Integration and Application of a Home Treatment Program: A Study of Parents and Occupational Therapists

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The purpose of this article is to describe parental adherence to home treatment programs. A qualitative exploratory study with six parents and eight occupational therapists who used the brushing and compression technique (Wilbarger Protocol) was conducted. Participants were interviewed one or two times, exploring their experiences in adhering to the protocol. Data analysis focused on facilitators and hindrances to parental adherence and on occupational therapists’ strategies used to encourage it. Parents identified their children’s responses to brushing, its perceived efficacy, and interaction of the protocol with family daily schedules, as factors influencing their adherence. Occupational therapists identified only family daily schedules as influencing parental adherence. The findings are discussed in the context of the ecocultural theory of family accommodations.


Home treatment programs are sets of activities introduced by occupational therapists to be performed at home (Segal & Hinojosa, in press). These activities may be new to the family or they may be adaptations of existing ones. In the former case, the home treatment program requires adaptation to daily routines; whereas, in the latter case, the adaptation is already in the family’s habits (Forsyth & Kielhofner, 2003).

Issues in the integration of home treatment programs were studied by Hinojosa (1990), Hinojosa and Anderson (1991), and Law and King (1993). All three studies focused on families with children with cerebral palsy. They found that there are concrete and conceptual issues that influence the integration of home treatment programs into the daily lives of families. Among the concrete issues, they found competing demands, lack of time and support, and lack of skill, all of which hinder the integration of home treatment programs into family life. Conceptual and psychological issues, such as the different roles of parents and occupational therapists, and different values and priorities, may also hinder the integration of home treatment programs. Thus, the integration of home treatment programs into the daily lives of families is a complex phenomenon that needs to be addressed on several levels.

Family routines give order and organization to daily life (Fiese et al., 2002; Schuck & Bucy, 1997; Segal, 2004) and reveal a family’s values and priorities (Segal, 2004; Segal & Frank, 1998). Having a family routine facilitates the construction of family rituals such as dinners and bedtimes, birthdays and anniversaries, and religious and national holidays (Fiese et al., 2002; Schuck & Bucy, 1997; Segal, 2004). Such family rituals would be described in occupational therapy as occupations, or purposeful activities that are imbued with meaning to the participating individuals (Hinojosa & Blount, 2004). Therefore, the challenges involved with integrating a home treatment program into a family’s daily life may be more complex than simple scheduling.

The number of studies of the different issues relating to family routines, activities, and occupations in occupational therapy have increased in the last decade.
At the time of the discussions, only the first author, a clinician (who was an adjunct professor), and another clinician (who was a doctoral student) from the same department. The discussion began as a lunchtime conversation about the prevalent use of the deep pressure and joint compression technique that is commonly known as brushing and compression, or the Wilbarger Protocol (Wilbarger & Wilbarger, 2004). This technique is part of the Wilbarger approach to the treatment of sensory defensiveness (Wilbarger & Wilbarger, 1991; 2004). Our discussions focused on the brushing and compression protocol, and the issues involved with integrating it into the daily lives of families. At the time of the discussions, only the first author was a parent and she believed that it would be close to impossible to adhere to such a program. Additionally, the clinical experiences of the other two participants in these discussions (Bernadette Mineo and Panagiotis A. Rekoutis), as well as cursory inquiries made of other clinicians, were that most caregivers do not apply the interventions every 2 hours as is recommended. Based on these discussions, we developed a research study whose findings are presented and discussed in this article.

The purpose of the study was to discover and understand what facilitates parental adherence to the Wilbarger Protocol and what hinders it, from the point of view of parents and occupational therapists. Additionally, we wanted to find out what strategies occupational therapists use to increase the likelihood of parental adherence to the brushing and compression program.

Brushing and Compression Program

The brushing and compression program is part of the Wilbarger approach to the treatment of sensory defensiveness (Wilbarger & Wilbarger, 1991; 2004). This approach consists of three essential components: (a) client and caregivers’ education, (b) sensory diet, and (c) the brushing and compression program. Brushing and compression is a deep pressure and joint compression intervention that should be administered every 90 to 120 min. It is designed for children from 2 months to 12 years of age. Appropriate administration of brushing and compression, and the frequency of its administration, are considered essential for the success of interventions. There is no written description of how brushing and compression should be applied because the developers of the approach believe that actual training is required to master the interventions (Wilbarger & Wilbarger, 2004).

Methods

We selected an exploratory qualitative design in which we interviewed parents and occupational therapists to allow us...
to explore a variety of issues. In-depth interviewing is a data collection approach whose purpose is to understand the experiences of other people (Rubin & Rubin, 2005; Seidman, 1998). The study was approved by a university committee supervising research with human participants. All participant’s names have been replaced with pseudonyms to ensure confidentiality.

The research project was presented in the research course sequence of the postprofessional program at New York University. Claudia Beyer and Parul Dhankhar, who were postprofessional master’s degree students at that time, elected to join the project as their graduate research project. Claudia Beyer elected to interview parents and Parul Dhankhar elected to interview therapists. Both engaged in the analysis of their own data and completed their research projects independently. Additionally, Ruth Segal interviewed two parents and Panagiotis A. Rekoutis interviewed two therapists. At this point, Parul Dhankhar and Panagiotis A. Rekoutis withdrew from the study. The final analysis of the complete set of data using the constant comparative method and the writing of the manuscript was conducted by the authors of this article.

Participants

Participants were recruited from private occupational therapy clinics using flyers and presentations to clinic staff members. In total, six parents (five mothers and one father) and eight occupational therapists participated in the study. One parent was not used for this article, however, because the intervention was so aversive to the child that the family did not engage in any part of the home treatment program.

Five of the six families were dual-parent families. The single-parent family consisted of a mother and one child. The number of children in the families ranged from one to two. All of the children were boys, ranging from 4 to 7 years of age, who received occupational therapy and were directed to use the brushing and compression program by their occupational therapists. The children whose parents participated in the study were not evaluated by the researchers, because the focus was on the parental experience of applying the brushing and compression at home. The occupational therapists participating in the study were affiliated with private clinics that served large and small urban areas. They had 4 to 12 years of experience as occupational therapists. All of the therapists had learned about the Wilbarger approach in academic educational programs. Six of eight therapists learned about the Wilbarger approach to the treatment of sensory defensiveness at a conference, one attended a workshop offered by Wilbarger, and one was trained in the Wilbargers’ clinic.

Data Collection and Analysis

Data collection consisted of one to two interviews with each participant. The interviews lasted 45 to 90 min each and were transcribed verbatim by a professional transcriber. Some of the interviewees preferred to be interviewed once; and their interviews, therefore, were typically longer. The parental interviews consisted of open-ended questions about the following topics: (a) their understanding of the protocol in terms of the reasons it was prescribed and what effects it should have, (b) the process of learning to apply it, (c) how they integrated it into their daily routines and how they coped with challenges to this integration, and (d) what were the processes that lead them to halt the protocol’s application. The occupational therapists’ interviews also consisted of open-ended questions that covered the same issues, with a greater focus on their strategies of helping parents to integrate the protocol into the family’s daily life.

As described previously, the first data analysis was performed on partial sets of data for the purposes of completing the research requirement for the postprofessional degree in occupational therapy. The second data analysis was conducted by the authors using the constant comparative approach to data analysis (Bogdan & Biklen, 2003; Glaser & Strauss, 1967; Strauss & Corbin, 1998). In this analysis, parents’ and occupational therapists’ data were analyzed together to construct themes that will subsequently be presented.

The research questions guided the analysis. We looked for the following: (a) descriptions of what parents were doing to integrate the brushing and compression into their daily lives, (b) successful and failed attempts at integration, (c) parental perceptions of what facilitated or hindered the success of their attempts, (d) occupational therapists’ perceptions of facilitators and hindrances to the success of parental adherence to the brushing and compression program, and (e) the strategies that occupational therapists used to support and encourage parental adherence to the program.

The process of analysis followed the guidelines of the constant comparison method (Bogdan & Biklen, 2003; Glaser & Strauss, 1967; Strauss & Corbin, 1998). With this approach, we analyzed the data using conceptual codes in the process of open coding. In this process, segments of data were labeled using abstract concepts that allowed for grouping of these segments into larger conceptual categories. The categories were analyzed for meaning and processes. Axial coding (the coding of the emerging categories themselves) focused on the conditions and situations that facilitate or hinder parental adherence. Finally, the analyzed categories were synthesized into the themes that will be
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Trustworthiness

Data were collected from parents from a number of occupational therapy clinics, who therefore had contact with a number of different occupational therapists. The occupational therapists were recruited from large and small urban areas, and from various clinics. Most of the therapists did not work in the clinics from which the parents were recruited. As mentioned previously, there were two stages of data analysis that allowed for analysis by the two authors and in different constellations: parents’ data, therapists’ data, and combined data.

The independent analysis of the two authors resulted in similar major categories. The differences in the concepts, particularly in the axial coding, were discussed until they were resolved.

Findings

The findings presented here are organized around two major categories: (a) hindrances or facilitators to the integration of brushing and compression into the family’s daily life, and (b) the strategies that therapists use to support parental adherence to the home treatment program. The integration of the home treatment program category further consists of three subcategories: the children’s responses to the intervention, the parents’ perceived efficacy of the intervention, and the family daily schedule. The occupational therapists’ perceptions of these issues are presented as well. Finally, training parents in the technique and working with the family’s schedule—the two strategies that therapists use to increase adherence to the brushing and compression programs—are presented.

Of the six parents who were interviewed for this study, three reported that they adhered to the 2-hour schedule for about 2 weeks or longer; two realized from the beginning that such a schedule was impossible and settled for twice a day; and one tried to do the best she could, which amounted to a maximum of 5 times a day. Typically, however, she managed to apply the protocol only 3 times a day.

Hindrances and Facilitators to Integration

Children’s Responses to Brushing

When talking about brushing and compression, parents consistently said that their children’s positive responses to the brushing were critical to maintaining adherence to the protocol. Additionally, their children’s negative responses to the brushing were the key factor in deciding when to discontinue the brushing. None of the parents interviewed reported their children’s dislike for the compressions; therefore, the focus of this theme is on brushing.

When parents discussed the issue of doing the brushing and compression, the children’s positive response to the brushing was a condition for actually following the protocol. As one parent, Rachel, said:

As a routine matter, adding a piece to a routine . . . it is easy. Unless it was an unpleasant thing, if it was a daily beating, for example. I mean, adding a chore like that isn’t too hard over a reasonable period of time. He liked it so much, he didn’t fight it. Yeah! It was just a pattern of what we did, and that was that.

In Rachel’s case, the experience of brushing was beneficial to her relationship with her son:

He was just totally softened and relaxed to it. So, for a long time, it was for me, it was really a milestone in our relationship, because I used to cry about it, because it was the first time I had a physical contact with him that wasn’t about struggling with him. You know, where I touched him and he would soften and feel good . . . And it was easy to sustain ’cause he was so happy with it.

Similarly, Denise described her son’s reaction:

And he never resisted, always welcomed it. He’s a child that loves to be massaged, loves baths, love swimming, loves any kind of tactile input. . . . playing upside down . . . you know . . . he’s into all that stuff.

And Henry said of his son, “He actually seemed to like it, too. I mean, he seemed to like the sensation. He doesn’t have any issues with being touched.”

Finally, Sharon, who went through the brushing with her son every 2 hours for almost 2 weeks, said that “he didn’t mind it,” whereas Cindy, who applied the brushing and compression twice a day, said that her son “is not into it.”

The children’s experience of brushing (as observed by parents and as related by the children) was the most common inducement to stop the activity. For example, Rachel said:

We started brushing and I did it until he started crabbing to me about it. It was no longer soothing and pleasant. He would start saying, “Oh, I don’t want to brush, I don’t want to brush.” I saw [the therapist] twice a week and I said, you know, he is starting to complain. She said, “Discontinue it.”

Similarly, Sharon talked about her reasons for discontinuing the brushing and compression applied at home, and applications done at the occupational therapy clinic:

Well, he would cringe. You could just see it in his body language. If somebody was brushing his arm he would be like this [shutting his eyes tight and cringing], so it was pretty obvious. Then if someone asked him, “Is this bothering you?” he would say, “Yes.” So it was very obvious and it
seemed to come on kind of strong [and] very quickly, as I recall. I am not a hundred percent sure about that. It was, that is, was sort of annoying; it was annoying all of a sudden.

Beth described a similar experience that led her to stop the brushing with her son:
But then I think that he was able to tell me and that’s when we . . . decided we weren’t going to do it for a while, because he didn’t want it anymore, and the more he was verbal, [the more he refused it]. But he likes the joint compression, but he didn’t want to be brushed. And I do joint compressions on him all the time.

Similarly, Cindy said of her son, “He also started to say to me, ‘I really don’t like the brushing part much, but . . . I like the choinks’ [the family invented this word for the joint compression].”

Children’s responses to the brushing and compression appear to be an important factor in the integration of the brushing and compression program into the family’s daily life. Children’s initial positive responses encouraged parents to continue applying it, whereas children’s negative responses led parents to stop or initiate stopping the application of the intervention. This finding supports Hinojosa’s (1990) conclusion that mothers of children with cerebral palsy would not adhere to aspects of home treatment programs that caused their children discomfort or pain.

When the participating occupational therapists described the brushing and compression programs, they described how children may have different responses to this intervention. For example, Helen said:

While I’m using it [the program], it depends on the child, actually, because you’ll get a wide range—you get different responses. Some kids really like it. They like it and they enjoy it and they’ll sit there . . . But there are other kids that are just like “whoa.” You know . . . like, “I don’t like that.” . . . So you do see, initially, either they like it or they don’t.

Christine was the only occupational therapist who commented on the possible relationship between children’s responses to the brushing and parental adherence to the program. She said, “If a child has a problem with it [the brushing] . . . it’s tough to have a successful implementation.” She added that problems with adherence may be related to cultural attitudes about touch. When touching another person is considered inappropriate in a particular culture, the brushing and compression program cannot be implemented.

Another aspect of children’s responses to the brushing and compression was raised by Cindy, who said that her son complained that she was not doing the brushing as well as his occupational therapist. Cindy added that she had to demand that the therapist teach her how to apply the brushing appropriately. Two of the participating therapists concurred with Cindy. For example, Mary said, “They’re [the parents] just afraid. They don’t want to hurt their child. So they do it really, really light.” This observation supports Hinojosa’s (1990) findings: Parents who do not feel skilled at performing the home treatment program will not engage in it.

Perceived Efficacy
Parental observation of the immediate effects of brushing and compression was another aspect that influenced their ability to stick to the protocol. Rachel, whose son’s immediate response to the brushing and compression was positive, said of the sustainable effects of the protocol:

I am completely convinced that brushing [was effective]. Just because he responded that first instant, if nothing else. [But] really it is part of the whole thing, and [it] put a lot of pieces together for him. But he had a lot of OT; he had brushing and many different interventions. It is very difficult to say, “It is the brushing.”

Beth’s response was similar to Rachel’s:
I think there was a change . . . I mean, it’s hard to say, you know, there were a lot of other things, but I think he definitely became more comfortable with touching messy things. . . . He seemed a little more comfortable with people coming into his personal space and he was just a little more centered . . . and more even, you know, his mood was just more even and that’s what I noticed, and I attribute that a lot to the brushing, I do.

Neither Rachel nor Beth applied the brushing and compression every 2 hours. Sharon, however, who applied the brushing and compression every 2 hours, said:

It didn’t seem to me to be doing anything. And so we made it almost through the full 2 weeks. It was getting harder and harder to be really diligent about it . . . [so] I asked [the occupational therapist] if we could reduce the amount of brushing, because it seemed like it just wasn’t doing anything. And she was like, “Yeah. Why don’t you do morning and nighttime?” So I did that. That was fine, but it still didn’t have any effect whatsoever.

Cindy, who brushed her son twice a day, described her concerns about the usefulness of the protocol:
I was wondering, was it having any efficacy at all. . . . It seemed like he was sleeping a little longer at night—that was the only change I noticed in his schedule—but I didn’t know if it was coincidence or causation.

After a long weekend, however, in which the protocol was not applied and the family did not follow its regular schedule, Cindy noticed that the sleep pattern did not revert back to what it was before the brushing and compression, and she concluded that the protocol had no effect on her son.

Denise differentiated between the immediate and long-term effects:
Now, I think that even more, I think that brushing is one key of the puzzle. I think it’s useful . . . but I don’t think it’s a panacea. . . . At home, I would say it did have the effect of sort of . . . ah . . . what is the word . . . it sort of put him in a trance a little bit right afterwards. I mean, he was really relaxed, but it would wear off fairly quickly and he’d get back to his old self . . . [The long-term effects were] not noticeable. It’s not as if . . . after the 2 weeks [when] we weren’t brushing anymore, he was completely different . . . No! I could not say that, in honesty.

When discussing the efficacy of the brushing and compression, Denise differentiated between long-term and short-term effects. She perceived some very short-term transitory effects but no long-term effects on her son’s behavior.

Henry saw long-term differences, especially about his son’s falling asleep:

... And it works . . . I mean, it really calmed him down; every night when he had to go to sleep, he would run around; it would take him a long time to settle. That passed in like a week, I would say, after we started brushing. So, yeah . . . so, he has been brushed since and compressed since . . . not as frequently, though . . . And it worked, which is why we stuck with it, of course.

Although the participating occupational therapists were aware that different children have different immediate responses to the brushing and compression, they did not connect it with parents’ perceptions regarding the efficacy of the intervention. Most of the therapists expected an effect after only 2 weeks, during which the brushing and compression was supposed to be applied at least three times a day. For example, Diane said, “And sometimes that’s [that schedule is] overwhelming for people, but I’ll say, ‘Let’s do it that way for 2 weeks and then evaluate whether we see any changes.’”

As the parents described previously, however, if there were no immediate results, it was difficult to adhere to the program for 2 weeks.

**Families’ Daily Schedules**

When discussing integrating the brushing and compression protocol, the parents discussed the prescribed frequency of the protocol and the way that they managed to integrate this activity with only minimal disruption to the daily life of the family.

Rachel, who described herself as “a parent who is very big on routines,” said that when the occupational therapist suggested she apply the protocol every 2 hours, she laughed, saying, “Three times a day—that’s what I call ‘pushing it’.” Rachel said that she tried “to incorporate it into the part of getting ready for the morning and the part of getting ready for the night.”

Similarly, Cindy described her response to the suggested frequency of the protocol:

I agreed to start trying to do it and she [the occupational therapist] did say, “Try to do it . . . four or five times a day.” No way! It’s just not happening; it was not possible [the] way his schedule and my schedule are.

Cindy added, “Yeah, at night after dinner, some time in that range of before bedtime . . . after I’ve given him a bath, I typically brush him then, then he gets in his pajamas.” Both Rachel and Cindy settled for doing the protocol twice a day as part of dressing and undressing routines.

Beth is an occupational therapist who used the brushing and compression on her 23-month-old son after he was assessed by another occupational therapist. She said that she managed to apply the protocol a maximum of 5 times a day, but most days she managed to do it only twice. As she said: “Being a working mom, and I’m someone who knows how to do all this [the brushing and compression], it was very hard to implement; even though it only takes, whatever, 5 minutes really, it was hard to implement.”

Beth tried to engage her son’s babysitter but that did not work well, so she settled for doing it herself before she left for work and after she returned. On the way she incorporated the protocol into daily life, she said:

Transitions were not such an issue, I mean not really, I did it [brushing] really when I could, you know. I did it in the morning . . . I did it when I came home from work, like five-thirtyish, and then I did it before we went to sleep.

Later, she added, “I incorporated into my [emphasis added] daily routine . . . um . . . unless I saw a time that he was having a really, really hard time.” It seems that because Beth’s son was so young, the main obstacle to following the protocol was the mother’s schedule.

Of the three parents who reported that they managed to incorporate the brushing and compression protocol as prescribed—every 2 hours—only one managed to incorporate the protocol into her daily life by herself. As Sharon, the mother, described:

So we were asked to do the brushing every 2 hours with the compression, so we did it right away. We went in, I did him everywhere. I did him in Barnes & Noble bookstore. I brushed him in the house and in the museum and everywhere. I mean, wherever we were, every 2 hours, and I really tried to be diligent about it.

She added:

Well, you know what it is like. It’s like if you go for long-term nursing, which we did also. You are sort of used to just nursing in different places. I wasn’t nursing anymore by that time, but I had that attitude. Like, “Okay, here we go! Time to do it!” I think that might be part of it, too.

In her view, “it would be a challenge if your life wasn’t fluid enough that you could do it. I mean, then it would be
hard.” That is, in order to integrate a frequent activity into one’s daily life, the daily life cannot be organized as a schedule, as a linear set of activities, but rather activities should be enfolded within each other (Bateson, 1996; Segal, 2000).

The last two parents managed to incorporate the protocol every 2 hours. Their main efforts, however, were focused on coordinating all the adults in the children’s lives, rather than implementing the protocol themselves. For example, Denise described:

His mother [Denise] or father would do it in the morning . . . uh . . . at let’s say 8 a.m. and then he had a 10 a.m. brushing at school by one of the teachers, again at 12 p.m. at school, and again at 2 p.m. at school. So three times at school and then at 4 p.m. at home by the babysitter; 6 p.m., usually the babysitter; and we would do a last brushing at 8 p.m. My husband and I, during the weekdays, would really only do it twice a day, 8 in the morning and 8 at night.

During the weekends we would just use . . . um . . . you know . . . we would alternate between my husband and myself, you know, keep an eye on the time and every 2 hours, it would be one of us that would do it to him.

Denise, however, added about integrating the protocol into daily life:

It’s like any habit. I mean, brushing your teeth—it’s hard if you haven’t done it, you know, [like] taking out the garbage is hard if you have to do it. So, if it’s hard, it’s an inconvenience. Hard for the parents, not for the [child], you know. It was just one more thing to check off on the list of the 100 things you have to do in a day when you have kids. And it was just, you know, that kind of an inconvenience, not a mass inconvenience.

Denise said about sticking with the every-2-hour schedule:

Well, we have a very rich routine life, so that wasn’t so much of a problem; I mean, if we were in the car, for example, yeah, I would do it in the car or . . . we would be 15 minutes late for it.

Like Sharon, Denise talks about flexibility in daily life. Although they are discussing different types of flexibility, they both reveal an attitude that says: sometimes one needs to be flexible when dealing with the family in order to achieve one’s goals.

Finally, Henry, the father of a child with PDD-NOS (pervasive developmental disorder, none otherwise specified), said:

The OT at the time taught us, and all the ABA [applied behavioral analysis] therapists, how to do brushing and then we ran a regimen. It was pretty easy to put it into the ABA program because they were there all the time—the therapists. At that point, we had 40 hours a week, I think. So, I can’t remember how often we did it, maybe every second hour, I think.

All the therapists were doing it. Sometimes if we were very tired in the evening the parents might have slid [sic] off a little, I think . . . but you know . . . he was pretty much brushed every second hour.

Henry described no difficulty in incorporating the protocol into the child’s daily life because of the child’s intensive ABA program.

ABA is kind of a carrot-and-stick program, where in order to get the child to do what you want them to do, you promise them a reward. And his reward for being brushed was that he would be allowed to watch his favorite movie on TV and he did. In this case, the burden on the parents was not so onerous because, like Rachel and Cindy, they only had to perform the protocol twice a day. But even then, they tended not to follow it.

To summarize, the issues that stood out in discussions with parents about integrating the Wilbarger Protocol into the family’s daily life are as follows: (a) it is an inconvenience, (b) the morning and evening routines (when the family has a clear and organized routine) are the most suitable times in which to integrate brushing and compression, and (c) a general attitude of flexibility toward the daily routine may make it easier to integrate the protocol into the family’s daily life.

The eight occupational therapists who participated in this study knew that implementing the brushing and compression protocol is challenging to families and that it does not fit all families. As Tess said:

I think it is the time element . . . you look at [family] routines, and days don’t always go as planned and dinner isn’t always as planned, and I think that parents might have really good intentions, but life happens and 2-hour intervals go without sometimes parents remembering to do [the protocol]. So I think that is the really tough part, that’s the big part.

Christine also said,

I think that when implementing this, [the occupational therapist] really needs to look at the whole family unit and components in it . . . [because] you have to decide whether or not it’s an appropriate tool to use because you don’t want to set up a family for failure.

Nicki presented it simply as “it may not be appropriate for the family and their lifestyle, because it is an intense program.”

Strategies Used by Therapists

All of the occupational therapists believed that educating parents—about their children’s sensory issues, how these issues affect the lives of their children, and how the intervention works—would convince the parent to invest the
time and effort to do it. For example, Lilly described in detail how she presented the intervention:

I’m telling them the rationale behind it. What we are hoping to gain from it. I’m telling them about the whole sensory integration thing, you know. What sensory integration is, and how and why there is dysfunction, what could cause a dysfunction, and what we see with the dysfunction. And so, you know, like trying different techniques and one of them may be the brushing program—how we can make the child become more alert and organized and calm so they can sit and attend. So you basically just give them a little bit of background to what SI [sensory integration] is, what we are hoping to gain from doing the brushing program, what the brushing program would do, the importance of doing it, where to brush and where not to brush, when to do it and when not to do it. . . . So you’re just educating the parents on a brushing protocol at home. That’s what I tell them. Then I ask them, “Do you have other questions?”

Diane stated simply, “I feel that the more you can educate the parent as to why the child is behaving as he/she is, the more chance you have of them following through on something.”

In addition to educating the parents about the intervention, some occupational therapists are working with parents to help them integrate the intervention into their daily lives. As Christine said, “I usually sit down with the family and look at their daily schedule, and you know, we kind of go through it.” Going through it means that the occupational therapist suggests times and activities in which the intervention can be embedded. Additionally, some therapists used a visual aid, as Christine described:

I make a graph for them and I have it every week. They have this graph on a refrigerator and I highlight the block of time so they can fill [it] anytime. And I told them to be realistic with me. I mean, if that day they can only do it, you know, one or two [times], you know, I want to know.

Tess, however, disagreed with the use of a chart:

They [parents] feel like little kids reporting back to a teacher, because you really say it is so important, it is so important. And they come back and say, “Well, you know, I did my best, but it was really hard. You know, I did it in the morning, did it in the afternoon, did it in the evening, it was the best I could do.”

Lilly, who uses charts, mentioned that she sometimes asks the child whether his or her mother [sic] did the brushing and compression, and uses that information to confront parents about their adherence to the program.

In spite of these efforts, the occupational therapists reported that parents have difficulties following the 2-hour schedule. The therapists’ efforts to support parents also took the general approach of educating the parents in the hope of increasing their commitment to the intervention. One approach was to show parents that there is a connection between the intervention and the child’s behavior. Christine explained how she uses the chart in this regard:

And there is a “comment” section so if [the child] had a particularly bad day or a very good day, maybe you can see a correlation and that’s a nice way [to reveal a connection]. Also, bring parents to experience it visually and they can see, “Whoa, I was really onto my brushing and had a great day, and you know, today I missed two times. He [the child] fell apart there.”

Another approach to the education of parents is to ask them to “humor” the occupational therapist and apply the protocol for 2 weeks and then come back and assess the situation. For example, Tess said:

If I have a relationship with the family, what I say to them is sometimes, “Just humor me for 2 weeks or for a week at least, and we have a list of our concrete behaviors. Let’s come back in a week or two and let’s look back at the list.” And if it [the protocol] helped, then we will see the behaviors go down. If it didn’t, we have to try something different.

The strategies that occupational therapists used to enhance parental adherence to the brushing and compression program were: (a) educating parents about the relationships between sensory issues and children’s behaviors, and about the intervention and its theoretical underpinning; (b) looking over the family’s daily routines with the parents and suggesting times when the program may fit in; (c) giving parents charts to fill in whenever they implemented the protocol and checking up on their adherence; and (d) asking the parents to try the program for 2 weeks to evaluate the efficacy of the protocol.

Discussion

The findings of this study indicate that from the parents’ point of view, there are three major issues in adhering to the brushing and compression program: children’s responses to the intervention, the intervention’s perceived efficacy, and issues in the integration of the program into the family’s daily routine. Occupational therapists, on the other hand, identified only the latter as an issue with program adherence. When it came to integrating the program into the family’s daily life, parents identified the following challenges: a frequency of every 2 hours is too much; and finding activities, or routines within which compression could fit naturally, is very difficult. Similar to parents, occupational therapists identified finding the activities within which the program can be integrated a challenge to parental adherence. An additional issue that the occupational therapists raised was parental knowledge of the meaning of sensory regulation and modulation difficulties, and their effect.
on the nature of children's participation in daily life and, in turn, on the family's daily life.

**Family Daily Life and Integration of Programs**

Ecocultural theory of family accommodation (Bernheimer et al., 1993; Gallimore et al., 1989) suggests that families construct their daily routines in relation to their perceptions of their ecocultural niche. The ecocultural niche consists of the following domains: family subsistence, availability of services, home/neighborhood safety and convenience, domestic workload, childcare tasks, child peer groups, marital roles, instrumental and emotional support, father or spouse role, and parent information (Bernheimer & Koegh, 1995). The daily family routine and every activity in this routine reflect how the family perceives and uses these domains to raise their children according to their values, beliefs, and social and cultural circumstances. For example, Henry and Denise had instrumental support (ABA therapists and teachers, respectively) enabling them to adhere to the brushing and compression program. Rachel and Cindy, who applied the brushing and compression twice a day, did not believe that they could engage instrumental support to apply the program because of a lack of trust in the ability of others, or because brushing seemed stigmatizing to perform at school.

Another mother's statement (“I won’t have my house centered around brushing”) is an example of how family values influence adherence to the program. In this statement, the mother reveals that brushing and compression is not a priority for her family and, therefore, an intensive home treatment program (such as brushing and compression) may not be appropriate. Christine, one of the occupational therapists who participated in this study, recognized that this home treatment program may not work for some families and suggested alternative activities even if she believed that these activities were not as effective as brushing and compression.

The issues influencing the integration of home treatment programs into a family's daily life, which were identified by the participating parents in this study, support the findings of Hinojosa (1990), Hinojosa and Anderson (1991), and Law and King (1993). Home treatment programs that are too burdensome and interventions that seem to conflict with parenting (e.g., causing pain or discomfort to the child) will not be integrated into the family's daily routines. The principal finding of this study is that parents are evaluating the effects of the intervention. This motivator for adherence, however, does not appear in the previous studies. This difference across studies may be attributed to differences in the disabilities of the children whose parents participated in the studies.

The findings of this study, like the conclusions of Hinojosa (1990) and Hinojosa and Anderson (1991), indicate that interventions need to be embedded in naturally occurring activities and occupations at home. In this study, parents and occupational therapists identified only dressing and undressing as occupations within which the Wilbarger Protocol could be embedded without interference with the flow of the naturally occurring routines. It seems that these findings from two different studies indicate the need for further research of this phenomenon. An additional interesting finding of this study was that mothers' employment status did not co-occur with either adherence or nonadherence to the protocol. This finding may indicate that organizational skills rather than availability of time are better predictors for adherence to home treatment programs. Further research, however, is needed to draw conclusions from this finding.

Occupational therapists' strategies for encouraging parental adherence to the brushing and compression protocol focused on educating them and suggesting times and activities during which the program could be performed. Despite these efforts, all of the therapists agreed that adherence was very poor. These strategies, however, did not address any of the issues raised by parents or any of the aspects of the families' ecocultural niches that could have been used to enhance adherence. The parents in the study indicated that the most important aspect of the home treatment program was their children's response to it. Few of the therapists mentioned this as an issue in parental adherence.

**Conclusion**

**Implications for Practice and Research**

The study's findings suggest that occupational therapists who select the brushing and compression program need to inquire about children's responses to the brushing and compression program at home, and about parental expectations for change as a result of this intervention. It seems that these issues should be a continued conversation between parents and therapists for the duration of the intervention as children's responses change over time.

Although therapists should continue to educate parents about this intervention, it is important that they keep in mind that parents' lives may not revolve around occupational therapy and the child who needs this particular intervention. To increase the likelihood of parental adherence to the brushing and compression program, occupational therapists should explore the parents' burden of care, the availability of support, and other issues identified by the ecocultural theory of family accommodations.
In terms of supporting parents in applying home treatment programs once they are committed to doing it, occupational therapists need to focus more on the organization of the family’s daily routines rather than finding the time slots for engaging in home treatment programs. In particular, not all available time slots in a family’s daily routine can be filled with planned activities and occupations. The family may need some unstructured time to relax or just enjoy each other’s company. Therefore, embedding interventions in existing routines or actual help from another person, or both options, might be a more successful way of engaging parents in interventions.

Finally, occupational therapists need to understand that occupational therapy home treatment programs may be only one aspect of the family’s daily life. Families prioritize the activities and occupations they should and want to engage in and perform only those they consider most important. Occupational therapists need to understand and acknowledge that their values as professionals and their belief in occupational therapy interventions may not be shared by the families whose children they treat. The best way to engage parents in home treatment programs is to show them that the programs are effective. In the examples used here, scientifically rigorous studies showing the efficacy of the brushing and compression program would be the best approach to engage families in following up with the home program. Additionally, such studies would help therapists identify the type of change expected from the intervention and would facilitate parents’ ability to identify these changes and encourage them to continue with the programs. No such studies exist, however, and future research should aim at establishing the efficacy of the Wilbarger Protocol.

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Endnotes

1. An in-depth review of the theory and a discussion of its suitability for occupational therapy can be found in Segal & Hinojosa (in press).
2. It is important to note that the sole purpose of the study was to identify factors that influence the successful integration of home treatment programs into the daily lives of families rather than the efficacy of the Wilbarger approach.

References


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