



Full Length Research Article

DETAILED VIEW OF PARENTS OF DISABLED CHILDREN AFTER BOBATH APPROACH

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ABSTRACT

Purpose: While numerous pediatric therapy decisions are made by parents, minimal research has been conducted on parents' perspectives regarding their experiences during high intensity interventions of neuro-developmental treatment (NDT). The purposes of this study were to: 1. investigate the perceptions of parents of children with disabilities regarding their child's participation in an intense pediatric therapy program (NDT); and 2. Examine if differences occur in functional skills of children with motor disability after an intensive NDT program.

Methods: A mixed design of qualitative and quantitative methods was used. Participants included 5 parents/caregivers of children with disabilities and their children (1-17 years of age). To explore parents' perspectives of the intensive program, a phenomenological approach of inquiry was conducted through direct interviews and observations. Intervention intensity was 2-4 hours per day of direct handling for a 1 or 2 week duration. Functional skills were measured pre- and post-intervention using the Goal Attainment Scale (GAS) and the Canadian Occupational Performance Measure (COPM).

Results: Child participants demonstrated significantly improved ($p < .001$) scores on the GAS and COPM pre-to post-intervention with the NDT intensive program. Parents valued the intense format of the NDT program. Seven themes were identified as critical to their children's therapy programs: 1. Positive effects were seen with increased intensity; 2. Expert, compassionate therapists were valued; 3. Team collaboration was vital; 4. Objective, realistic goals were required; 5. Home programs with teaching were needed; 6. Funding and scheduling were challenging; 7. Children and their families had individualized needs.

Conclusion: A short-term, intensive NDT program consisting of 2-4 hours of intervention daily for 1 or 2 weeks improved functional skills of children with disabilities. Parents highly valued the intensive program and its benefits for their children. Key words: Bobath approach, Gross Motor Function Classification System (GMFCS)

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INTRODUCTION

While numerous pediatric therapy decisions are made by parents, minimal research has been conducted on parent's perspectives regarding their experiences. The purposes of this study were to investigate the perceptions of parents of children with disabilities regarding their child's participation in an intense pediatric therapy program (NDT); and Examine if differences occur in functional skills of children with motor disability after an intensive NDT program.

MATERIAL AND METHODS

A mixed design of qualitative and quantitative methods was used. Participants included 5 parents/caregivers of children with disabilities and their children (1-17 years of age).

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Study Participants

A convenience sample of patients and their parents coming at the OPD of Jaipur hospital college of physiotherapy and at my physiotherapy center were approached to participate in the study.

Inclusion Criteria

- Age range- 1-17 years
- Documented Diagnosis of CP

- Participation in 70% of the intensive NDT program
- The final sample was 5 parents and 5 patients
- 2 sessions of 10 days intensive NDT was given for 2-4 hours per day, 5 days a week.
- 3 patients participated in one session and 2 participated in the 2nd session.
- 2 boys and 3 girls participated in the intensive NDT program.

Neuro-developmental Treatment Protocol

A thorough assessment was performed and ongoing with each child, and direct handling was modified throughout each session. Handling consisted of elongation activities of muscles (if needed) coupled with activation of postural muscles and graded midrange control (with muscles activated during transitional movements such as slowly moving sit to standing) during age- appropriate play and functional activities. Emphasis was on optimal skeletal alignment, base of support and center of gravity shifts while providing sensory information and activating musculature during functional activities. Children were kept motivated with age-appropriate, meaningful functional tasks (including play) . Alignment, base of support, and center of mass (ABCs) were addressed during each intervention session. Core muscle activation including flexion with rotation or extension with rotation (or both) was facilitated as needed.

Instrumentation

Qualitative Research

An interview questionnaire consisting of 15 open-ended semi-structured questions was used with the parents for the qualitative component of the research.

Interview Guide

The parent questionnaire consisted of the following Interview Questions:

- What has been your, your child's, and your family's experience of having your child participate in this five (or ten) day intensive NDT program? Probe: Describe the process; tell me what brought you to the program and what instructions or information you were given prior to the process. How did you feel about this program initially?
- How were you and your child's needs met through this NDT program?
- What were the hopes for you and your child during this intensive NDT program?
- What needs or hopes for you or your child were unmet with this intensive NDT program?
- What could have been done to better help you with this whole experience?
- What has been the hardest part for you and your child about this program?
- How have you dealt with any difficulties with the program?
- What has been the easiest part for you and your child about the program?

- How has this intensive program differed from other therapy your child has received? (Probe: be sure to inquire regarding the duration and frequency of therapy)
- Was there anything that happened specifically (positively or negatively) that you would like to share about the intensive NDT program?
- Describe your experience with the therapists during this program.
- If there were three top things you could discuss or pass on to other parents about the intensive NDT program -what would they be?
- What would you do differently or what would you tell other parents or children to help them with this NDT program?(if applicable-asked only if family participated in the intensive NDT program previously)
- How was the home program for you and your family?
- Is there anything else you would like to add?

Forms were used to:

Collect demographic and descriptive data,
Document intervention and scoring of goals,
Record attendance for the patients, their parents.

Quantitative Research

Classification of Children Using GMFCS

Children participating in the study were classified using the Gross Motor Function Classification System (GMFCS). Five levels of mobility independence exist in the GMFCS ranging from Level I (walking without restriction) to Level V (self-mobility is severely limited). The GMFCS provides a uniform way for clinicians to classify gross motor function in children with neuro-motor disabilities, and to assist with specific comparisons in intervention effectiveness for varying levels of function in children with CP and other neuro-motor disorders.

Goal Attainment Scale

The GAS level of attainment scale ranges from -2 (much less than expected) to +2 (much more than expected). The GAS has many applications in the rehabilitation field due to its ability to assess change during many forms of intervention, and is commonly used to augment standardized measures of classification and outcome. Goals that are specific, measurable, achievable, realistic /relevant and timed (SMART goals) are recommended. Recent studies have found parents often place "greater value on those aspects of functioning that are not readily measured by traditional outcome measures.

Canadian Occupational Performance Measure

The Canadian Occupational Performance Measure (COPM) is an individualized outcome measure to identify problem areas, evaluate performance, and satisfaction relative to the problem areas. The COPM is administered using a semi-structured interview format using a 10 point Likert scale. The scaling for each of the three scales are as follows: Importance-scores range from 1 (not important at all) to 10 (extremely important); Performance-scores range from 1 (not able to do

it) to 10 (able to do it extremely well); and Satisfaction-scores range from 1 (not satisfied at all) to 10 (extremely satisfied). The reliability of the COPM has been found to be well above the acceptable range (>.84), and content, criterion, and construct validity is supported.

Data Collection Procedures

- Consent taken
- Demographic information
- Parents interview
- Goal setting for patients and pretesting with GAS and COPM and
- Intensive NDT intervention 2-4 hours per day for 5-10 days
- Post intervention parents interview taken analysis of both qualitative and quantitative data done

Qualitative Data Collection

Interview scheduled and data collected of all the 5 patients interview duration 50-80 mins the parents were encouraged to share all experiences both positive and negative data collected after 2nd session of NDT

Demographic data of patients and parents recorded

Quantitative Data collection

Individual therapists treating the children during the intensive program collaborated with the family after the initial evaluation of the child to set specific functional outcomes for the child. The outcomes were written using a 5 point Likert scale as specified on the GAS. The GAS was scored on the first day and after each week of intervention. The goals were reviewed by therapists known to the children to ensure they were appropriate and an accurate reflection of the child's functional levels. The COPM was explained to the parent (and the child if appropriate) during the first intervention session and scored on the first day and after each week of intervention. Children received NDT intervention delivered by physiotherapist occupational or speech therapists consisting of direct therapy for two to four hours during five consecutive days, or for ten days (with one weekend off).

Data collection limitation

- No control group was taken.
- Parents may not be able to share all information in one post intervention interview

Data Analysis and presentation

Qualitative analysis: Interview recorded and the data then presented well with structural and textural description of the intensive NDT intervention.

Assumptions by the therapist:

- Parents and caregivers of individuals with disabilities have unique circumstances as compared to parents/caregivers of typically developing individuals.
- Many individual and contextual factors influence

perceptions of parents and the care of children with disabilities.

- Therapy is an important entity for families of children with disabilities.
- A variety of intervention options exist but may not be available to all families of children with disabilities.
- Frequency, intensity and duration of intervention for children with disabilities vary.
- The amount of collaboration between individuals treating children with disabilities may differ.
- The availability of therapy can vary in different programs and states.
- Appropriate therapy is just one of the many needs for children with disabilities.
- Therapists and parents try to do the best they can with children with disabilities.

RESULTS

Results and Presentation of Qualitative Data

Parent's interviews were conducted during two intensive program sessions:

All caregivers spoke Hindi, and translation was required. All interviews ranged from 50-85 minutes in length

Description of Children Participants (Quantitative Data for GAS and COPM)

A total of five children participated in the two intensive programs. The mean age of participants was 7 years, 5 months (range 1-10 years). The majority of children functioned at the GMFCS Level III-V (more severely involved), and three children functioned at the GMFCS Levels I or II. For the first intensive session, a total of 3 children participated in the intensive program. Three children participated for half days only. Two of these children participated in the two week session (and were two years old); and one child participated for only one week, but for the full day. For the second intensive session, a total of 2 children participated in the intensive program. Two of the children participated in half day sessions only (one of these children was age two). Three children participated in both the intensive programs. Individualized goals were written for each week of the intensive program. Using the GAS, goals were collaboratively written with the parents and the therapist treating the children for the 2nd session.

Quantitative Results

A total of 5 participants received NDT intensive intervention. The distribution of severity of each of the participants is represented in. Three participants were involved in both intensive sessions. All the children completed at least 70% of the intervention sessions, attended both pre- and post-test sessions of the GAS, and were included in the statistical analysis of the GAS. One participant completed 70% of the intervention sessions, attended the pre-testing of the COPM, but was not present on the last day for post-testing of the COPM, so was not included in the statistical analysis for the COPM.

Table 1. Days of Study for Intensive Programs

1-2	3	3-4	4-6	8+	
Obtain demographic, Consent/ Assessment forms, Scheduling parent interviews	Therapist in- serving; Children assessed and goals established; Pre-testing using COPM	servicing; GAS Pre- testing using GAS and COPM	NDT Intensive Intervention: 2-4 hrs/day for 5 or 10 days total	1-hour Interviews with Parents, Post-testing weekly using the GAS and COPM	Begin Transcription of interviews and data analysis.

Table 2. Quantitative Data Analysis

Dependent Variable	How measured? (scale)	Independent Variable	How measured?	Examine	Statistical test
GAS	Ordinal (5 point Likert scale converted to t-score)	Children will be classified in severity using GMFCS-Level I-V	Interval -2,-1,0,+1,+2	Means	Wilcoxon signed-ranks, paired t-test
COPM	Ordinal (10 point Likert scale)	Children will be classified in severity using GMFCS-Level I-V	Ordinal 1-10	Means	Wilcoxon signed-ranks, paired t-test

Table 3. Child Demographic Characteristics

Child #	Gender	Age at time of data collection (yrs mths)	GMFCS Level				
			I	II	III	IV	V
1	M	16:3			X		
2	M	2:11			X		
3	F	6:9					X
4	F	2:2			X		
5	F	17:6					X

Table 4. Summary Demographic Information of Children Participants (n=16)

Variable	Summary Data
Age	
• Mean Age	7yr 5mth
Gender	
• Male	2
• Female	3
GMFCS Level	
• I	0
• II	0
• III	3
• IV	1
• V	1

Table 5. Caregiver Demographics Characteristics

Participant	Relation to Child	Child's Age (yrs: mths)	GMFCS Level of Child
1	Mother	16:3	III
2	Mother	2:11	III
3	Mother	6:9	IV
4	Mother	2:2	III
5	Mother	17:6	V

Table 6. Pre- and Post-Test Scores using GAS and COPM

Outcome Measure	Statistical Significance
GAS	P<.001
COPM	P<.001

Table 7. Pre- and Post-GAS Scores with T-Score Conversion

Child	# of Goals	Pre- GAS	Average Scale score	T-score	Post-GAS	Average Scale score	T- score
CO1	3	-6	-2.00	22.62	-3	-1.00	36.31
CO2	3	-6	-2.00	22.62	3	+1.00	63.69
CO3	4	-8	-2.00	20.98	-2	-0.50	42.75
CO4	3	-5	-1.67	27.18	-1	-0.33	45.44
CO5	2	-4	-2.00	25.19	1	+0.50	56.21
wk1							
CO5	2	-1	-0.50	43.79	1	+0.50	56.21
wk2							

Table 8. Pre- and Post-COPM Scores

Week 1 or 2, Child # & Discipline Goals	Pre-Perf	Post-Perf	Pre-Satis	Post-Satis
CO1-PT1	2	8	3	9
CO1-OT1	2	9	2	9
CO1-OT2	2	9	2	9
CO2-PT1	4	6	2	5
CO2-PT2	6	7	5	7
CO2-OT1	4	6	6	7
CO3-PT1	5	5	5	5
CO3-PT2	1	3	1	3
CO3-OT1	2	3	1	3
CO3-OT2	1	5	1	5
CO4-PT1	2	4	5	7
CO4-PT2	3	4	10	10
CO4-OT1	2	6	3	8
1CO5-PT1	7	7	1	10
1CO5-OT1	4	8	1	10
2CO5-PT1	7	8	10	10
2CO5-OT1	8	10	10	10

Table 9. Qualitative Study Results-Clustering of Invariant Constituents of Caregivers' Experiences into Themes

Theme	Invariant Constituents
Effects of increased intensity of intervention were viewed as highly beneficial by caregivers.	Loved intensive and felt like it was what my child needed
Unique qualities of the therapists such as expertise and compassion were important to the caregivers.	Specific times of increased therapy recommended Experts in field and knowledgeable NDT handling expertise Mutual respect Celebrate accomplishments with us Flexible and compassionate It is important to communicate well Warm people and nice atmosphere Liked new set of eyes and fresh perspective I'm not a therapist
Team collaboration as part of the intensive program was highly valued by the caregivers.	Liked team of OT, PT and SLP working together
The focus of specific time-intensive goals written to improve functional abilities was meaningful to caregivers.	Liked working and ideas for other "regular" home therapists Caregivers liked giving input on goals Setting specific goals for weeks increased focus of team Having specific goals helped setting realistic outcomes Working on building foundational skills first helped with goals and carry-over
Specific home programming with specific suggestions for carry-over when not in therapy was viewed as beneficial to caregivers.	Liked home program with pictures and Power point with suggestions Important for therapists to explain what they are doing with therapy suggestions for home. Home program helped carry-over for day to day activities
Scheduling the intensive program with families and insurance coverage for the program could be problematic.	Intensive was intense and required specific scheduling for families including changing routines-(this could be tough and stressful) Financial and insurance coverage for needed regular therapies and for intensive therapy is difficult
Each child is unique with different strengths and difficulties.	Kids do things on their own schedule sometimes Children with disabilities present unique care giving challenges Some kids do better in clinic vs. home setting Social interactions are important for families

There was no attrition of subjects affecting the study. The NDT intensive weekly GAS intervention mean scores were significantly different following intervention ($p < .001$) from pre-test mean scores. The hypothesis that a difference would occur in GAS scores after intensive NDT intervention was supported. The NDT intensive weekly COPM intervention mean scores were significantly different following intervention ($p < .001$) from pre-test mean scores. The hypothesis that a difference would be found in COPM scores after intensive NDT intervention was supported. Per Law and colleagues¹, change in two or more points on the COPM indicates a minimal clinically important difference (MCID). The NDT intensive weekly COPM performance and satisfaction post-intervention scores had more than a 2 point difference compared to pre-intervention scores indicating a MCID

Presentation of the Data-Qualitative Results

The feedback was as follows:

Effects of increased intensity of intervention and the unique qualities of the therapists such as expertise, being a good teacher, having compassion, good listening skills and providing hope were essential keys to the success of the intensive program for caregivers. Team collaboration as part of the intensive program was highly valued by the caregivers. Collaboratively setting objective, realistic goals to improve functional abilities of the child was an effective strategy for goal attainment and highly valued by caregivers. Home programs with therapists teaching intervention techniques were viewed as essential for carry-over in the home and other settings. Intervention must be based on individual needs and abilities of the child with the disability and family.

Textural Descriptions

Perceptions of the intensive program experience were individualized. Reviewing individual textural descriptions provides insight for understanding “the big picture” of the experience with each caregiver.

Structural Descriptions

The setting, context and specific qualities of the program accounting for “how” thoughts and feelings surrounding the experience with the intensive program were formed revealed the deeper meanings of the intensive program

Composite Textural-Structural Description

Caregivers have many concerns and decisions regarding the optimal therapy for their child. Each family has unique needs, concerns, strengths, and difficulties. An intensive program is one option for providing increased therapy in a short period of time. Although attending an intensive program often required extensive family scheduling and was expensive, caregivers viewed it as “worth it and beneficial for the child.” Both the caregiver and their child seemed to reap benefits from the intensive program. Caregivers liked the continuity of therapy with the intensive program. Children were able to continue with intervention the next day beginning with skills they achieved the day before and working from this point rather than waiting a week in traditional therapy models. Caregivers expressed improved carry over and felt like gains were not lost in between the weeks. The therapy was more aggressive, and expectations were met quickly. The repetition with the intensive program allowed more practice for the children to assist with goal attainment. An essential aspect of the collaborative effort during the NDT intensive program included home programming. Parents and family members wanted to be able to maintain gains achieved during the intensive program and were excited about receiving suggestions for carry-over at home.

DISCUSSION

This study provides evidence that a short-term intensive NDT program improved functional skills when a collaborative approach focused on realistic, quantitative goals of primary importance to children, caregivers, and therapists. Caregivers found intensive therapy to be beneficial with qualitative changes and positive outcomes achieved during an intensive program. Both the GAS and COPM were found to be effective tools for experienced NDT- trained clinicians to document quantitative changes in PT, OT and SLP goals. Although a small sample size was used for the quantitative data, statistically significant changes were found in functional skills. This study provides evidence to support NDT with an increased intensity for children with neuro-motor disabilities for goal attainment and improving function. It also provides qualitative evidence supporting intensive NDT as a therapeutic intervention option valued by caregivers. In this study caregivers voiced opinions and shared perceptions and experiences regarding an intensive therapy option and how the intensive program met the needs of their family and child. A range of design and methodological factors contributed to the positive results of the study:

- A mixed method design combining both qualitative and quantitative data added rigor to the study.
- Children and adolescents with similar neuro-motor impairments participated (homogeneous sampling e.g. delayed functional skills; majority of children functioning GMFCS Level III-V).
- A homogeneous group of parents of children with disabilities were interviewed (majority of parents were from Milwaukee area with similar availability of services).
- NDT intervention was provided according to a specific NDT protocol by certified/trained NDT therapists and instructors.
- Quantitative outcome measures were appropriate for measuring changes over time with interventions and all discipline goals were written using SMART guidelines.
- Intensive intervention was provided daily.
- Children served as their own controls in the quantitative aspect of the study with weekly pre-to post-intervention testing; maturation was not a factor in the changes in functional skill level.
- Documented changes in the children’s performance on functional goals were parent- identified areas of greatest priority.
- Caregivers were present throughout the majority of the treatment sessions increasing validity of study for sharing perceptions of intensive program.
- Extensive home programming and education were provided for carry-over and further intervention.

Clinicians continue to seek appropriate, clinically relevant research to assist with decision-making for selecting optimal interventions for children. Intense activity-based practice and high intensity intervention have been found successful for improving function in individuals with neuromotor disabilities.

Conclusion

Intensity of intervention is a hot topic currently in pediatric research. Caregivers of children with disabilities voiced positive support for an intensive NDT program. Increased intensity of intervention using the NDT approach had a positive functional impact on children. The GAS and COPM were found to be clinically relevant, inexpensive objective outcome measures for examining changes in function pre-to post-intervention during a short time period. Collaboration and home programming was of utmost importance for optimal outcomes and caregiver satisfaction.

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