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Abstract

This study examines how parents felt about the way in which physicians informed them of their child's disability. The results are generally positive but this may be due to the passage of time and/or other factors. However, the study is valuable in showing that isolated and rural areas require more support and follow-up, and there needs to be more accurate and supportive communication between families and health care professionals. **Keyword: Professionals**

Parental Perceptions of Physicians' Communication in the Informing Process

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Abstract: Parental response to the informing process was examined through structured interviews with 50 parents of preschool children with handicaps. Influences of the children's age, severity of handicap, and parental perceptions of the manner of the informing professional were also investigated. Results indicated that the majority of parents were told of the handicap after minimal contact with the physician and during the child's first month of life. Parents indicated a need for sustained and supportive communication as well as information on available community resources.

Investigators have suggested that parents display a variety of reactions when presented with the formal diagnosis that their child has a handicapping condition. Historically, parental reactions of shock, grief, disappointment, and diminished coping abilities have been reported (Kohut, 1966; Ross, 1964). In more current literature, investigators have postulated that parental responses and adaptations to a child with handicaps may be an extension of the coping and adapting skills that they use in dealing with other family stressors (Fortier & Wanlass, 1984; Schneider, 1983).

Because of the lack of empirical data to support stage approaches, Blacher (1984) questioned the commonly held belief that parents go through sequential stages of adaptation and coping. Professional overreliance on the stage approach to adjustment has been supported by researchers (e.g., Allen & Affleck, 1985) as well as by parents of children with handicaps (Featherstone, 1980; Searl, 1978). Yet, parental responses may be influenced or mediated by variables such as the perceived severity of the handicap, interpersonal relations within the family, prognosis, and age of the child at the time of informing (Cautley, 1980; Davidson & Dossier, 1982; Lipton & Svarstad, 1977).

The point at which parents have been given the diagnosis of their child's handicapping condition, usually by a physician, can be a time of crisis, during which constructive professional help is crucial (Adams, 1982; Bristol, 1984). Prior to passage of P.L. 94-142 and the establishment of educational programs for school-age and preschool-age children with handicaps, physicians were more likely than not to recom-

mend that such children be institutionalized (Connaughton, 1974; Kelly & Menolascino, 1975).

Unfortunately, there have been few attempts to determine whether the increase in community-based programs and concomitant decrease of institutional placements have impacted on physicians in terms of their advice and communication content to parents. In surveys conducted by Adams (1982) and McDonald, Carson, Palmer, and Slay (1982), responding physicians reported awareness of parental displeasure at their failure to provide the families with information regarding the handicap or referrals to community- and public-school-based educational or therapeutic programs. These physicians also acknowledged parental unhappiness with the content and format of the informing process.

The informing process is, in actuality, a communication process that may be crucial to parental attitudes and actions regarding their children (Blacher, 1984; Lavelle & Keogh, 1980). Howard (1982) indicated that the initial parental coping may be positively or negatively affected by the information given, compassion shown, and listening ability demonstrated by the informant. Frank and detailed communication at the time of informing has been shown to facilitate trust in the professional (Ballard, 1978), but there has been additional evidence indicating that the informing process also requires supportive communication in the form of reassurance, encouragement, and support for the family system (Richardson, Guralnick, and Tupper, 1978; Svarstad & Lipton, 1977).

The informing process may need to extend over time, as parents may not comprehend all

the information the first time it is presented (Turnbull & Turnbull, 1986). Moreover, parents have indicated a desire to communicate with professionals who will listen to them and support, not push, them in their decision-making with regard to their child (Allen & Affleck, 1985; Howard, 1982).

The more recent investigations of the content and impact of the informing conference or process, however, have been from the perspective of the physicians rather than the parents toward whom the content has been directed and upon whom the impact is both immediate and long-term. In this study we examined the perception of parents of the methods used by professionals to inform them of their child's handicapping condition. We also examined whether parental perception varied as a result of the type of handicapping condition and age of their child at the time of diagnosis.

Method

Sample

The sample consisted of 50 parents of children with handicaps who were newborn to 4 years of age. These children were professionally diagnosed for a handicapping condition within the first 18 months of life. All families resided in North Dakota in or near the largest populated cities/towns in which community early intervention programs were offered. Subjects were recruited from the accessible population in the five regions of the state through the early intervention programs operated under the direction of Division of Health and Human Services and nonpublic school providers in the three largest cities. Public schools were not included in this study because children enrolled in those programs were closer to 5 years of age. We believed that 5 years was too long for parents to recall the informing events accurately.

Family size, marital status, and the handicapped child's birth order and gender did not affect eligibility for participation in the study. The types of handicapping conditions of the children ranged from moderate to severe retardation with associated disabilities (e.g., epilepsy, cerebral palsy). Only those parents who had children who were actively enrolled or involved in community-based early childhood special education programs were invited to participate. The subjects were recruited through letters sent to parents by early childhood special education program directors throughout the state. Pro-

gram directors were requested to contact their parents by mail to describe the purpose of the study and request participation. Parents who responded affirmatively to this inquiry also gave permission to be contacted by telephone to schedule the structured interview, which was conducted in the subject's home.

Procedure

We developed a structured interview questionnaire to collect social and familial data and determine their possible influences upon perceptions of the informing process. Items were also included that measured: (a) perceived role of the informant, (b) perceived severity of the handicapping condition, (c) recalled age of the child at the time of the diagnosis, and (d) recalled number of contacts with the informant prior to the initial diagnosis. The items on the questionnaire were derived from those used in previous investigations on this topic (e.g., Abrahamson, Gravink, Abramson & Sommers, 1977; Connaughton, 1974; Cunningham & Sloper, 1977).

A Likert scale was developed to measure degrees of parent's opinions regarding statements representative of professional methods during the informing conference. Approximately equal numbers of positive and negative statements that represented this variable were developed. Subjects were requested to indicate their degree of agreement or disagreement by responding in one of five ways: strongly agree, agree, uncertain, disagree, and strongly disagree. The subjects were informed that there were no wrong or right answers and that they could ask for clarification of items. Each interview took approximately one hour to complete.

Analysis

Upon completion of the interview, we computed a score by summarizing the values assigned to each response. A value of 5 points was assigned to each response indicating strong agreement with a favorable statement; 4 points, agreement; 3 points, uncertain; 2 points, disagreement; and 1 point, strong disagreement. For unfavorable statements the scoring procedure was reversed because disagreement with an unfavorable statement was assumed to be equivalent to agreement with a favorable statement.

Table 3

Parental Perceptions (in %) of Professional Methods of Informing

Questionnaire items	SA	A	U	D	SD
The professional who informed you of your child's condition:					
1. Appeared straightforward, direct, and open.	38	46	4	4	8
2. Appeared hasty, hurried, and rushed.	10	10	4	62	14
3. Appeared to be caring and showed concern.	24	38	20	12	6
4. Presented a cloudy, hazy, unclear picture of the condition to you.	22	22	6	40	10
5. Bettered your awareness of the child's medical condition by directly relating medical facts to you or indirectly by referring you to another profession.	14	48	2	32	4
6. Appeared to pity you and feel sorry for you.	4	4	14	62	16
7. Appeared truthful and honest.	20	64	4	8	4
8. Appeared pessimistic and tended to anticipate the worst; gave you a gloomy outlook on the future.	22	8	16	42	12
9. Either himself or through referrals bettered your awareness of how the child would function in the home in everyday activities.	8	22	6	38	26
10. Appeared irritated to annoyed with answering your questions.	6	14	6	42	22
11. Appeared calm, collected, and self-controlled.	24	64	2	10	0
12. Attempted to mislead you, encouraging you to believe that which you thought might be unlikely.	8	10	0	66	16
13. Used precise and distinct terms and words that you could understand clearly.	14	48	4	20	14
14. Provided an improper amount of information, either too much or too little.	8	40	0	48	4
15. Offered suggestions or ideas on how to inform important people in your life.	2	4	6	50	38

Note. Percentages across the individual items total 100%, with the exception of Item 10. In this case, 10% of the parents reported that they did not ask questions. Thus, the total percentage in this category reaches only 90%. SA = strongly agree, A = agree, U = uncertain, D = disagree, SD = strongly disagree.

home. These parents recalled that they were sent home with no knowledge of what to expect from the child and no information regarding strategies for facilitating growth and development. Further, they reported that most assistance in this area came from mental health agencies or early intervention programs, and such services were often received only after the parent had made a concentrated effort over a period of time to find such help. Some professionals were viewed with hostility when they refused to refer parents to other specialists.

The majority of the parent sample (88%) reported disagreement or strong disagreement with Item 15, which related to suggestions on how to inform significant others. A larger number of parents, however, did express wishes for counseling and more information on how to relate to others. Some parents stated that this was not a high priority concern but that they would have found such information helpful.

With regard to Item 14, almost equal percentages of parents reported either strong agreement-agreement (48%) or strong disagreement-disagreement (52%) related to the amount of information provided. Of those who strongly agreed or agreed with the statement, 91.7% reported that the amount of information was too little and 8.3% expressed that the amount was too much. These findings reveal that a large

number of these parents received a limited amount of information and desired much more.

Discussion

Although the overall pattern of the parents in the sample was generally more positive in nature than the literature would lead one to expect, tendencies on the part of the parent to give inaccurate description as a result of the passage of time may have contributed to the favorable reports. The fact that there was a biased sample (i.e., parents had enrolled their children in an intervention program) could also contribute to a generally positive recollection of the events. Although some parents recalled their situation vividly, others expressed difficulty in remembering their situation, and others expressed difficulty in remembering their exact reactions and feelings at that time. Several reported that their feelings of bitterness, resentment, and hostility toward the informant had diminished with time. In some cases it was also possible that the respondents provided answers that they thought would satisfy the researchers.

It appeared from the responses that parents perceived that many of the physicians during the informing conference reflected pessimism and lack of clarity about the child's future. Such perceptions could be related to the immediacy

Results

The mean age of the 50 parents who comprised the sample was 29.8 years (range = 21 to 43). As can be seen from Table 1, the majority of respondents were married mothers. The greatest number of respondents reported that they were homemakers. Other occupations are shown in Table 1, as are educational levels.

Table 1
Selected Family Characteristics

Family Characteristic	n	%
Type of family		
Married	49	98
Single	1	2
Gender of respondent		
Female	45	90
Male	5	10
Occupation of respondent		
Homemaker	34	68
Professional/technical worker	5	10
Farmer	3	6
Manager/proprietor	2	4
Others	6	12
Educational level		
Less than 12th grade	2	4
High school graduate	14	28
Some college	12	24
Associate or technical degree (2 year)	9	18
Bachelor's degree	11	22
Graduate work	2	4
Gender of child with handicaps		
Male	27	54
Female	23	46

These parents had lived at their current residence an average of 12 years (range = 1 to 39). With regard to the number of children living at home, 62% reported two children or less living at home, and the remaining 38% indicated that three to five children were living at home. The handicapped child was the youngest in the family for the majority of families (58%); 14% indicated that the child was an only child. The mean age of the children with handicaps was 36 months (range = 9 to 70). All of these children were living at home.

As can be seen in Table 2, the majority of the subjects were informed of their child's handicapping condition by a physician. Comments from those interviewed suggested that pediatricians and obstetricians were the primary medical informers. Table 2 also shows the age of the child at the time of the initial diagnosis.

Table 2 also shows that between the birth of the child and the time of the informing, there were relatively few contacts with professionals. None of the participants reported follow-up

Table 2
Selected Variables Related to the Informing Process

Variable	n	%
Age of child at initial diagnosis		
Within first month ^a	27	54*
Between 1 and 6 months	13	26
Between 6 and 18 months	10	20
Professional identification of informer		
Physician	47	94
Nurse	1	2
Mental health professional	2	4
Contacts prior to diagnosis		
Informed at initial meeting	26	52
Informed within one to five contacts	24	28
Informed after six or more ^b contacts	10	20

* Of this group, 85.2% were diagnosed within the first 7 days. ^b Fifteen or more.

communication with the informant subsequent to the informing session.

Table 3 describes the parental perceptions of the professional manner used during the informing interview. Parents perceived that professionals handled the informing procedure in a generally positive manner; a majority of the sample indicated agreement with the most desirable answer. Responses to several of the questionnaire items are of importance, however. Responses to Item 4 indicate almost equal distributions between the strongly agree-agree categories and the strongly disagree-disagree categories. Approximately half of the parents recalled that the picture of the condition was clear, whereas the other half viewed it as unclear or hazy. In spite of this, a relatively large percentage of the parents (62%) reported that they were better aware of the medical condition and the medical facts (Item 5) as a result of the professional informing. Although a majority of the parents agreed or strongly agreed with the statement in Item 5, they still reported confusion regarding the implications of the condition to their child and situation.

It is of some significance to note the responses of those parents who responded to Item 8. Though 30% of the parents reported dissatisfaction with the professional whom they perceived as being pessimistic and projecting a gloomy outlook for their child, 60% indicated disagreement with this negative view of the informant.

The two items that yielded a majority of negative responses regarding professional methods of informing were Items 9 and 15. With Item 9, 64% of the parents disagreed or strongly disagreed with the statement related to awareness of how the child would function in the

with which the majority of parents were informed (54% informed within first month) and the minimal number of contacts with the informant (52% informed at first encounter). It could also be that the physicians were themselves uninformed regarding the availability and outcomes of early intervention and continued to hold negative perceptions about children with handicaps.

These findings may be unique to rural communities and states in which social and educational advances are slow to be adopted. Medical and health care professionals in such communities may be reluctant or resistant to change despite evidence to the contrary.

Whatever the source of the problem, professional development efforts directed at medical and related health-care professionals in rural areas remains a high need area. Physicians, related health-care professionals, and educators need to forge a new partnership to facilitate accurate and supportive communication with families during and after the initial informing process. Information and follow-up services should be developed and made available to parents in these low population areas.

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