. People exaggerate and [I prefer] maybe something a little more professionally done 'cause you know how people can kind of get carried away.

Seeking Connection and Support

Parents sought connection with other parents, both from their inner circle and from other parents of children with scoliosis. This need was for information and/or emotional support. This theme includes how mothers and fathers differ in their needs for connection with other parents, and circumstances for and timing of needing supports from parents of children with scoliosis.

Many parents reported emotional difficulties during their child's journey with scoliosis. Parents often cited spouses and partners as sources of connection and support. Parents tended to rely on existing support systems through parents in the child's regular activities rather than seeking professional support. "We have a good support group with her dance. It's like another second family; they're really close." Strong themes of stress and anxiety about the medical aspect of their journey with scoliosis were present, and many parents expressed sadness due to the child's medical challenges. Three mothers identified feelings of guilt due to having been the source of their child's genetic inheritance of scoliosis and sought connection with other mothers who shared the same feelings: "I felt bad because I know it's hereditary and I know it's on my side."

When asked about attending parent support groups, fathers appeared to express less need for emotional support than the mothers and focused more on obtaining information. A father said "Well, for emotional support, I don't think we needed anything. We were shocked at first, of course." Instead, he sought "an understanding [of scoliosis] where I can explain to the missus." Another father, when asked about where he would go for emotional support, said "Nowhere. I'll just read online, figure out what she has, and then try to help her out as best as I can." When asked about attending parents support groups, another father expressed "that's actually a question for my wife. Myself, I wouldn't be interested but my wife probably would be. I honestly don't think I'd have the patience for that." The fourth father also deferred to his wife. "You'd have to talk more with my wife and like I'm just kind of at the moment taking information [in], and talking with [the clinic]." Mothers tended to connect with other parents for informational support, and a few mothers expressed particular needs for emotional support from another mother.

Timing for parent connections was key. Although initially preferring information from medical professionals, after becoming familiar with their child's specific needs parents sought experiential perspectives and stories from other parents.

So I sort of just tried to let it come from medical professionals and... then after the healing process begins maybe that's the time to start hearing people's stories and how their lives changed from it and how they're able to carry on with a regular life, without it being horror stories.

Both mothers and fathers were less likely to seek connection with others if "things were going well." A mother said "It really all depends. Perhaps if our experience were more negative then I could understand wanting to get some ideas or bouncing something off but no I wouldn't say I need it. I'd be open to it if someone needed support from me." Similarly, a father said, "If she can handle (the brace), great, and if she can't handle it, then we may seek something else." Another mother reported that her need for support from another parent varies day by day:

There are days when I need a whole bunch of support and there are other days when I'm like oh my, what do I do with this winey kid who has got a sore back. So, I just need a quick vent and just move on. ... It's the parents who are looking for help. [my daughter] is not out there looking for it, the same way as I am.

A few parents expressed no need for social supports, had none to rely on, or were too busy, like this mother of two children with special needs.

I'm going to be honest. I don't rely on a lot of other people. ...Between my son's [diagnosis], my daughter who has [comorbidity], ... I don't have time to go to a support group to deal with life cause I'm in it. For me I'm a warrior, pick up my battle axe and go to town. My support group is my plan and my structure. ... And sometimes I feel bad for saying that cause a lot of people lean on those things: family, friends, support groups. And I'm like, "Does that make me weird?"

Parents wanted the clinic to connect them to a potential pool of parents, vetted by the clinic, who were willing to support others, one-on-one, as this could provide quick responses to simple questions. Six parents stated that they would be willing to support another parent, especially when their family was further along in their journey. A small group of mothers wanted access to other parents specifically to receive information that was not forthcoming from the clinic.

I think to me like all along the way it would have been great to have just something other than the doctors. ... It really would have been great to have another side offered... like a parental side or "hey there are other options out there, we don't promote them you know cause we don't know all the information on it but like, hey, there is more information out there".

Most parents reflected that it would be beneficial to have the option of being connected with other parents, vetted through the clinic, so they could have the option whether to access others.

I know, personally, I probably wouldn't go to a parent support group just because of the timing and ... you're busy, but if you were given information and you could spend 10 minutes here or there trying to find, like going on that and finding that information it would be helpful, I think.

This mother summarized the sentiment expressed by many parents:

I can't complain about what I got in terms of help from the [clinic] but maybe yeah somebody who's actually gone through it... So, if that was organized through the [clinic], say, "if you were interested here's some contact people" they could be anywhere we could Skype or just say "hey, this is what we're going through, is that normal?"

Discussion

These findings provided insight into the experiences and needs of parents as their children went through different stages of scoliosis treatment, parents' decisions to self-manage their child's care, and supports that have been helpful and are desired in meeting parental needs. This research filled a significant gap in the literature related to parents' needs and a potential role for nurses in meeting those needs. Parenting a child with scoliosis through the stages of scoliosis treatment and management can be a complex (Lysenko et al., 2016) and stressful (LaMontagne et al., 2003) process, and it is an experience that is not uncommon, given an AIS prevalence rate of 0.5–5.2% for children between 10 and 16 (Konieczny et al., 2013). Research on the experience of parents is scant (Tones et al., 2006). This research used a qualitative approach to understand our participants' experiences with a goal of identifying these parents' needs and discerning how or whether these needs are being or could be met by clinic nurses.

Like research by Rullander et al. (2013), our data reflect emotional, social, and informational needs of parents. Parents had emotional needs related to fear, stress, and anxiety associated with their child's condition, treatment, and prognosis. Social needs included parents' (mostly mothers') desires to connect with other parents who share their experience, and who may be able to provide some insight and support. Informational needs included a need for specific medical information unique to their child's diagnosis and management.

Information on Medical and Complementary/Alternative Therapies

At the time of diagnosis, the parents' primary need was informational, which they sought initially through the scoliosis clinic. Consistent with findings of Salisbury et al. (2007), parents practiced both emotion- and problem-focused coping strategies. Parental fear and uncertainty can be mediated by receiving individualized medical information, and, later, by connecting with other parents to learn about their experiences and to gain social support. Parents in our study attempted to mediate their own stress and anxiety with socio-emotional coping styles while awaiting spinal surgery. Parents were most reassured by the trusting relationship

developed between them and clinic staff and surgeons. They were comforted by the surgeons' delivery of surgery details and recovery information.

As their journey progressed, and often in absence of information and support, parents sought their own information through online resources, finding other parents with similar experiences or sought alternative and even non-standard treatment approaches. Complementary and alternative medicine (CAM), sometimes called holistic medicine, has been found to be an increasingly popular choice among families of children with chronic illnesses and disabilities in North America (American Academy of Pediatrics Committee on Children with Disabilities, 2001). The pediatric hospital at which our sample was recruited has done research into other specialty pediatric clinics on site and has found 71% of pediatric patients reported using CAM (Adams et al., 2013). Parents may turn to CAM therapies when biomedical treatments are complex, uncomfortable, or do not offer the promise of a cure (American Academy of Pediatrics Committee on Children with Disabilities, 2001). This may explain why some parents in our study preferred CAM over conventional approaches to scoliosis treatment in Western medicine (observation, bracing, and surgery). With access to the internet, parents discovered treatments that were available in Europe, and not being familiar with different approaches to care, were confused when options like specific exercise programs were not offered by the clinic (Bettany-Saltikov et al., 2016).

Parents whose child required a long period of monitoring, with or without intervention, took initiative in developing treatment plans and activities with multi-disciplinary medical professionals. Toye et al., 2016, reported in their exercise study for scoliosis, that parents who were not assigned to the exercise treatment group said that "they would have sought alternative therapies" (e.g., Yoga or Pilates: p. 1843), just like parents in our study did. Additionally, similar to our results, Toye et al., 2016, reported that parents chose to do something rather than nothing as that increased their sense of control.

To date there is little evidence that CAM therapies are beneficial in the treatment of pediatric scoliosis. One systematic review of spinal manipulative therapy for Adolescent Idiopathic Scoliosis found only four studies with small sample sizes and concluded there was insufficient evidence to determine efficacy (Théroux et al., 2017). The Scoliosis Research Society (2020) states, "Alternative treatments to prevent curve progression or prevent further curve progression such as chiropractic medicine, physical therapy, and yoga have not demonstrated any scientific value in the treatment of scoliosis." A recent systematic review concluded that although some scoliosis-specific exercise (SSE) trials have demonstrated improvements in radiographic as well as patient-reported outcomes, overall, there is insufficient evidence to prove that SSE can reduce Cobb angle or improve trunk balance and Quality of Life (Fan et al., 2020). This

creates an ethical tension between the biomedicine-trained orthopaedist/nurse and the family who wish to seek CAM treatment.

Self-managed Care

Previous research (Simons et al., 2001; Ygge and Arnetz, 2004) has demonstrated parents' desire to be involved in their child's medical treatment, and our research supports this theme while providing a more in-depth discussion of treatment planning and parental involvement, even to the point of some parents assuming a case management role. In a study on relatives of patients with traumatic brain injury (Guldager et al., 2019), a "warrior" category of caregiver was identified: those who took an active role in training and rehabilitation and provided their own insights on the patient's condition with the health care professionals. These warrior relatives share features in common with the parents in our sample who took charge of their child's progression through scoliosis treatment. In their study, Guldager et al. (2019) also identified "observer" relatives who accepted the treatment decisions of medical professionals more passively. In the current study, we also perceived that some of our parents were in this category; while prepared to work with their child, they accepted treatment decisions without apparent question.

Research suggests that health outcomes tend to improve for families that engage in self-management of chronic conditions (Ryan and Sawin, 2009). Parents demonstrated increased efficacy when they were given activities to do with or for their child. Self-management of health conditions like scoliosis, however, may come with risks of misinformation, and case management of children would, optimally, be directed by medical professionals with involvement from family members. In one of the few studies on family self-management, researchers Ryan and Sawin (2009) reported that there are insufficient processes in place for clinics/hospitals to support family self-management (Ryan and Sawin, 2009). Families are typically left on their own to research and evaluate health promoting activities for their child (Ryan and Sawin, 2009), as the parents in our study reported.

Parent/Child Engagement

Parents were very engaged with their children's treatments. The mother who may have mis-spoken about herself rather than her child needing surgery may have been an example of a mother displaying empathy, imaging what one's child is going through *as if* it were oneself, that loses the *as if*. Informal (non-professional) caregiver empathy has been linked to positive outcomes for the cared for when the cared for are dementia patients (Panyavin et al., 2015), but research on the effects of empathy on the caregiver (whether of elderly incapacitated, Panyavin et al., 2015; or of general-

population adolescents, e.g., Manczak et al., 2016) have produced mixed results (Jütten et al., 2019). Caregiver empathy produces both positive and negative outcomes in the caregiver. Research on empathy suggests that we ought to be studying two dimensions of empathy separately to better understand the effects: these are a cognitive component (being able to understand what someone else is experiencing), and an affective component (feeling what someone else feels; Baron-Cohen and Wheelwright, 2004). The mother in our study who has lost the *as if* seems to be experiencing a high level of affective empathy. In a recent study on informal caregivers (Jütten et al., 2019), the higher the caregiver's affective empathy, the higher their anxiety. Cognitive empathy produced more healthy outcomes, and the authors recommend interventions that would decrease affective and increase cognitive empathy in caregivers. While we observed strong identification in only a few of our participants, it seems prudent for clinic nurses to watch for this type of over-identification in parents of adolescents receiving news of a scoliosis diagnosis or potentially challenging treatments.

Parental Protection

In our study, parents played a protective role, shielding their child and themselves from negative information. Parental protection of the child and other family members, as seen in our study, is present in the literature for other chronic health conditions such as congenital heart disease (CHD), whereby parents typically safeguarded their child, the other parent and themselves when managing their child with CHD (Rempel and Harrison, 2007). Our participants safeguarded their child from too much information about surgery, and in some cases also safeguarded themselves from knowing too many risks about surgery. Again, trust in the health care providers was critical in families being able to protect themselves and their families.

Connection with Other Parents

In our research, parents reported a spectrum of emotions, including feelings of guilt at being responsible for having been the source of their child's genetic inheritance of scoliosis. Research by LaMontagne et al., (2003) found similar themes of guilt at the genetic role they played in their child's scoliosis, and one can expect that these feelings of guilt contribute to parental anxiety and general negative emotions surrounding their child's condition. In our study, parents believed that connection with other parents would be the most effective means of reducing this anxiety and guilt, as parents could engage in supporting one another amid these emotions.

As children undergo treatment for scoliosis, it is understandable that their parents experience their own stress related to their child's condition. Parents in our study reported wanting

contact information for a parent who was further along the journey, or access to a monitored social media site, both of which could be facilitated through a clinic. According to [Garrity et al. \(2019\)](#), parents whose children had undergone spinal fusion had specific opinions about what kind of information they would convey to other parents considering surgery.

Study Limitations

This research was based on interviews done through one clinic. Parents who were willing to be interviewed may have tended to be more involved parents, and thus resulted in data that suggested a general desire to play an active role in their child's treatment. We had mostly Canadian participants, and only four fathers. Fathers' viewpoints tend to be under-represented in research ([Schippers et al., 2020](#); [Swallow et al., 2011](#); [Tiedje and Darling-Fisher, 2003](#)). While we intend this information to be useful to practitioners in other places and contexts, we acknowledge that our sample may not be fully representational.

Implications for Future Research

Although the sampling strategy moved from a convenience sample to a more purposive sample, in our sample there were only four fathers represented. In addition, there were still a limited number of families of children with comorbidities in addition to the scoliosis, and there were few rural families. Preliminary data indicate that children with co-morbidities and rural families may have more challenges negotiating the realities of life with scoliosis, and further research of these populations is needed to continue to improve specialized health services and address patient and family needs.

Clinical Implications

Effective communication between parent and medical staff is important as it allows parents to play a significant role in their child's treatment. Clinic nurses are in an ideal position to meet the needs of parents by providing education and facilitating social support in the scoliosis clinic. This research has identified several ways in which parents can be supported by a scoliosis clinic nurse. As orthopedic surgeons are typically focused on surgical treatment plans, clinic nurses may be able to address the unmet needs of parents that have been identified in this study.

Nurse led models of care are well situated to provide continuity of care as RNs play a crucial role ensuring individuals, families and/or caregivers are included in the design of cohesive and manageable care plans, grounded in the individual's unique values, goals and preferences and needs ([Swan et al., 2019](#)). With their focus on self-management, education, counseling of families and individuals, advocacy, population health management, teamwork and collaboration,

communication and transition planning, and person-centered care planning, nurses are ideally situated to foster consistent care across the continuum of care, especially when applying this lens to those who suffer from chronic illnesses ([Swan et al., 2019](#)). Patients and their families in the scoliosis clinic are often followed for many years. Their unique needs around support and education would be well met with a coordinated nursing approach.

[Figure 1](#) indicates specific roles for clinic nurses as they support parents. Reliable individualized medical information regarding the child's curvature, x-rays, and future implications is a critical need for parents, and clinics can provide this medical information through clinic visits, online resources, and educational websites. Since many parents felt overwhelmed at their initial clinic visit, a follow-up phone call or email with a clinic nurse could help to answer questions and provide additional resources after families have left the clinic. With excellent resources, parents may be less likely to turn to potentially unreliable online sources. Some parents reported a need for connection with other parents who share their experiences and may benefit from contact information for volunteer parents willing to support others.

A clinic nurse could also relieve parent stress by taking the leading role in providing resources for the child's school. By developing an information letter specific to the child, or by providing a standard brochure relevant to all patients, clinic nurses could provide medical education and provide suggestions for any necessary accommodations.

Parents expressed a strong desire for access to and information about complementary and alternative therapies for scoliosis. Western-trained scoliosis surgeons may have little to no training in CAM to prepare them to support families in navigating the vast array of CAM modalities. Scoliosis clinic nurses should be prepared to discuss such therapies openly with families and provide evidence-based recommendations. Discussing non-standard treatments in an open manner would help to educate parents and empower them to make informed decisions about potentially un-proven treatments. The American Academy of Pediatrics has offered helpful tips on talking with patients about CAM ([Mosavat et al., 2018](#)). [Renella and Fanconi \(2006\)](#) outlined a practical algorithm for evaluating and making recommendations on CAM based on safety and efficacy. These approaches can help balance the parents' desires for holistic medicine and the clinicians' responsibilities in providing evidence-based recommendations.

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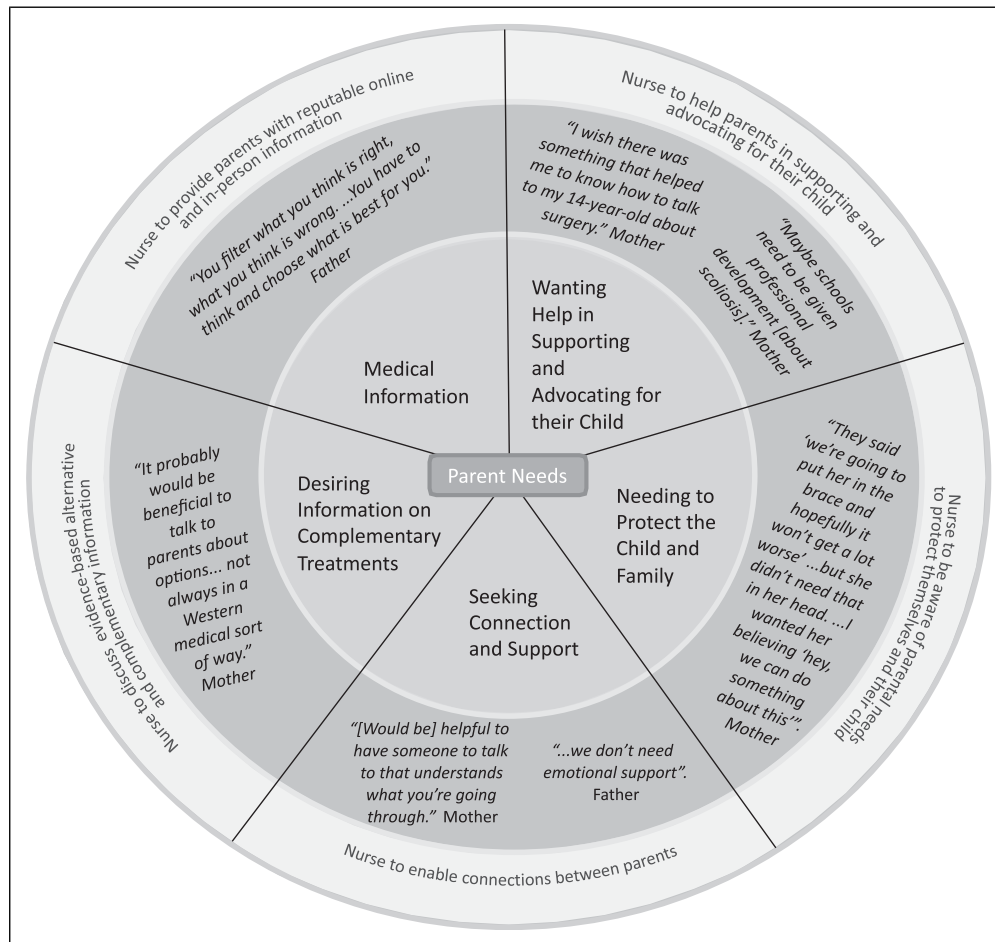


Figure 1. Parent needs and suggested nurse roles.

Author Contributions

LRW, LGR, SSH, and KS conceptualized this project. KS recruited participants. LGR and NG did interviews. LGR and NG and LRW did data analysis and conceptualized the findings. NG did an initial draft of the paper. LRW and LGR wrote the final manuscript which involved editing from SSH, KS, and NG. SSH and KS were involved in situating this project within nursing research and practice. The revision was led by LGR. All authors agreed on the final manuscript.

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Supplemental Material

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