

Orthodontic treatment for disabled children: motivation, expectation, and satisfaction

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SUMMARY This study was designed to measure motivation for and expectations of proposed orthodontic treatment for disabled children, and to examine the level of satisfaction with the results of this treatment, in the eyes of the parents. A two-part questionnaire was sent to the parents of consecutively treated disabled children. The first part was sent to the parents of all the patients treated, while the second was only sent to those whose child had completed treatment. The response rate was over 90 per cent. The parents expected improvement in the child's appearance with a concomitant improvement in his/her social acceptance. These expectations from the treatment were found to be exaggerated, with only a minority of the parents claiming a marked improvement in their child's everyday functioning (four out of 27), or a significant social improvement (six out of 27). Nevertheless, most of the parents (26 out of 27) were satisfied with the treatment, and reported that 17 of the children themselves, who were aware of a change, considered it an improvement. A majority of the children understood the reasons for treatment, in the most general of terms. Close friends regarded treatment results as positive (20 out of 27). With only one exception, the parents stated that they would repeat the procedure, given the same set of circumstances, and all of them would recommend it for other disabled children. It may be concluded that even though orthodontic treatment in this group of patients does not yield the desired social influence, the individual benefits from the treatment are worthwhile.

Introduction

The more attractive one's external appearance, the greater the likelihood of receiving positive peer appraisal, which supports a positive internal self-image (Jacobson, 1984). The face is the primary focus of identification and a rich source of non-verbal information (Ekman, 1978), and first impressions are of primary importance.

Children with physical or mental disability usually have a different facial appearance, which generates a far-from-desirable first impression. The high prevalence of malocclusion among these children (Oreland *et al.*, 1987), poses an additional obstacle to social acceptance, from an aesthetic point of view, but also because it may compromise all aspects of oral function. Malocclusion, even of a minor degree, may bring

about alteration in mastication or swallowing patterns. It may also create difficulty in the articulation of certain sounds and effective speech therapy may require some preliminary orthodontic treatment (Proffit, 1993).

In relation to facial aesthetics, Lew (1993) has shown that, from the point of view of the patient, teeth are second in importance only to facial complexion. Most individuals who have had orthodontic treatment feel that they have benefited, even though dramatic changes in facial appearance are not always evident (Ostler and Kiyak, 1991).

Children with disabilities pose a burden on their families and their environment, in all aspects of their day-to-day care and well being. Orthodontic treatment cannot resolve their

medical and physical handicap, and will place new and extra burdens on the children and their parents. Some of the operative and management problems encountered in performing orthodontic treatment on these patients, have been addressed in the literature (Becker and Shapira, 1996; Chadwick and Asher-McDade, 1997). An obvious ethical question that arises is whether it is justified to subject them to a prolonged demanding treatment, when the overall (i.e. not just dental) benefits may be questionable. To the best of our knowledge this issue has not previously been addressed.

The purpose of the present study was to evaluate the motivation for and expectations of disabled children and their parents from orthodontic treatment, the degree of satisfaction with the treatment outcome, its social implications, and whether it may be considered worthwhile.

Subjects and methods

Following a preparatory telephone call, part 1 questionnaires, relating to pre-treatment motivation and expectation (Figure 1) were

mailed to the parents of 46 out of 50 disabled patients treated consecutively between 1989 and 1997. The treatment was performed in all cases at the Center for the Treatment of Craniofacial Disorders in Handicapped Children, the Hebrew University, Jerusalem, Israel. The remaining four patients could not be located. The mean age was 12.9 years with a range of 7–21 years. Completed questionnaires were received from 44 patients, a response rate of 95.6 per cent.

Thirty-three part 2 questionnaires (Figure 2), dealing with post-treatment satisfaction, were prepared for sending only to those of the above sample whose treatment had been completed and were out of retention for at least 1 year, or were permanently retained. The four families who could not be located for the part 1 mailing, were all completed cases, which meant that only 29 families received the questionnaire. The mean age of the patients was 12.7 years with a range of 7–18 years. Completed part 2 questionnaires were returned by 27 patients, a response rate of 93.1 per cent.

The medical diagnoses of the patients concerned are listed in Table 1.

Figure 1 Orthodontic questionnaire—part 1.

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1. Who referred you or suggested orthodontic treatment?
 - (a) Self
 - (b) Physician
 - (c) Dentist/dental specialist
 - (d) Social worker
 - (e) Relatives/friends
 2. Where does the child live?
 - (a) At home
 - (b) With an adoptive family
 - (c) In an institution
 3. If the child lives in an institution, how frequently does he/she come home?
 - (a) Every evening
 - (b) Once/twice a week
 - (c) Once/twice a month
 - (d) Less than once a year
 4. What is the child's attitude to orthodontic treatment?
 - (d) He/she does not understand why we are doing it
 - (e) He/she is aware of the dental problem, but is not interested in treatment
 - (f) He/she is aware of the dental problem and is interested in treatment
 - (g) He/she is highly motivated for treatment

5. Did close friends (relative and neighbours) influence you in deciding to seek treatment for your child?
Yes
No
6. The orthodontic treatment needs your full co-operation. To what degree are you prepared to assist in the home care of the child during treatment (brushing the child's teeth, care and maintenance of the appliances, and other relative functions)?
(f) Prepared to take full responsibility for care and maintenance of the teeth and the appliance
(g) Prepared to travel to institution or protected housing to perform this function
(h) Prepared to guide and encourage the staff of the institution to perform this function
(i) Not prepared to assist at all
7. You chose to subject your child to orthodontic treatment. In the light of the fact that he/she is incapable of understanding and/or appreciating the value of this treatment, do you have reservations regarding the ethical wisdom of this decision?
Yes
No
I don't know
8. Do you believe that straightening of the teeth will make your child more attractive and socially accepted, which may improve his/her quality of life?
Yes
No
I don't know
9. Do you believe that the orthodontic treatment may improve his/her function in society?
Yes
No
I don't know
10. Do you believe that straightening your child's teeth may positively influence your own social acceptance?
Yes
No
I don't know
11. Are there other reasons that motivated you for seeking orthodontic treatment, besides enhancing dental/facial appearance?
Improve dental health
Improve mastication
Improve speech
Eliminate drooling

The results are grouped according to the issues evaluated and analysed to determine the frequency of each variable.

Results

Most of the patients participating in this study lived at home or with an adoptive family (Table 2). Of those living in an institution, three of the children returned home every evening, five once/twice a week, two once/twice a month, and one did not return home at all.

Referral patterns are shown in Table 3. Close friends had influenced only 11 of the 44 sets of parents to seek treatment. The most common

reason for seeking orthodontic treatment was improvement in facial appearance, although additional functional reasons such as improvement in dental health, mastication, speech, or reduction of drooling, were also cited by 16 of the 44 parents (Table 4).

Each parent was also asked about the child's awareness of the dental problem, and motivation for orthodontic treatment. The findings are presented in Table 5.

Among the children living at home, all the parents were willing to make any necessary effort in order to help their child with the day-to-day care and management of the appliances, which had been a condition for acceptance of the

Figure 2 Orthodontic questionnaire—part 2.

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1. How satisfied are you with the results of the treatment?
 - (a) Dissatisfied
 - (b) Satisfied, but feel that the effort exceeded the value of the outcome
 - (c) Satisfied
 - (d) The results of the treatment exceeded our expectations
 2. Do you feel that straightening of his/her teeth improved his self-image?
 - (b) No, the child is unaware of improvement
 - (c) The child is not satisfied with the results of the treatment
 - (d) The child sees improvement and his/her confidence has been enhanced
 3. How did your close friends (relatives and neighbours) react to the fact that your child has been treated?
 - (c) There was no obvious reaction
 - (d) They encouraged us all along the way
 - (e) They were enthusiastic with the treatment results
 4. Do you feel that the orthodontic treatment has improved the child's everyday functioning?
 - (d) There was no change
 - (e) The progress was not significant
 - (f) There was a marked improvement
 5. Do you feel the treatment changed his/her social life?
 - (e) No, the treatment had no influence on his/her social interactions
 - (f) The treatment slightly improved his/her social life
 - (g) The treatment improved his/her social life markedly
 6. Would you put your child through the same treatment again?

Yes

No
 7. Would you recommend orthodontic treatment to other handicapped children, if the need exists?

Yes

No
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Table 1 Distribution of patients related to medical diagnoses.

Diagnosis	Part 1	Part 2
Mental retardation	13	9
Cerebral palsy	8	5
Down's syndrome	7	3
Muscular dystrophy	6	6
Autism	3	2
Lennox Gastaut syndrome	2	
Russell Silver syndrome	1	
Coffin Lowry syndrome	1	
Behr syndrome	1	1
Congenital kyphoscoliosis	1	1
Incontinentia pigmenti	1	
Total	44	27

Table 2 Residence of the orthodontic patients.

At home	32
Institution	10
Adoptive family	2

Table 3 Source of referral for orthodontic treatment.

Parents	20
Dentists	18
Physicians	4
Relatives/friends	1
Social worker	1

Table 4 Most common reason for seeking orthodontic treatment.

Improved facial appearance	28
Improved facial appearance and oral function	9
Improved oral function and dental health	7

Table 5 Child's attitude to orthodontic treatment.

Child is aware of dental problem, and interested in treatment	16
Child is highly motivated for treatment	15
Child does not understand the reason for treatment	12
Child is aware of dental problem, and antagonistic to treatment	1

Table 6 Parents' expectations from the orthodontic treatment, regarding their children's or their own social life.

Improve child's quality of life	43
Improve child's function in society	37
Improve parents' social acceptance	22

child for treatment. For those in an institution, the findings were that the parents were willing to guide and teach the attendant staff, but were not prepared to go to the institution regularly in order to take direct responsibility for routine home care.

Most of the parents (41 out of 44) considered it ethically justified to place this additional burden on their disabled child, in order to achieve the orthodontic results. None considered it unjustified, while three were unable to answer this question.

The parents' expectations from the orthodontic treatment are presented in Table 6. With only one exception, the parents expected that treatment could improve the child's quality of life. Most of them presumed that improving their child's appearance and/or oral functions, might consequently improve their future acceptance within society. Fifty per cent considered that, since they believed their child could become more socially acceptable, this would reflect positively on their own social status, while the other half did not consider this would make a difference.

Table 7 Parents' satisfaction with treatment results.

Very satisfied (results exceeded expectations)	11
Satisfied	13
Effort excessive in relation to outcome	3
Dissatisfied	0

Table 8 Impact of treatment results on child's everyday functioning.

Slight improvement	16
No change	7
Marked improvement	4

Table 9 Impact of treatment results on child's social life.

No change	11
Slight improvement	10
Marked improvement	6

Part 2 of the questionnaire revealed that most parents considered that either the results of the treatment exceeded their expectations or, at least, they were satisfied with the outcome. Only three out of 27 felt the effort was excessive in relation to the outcome, but none reported total dissatisfaction (Table 7).

Among the disabled children themselves, 17 were aware of a positive treatment change, while the remainder were indifferent to the results. In general, the parents felt treatment had improved their child's self-esteem and confidence. Effective changes in self-image were related in part to whether the parents' request for treatment had been based primarily on aesthetic or functional criteria.

Twenty parents reported that their child's closest friends had been encouraging or had been enthusiastic with the results of treatment. The other seven did not notice any particular reaction from close friends.

The parents were asked about the impact of the treatment on the child's everyday functioning and social life, and their answers are shown in Tables 8 and 9. A minority reported a marked positive influence of the treatment, while most

of the parents reported only slight improvement, or no change.

Given the same set of circumstances and with only one exception, all of the parents stated that, in the light of their experience with the treatment, they would make the same treatment choice again. The single set of parents who would not repeat the treatment stated that their child was living in a distant institution, which had made appropriate home care and responsibility for the management of the orthodontic appliances impossible for them.

All the parents stated they would recommend orthodontic treatment to other handicapped children, if indicated.

Discussion

The high response rate reflected a positive attitude and a willingness to co-operate among the parents, even several years after treatment had been completed. Given that the parents are integral partners in the treatment delivery system to these patients (Becker and Shapira, 1996), there is reason to believe that this was a key factor in the high response rate.

The domestic data suggest that most of the parents who sought treatment for their disabled children were among those whose affected children lived at home. These children had received continuous daily attention from highly-motivated parents who seemed prepared to go to great lengths to improve the child's well being, within the family unit. Among the children living in institutions, only those who came home frequently received orthodontic treatment, the results of which the parents considered to have been worthwhile.

The high motivation of the parents in this study is also demonstrated by the fact that 20 of 44 parents had requested orthodontic treatment on their own initiative (internal motivation), and were not referred by professionals or influenced by their close associates. This is in contrast to the study of Kiyak and Beach (1984) on orthognathic patients, who suggested that influences from 'significant others' are a very important motivating factor for seeking this treatment (external motivation).

The referral pattern reveals an additional noteworthy observation. Dentists referred 18 of the 44 patients, while physicians and social workers referred only five. The results of the investigation compare well with those of Breece and Neiberg (1986) on random healthy American patients, where dentists were found to be a very important source of referral for orthodontic treatment, but differ from those of Lew (1993), who reported only 20 per cent of patients from this source. This clearly indicates that dentists treating the handicapped are highly skilled in managing these children and hence are aware of the therapeutic potential of orthodontic treatment. On the other hand, while physicians and social workers are more involved with 'the more serious' aspects of a child's disability, they are less dentally aware and possibly relate the need for orthodontic treatment as trivial or superfluous. This may account for the difference in their referral of handicapped children for orthodontic treatment, when compared with their attitude to the general population (Lew, 1993).

Any initiative offered by relatives and friends appears to have been insignificant in encouraging this section of the population to request orthodontic treatment, compared with their influence in the normal children (1 case, or 2.5 versus 23 per cent; Breece and Neiberg, 1986). This would lead us to believe that an educational campaign, aimed at those professionals involved in other aspects of the child's treatment and at the public in general, could provide benefit for these children.

Most of the children had some idea of the purpose of the treatment and the parents felt that any added discomfort was minor, bearable, and ethically justifiable. The validity of this answer is open to question, since only parents (including adoptive parents) of children undergoing treatment were polled and a degree of self-interest may have injected bias into their answers. Furthermore, since this was a retrospective study, the parents were already aware of the final results.

Within the general population, improvement in the dentofacial appearance is the most important single factor motivating parents to seek

orthodontic treatment for their children (Lew, 1993). However, in this population, improvement in oral health and function assumes greater importance, 36.4 per cent compared with 21 per cent for a normal adult orthodontic population (Lew, 1993). This is not surprising in the light of the increased frequency of impaired oral functions in the handicapped population (Oreland *et al.*, 1989; Limbrock *et al.*, 1990). An alternative hypothesis is that the desire for treatment stems from reasons of function, because of the parental perceptions that there are more legitimate reasons for treating their child, than those based solely on facial appearance. This is particularly true when the children are not aware of abnormal appearance, but where the parents are motivated to change it.

Given such high expectations, it is both challenging and intimidating to treat these children. Can orthodontic treatment alone change the whole social life of these children and their families?

To look at the answers concerning any real change in the social life of the patients and their families, an objective impression may be gained that the orthodontic treatment was largely a failure. Marked improvement in everyday functioning and social interaction was noted only in a minority.

Nevertheless, 17 of the children noted positive change in their facial appearance and 20 parents reported a positive reaction among close friends (including relatives or neighbours). Satisfaction with the results was noted by 25 out of 27 parents—not only with the facial/dental changes, but also with positive changes in oral functions, improvement in the swallowing pattern, in the related drooling, speech, and even mastication. They also reported that, in those children who were aware of the improved appearance, this resulted in associated improvements in aesthetic self-satisfaction and self-confidence. All the parents would recommend it to others and all (except one) would repeat the procedure, given the same initial circumstances.

This apparent paradox can be explained in terms of the families of disabled children and even the children themselves accepting that perfectionism is beyond their reach. For them,

incomplete improvement (not conforming to ideal orthodontic standards) can be considered sufficient.

Orthodontic treatment may represent the first challenge to the patient of accepting responsibility. Despite a parent's ability and willingness, the child must wear the appliance, and be responsible for maintaining adequate oral hygiene alone or permitting the parents to do it. This can create a sense of accomplishment and build self-confidence, even in the disabled child. Positive reinforcement and compliments from close friends, during and after treatment, contribute to and explain their satisfaction with therapy.

The results compare well with those reported by Albino *et al.* (1994), for a normal orthodontic population. They found that parent-, peer-, and self-evaluation of dentofacial attractiveness significantly improved after treatment, but treatment affected neither parents, self-reported social competency or social goals.

On the other hand, there are moral and ethical questions, regarding the justification for subjecting the disabled child to orthodontic treatment, as an elective procedure (Strauss, 1983). The results of this investigation show that even though marked social improvement is frequently not achieved there is incontestable agreement among the children and their parents regarding the benefits of the treatment.

In common with others (Chadwick and Asher-McDade, 1997; Strauss, 1988), the authors consider that, in the absence of other factors, to deny treatment because of severe handicap alone is no longer justifiable.

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