

**Parental Compliance in Physical Therapy
Programs of the Public School**

**A Thesis submitted to the faculty of
The University of Houston at Clear Lake City**

by

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**In partial fulfillment of the requirements
for the degree of Master of Arts**


in

Behavioral Sciences

May, 1980

We the undersigned, certify that we have read this thesis and approve it as adequate in scope and quality for the Master's degree in the Behavioral Sciences.


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ACKNOWLEDGMENTS

I would like to express my sincere gratitude to my advisor, Dr. Cheryl Rampage, for her continuous support, direction, and unending patience during this project. I would also like to thank Dr. Pat Doyle for his time and constructive criticism. I thank Laurie Proctor for her time and assistance in preparing this project.

Lastly, I express my great appreciation to my husband, John, who has been so patient, supportive, and giving throughout this entire school experience.

Abstract

Handicapped children have been attending regular school since 1975 when P.L. 94-142 was signed. These handicapped children bring many educational as well as physical problems with them into the classroom. In many instances, the assistance of a physical therapist is needed to obtain the maximum from this student in the classroom environment. In trying to achieve the maximum learning for each handicapped child, parental compliance becomes essential in follow through with the school programs. The school must also follow through with programs established in the home. This research attempts to gain a wider perspective in the area of parental compliance and the factors which may influence compliance when a handicapped child is involved. The subjects were 36 children with a variety of disabilities and 35 parents. The children ranged from age two-eighteen years, with 22 females and 14 males. Each child was evaluated and then classified into a functional category using the PULSES Profile (Adapted) as criteria. The parents were also categorized as compliant or noncompliant based on a set of criteria. A chi square statistical test was performed which resulted in not rejecting the null hypothesis. It was not possible to determine how compliant and noncompliant parents differ. It could be inferred from the results, however, that a parent may tend to be more

compliant if the child does function almost independently. It was theorized that adaptative aid reinforces the fact that their child requires special assistance. The parents follow the physical therapy program because of this constant reinforcement and hope that someday the child can function without the adaptative aid. The ability to identify a potential noncompliant parent and intervene would assist the child in achieving his or her full potential.

Parental Compliance in Physical Therapy

Programs of the Public School

In 1975 United States President Gerald Ford signed Public Law 94-142, which states that all handicapped children have a right to education. Under this law a child is considered handicapped when he or she requires special education and related services. A child is classified handicapped or in need of special education whenever he or she has a learning disability, any physical limitation, visual disorder, speech and language disorder, emotional disorder, or a combination of these disorders. In its most general sense, Abeson and Zettel (1977) describe special education as the "specifically designed instruction to meet a child's unique needs" (p. 114). For example, a teacher may use gross motor activities to teach a child with a perceptual motor dysfunction the letters of the alphabet. This is considered an unusual teaching technique. Related services are in addition to those necessary for the child to benefit from the special education instruction. Physical therapy, occupational therapy, and resource instruction are related services.

An individualized education program is required by P.L. 94-142 for each handicapped child. The program must address the specific special educational needs of the child, and as part of the program, a statement is made as to what services

will actually be provided for the child. For example, physical therapy will be given two times weekly with the following goals to be achieved.

When attempting to meet the goals specified in the individualized education program, it is necessary to consider which factors will influence the attainment of these goals. Some factors which may influence the attainment of the handicapped child's educational goals are parents' compliance, regularity in school attendance, frequency of the related services, and the developmental level at which the child is functioning.

This paper will explore one particular factor, parental compliance, which may influence the attainment of a handicapped child's educational goals.

Zifferblatt (1975) and Gentry (1977) define compliant behavior as a class of behaviors with a specific set of cues or antecedents and consequences. The cues can relate to a request by a doctor, relate to physical symptoms, or specific instructions. A simpler definition of compliance in medicine is the degree to which a patient adheres to a prescribed regime (Mayo, 1978). Whatever the definition, it should be operationally defined or stated in exact terms as to what behaviors comprise compliance.

There have been several studies on compliance in different settings. Studies have also been made in following a medical prescription and in physical therapy

programs. Wilker and Stoycheff (1974) found in a study of recommendations made to parents of retarded children in a pediatric facility that if one to two recommendations were made, two thirds complied; and if three to four recommendations were made, one fourth complied. Thus, the fewer the recommendations, the better the compliance.

While Mayo (1978) estimated the percentage of patients who followed doctors' orders was 75-95%, it seems that this percentage varies according to whether a person had overt signs and symptoms. Podell and Gray (1975) found that if a person had symptoms, 80% kept their appointments; while persons without symptoms, 50% failed to keep appointments. Podell and Gray also stated that compliance dropped to 40% for long term disability or rehabilitation, whereas for short term disability it was 80%. This trend of poorer compliance with the long term disability is seen in Treusch and Krusen (1943) study of arthritic patients. Only 26.6% of their 218 patients carried out the physical therapy treatment at home one year later. When considering these studies, it appears that the lowest degree of compliance is with recommended physical therapy appointments; there was only 50% compliance (Mayo, 1978). In summary, it appears that there is 50-50 chance for voluntary compliance based on whether a person has a long term problem with symptoms and is seen in an out patient setting.

A terminator, dropout, or noncomplier is not easily defined. Noncompliance in physical therapy can be defined as either failing to carry out, or only partially carrying out, the prescribed treatment. The patient may be erratic in coming to treatment, or might add something to the treatment program that is not prescribed by the therapist.

The figure for noncompliance seems to vary from 25-75% for all patients (Finnerty, 1978; Matthews, 1975). In most patient care facilities, the noncompliance rate is 40%. One study in ambulatory care settings (Hertz & Stamps, 1977) found that the broken appointment rate ranged from 16-44%. Pediatric out patient facilities reported 20-40% missed appointments (Mayo, 1978).

Other factors that may or may not affect compliance are socioeconomic status, personality characteristics, severity of the illness, attitudes, program instruction, and the amount and type of reinforcement. Mayo (1978) found correlations between noncompliance and socioeconomic parameters with persons of low and high socioeconomic status less compliant. Stearn, Gross, and Moore (1977) state that early terminators, persons who failed to keep appointments in a drug study, were of lower social class. Other studies (Davis, Estess, Simonton & Gonda, 1977; Matthews, 1975; Podell & Gray, 1975), however, show no existing correlations in socioeconomic status. All researchers do agree that

there is some degree of noncompliance found in all socioeconomic groups, all persons, and in all settings; however, there is general disagreement over the relationship between noncompliance and socioeconomic class. Research does indicate that compliance is generally unrelated to occupation and sex.

Personality characteristics are unclear in the noncompliance patient. Personality orientation inventories are not effective predictors of dropouts according to Iverson, Jurs, and Wenger (1976).

Matthews (1975) states that there is no consistent relationship between severity of illness and compliance in the literature. Podell and Gray (1975) found that a person's attitude toward his or her illness, therapy, and doctor are all factors which have affected compliance. A person who denies his or her illness is more likely to be noncompliant. Mayo (1978) documented that the actual severity of the disease didn't affect compliance, but rather the important factor was the patient's view of the seriousness of the disease. A person viewing his or her illness as serious is more likely to be compliant.

Recent studies (Mayo, 1978; Podell & Gray, 1975; Van Camerik, 1978; Wilker & Stoycheff, 1974) all found education was another factor that would affect compliance in protocols. The less formal education the greater the chance

of noncompliance. Not only is the level of education an influence on compliance, but so is the amount of education a person receives regarding his or her specific case, treatment, or program he or she is to follow. A person who understands the purpose and the details of a regime, may be more compliant (Matthews, 1975). Along with this patient education, the patient must know what to expect and be aware of positive or negative adverse reactions. These reactions are usually the most common sources of patient noncompliance, and the easiest to correct. Patients need to have relevant facts brought to their attention so they know what to expect. If a patient is given adequate feedback, he or she is better prepared and more compliant. Several studies (Duehn & Proctor, 1977; Podell & Gray, 1975; Van Camerik, 1978) suggested that a regime which produced negative side effects usually was not continued.

In programs where instructional sessions were used for patient education (Treusch & Krusen, 1943), it was most beneficial if there were at least two sessions. Complexity of the recommendations given, as well as how much it interfered with daily life routines, affect compliance. Compliance was better if the regime was simple with few items to be done.

Another factor affecting compliance is social disorganization. Stress in the family can be a type of social

disorganization. Hertz and Stamps (1977) reported that if there was social disorganization in the family, patients were likely to be poor in keeping appointments.

Several studies have investigated ways to improve patient compliance. Compliance was improved with personalized, continuous, convenient, and courteous care (Podell & Gray, 1975). Duehn and Proctor (1977) state that the quality of the clinician-patient interaction may be the best indicator of continuance. In looking at the clinician-patient interaction, some interesting facts have been found. Generally, it was found that doctors tended to have the impression that patients complied although they did not (Podell & Gray, 1975). Experienced professionals largely overestimated the degree to which patients complied with their advice.

Factors affecting compliance in cases dealing with children may include attitude of the parents, educational level of parents, family structure, and whether there is agreement between the parents' view of the problem and the problem as it exists. There have been several studies evaluating these possible factors. Parents are more compliant if their child is perceived to have severe disease and is symptomatic (Mayo, 1978).

Wilker and Stoycheff (1974) stated in their three point hypothesis, that parents would follow through with

recommendations if they accepted the diagnosis of mental retardation given their child. Wilker and Stoycheff (1974) further stated that the most significant predictor in follow through with recommendations was whether the mother of the hospitalized child agreed with the diagnosis during the hospitalization. They concluded that the mother must realize the importance of proper child care in order for her to be maximally compliant.

Fabry and Reid (1978) found in their study with severely handicapped children that parents followed suggestions best when they were praised for their behavior and could model the instructor's behavior. Parental compliance improves with this positive and immediate reinforcement.

In the pediatric setting, the feelings of the family toward the services rendered while their child was hospitalized also affected compliance. If parents were pleased with the services and perceived the professionals as truly concerned about their child, there was better compliance. Duehn and Proctor (1977) further indicated that parents would terminate services only if services were not effectively delivered, or not delivered to the consumers' expectations.

In the research reviewed, it appears that there are numerous methods to measure whether a person, parent, or

child is compliant. Compliance can be measured by asking the patient about adherence to a program, in the form of a questionnaire. A written report by the patient can also be used. Mayo (1978) showed that patients tended to overestimate their degree of compliance when compared to other objective measures.

More objective measures include attendance records in clinics, quantitative measures such as drugs found in the urine or blood, number of pills left in the medicine bottle, and the number of medication refills.

In physical therapy, compliance is more difficult to measure. One must rely primarily on patient report. When a physical therapist evaluates compliance in the public school setting, he or she relies almost entirely on parental report. One can see, that in order for a handicapped child or student to benefit from a related services, such as physical therapy, the therapist must consider how to achieve parental compliance in the program. The parents are the key to a successful program of physical therapy in the public school setting.

Based on the research reviewed, several conclusions may be made in trying to determine compliance in a pediatric case. The subject population being investigated is of low socioeconomic status and the parents often deny there is an illness present indicating noncompliance. There is stress

present in the family, another indicator of noncompliance. These factors as a whole will suggest parental noncompliance.

The majority of the children in the subject population have long term illnesses and chronic disabilities which indicate an inability to care for oneself.

Long term illness and chronic disability, two factors affecting parental compliance, have already been investigated. Although long term illness is not considered synonymous with a dependent level of functional status, these terms are similar enough that one may suspect similar findings when comparing parental compliance and their child's functional status. A child who is functionally dependent usually has a long term chronic illness. Thus, one would suspect the parent to be noncompliant. This research will attempt to directly investigate the area of parental compliance and functional status of the child.

The working hypothesis as derived from the above factors states a positive correlation exists between a parent's compliance in following a physical therapy program for their child and the degree to which the child is independent in functional status.

Method

Subjects. Subjects were 36 children enrolled in the Galveston Independent School District. All the subjects received physical therapy. The subjects ranged in ages from

two to eighteen years. The breakdown of subjects per age was as follows:

two years	1	ten years	1
three years	3	eleven years	3
four years	2	twelve years	1
five years	8	thirteen years	1
six years	5	fourteen years	1
seven years	2	seventeen years	2
eight years	4	eighteen years	1

There were 22 females and 14 males. The racial breakdown was, 13 Black, 10 Mexican-American, and 13 White. The disability classification of the subjects included acute paraplegia, acute trauma to a joint, apraxia, ataxia, behavioral disorders, cerebral palsy, congenital disorders, developmental delays, Guillain-Barre syndrome, head injury, hemiparesis, perceptual motor dysfunction, mental retardation, poliomyelitis, and spina bifida.

The parent who attended the parent-physical therapy meeting and performed the physical therapy recommendations was the selected sample parent. The parents ranged from age seventeen to sixty years. There were 17 single parents and 18 married parents. The marital status of one parent could not be determined. Of all the parents, 25 agreed with the diagnosis given their child, while 8 disagreed with the diagnosis given their child. In three cases, it could not

be determined if the parent agreed or disagreed with the diagnosis, the reason for this being that the parents had just had their child evaluated and heard the diagnosis for the first time. The socioeconomic breakdown was as follows: 24 low income families and 11 middle income families. Socioeconomic status information was not available on one parent. The breakdown for long term and short term disability for the subjects was, 3 short term and 33 long term disabilities.

The two samples, children and parents, are independent groups. The subjects are different and unrelated sets.

Instrument. The PULSES Profile (Adapted) (Granger, 1976) . gives a global functional status. The categories for measuring activities of daily living are six mutually exclusive definitions. It provides for an objective evaluation of physical functioning and psychosocial behaviors. The six categories are, physical condition, self-care activities, mobility activities, sensory components relating to communication, excretory functions, and intellectual and emotional adaptability. The best score is 6/6 and the worst score is 6/24. See Appendix.

Procedure. Every child was first given a physical therapy evaluation. The children were then categorized into either a relatively independent, relatively moderately dependent, or relatively dependent functional status,

according to the criteria in the PULSES Profile (Adapted) (Granger, 1976). Only the first four characteristics of the six in the Profile were used, physical condition, self-care activities, mobility activities, and sensory components. The children were categorized as relatively independent for functional status if their Profile score was 4-5, as relatively moderately dependent if their Profile score was 6-7, and relatively dependent if their Profile score was 8-12.

After this initial evaluation, an ARD (Admission, Review, or Dismissal) meeting was scheduled. The educational diagnostician, parent, physical therapist, teacher, and any other persons who evaluated the child attended. The physical therapy program was written out, usually no more than four items, and instructed to the parent. Then the parent was given the opportunity to perform the program getting appropriate feedback from the physical therapist. At a later date, one month after the initial evaluation, the parent was asked to return to go over the physical therapy program again.

The parent of each child was then categorized as compliant or noncompliant. In order to be compliant, the parent had to meet the following criteria: attend the parent-physical therapy conference, demonstrate the physical therapy program requiring minor corrections, attend the ARD

conference, and bring the child to school for physical therapy. If the parent did not meet all four criteria, the parent was categorized as noncompliant. All participants were dealt with in accordance with the ethical standards of the APA.

There was no treatment given, thus no independent or dependent variables.

Results

A Pearson chi square statistical test was performed on the data. The results were not statistically significant at the .05 probability level with an obtained magnitude of 2.73 and two degrees of freedom. The two groups of parents do not appear to be different in terms of their child's functional status.

It was found that 11 children were relatively independent, 11 children were relatively moderately dependent, and 13 children were relatively dependent. There were 20 compliant parents and 15 noncompliant parents. It was not determined if one parent was compliant because they left the school district prior to the completion of the study.

Insert Table 1 about here

A correlation coefficient statistical test was

performed on each of the criteria in the PULSES Profile, physical, mobility, self-care, and sensory. The results demonstrated no correlation between the criteria.

Discussion

The results could not support the hypothesis of a positive correlation between a parent's compliance in following a physical therapy program for his child and the degree to which the child is independent in functional status.

In analyzing the data several trends appear in the frequency distributions. The frequency distribution indicated a 53% trend that noncompliant parents tended to have more dependent children. There was a 40% trend of a compliant parent and a relatively moderately dependent child. Several factors may affect those trends. The parents may become overwhelmed with their child's degree of involvement and feel it is useless to follow a physical therapy program. Another factor is if the child has a long term disability requiring assistance, the parent may not see significant and immediate progress to reinforce adherence to a program.

The frequency distribution for the criteria in the PULSES Profile demonstrates a 64% trend of compliant parents with a child who is independent in self care. The parent who was compliant tended to have a 55% trend where the child

was independent in mobility but required ambulatory aids. This may indicate that in order for a parent to carry out a program the child must be fairly independent requiring little assistance, and therefore be minimally disruptive to the family regime and structure. The physical handicap, whether it be braces, crutches, or a wheel chair, may be a visual reinforcer to the parent reminding them their child is not "normal" and requires special help to meet their needs, even though the child functions almost independently of the parent.

There was a 57% trend of compliant parents and children who have no visual impairment or communication disorder. This may indicate a parent tends to get more feedback from their child who is verbal and reinforces continuing the program.

The author speculates that parental compliance occurs more often when the child is able to do his own self-care activities, is independent in transferring and walking but requires ambulatory aids, is independent in communication, and is without visual impairment.

Parental noncompliance tends to occur more often when the child is independent in walking and transferring but has assistive devices, has a mild communication or visual disorder, and is either independent in self-care activities or dependent upon assistance in self-care activities.

All of the proposed trends may have occurred just by chance.

It would seem important to be able to recognize or predict a case where parental compliance is questionable. After early identification one could implement a plan to improve compliance. Research indicates several techniques to improve compliance: more education of the parents to understand the purpose and goals of the program, reducing recommendations to two, setting up a positive and successful session where the parent will receive immediate and positive reinforcement, frequent review and instructional sessions in the home environment, education of the parents toward their child's disability and the future implications, and, lastly, continuing to assess a parent's expectations and modify these expectations when appropriate.

We need to explore these suggestions and implement them into our educational setting if we hope to allow the handicapped child his right to an education and to function at his maximum capacity.

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Table 1
Frequency Data:

Parent	Compliant	Noncompliant
Children		
Relatively Independent	O 7 E 6.2	O 4 E 4.7
Relatively Moderately Dependent	O 8 E 6.2	O 3 E 4.7
Relatively Dependent	O 5 E 7.4	O 8 E 5.6

Appendix

PULSES Profile (Adapted)*

P - Physical condition including diseases of the viscera (cardiovascular, gastrointestinal, urologic, and endocrine) and neurologic disorders:

1. Medical problems sufficiently stable that medical or nursing monitoring is not required more often than three-month intervals.
2. Medical or nurse monitoring is needed more often than three-month intervals but not each week.
3. Medical problems are sufficiently unstable as to require regular medical and/or nursing attention at least weekly.
4. Medical problems require intensive medical and/or nursing attention at least daily (excluding personal care assistance only).

U - Self-care activities (drink/feed, dress upper/lower, brace/prosthesis, groom, wash/bathe, perineal care) dependent mainly upon upper limb function:

1. Independent in self-care without impairment of upper limbs.
2. Independent in self-care with some impairment of upper limbs.
3. Dependent upon assistance or supervision in self-care with or without impairment of upper limbs.
4. Dependent totally in self-care with marked impairment of upper limbs.

L - Mobility activities (transfer chair/toilet/tub or shower, walk, stairs, wheelchair) dependent mainly upon lower limb function:

1. Independent in mobility without impairment of lower limbs.
2. Independent in mobility with some impairment in lower limbs; such as needing ambulatory aids, a brace or prosthesis, or else fully independent in a wheelchair without significant architectural or environmental barriers.
3. Dependent upon assistance or supervision in mobility with or without impairment of lower limbs, or else partly independent in a wheelchair or else there are significant architectural or environmental barriers.
4. Dependent totally in mobility with marked impairment of lower limbs.

S - Sensory components relating to communication (speech and hearing) and vision:

1. Independent in communication and vision without impairment.
2. Independent in communication and vision with some impairment such as mild dysarthria, mild aphasia, or need for eyeglasses or hearing aid, or needing regular medication.

3. Dependent upon assistance, an interpreter or supervision in communication or vision.
4. Dependent totally in communication or vision.

E - Excretory functions (bladder and bowel):

1. Complete voluntary control of bladder and bowel sphincters.
2. Control of sphincters allows normal social activities despite urgency or need for catheter, appliance, suppositories, etc. Able to care for needs without assistance.
3. Dependent upon assistance in sphincter management or else has accidents occasionally.
4. Frequent wetting or soiling from incontinence of bladder or bowel sphincters.

S - Intellectual and emotional adaptability, support from family unit, and financial ability:

1. Able to fulfill usual role(s) and perform customary tasks.
2. Must make some modification in usual role(s) or performance of customary tasks.
3. Dependent upon assistance, supervision, encouragement or assistance from a public or private agency due to any of the above considerations.

4. Dependent upon long-term institutional care (chronic hospital, nursing home, etc.) excluding time-limited hospitalization for specific evaluation, treatment or active rehabilitation.

*PULSES total: best score is 6/6; worst score is 6/24.

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