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VACATION PATTERNS OF FAMILIES WHO HAVE A CHILD WITH DOWN'S SYNDROME

BY

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ABSTRACT

This study investigated the question "How does a child with Down's syndrome impact family vacation patterns?" Interviews were conducted with 25 families who had at least three children, one of whom had Down's syndrome. Four major conclusions were drawn. First, in the amount of time spent in family leisure, vacations were second only to sports-related activities and were equal to television and VCR viewing. Second, camping was identified as the favorite family leisure activity. Third, factors affecting family vacations included time constraints, location of family vacations, lack of recreational opportunities, and physical and/or behavioral problems experienced by the child with Down's syndrome. Finally, in most cases the presence of a child with Down's syndrome did not significantly alter family vacation patterns. Some families, however, exhibited extreme adjustments based primarily on severe physical complications and/or behavioral problems associated with Down's syndrome.

INTRODUCTION

While societal changes such as increasing education levels, broken marriages, and economic pressures are causing many family roles to decline in importance, the leisure role of the family seems to be increasing in value (16, 20, 22). Spending time with the family has been identified as American's number one leisure objective (34). In spite of the current recession and individual financial constraints, families are enjoying travel as their favorite family leisure activity.

The vacation patterns of families who have at least one child with a disability might be very different from those families who have no children with disabilities. This supposition is based on differences in child care responsibilities, medical needs, transportation, financial obligations, other special services required for the disabled, and the ensuing constraints to time. Given that these responsibilities draw upon time which might otherwise be available for leisure pursuits such as vacationing, the presence of a child with a disability may place severe constraints upon family vacation opportunities and format.

STATEMENT OF THE PROBLEM

This qualitative study explored the question "What are the vacation patterns of families who have a child with Down's syndrome?" The following aspects of family vacations were investigated (a) family leisure participation, (b) family vacation preferences, (c) factors affecting family vacations, and (d) the impact of a child with Down's syndrome on family vacations.

REVIEW OF LITERATURE

A review of literature was conducted to explore research addressing family leisure and more specifically, family vacations among families who have a child with a disability. Although research has been extensive in the areas of leisure and family as separate entities, few studies have been conducted on the role of leisure within the family. Epperson (5) noted that "except for two sociologists, Orthner and Kelly, the writing and research on family leisure has come primarily from the marriage and family discipline" (p. 1). Some of the research reviewed for this study was found from the disciplines of family systems (1, 6, 7, 11, 18, 26, 28, 32), leisure (12, 13, 15, 24, 29, 30), and sociology (3, 8, 21-23). The literature dealing directly with vacationing for the disabled and their families was found to be scarce (17, 25, 26, 33, 35).

The literature provides few theoretical frameworks for family leisure. Most studies have been descriptive and have tended to ignore theoretical issues (2, 7). Although a number of authors have stated that the family is the most frequent group engaging in recreational activities (e.g., 10, 22, 23), few studies have focused on the specific interrelationships between leisure activities and family behavior (1, 2, 36). Furthermore, a paucity of literature addresses the effects of a child with a disability on family leisure.

METHODOLOGY

In order to explore the interrelationships between vacation patterns and family behavior, in-depth qualitative interviews were conducted. This study was of an exploratory nature, intended for heuristic rather than prescriptive purposes.

Subjects

Previous research has shown that a number of characteristics can affect family leisure needs, attitudes, and choices (4, 7). In order to control some of these factors, the 25 families included in the study were required to meet the following specific criteria: (a) families had a

child with Down's syndrome, (b) families had at least three children, (c) families resided in a rural setting within 200 miles of Chico, California, (d) parents were married and both lived in the same house, (e) both parents were Caucasian, (f) at least one parent was employed at full-time status, and (g) both parents had earned a high school diploma. Furthermore, a purposive sample was used. The selection process was not intended to produce a representative sample of families who had a child with Down's syndrome living in California. However, the sampling process did assure that the families who were interviewed met the study criteria.

Due to the wide variation of behavior patterns associated with Down's syndrome, a behavioral profile was developed to further limit variance among the families. In order for the family to be included in the study, the child with Down's syndrome had to have been (a) enrolled in a trainable mentally retarded (TMR) classroom, (b) exhibiting minimal disruptive behavior as judged by the parents, (c) ambulatory, (d) able to communicate verbally or through sign language, (e) independent or requiring minimal assistance with daily living skills, and (f) medically controlled with regard to seizures, if present.

Instruments

The following instrumentation was implemented (a) in-depth interviews were conducted and audio-taped with the entire family present, (b) field notes were taken during each interview, and (c) the responses and notes were reviewed by the subjects to verify accuracy and validity.

Design And Procedures

In the spring of 1990 all special education directors of rural counties within the study area (Northern California north of Stockton) were contacted and the purpose of the study was described. Of the 24 county special education directors contacted, 18 agreed to participate in the study. Letters of invitation were sent to the directors who in turn routed them to teachers of children with Down's syndrome. The teachers selected families who met the characteristics for inclusion in this study.

The letters were then sent home with the children and given to their parents. The letter invited interested families to participate in the study by mailing a response postcard to the investigator or by calling the investigator directly. Upon receiving the postcards or phone calls, the investigator checked to verify the families met the appropriate criteria and then invited the families to participate in the study.

Data collection began by scheduling interviews with the entire family present. Interviews were conducted in the homes of the families and were completed in less than two hours. The interviews were audio-taped and later transcribed. The period of data collection was approximately one week per two families for a total of ten weeks. The interview procedure included collection of family demographics and verbal responses to a

series of questions addressing family vacation preferences. Interviews were conducted at the end of the vacation season in late summer and early autumn so that vacation experiences would most probably be recent.

RESULTS

The findings are organized into two sections. The first section briefly describes the families in demographic terms. The second section includes an analysis of four common themes which relate to family vacation experiences in families with a child who has Down's syndrome. A brief discussion of the data is followed by selected direct quotations from interview transcripts. These quotations contribute to the richness of qualitative analysis.

Family Demographics

The mean length of the marriages was 15.7 years with a standard deviation of 6.9 years. The mean age of the fathers was 40.2 years with a standard deviation of 7.3 years. The mean age of the mothers was 38.2 years with a standard deviation of 6.5 years.

Ninety-two percent (23) of the fathers and 32% (8) of the mothers were employed full time outside of the home. Sixty percent of the fathers and 32% of the mothers held a college degree.

All families had between three and seven children, with 3.6 as the mean number of children. Ages of the 90 children interviewed ranged from 1 to 30 years old. The mean age was 10.7 years with a standard deviation of 5.8 years. The mean age for those children who had Down's syndrome was 8.7 years of age.

Interview Results

After extensive analysis of the audio-tape transcripts of family members discussing their vacation patterns, four categories emerged: (a) family leisure participation, (b) family vacation preferences, (c) factors affecting family vacations, and (d) the impact of a child with Down's syndrome on family vacations.

Family Leisure Participation

Family members were asked to reflect on family leisure experiences during the month immediately preceding the interview. Seasonality may constitute a role in the findings of this study. Because many or even most families with school-aged children vacation and spend leisure time together during the summer, these types of leisure experiences were probably more recent in the subjects' memories. While participants'

responses may have reflected their most recent family leisure experiences, the investigator used probes to determine the representativeness of the family leisure during the previous month as compared to the rest of the year. Some of these probes included "Was your families' leisure last month any different than other months? If so, how?" and "how do vacations, special visits, reunions, and such fit into your family leisure pattern?" Table 1 provides a listing of family leisure activities participated in during the previous month.

These data suggest that in the amount of time spent in family leisure, vacations were second only to sports-related activities. Television and video recorder watching tied with vacations as the second most frequently occurring family leisure activity. All 25 families identified some sort of sport-related activity as common among their family leisure repertoire during the previous month.

We all go skiing, play softball together, racquetball, tennis, go to the movies, and have water balloon wars.

We do a lot together. Everything--houseboating, swimming, hunting, fishing, picnics and hiking.

It appeared that the parents and children showed feelings of excitement as they talked about their family leisure. During each interview, family members would collectively contribute to the conversation to create an understanding of their family leisure for the researcher. Although family members were encouraged to elaborate on the type of activities pursued, sports-related activities, which accrued a total of 53 responses, was clearly predominant over other forms of leisure activity.

Not surprisingly, the types of sports-related activities mentioned by respondents tended to take place outdoors. Family members expressed specific comments about their enjoyment from spending time with their family outdoors.

I love going camping, hiking, walking, enjoying nature, and anything outdoors. I feel close to my family and to nature when I am outside.

There is so much more freedom (outdoors). Everyone can be themselves and be spontaneous. Our family seems to be closer after a vacation or time together outside.

As family members discussed their leisure time together, the investigator noted a strong willingness to share and to express feelings of warmth toward each other. Vacations were viewed positively by family members and described as opportunities to build family cohesion, enhance communication to build family cohesion, enhance communication, and relieve stress.

Family Vacation Preferences

Camping vacations (17) and other forms of vacations (13) were tied with television and VCR watching as the second most common family leisure experience reported in the month prior to the interview. When asked to identify their favorite family leisure activity, 37% of all responding family members identified camping and 31% mentioned travel. Table 2 lists favorite family leisure activities. Although the majority of families (72%) spend one week per year vacationing, all responding participants expressed a desire to spend more vacation time together.

The following quotations illustrate family members' enjoyment of camping and travel.

Camping to the coast or to Colorado is our favorite thing to do together. Camping has always been an important activity.

We love to go camping and do scouting events, like hiking and swimming. We also go bicycling, fishing, and play tennis.

Our family loves to camp. The kids can be themselves. There is so much freedom.

Camping. We really do it up. We buy marshmallows to roast and let the kids swim for hours. We all sit around the campfire and talk about all sorts of things. We really enjoy ourselves.

Other types of vacationing than camping were also identified as a favorite form of leisure. These included going to Disneyland, Hawaii, and snow skiing.

Interestingly, 7 families took almost no vacations. Two of the families responded that they had only taken one vacation during the last seven years.

We haven't had a vacation in 7 years. No time, no money, and we have been buried in medical bills.

We have only been on one vacation in the last 7 years. We went to New Hampshire to visit family. Boy, that was great.

Two additional families reported that, because of their child with Down's syndrome, they take no vacations at all.

We don't go on vacations. Ever since the kids were born we don't get away for overnights. We will get a babysitter soon to watch (child with Down's) so the rest of us can go to dinner and to the movies. Maybe

when (he) gets older he can come with us.

We used to travel alot, but it is hard with (child with Down's). He does not travel well. Plus he is sick a lot. We used to camp at the ocean, but now that (he) is with us we don't because he has respiratory problems. We have had to pull up stakes in the middle of the night a few times. So now we just don't go.

Table 3 shows the frequency and location of family vacations.

The vacation patterns of several families were particularly constrained by their child with Down's syndrome. Two families had taken vacations only once in seven years and expressed that medical bills (for care of their child with Down's syndrome) and time were the primary constraints to getting away for vacations. Two other families stated that they never went on vacations due to their child with Down's syndrome. In all four of these cases, the justification for remaining at home related specifically to severe physical and behavioral complications experienced by the child who had Down's syndrome. The data suggest that those families whose child with Down's syndrome had physical and/or behavioral problems were limited to the home environment as their primary location for family leisure, including vacations. Other studies (14, 36) also found that leisure barriers (such as time constraints and child care responsibilities) cause families to spend leisure time primarily in home-based activities.

Factors Affecting Family Vacations

Family members were encouraged to identify as many factors as possible which might affect their family vacations in a positive or negative way. Four major themes developed from this question (a) time constraints, (b) location of family vacations, (c) lack of recreational opportunities, and (d) physical and/or behavioral problems with the child who had Down's syndrome.

Ninety-six percent of responding family members expressed that time was the primary barrier to family leisure in general and specifically to vacations. Work schedules and individual commitments away from the home were identified as the most significant barriers to spending leisure time together. Constraints to family vacation time are discussed in other studies (19, 27).

Parents from six (24%) of the families purposely arranged their work schedules to create split shifts in order to personally provide child care. It was noted by all six of those sets of parents that this decision was made not only to save money, but out of their frustration in finding adequate care for their child with Down's syndrome. Although this strategy resulted in saving money, families expressed spending only "about 10" hours per week together as compared to the rest of families who reported spending an average of 27.3 hours per week together.

Only one family, who spent an average of 70 to 80 hours per week together, expressed satisfaction with the amount of time they spent together. The remaining 24 families voiced feelings of frustration toward not having more time together.

The results of this study support the findings of Holman and Epperson's (7) research which identified time as the primary barrier to family leisure. All families interviewed in the present study indicated they would prefer more vacation time together. Work schedules and individual commitments away from the home were the most predominant barriers to spending vacation time together.

Although many individuals expressed they would prefer to spend more leisure time away from the home, 21 (84%) of the families spend at least 70% of their family leisure time at the home. As was mentioned above, physical and/or behavioral problems experienced by the child with Down's syndrome caused some of the families to be constrained to the home as the principal location for family vacations.

Twenty families (80%) complained that their communities did not offer adequate recreational opportunities for their families. More recreational facilities, integrated programs, a transportation system, increased variety of existing programs, and weekend programming were some of the desired changes that families would like their communities to implement.

When families were asked to discuss what factors affected their family vacations, 19 parents identified issues related to their child with Down's syndrome. These comments are incorporated into the following section.

The Impact Of A Child With Down's Syndrome On Family Vacations

In the majority of cases, the presence of a child with Down's syndrome did not significantly limit family vacation patterns. Seven families, however, did exhibit extreme adjustments.

Everything has been put on a halt since we discovered (she) had Down's syndrome because we spend so much time going to specialists.

We gave up camping and all outdoor activities because of her heart and ear problems.

(His) behavior dictates where we go and what we do. We stay at home a lot because of him.

Those families who had children with behavioral and/or physical problems said their family leisure was primarily limited to the location of the home. Wandering, verbal outbursts, and medical complications which included respiratory problems, obesity, and a suppressed immune system have resulted in altering the location and nature of family vacations.

There have to be considerations. She is not physically capable of doing what other 8 year olds can do. She can't run or walk as far. She is heavy and gets tired. We still go camping and to the park. We don't go far or we take a wagon which she rides in.

We need to supervise him closely. He wanders a lot. He is not as bad as he used to be. When he was first born, it was difficult to have people over because we were embarrassed.

Of those families who had a child with a behavioral problem, proper supervision was identified as essential in public areas. Many times families said they would cancel plans for traveling to avoid the constant supervision and intervention required for a child with Down's syndrome.

We used to do a lot of things. (He) does not do well in public places. He becomes loud, uncontrollable, and wanders. This really limits what we can do on our vacations.

He takes extra supervision. We can never totally relax because he cannot be trusted. He will either wander off or get into trouble. There is always a certain degree of stress.

Because (he) is so difficult in public, we usually leave him and just the four of us go. We usually get a sitter or send him to camp. And that is not really a family vacation. It would be great to have sitter come along with us on vacations to help out.

Those families who had a child with physical problems said their family vacations were impacted significantly. Many outdoor activities like hiking and backpacking were no longer a part of their family leisure due to asthma, heart problems, ear infections, and susceptibility to illness.

DISCUSSION

Based on the information obtained through the interviews, the following discussion and conclusions were generated. This section is organized according to the four major categories which emerged from the data.

Family Leisure Participation

Families in the study spent the majority of their leisure time involved in (a) sports-related activities, (b) vacations, and (c) television and VCR watching. A great deal of family leisure time was spent at home in passive activities such as television or VCR viewing. Although not

surprising, these data clearly reinforce the importance of leisure education for families. The findings imply that families could become more aware of leisure opportunities and resources in their communities and even in their own homes.

The types of sports-related activities mentioned tended to take place outdoors. Family members made specific comments about their enjoyment of spending time with their family outdoors. Those families who tended to spend the majority of their time together in the outdoors expressed more positive feelings toward each other compared to those families who spent most of their time indoors. These findings coincide with a study which revealed that the most frequently mentioned activity which strengthened the family was enjoying the outdoors together (31).

Family Vacation Preferences

Travel was identified as a common family activity among the respondents. In particular, most families stated that camping was their favorite type of family vacation. Family members spoke fondly of past vacations or up-coming trips. Rosenblatt and Russell (26) suggested that family vacations may have contrary effects depending upon the family. In some cases, family vacations may result in family members "experiencing less anger, arguing, and tension on the vacation than they usually experience when not on vacation" (p. 214). On the other hand, family vacations may result in increased tension and conflict due to the inability to avoid problems through other diversions such as work and school. Findings from the present study imply that the responding family members enjoyed vacations and viewed them as positive family experiences.

All of the responding family members in this study stated that they would like to travel more. This desire to repeat the travel experience indicates enjoyment among the family members. However, family members expressed several reasons why they do not travel as much as they would like. Some of these reasons include lack of appropriate recreational programming for their child with a disability and lack of proper supervision available at vacation sites (e.g., playgrounds, swimming pools, resorts, etc.). This implies unique challenges and opportunities for the travel industry. Implementing recreational programming, respite care, and/or proper supervision for the child with a disability could make vacationing an even more enjoyable experience for these families. At the same time, travel and related industries would be tapping a market segment which is currently under-served.

Factors Affecting Family Vacations

Factors which cause families to not travel as much as they would like include barriers such as lack of time, vacation location, lack of recreational opportunities, and physical complications and/or behavioral problems experienced by the child with Down's syndrome. These barriers, which have been identified in other studies (14, 36), cause many families to spend their vacations primarily in home-based activities. At-home

vacations may not be very fulfilling because, unfortunately, families reported spending a large portion of their leisure time at home in default activities such as watching television and videos. Whether families spend their vacation time traveling or at home, family members could benefit by negotiating with each other as to how they would like to spend their vacation time.

The Impact Of A Child With Down's Syndrome On Family Vacations

In 18 of the families interviewed, the presence of a child with Down's syndrome did not significantly alter family vacation patterns. However, seven families stated that they made extreme adjustments in their family vacations. Those families who had a child with physical complications said that many outdoor activities and especially physically demanding activities, such as hiking and backpacking, were no longer part of their family vacations.

Those families who had a child with behavioral problems indicated that close supervision was essential in public areas. Many families viewed close supervision as such a burden that they refused to make plans which involved going to public environments.

This issue provides an opportunity to leisure service providers as well as to the travel industry. Families with children who have disabilities need to develop an awareness of community resources and to acquire the skills necessary for proactive involvement in the development of community-based leisure opportunities. Parents in this study viewed recreation integration as a positive experience for both the child who has Down's syndrome and for other children. However, minimal parental involvement in advocating for community services reduced the chances of meeting both family and individual leisure needs. It seems that many parents were not aware of the available resources and processes toward creating change. At the same time, the travel industry and service organizations may need to increase both their outreach efforts and their repertoire of programs.

Traditionally children with a disability have been sent away to special camps while the rest of the family vacations elsewhere. While families in this study enjoyed sending their children to such camps, they clearly expressed preferences for being able to include their child with a disability in family vacationing.

In addition to more integrated travel packages and recreation programs, service providers could offer leisure environments with reduced risk to lessen the supervisory burden on parents. Periods of care for children with disabilities might allow parents to enjoy several hours a day of resort-based leisure such as snorkeling or skiing.

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TABLE 1
FAMILY LEISURE ACTIVITIES

Activity	n	Activity	n
Sports-related activities	53	Watching sports events	5
Vacations		Visiting relatives	5
Camping	17	Gardening/home projects	5
Other	13	Board games	4
Television	15	Car rides	1
Videos	15	Shopping	1
Church-related activities	14	Going to the park	1
Eating out	12	Visiting geological sites	1
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Total responses = 162			
Average responses per family = 6.5			

TABLE 2
FAVORITE FAMILY LEISURE ACTIVITIES

Leisure Activity	Percentage of Responses
Camping	37.3
Travel	31.3
Swimming	10.4
Houseboat	7.5
Baseball	4.5
Golf	3.0
Other	6.0
Total	100.0

Note. Not all subjects responded.

TABLE 3
NUMBER AND TYPICAL DESTINATIONS OF FAMILY VACATIONS

Vacations per year	No. of families	Typical destinations	Destination frequency
3	4	Camping The mountains The coast	4 2 2
2	5	Camping Mt. Shasta Southern California	4 2 2
1	9	Camping The mountains The coast Disneyland Universal Studios Knott's Berry Farm	8 5 5 3 2 2
Every 2 years	3		
Once in 7 years	2	New Hampshire	1
None since birth of child with Down's syndrome	2		

n = 25

Note. Families could mention as many or as few typical destinations as they desired.