

Understanding the Educational Needs for Parents of Children With Clubfoot

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PURPOSE: Identify educational needs of parents of children born with clubfoot and the role of healthcare providers throughout the treatment process.

METHOD: A qualitative study using interviews with 30 parents. All subjects were asked the same 12 questions regarding their perceptions and experiences. Common themes were identified from the data collected.

FINDINGS: The parents' educational needs fell into the following 2 categories: (1) understanding the process of treatment and (2) problems concerning the bracing portion of treatment. Themes exposed the effects on daily living and accommodations made to follow treatment. Parents perceive that the role of the healthcare provider is to present how-to information, specify consequences of the risks, promote awareness, provide encouragement and support, and remind them of positive effects to be expected when treatment is completed.

Clubfoot is the most common musculoskeletal birth defect affecting one in 750 live births (Figure 1). From the moment clubfoot is diagnosed (often on 4-month fetal ultrasound), parents are placed in a position to make treatment decisions for their child that has lifelong ramifications. Left untreated, the deformity persists, joint stiffness occurs, ambulation is often painful, and wearing normal footwear is impossible (Faulkes & Luther, 2005). Coping with an obvious physical deformity, concerns about potential disability and future limitations generate anxiety in parents of children with clubfoot. In the last 30 years, the duration of traditional treatment for correction of clubfoot deformity has been several months of manipulation and casting followed by surgery (extensive surgical release), which has been associated with residual pain, stiffness, and early arthritis (Dobbs, Nunley, & Shoenecker, 2006; Ippolito, Farsetti, Caterini, & Tudisco, 2003). Parents, therefore, are concerned about this treatment option.

A change in the standard of care for this particular deformity occurred in the last 5–7 years, with the resurgence of the Ponseti method (Box 1). Correction of the deformity with this method is usually obtained within 6–8 weeks. The Ponseti method consists of weekly manipulations and castings of the foot followed by nighttime bracing. In 90% of the cases, a minor procedure called a percutaneous tenotomy (cutting of the Achilles tendon) is needed with the

last cast to completely correct the deformity. This can be done under local anesthesia in the office (Ponseti, 1996). Current bracing protocol has extended to 4–5 years of nighttime wear to prevent relapse of the deformity.

Information on surgery as the traditional treatment of clubfoot was readily available in the public domain. No public information was widely distributed or available about the Ponseti method until 1998, when it was first posted on the University of Iowa's Virtual Hospital website. Coincidentally, the Internet was altering the way the public obtained healthcare information. As consumers became savvier at using the Internet to locate healthcare information, more parents were seeking information about the nonsurgical treatment option for their infants born with clubfoot. This particular trend was illustrated by Morcuende, Egbert, and Ponseti (2003), which showed the dramatic increase in new patients being seen at University of Iowa Hospitals and Clinics (UIHC) from 1998 to 2001 specifically for this nonsurgical treatment option.

The current availability of Internet healthcare information now allows parents access to education previously provided only at clinic appointments. Online healthcare information brings its own inherent challenges such as understanding what role the healthcare provider now assumes in educating patient/parents and the extent of their educational needs. The purpose of this study was to identify educational needs of parents of children born with clubfoot and how treatment methods affect their daily life. Through greater awareness of the parental perspective of educational needs, healthcare providers can better answer their questions, provide resources for support,

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FIGURE 1. Newborn with bilateral clubfoot.

help parents make informed decisions, and assist them to follow the treatment regimen in their daily lives.

Material and Methods

A qualitative study using one-on-one interviews was conducted with parents (23 mothers and seven fathers) of children born with clubfoot. All of the parents interviewed were from the United States, although our center also treats patients from abroad. Inclusion criteria for parents to participate were that they must currently be a minimum of 18 years of age, be the child's legal guardian, and able to understand and converse in English. In addition, their child must be at least 3 years of age to capture the experiences of parents with a child who had undergone the bracing portion of treatment. This study was approved by institutional review board.

Demographic data included the participant's current age, educational level, insurance status, reliance on child care/babysitter, travel distance, type of bracing used in their child's treatment, child's age at initial treatment, and location of treatment occurring prior to our center.

Parents were approached at their child's return appointment at our center from the period of January 2007 to December 2008. Consents were obtained at that

Box 1.

Basic Concepts of Ponseti Method

Ideally initial treatment started within the first couple weeks of life

Gentle manipulation and stretching with application of well-molded casts

Long-leg casts (toe to groin)

Usually done weekly and takes 5–7 casts

Percutaneous Achilles tendon tenotomy and cast for 2½–3 weeks

Night time bracing for 4–5 years

With relapse these principles are reapplied

time. The interviews were done either face to face (4) or over the phone (26). All subjects were asked the same 12 questions listed in Table 1 regarding their perceptions and experiences with their child's clubfoot treatment. Couples were interviewed separately. Participants were allowed to elaborate and expound on any of the questions providing further reflection of their experiences. The interviews were conducted by the same interviewer. Notes were taken during the phone or face-to-face interviews. We concluded data collection after interviewing 30 participants as the review group agreed that saturation of the data was occurring. Repetition of information, as well as the depiction of similar stories in their individual treatment experiences, was occurring.

DATA ANALYSIS

The responses were grouped in themes using content analysis techniques. Content not relevant to the questions being asked was not included in the analysis.

Findings

Not all participants responded to each demographic question. Thirty parents were interviewed and only six were couples. There was an array of home care situations with one third of the parents labeling themselves as stay-at-home caregivers, whereas one third reported relying regularly on some type of daycare. Participants traveled anywhere from 80 to 1300 miles to seek treatment at our center. Almost half of the participants had started treatment for their child elsewhere before coming to UIHC. See Table 2 for further details.

RESEARCHING TREATMENT

Parents used multiple sources to research clubfoot treatment before coming to UIHC. See Table 3 for sources and

TABLE 1. INTERVIEW QUESTIONS

1. What kind of research did you do before seeking treatment for your child? (Internet, physician referral, coworker, friend, relative)
2. What advice would you give to a parent with a child newly born with clubfoot?
3. What part of treatment is most confusing?
4. What piece of knowledge could have been better relayed to you from nursing staff or physicians?
5. What problem concerns you the most or what problem have you encountered with the bracing part of treatment?
6. Were there financial concerns or decisions you encountered regarding treatment options?
7. What could we as nursing staff do to assist you or make the treatment process more comfortable?
8. Can you describe positives regarding treatment options?
9. Can you describe negatives regarding treatment options?
10. What could we as nursing staff do to assist in compliance with the treatment regimen?
11. How do you keep life from interfering with the bracing treatment?
12. What accommodations did you have to make to comply with treatment?

TABLE 2. DEMOGRAPHIC DATA OF PARTICIPANTS

Age range 20–43 years with average 34 years
Educational levels
High school degree (n = 3)
2-year degree (n = 8)
4-year college degree (n = 11)
Graduate school degree (n = 8)
Payment for treatment costs
Full out-of-pocket expenses (n = 7)
Medicaid/Title IXX coverage, partial/full insurance coverage (n = 22)
Private foundation (n = 1)
Length of the interview average 25 min (range: 10–48).

words of advice participants would give to parents of a newly diagnosed child.

CONFUSION REGARDING TREATMENT

Nearly two thirds of the parents interviewed stated that they have some confusion regarding their initial understanding of the Ponseti method of treatment. After their child was going through the process of treatment, further areas became difficult for most participants. The most confusing and frustrating part of treatment was about understanding the specifics of the treatment and coordinating the clinical visits, as well as sorting through conflicting information and second opinions from Ponseti-trained physicians. Difficulty in understanding the medical terminology was a common complaint. One father reported confusion in understanding the terminology as the “tenotomy” is referred to as a procedure. “Is this a surgery for the nonsurgical method? Both the Ponseti method and the traditional methods start initially with casting and then vary in the type of procedure.” Identification of problems including casts slipping, proper brace fitting, correct application, and wearing of the brace was confusing for one sixth of participants (see Tables 3 and 4).

FINANCIAL CONSIDERATIONS

Over half of the participants stated that financially they would do anything for treatment of their children’s feet. One third of the participants stated that they used savings or credit to finance treatment. One father had undergone surgery for correction of his clubfoot and now lives daily with pain and stiffness. He stated, “our car was repossessed in exchange for my child walking and I would do it all over again.” Another mother reported, “exhausting all options and ready to mortgage the house to get treatment at UIHC.” Half of those interviewed reported that time and distance to travel were negative aspects of seeking the Ponseti method of treatment for their child. The hardship felt was time away from work and normal home life.

POSITIVES VERSUS NEGATIVES WITH TREATMENT OPTIONS

The powerful force behind those traveling this far for treatment was knowledge of the negative long-term surgical side effects versus positive long-term outcomes with

TABLE 3. FINDINGS AND QUOTES FROM PARTICIPANTS

Sources Utilized in Researching Treatment (n = 30)	Internet (n = 28) Physician/midwife referral (n = 21) Friend/other parents (n = 5) Relative (n = 4) Coworker (n = 1)
Advice for other parents	Quotes from participants “Go to UIHC” “The Ponseti method is the best” “Do your research” “Be as educated as possible” “Visit chat room sites for other’s experiences” “Seek a second opinion if not happy with current treatment” “Do not be afraid to ask questions of technicians” “Your child will be normal” “Your child will have no limitations”
Confusion regarding treatment	Quotes from participants
Initially no confusion	“Ponseti method pretty straightforward” “All explained well” “Always knew what was going on”
Developing problems	“Logistics of getting treatment, coordinating everything” “Too fast moving from initial consultation to casting” “Not enough time to absorb the details and what we were getting into” “First day and final cast with tenotomy” “Never understood the braces” “Why brace both feet if unilateral?” “When is treatment completed”
Conflicting information from Ponseti trained	“Uncertainty of physician’s treatment and confidence in his treatment expertise” “Wondering moments” “Shocking to see the foot go through the stress”
Medical terminology	“The tenotomy confused as surgery” “Cap refill” “Technical terms” “Parts of the feet”
Identification of problems	“How do you know when the casts slip” “Was never sure if the brace was put on correctly” “What is too tight” “swelling feet”

the Ponseti method. Parents responded favorably to the noninvasiveness of the Ponseti method and that “it did not involve surgery.” Two parents said, “insurance would have covered posterior medial releases (surgical option) for their child without question if they had chosen that type of treatment.” Four participants stated, “the surgical

TABLE 4. BRACING PROBLEMS

Resistance/self-removal (8)
Broken equipment (8)
Fitting/correct use (7)
Redness/blisters (6)
Return after relapse/length of bracing period (5)

option would have been much easier due to the length of bracing time commitment.” “Surgery is nice if it works then you know it is done.”

COMPLIANCE WITH TREATMENT REGIMEN AND NURSING INVOLVEMENT

Parents dealt with the bracing component of treatment by maintaining a consistent bracing routine and making it a way of life “just do it.” As the child got older, they found it helpful to explain the purpose of the brace to the child. Accommodations made by the parents to comply with treatment are listed in Table 5.

Two thirds of the respondents felt satisfied and comfortable overall with the nursing staff during the treatment process. Suggestions for improving treatment and increasing the comfort of the treatment included importance of a child-friendly environment with shorter wait times and material to occupy the children, access to nursing personnel to answer questions, family presence during treatment, and consistency in caregivers.

Suggestions for healthcare provider’s role to help parents stick with the treatment regimen included

providing education regarding the treatment and the risk of relapse. Parents asked that information about the risk of relapse and its causes should be repeated and emphasized at each clinic appointment. Provision of educational materials in the form of videos and pamphlets/booklets depicting positive outcomes was also suggested. Twenty-seven percent of the parents stated that stressing the long-term treatment with a finish line would be helpful in adhering to treatment. Twenty-three percent of the participants stated that following the treatment regimen is solely the parent’s responsibility by stating that “we either do it or don’t.” Offering information on support groups and website chat groups was requested. Further requests were for encouragement, reinforcement, and follow-up calls throughout the treatment process.

Discussion

In our interviews, we found that most parents utilized multiple sources when seeking treatment for their children with clubfoot. They relied on a combination of healthcare provider, relative/friends, and/or Internet in their search. These findings are consistent with literature on health information-seeking behavior that reports that consumers use the Internet for clarification and as a supplemental source of healthcare information. However, this information can often be overwhelming, especially when the information is contradictory (Crane-Cutilli, 2010). Finding a practitioner they trust often evolves into the practitioner helping them make treatment decisions. Healthcare information obtained from online sources is often brought to clinic appointments and healthcare practitioners are often asked to comment on the information (Herzeberger, 2008). In our interviews, the participants expected the nurse as well as the physician to be knowledgeable and help to interpret the information. This is emerging as the consumerist model, also called triangulation, which includes three components of the patient, the web, and the healthcare provider. Triangulation can potentially alter the long-existing characteristics of the physician–patient relationship, where the physician prescribes and the patient complies (Wald, Dube, & Anthony, 2007).

POTENTIAL BENEFITS TO USING THE INTERNET

Access to online support groups, better use of clinic appointment time, and a more collaborative team-like approach including the parents as partners are benefits related to the use of the Internet (Wald et al., 2007). In our study, a need identified in the interviews was for information on support groups and how to gain access to these resources to increase adherence to treatment.

TABLE 5.

Accommodations	Quotes From Participants
Swings/car seats/strollers (12)	“Difficult finding one that could use with the brace”
Few responsible for application of the brace/child assists (11)	“Had them help us when they got older”
“Part of the diaper bag” (7)	“Adjusted day care schedule” “Took on vacations”
Clothing modifications (6)	“Part of our luggage wherever we went” “Did not wear shorts” “Finding socks to fit the shoes” “Onesies with snaps” “Pajamas without feet”
Brace padding/adaptations (6)	“Color and decorate the brace”
Moving activities to the child (6)	
Bed modifications (5)	“Mattress on the floor” “Padding on walls surrounding the bed” “Moved to twin size bed earlier”
Travel time/time off work (5)	“Missed work days to come to appointments”
Explanations to the public re casts/brace (4)	“Questioned about child abuse”

Box 2.

Websites for clubfoot information and support networks

<http://www.ponseti.info/parents/global-help.org>
<http://groups.yahoo.com/group/nosurgery4clubfoot>

See websites for clubfoot information and support networks in Box 2.

PARENTS EXPECTATIONS OF HEALTHCARE PROVIDER'S ROLE

Parents expressed the need for their healthcare providers to be their partners as they requested continued support and guidance from the nurses and physicians. Ways providers demonstrate partnership, according to the sample, include continuity, accessibility via the phone, and by allowing parents to be involved and present during treatments. The healthcare provider must recognize that the dynamics of the patient/parent physician relationship have evolved; patients now demand greater involvement in health maintenance and care (Iverson, Howard, & Penney, 2008).

ADULT LEARNER CHARACTERISTICS

Involvement is a key component for success when looking at adult learner characteristics. All of the participants were considered adults at the time of the interview. Other adult learner characteristics that mirrored our parents' needs were the need for time to digest and reflect on the material given, how this will affect me (our family), repetition of information, mutual accountability, and a need for respect for the experiences and knowledge they bring to appointments (London, 1999). Setting up a clinical practice with these adult learning principles and characteristics as the educational framework attempts to meet the parents' expectations and in turn helps to define the healthcare professional's role in the immediate treatment process.

EARLY TREATMENT CONCERNS

The immediacy of what is going on with the casting and tenotomy portion of treatment is the utmost concern of parents during this early phase. The healthcare professional's role at this point is to dispel confusion and misunderstandings of the tenotomy. Parents at this time may be overwhelmed and need to know how to survive only from appointment to appointment. Addressing these concerns with simple directions and short-term goals is helpful during this time. This is the portion of the treatment when the healthcare professional is the most active as the child comes in frequently for manipulation and cast changes.

LATER TREATMENT CONCERNS

As treatment progresses, there are longer time periods between clinic visits. Instead of being seen weekly, the follow-up times lengthen to 3- to 6-month intervals. Parents' role expectations of the healthcare professional evolve into identifying solutions for problems encountered during the bracing portion of treatment and providing support with specific "how to" information, that is needed to guide parents during the difficult times between appointments. Helping parents understand that treatment is a 4- to 5-year commitment and providing them with suggestions of accommodations identified by parents (Table 5) incorporated into daily lifestyles may further help to increase compliance and success of treat-

ment. At this phase parents asked to be reminded of the long-term outcome and risks of not following treatment guidelines.

NURSING IMPLICATIONS

The nurse has the opportunity to play a large role in serving parents by answering questions regarding treatment options, especially when information is conflicting. The results of the Ponseti method of treatment, when done correctly, speak for themselves. The nurse should be an advocate for patients and their families in the treatment process and help the families recognize when treatment deviates from the standard. It is crucial for nursing to keep updated on evolving indications and results of Ponseti method research as it is ongoing and extending to complex cases, neglected cases, and in syndromes such as arthrogyposis.

LIMITATIONS

There is a research limitation with the sample by only including the parents of children over 3 years of age. A time lapse of at least 3 years has occurred; thus, parents' remembering the details and the amount of work that went into their research of seeking treatment, decision making, and concerns surrounding early portions of treatment may have faded. A true representation of their concerns and needs may not be depicted.

Another research limitation to be considered with this study is researcher bias, as the individual conducting the interviews was the nurse care coordinator who had an established nurse-client relationship with the parents. This relationship helped to establish a safe environment in which subjects felt comfortable in sharing personal thoughts and provided for more open responses. The interviewer attempted to make the interviews as nonthreatening as possible as the questions were covered in a conversational manner. The interviewer also gave the subjects permission to be critical of our current practice. If there was any hesitation regarding criticism, the participants were reassured that the purpose of the questions was to identify both positives and negatives in hopes of improving treatment to benefit future patients' experiences.

Furthermore, the notes taken during the interviews were discussed with other members of the research team and broken down into themes. Further assistance was given with the compilation of the data and sought expertise of those members who have familiarity with qualitative research.

Conclusion

Despite greater access of healthcare information specific to clubfoot treatment, this study confirms the need for individual patient/family teaching by the healthcare providers. Information that is available still needs to be interpreted, thus the need for the human component in this process. It is crucial for healthcare providers to recognize the role they play in providing assistance to parents' understanding of the treatment options, the expected outcomes, the importance of adherence to the treatment regimen, and continued support throughout

the process. The fundamental ideas and suggestions generated from this study representing the parents' perspective can provide a good foundation for future educational studies and formulating teaching plans for this patient population and those with other musculoskeletal problems.

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