# IMPORTANCE OF INFORMATION RELEVANT TO THE CARE OF CHILD CARDIAC PATIENTS, AS PERCEIVED BY MOTHERS AND STAFF

by

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A Field Study
Presented to the University of Oregon
School of Nursing
and the Graduate Council of the
University of Oregon Medical School
in Partial fulfillment of the requirements
for the Master of Nursing Degree
June 13, 1975

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This study was supported by a United States Public Health Service Traineeship from Grant Number 5A 11 NU 000 35-16 Title 2.

# ACKNOWLEDGMENTS

I wish to express sincere appreciation and thanks to my advisor, Dr. Julia Brown for her guidance, assistance, thoroughness, persistence, patience, and humor that made the completion of this study possible. Also I wish to extend thanks to the readers Barbara Gaines and Dr. May Rawlinson for their suggestions. A special recognition is given to Barbara Snell, Instructor in Pediatrics, who served as a consultant in the formulation of the study and gave her suggestions on the initial draft.

Grateful acknowledgment goes to the staff members and mothers who participated in this project. Also to my husband Don, goes thanks for his support and encouragement in my return to school. Finally special gratitude is expressed to our sitter Kathleen Hobbs for the love and attention she devoted to our girls Karen and Karla.

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# Chapter I

# INTRODUCTION

Communication between health professionals and patients has often been described as generally unsatisfactory, and a substantial obstacle to good health care. Research into the scope, nature, and roots of the problem remains limited, and therefore a solution is not imminent. The present investigation was undertaken in order to augment knowledge in this area. Specifically, this study concerns communication between mothers of children with congenital heart defects, and the staff attending these children, and focuses on specific items of information.

The need for sufficient, mutually understandable, and acceptable communication between health professional and client has long been recognized as basic to good health and effective medical treatment. Such communication can be complex and difficult due both to the layman's lack of knowledge of human physiology, disease and medical terminology, and to the professional's lack of knowledge regarding his client's perspective. In addition, the patient's physical discomfort or anxiety may interfere with his understanding or acceptance of the professional's message, regardless of its objective clarity.

Generally, health professionals regard the communication process as necessary for eliciting information from the patient for purposes of diagnosis, assessment of health needs, and identification of personality factors influencing the patient's condition. Generally, also, health professionals acknowledge the desirability of patient health education, and the necessity of the physician's communication of medical findings and instructions to the patient and his family. However, the amount, the nature, and the means of such communications have rarely been specified, and such decisions are left to the judgment of the individual medical expert. It would appear that the professional's role as health communicator has remained subsidiary to his or her role as diagnostician, prescriber, or agent of treatment.

Patients also recognize their need for health instruction. All the evidence indicates their strong desire for knowledge about their health status and medical treatment, and their dissatisfaction with the information they in fact receive. Despite this agreement between the two role groups concerning the importance of communication, somehow messages are not reaching the target population. This gap in communication poses a problem for health professionals, and must be resolved if patient satisfaction is to be achieved, patient care improved, and patient recovery maximized.

## Review of the Literature

The first conclusion which can be drawn from a review of the literature is that the amount and nature of the communication between staff and patients strongly influence the effectiveness of medical care. Thus, patient instruction has been shown to shorten the length of hospital stay (Helberg, 1972; Hirst, 1972), reduce the number of hospital readmissions, decrease the cost of medical care (Hirst, 1972), improve postoperative recovery (Ryan, 1967; Helberg, 1972; Boegli, 1972), lessen patient anxiety and tension (Janis, 1958; Skipper, et al., 1964; Meyers, 1964; Davis, 1968; Lindeman, 1973), and encourage compliance with medical regimens (Hill, 1962; Davis, 1968; Paul et al., 1972).

These findings specify only a few of the benefits of patient health education. More broadly viewed, such instruction is presumed to promote more active participation of patients and their families in health maintenance and in the prevention of illness, in the control and management of chronic illness, and in rehabilitation (Neal, 1962; Zola, 1963; Alt, 1966; Dodge, 1969; Hirst, 1972; Wang, 1972).

In principle, then, the need for educating patients in aspects of their treatment is well recognized by health professionals. In addition, the right of the patient to receive complete current information regarding his condition has been affirmed by the American Hospital Association. The Patient's Bill of Rights states:

> The patient has the right to obtain . . . complete current information concerning his diagnosis, treatment, and prognosis in terms the patient can be reasonably expected to understand. (American Hospital Association, 1972)

However, it is probably not well understood that withholding information or educational supportive therapy can be as devastating to the client as withholding other treatment such as drugs (Redman, 1974).

Nevertheless, this goal of adequate communication apparently has low priority, since rarely have the means for implementing this goal been specified or formally provided by setting up formal departments of patient education. Thus, of the 8000 private hospitals in the United States, only 30 boast of formal departments dedicated specifically to patient education (Hirst, 1972). Usually, whether treatment occurs in hospital, clinic, or office, the task of communication is left to the doctor to be conducted on a one-to-one basis with the individual patient. The responsibility of the individual physician for health education aspects of treatment is further emphasized by Weed (1969) who specifies patient education as one of the steps of treatment to be covered in his Problem Oriented Medical Record.

This system of communicating health information has apparently not been overly successful to date. Although health information has been disseminated in various forms for a number of years, surveys reveal that laymen generally are quite ignorant in health matters

(Tuck, 1972; Upchurch, 1972). Furthermore, a patient's knowledge of a disease does not necessarily increase after he has contracted that disease and is under treatment (Seligman et al., 1957). This fact suggests that patients may not learn significant amounts from their physicians. Attempts at planned instruction seem desirable to obtain better results.

However, it should be pointed out that the level of knowledge of patients does vary, being somewhat higher for patients with more education, and possibly for patients of higher socioeconomic status. Samora et al. (1961) found socioeconomic position to be positively related to the extent of health knowledge of the individual. However, this difference in knowledge may not be due to differences in desire to learn. Caplan et al. (1965) found no significant difference in the extent to which parents from differing socioeconomic strata actively sought information about prematurity.

Considerable evidence exists that many laymen do not comprehend the meaning of many of the medical terms in common use by health professionals. In reaction to this lack of understanding, many doctors tend to cut off all further discussion (Pratt et al., 1957). Consequently, when patients leave treatment, they frequently leave ill informed, and dissatisfied. And apparently, of all aspects of their medical care, patients are most critical of the difficulty they experience in obtaining information (Pratt et al., 1957; Robinson, 1961; Neal, 1962; Dodge, 1963; Alt, 1966; Linehan, 1966; Gozzi et al., 1969; Goodrich et al., 1970).

Patients and parents of children who are patients complain not only about their failure to receive enough information, but also about the lack of warmth and friendliness on the part of the staff, failure to take into account the patient's concerns and expectations, lack of clear-cut explanation, and use of medical terminology. All these contribute significantly to the patient's and parent's dissatisfaction with medical care (Pratt et al., 1957; Robinson, 1961; Alt, 1966; Neal, 1962; Dodge, 1963; Linehan, 1966; Gozzi, 1969; Goodrich, et al., 1970).

Most often health communication has been a one-way system of authoritative virtuosity and few investigations have focused on the two-sidedness of the staff-patient relationship. One comprehensive study of "what patients want to know" was carried out at a 250-bed community hospital in Beverly, Massachusetts, in 1963-64 (Alt, 1966, Linehan, 1966). Data were obtained by interviewing every fifth patient on his day of discharge from the hospital. In all 450 patients were interviewed. The major findings of that study were as follows: About half the patients had one or more unanswered questions on discharge and sixty-five percent said they had been given no time for instruction. The patients expressed dislike for the casual responses and evasion of their questions by physicians, interns, and nurses. They wanted to know what was done to them and why. They wanted the physician to sit down and talk with them alone, if only briefly. They wanted simple answers and fewer medical terms.

Another exploratory study was conducted in a voluntary general hospital in Geneva, New York, to measure the cognitive needs of a sample of 116 patients (Dodge, 1969). These patients were interviewed midway in their hospital experience regarding the kinds and importance of information which they felt they should be given. In general, patients were concerned with receiving information which would enable them to plan realistically for their immediate and future lives. They did not concentrate on "irrelevant" details (e. g., hospital routines). Rather, they were interested in questions of diagnosis and the etiology of their condition. Questions were frequent regarding their futures (Would the condition recur? Would activity be restricted?) and regarding time (How soon would they go home? How much total time would be involved?). Finally the patients placed more importance on being informed about the kinds of care they needed, than on knowing how the care could help.

Failure to obtain information they perceive as needed leads many patients to express dissatisfaction with their treatment. They may complain about their doctors, nurses, clinics, or hospitals, and they may change to a new doctor for care (Dodge, 1963; Skipper et al., 1964). Again, patients may seek information from other sources, such as television commercials, from neighbors, or from other patients in the clinic (Neal, 1962; Plaja et al., 1968; Harris, 1972). In reference to this phenomenon, it should be mentioned that such lay sources of knowledge are considered less desirable by the public than are physicians, hospitals, and clinics (Harris, 1972).

While generally patients express dissatisfaction with the information they receive during treatment, the bases for their dissatisfaction differ according to such patient characteristics as age, education, nature of treatment, and phase of treatment. With respect to age, Dodge (1969) found that adults under 40, in contrast to those over 40, wished to know how well they were progressing and when they could reach certain goals (e.g., removal of stitches). However, they expressed no desire for information on the "purpose of care", (undefined, but refers presumably to scientific explanation) nor how it would help. Dodge (1963) also reported that young female patients placed more importance on nurse-patient communication than did older patients of either sex.

With respect to education, Dodge (1969) reported that patients with some college education were most concerned about time factors, as, for example, how long the illness would last. These patients also manifested considerable concern over possible activity restrictions and their chances for recovery. High school graduates placed less importance on the above items, but stressed instead the details of surgery, self-care procedures, care received, test results, and cause of symptoms. Patients who had not graduated from high school were mainly concerned with their progress and the effects of care, as for example, whether treatment would reduce pain or enable them to walk.

According to Dodge (1969) patients demonstrated real differences in their rank ordering of the importance of information depending on whether they were medical or surgical patients. As might be expected, surgical patients were interested in the details of their surgery, and medical patients were interested in diagnostic tests and procedures and their results and in medications. Generally speaking, medical patients appeared more motivated to learn how to participate in their own care, whereas surgical patients manifested more passivity. Surgical patients were mainly interested in the care given to them, in time factors, and in activity restrictions imposed on them during convalescence.

Finally, time phases may influence the kinds of information desired. In studying parents of children diagnosed with leukemia, Hamburg and Adams (1967) noted that the information desired by the parents shifted over time. In the initial phase, only information of aid in handling the immediate situation appeared meaningful, as for example information on how to secure admission of the child to a research hospital. Information regarding the diagnosis was gradually assimilated over several weeks. Next, Hamburg and Adams noted, information about the etiology of the disease was accepted, presumably due to its function in reducing parental guilt feelings. Next came a period in which parents searched extensively for more knowledge pertinent to treatment. Finally, there arrived a time when parents needed help in coming to terms with the anticipated loss. Since expressed needs vary in different phases of the illness, it would appear desirable for plans for patient instruction to be coordinated to these phases.

Summing to this point, patients and staff agree in principle on the goal of good communication, but this shared goal is not being achieved, at least in terms of factors discussed, such as knowledge of disease, satisfaction with care, etc. In probing for the reasons for this failure, a number of possible factors are suggested in the literature. First, perhaps the failure is due to staff ignorance of principles of learning, and consequent poor teaching methods. There is some controversy as to the criteria indicating successful health teaching. The ultimate criterion would probably be better health of the patients due to changes in health practices. However, one other criterion for effective communication of health information appears to be retention of medical information (Ley, 1965; Ley, 1972, Kupst, 1974).

Thus, Ley has indicated that a number of factors influence patient learning and recall of instructions. These include the age of the patient, the extent of the patient's anxiety, the amount of information given, the nature of the information, the perceived importance of the information in the patient's eyes, and the order in which information is presented. For example, Ley found that the patient recalled best what information he considered to be important or what information was communicated first rather than what was presented later.

In communicating with parents of children with congenital heart defects, Kupst (1974) found repetition of information effective in recall. In a recall test immediately after an interview, both repetition of information by physician, and restatement of information by the parents were found superior to a single communication to parents or to a written summary of the child's condition. Of these two methods of repetition, parent restatement was found superior to physician restatement for long-term (one month) recall. If health professionals were cognizant of such research findings, they might be better able to plan their communication so that their clients would understand, accept, and remember the vital messages.

Second, failure in communication may arise in part from ambivalence on the part of the staff member, wavering between the desire to instruct patients and the wish to withhold information. Three-fourths of the clinical teaching faculty of one medical institution reported they would disapprove if a physician were always to tell patients the full extent of their illnesses (Pratt et al., 1957). Particularly when such diagnoses as cancer are involved, physicians are more likely to resort to information control and evasive replies (Quint, 1965). The withholding of information may then reflect the staff member's reluctance to convey bad news to the patient. But withholding of information may also be used as a weapon by the staff member to bestow on others, or to deprive others of, power and distinctive social status. It has been pointed out that the flow of knowledge is often blocked to protect existing status arrangements among hospital personnel, with the doctor's withholding knowledge from the nurse, the nurse's withholding information from the aide, and so on down the hierarchy to the patient (Skipper et al., 1964; Katz, 1969).

Third, the staff member may fail to recognize the fact that the patient's emotional state may interfere with his learning, and must be dealt with if communication is to occur. When the patient is a child, then the situation is even more complex. Not only must the emotional needs of the child be considered, but those of his parents as well. In their work with ill children and their families, Walker et al. (1971) emphasized that as much skill must be applied to the needs of the parents as to the care of the child. Woodmansey (1971) also claimed that parents of handicapped children need emotional support in order to accept the health messages given them. And

Gordon (1972) has pointed out the grave danger of simply presenting a diagnosis concerning a child, without providing guidance to the parents. He writes: "The making of a diagnosis unaccompanied by adequate guidance, may do little more than adding another handicap to a child who is already handicapped."

A fourth reason for the gap in communication between staff and patients is the difference in the perspectives of the two groups. They differ in their views as to "what the message should be." No matter how important a message is from the viewpoint of the health professional, if it is not salient to the patient, the patient will not accept that message. As a corollary, if the patient considers another bit of information important, no matter how minor it seems to staff, and if the patient does not receive that information, he becomes anxious. His anxiety may affect the patient-staff relationship and may interfere with his acceptance of all other messages (Robinson, 1961; Dodge, 1963; Zola, 1963; Meyers, 1964; Linehan, 1966; Davis, 1968; Dodge, 1969). When both staff and patient agree on what is important, right and proper, they can communicate more effectively. The World Health Organization has emphasized that health educators should adapt health education to the goals and purposes of the person they are teaching. "Learning takes place more effectively, when the experience has meaning for the learner." (WHO Technical Report No. 89, no date).

Staff members often assume that their own values and preferences are the values and preferences of their patients. This assumption may be unwarranted. Thus, a number of writers have cautioned against accepting the judgments of "medical experts" as to the knowledge, attitudes, interests, or wants of the lay public concerning medical information, unless these estimates are based on solid research. Only through continuing research into the interests and reactions of their clients can medical staff adapt their messages so that the messages have meaning to patients within the context of their world of reality (Knutson, 1965; Dodge, 1969; Aiken, 1970).

While recognizing that a communication gap generally exists between staff and patients, it should be pointed out that this gap is wider in some instances than others. Thus it appears from the literature survey that some categories of staff (in terms of disciplines, age, and status groups) recognize the need for communication more than do other categories of staff; and that some categories of staff apparently adopt the perspectives of their clients to a greater extent than do other categories of staff.

Dodge (1963), in a study of what patients want to be told about their health, reported a greater correspondence between the views of nurses and patients, than between the views of physicians and patients. While neither nurses nor doctors believed as strongly as patients that certain items of information were essential, nurses generally attributed more significance to communication than did doctors. In an analysis of the specific areas of consensus between nurses and patients, Dodge (1972) found that nurses agreed with patients that it was important to share information on diagnosis, length of illness, and ways in which patients could participate in care. Nurses considered it important to tell patients what to expect during hospital tests and after surgery, to acquaint patients with hospital routines, and to instruct patients in permissible and restricted activities during convalescence at home. Patients in their turn attributed little importance to these latter areas of information.

A difference exists, then, in the views on communication held by the various health disciplines. Variation also occurs within each discipline. Generally, lower status members of a discipline place less importance on staff-patient communication than do higher-status members. Thus, Dodge (1963) found that residents and interns tended to place less importance in instructing patients than did senior staff members. Within nursing, increased status rather than years of experience appears to be the factor most influencing views on the importance of communication. This lack of consensus among the various staff disciplines and statuses results in a rather hit-or-miss coverage of health information for the patient.

As stated earlier, effective communication regarding health problems is more complex when the patient is a child. Then the health professional must enlist the cooperation of the parents for optimal care of the child. To obtain such cooperation, effective communication is essential, including not only the provision of information but also the serving of the emotional needs of the parents as well. Parents of ill children occupy a peculiarly difficult position. Not only must they continue performing their everyday duties but they must assume new and unfamiliar tasks and responsibilities (Meadow, 1968). This increase in role load, plus the anxiety engendered by a serious diagnosis, result in a crisis situation calling for support and encouragement (Flesch, 1963).

When patients of ill children obtain information, and when their apprehension has been reduced, they are more likely to be satisfied with medical treatment. They are also more likely to give their children appropriate care (Robinson, 1961; Lewis and Lopreato, 1962; Dodge, 1963; Dye, 1963; Meyers, 1964; Skipper et al., 1964; Linehan, 1966; Dodge, 1969; Thomas et al., 1970; Pinkerton, 1970; Woodmansey, 1971; Freely, 1972). In the end, the children themselves benefit. As an example, Fishman (1971) found that handicapped children whose mothers obtained knowledge regarding their defect and discussed their handicaps with them were better adjusted and enjoyed higher self-esteem than did handicapped children whose mothers acted contrariwise.

The present investigation is concerned not with the general need for effective health communication between staff and patients, but with the specific gaps in communication which exist between staff and parents of children with congenital heart defects. The number of such children is large. It is estimated that every year in the United States, between 20,000 and 25,000 children are born with congenital heart defects (American Heart Association, 1970; Yancy, 1971). In the State of Oregon, the number of children born each year with congenital heart defects is estimated at 250-300 (private communication, February 5, 1974, from Mr. Howard Stroud, MPH, Executive Director of the Oregon Heart Association).

Parents of a child with a congenital heart defect become involved in the process of examinations and treatments for their child. This may mean numerous visits to doctors, cardiologists, and clinics, periods of hospitalization for tests and surgery, and follow-up examinations. At each of these contacts information must be given the parents. It is essential to determine what information parents think important to be told, as Brambilla (1968) concluded from her experience in teaching parents about heart surgery. The instruction plan should include not only material that nurses think patients should know, but also material that patients say they want to know.

Studies have been conducted which explore the level of the parents' cognitive knowledge of congenital heart defects. These studies indicate that the knowledge of parents is quite limited (Maxwell, 1962; Reiss and Menashe, 1972; Roberts, 1972). A search of the literature reveals many articles from the medical viewpoint emphasizing the importance of teaching the parents regarding congenital heart defects. Some articles also suggest the areas of information and emotional support to stress (Carter, 1959; Cooper, 1959; Glazer et al., 1964; American Heart Association, 1970; Roberts, 1972). No study, however, could be found which indicates what information is desired by parents of children with congenital heart defects.

## Statement of the Problem

The main purpose of the present study was to investigate the extent and areas of agreement and disagreement between professional staff and mothers of ill children concerning the importance of specific communications. To this end, opinions of mothers of children with congenital heart defects were compared with the opinions of staff members attending the children. Areas of comparison included information, the management of emotional needs, and preferred techniques for facilitating understanding.

In addition to this comparison of views of mothers and staff, it was the purpose of this study to determine whether or not systematic variations of opinions occurred within each role group. In the case of the staff, the effects on opinions of such factors as the discipline (e. g. nursing vs. medicine), and status (e. g. senior staff vs. student; senior physician vs. junior physician; charge nurses vs. staff nurses) were assessed. In the case of mothers, differences in opinion were analyzed in terms of the mother's education, of the child's form of treatment (e. g. medical or surgical), and of the length of time elapsed since initial diagnosis of the child's defect.

On the basis of the review of the literature it was possible to make certain predictions as to the nature of differences in opinions associated with such variables. These hypotheses were:

1. Mothers with more education tend to consider items of information generally as more important than do mothers with less education (Dodge, 1969).
2. Mothers of children who undergo surgery tend to consider items of information regarding surgery and postsurgery as more important than other items (Dodge, 1969).
3. Mothers of children treated by medical means tend to consider items regarding instructions and knowledge of medication as more important than other items of information (Dodge, 1969).
4. Mothers of children more recently diagnosed tend to consider items of information concerning tests and examinations more important than other items, such as those concerning incidence, prognosis, and the physiological functioning of the heart (Hamburg and Adams, 1967).

5. Nurses tend to consider information generally as more important than do medical staff (Dodge, 1963).

6. Senior staff (i.e., senior physicians and charge nurses) tend to consider information generally as more important than do students (both medical and nursing) (Dodge, 1963).

7. Senior physicians tend to consider information generally as more important than do junior physicians (i.e., interns, fellows, residents) (Dodge, 1963).

8. Charge nurses tend to consider information generally as more important than do staff nurses (Dodge, 1963).

9. Mothers tend to consider information generally as more important than do staff members (Dodge, 1963).

10. Nurses tend to express opinions about the importance of information more like those of mothers than do medical staff (Dodge, 1963).

11. Staff members of higher status tend to express opinions about the importance of information more like those of mothers than do staff members of lower status (Dodge, 1963).

Thus, the first four hypotheses concern differences in opinions among differing categories of mothers; the next four concern differences in opinions among differing categories of staff; and the last three hypotheses concern the relative similarity of the responses of mothers and differing categories of staff.

## Justification for the Study

Previous studies have revealed that patient satisfaction with treatment, and patient cooperation in treatment depend in part on patients' receiving the information which they desire. When patients receive such information, they are less anxious, and more open to other communications which the health professional may wish to emphasize. They also tend to recall instructions better, and to comply more fully with medical recommendations. Therefore, it would seem advisable for staff to become aware of the patients' perceptions of their own needs, and of the kinds of information to which they attach greater or lesser importance. In this way, instructional programs can be developed which can both meet the perceived needs of patients, and also educate patients to recognize the importance of other information for optimal recovery or health. From the findings of the present study, it is hoped that such a program may eventually be created for the education of mothers of children with congenital heart defects.

# Chapter II

# METHODOLOGY

## Setting for the Study

Three facilities within the University of Oregon Medical School served as the settings for the present study: the Congenital Heart Clinic of the Crippled Children's Division (CCD) of the State of Oregon, the Cardiology Clinic of the Outpatient Clinic, and inpatient units of the Medical School Hospital (specifically, four pediatric wards and the cardiac recovery room).

The Congenital Heart Clinic of the CCD provides diagnostic service free of charge to any child under twenty-one years of age, who is a resident of the United States. Treatment, however, is restricted to children who are legal residents of the State of Oregon. The present study concerns only those treated children with a known diagnosis of congenital heart defect. They arrive from all areas of the State, and represent all socioeconomic levels. The cost for their treatment is assumed by the State if their parents are unable to pay. Treatment is carried out by a team which includes senior pediatric cardiologists both from the medical school faculty and from private practice in the community, cardiology fellows, residents and interns in pediatrics and cardiology, medical students and their instructors, clinic nurses, and a medical social worker. From July to December 1973, 572 children received services in the CCD Congenital Heart Clinic. This represents an average of 95 children a month (CCD Statistical Printout dated July to December, 1973). In the author's observation, the ratio of staff to patients appears high, approximately 1:1 or 1:2. This staff-patient ratio should allow health teaching to take place.

The second facility, the Cardiology Clinic of the Outpatient Department, offers medical service to all local residents. Charge for care is based on a sliding scale, according to the patient's ability to pay. The low socioeconomic status of the majority of patients is evidenced by the fact that few seem to be able to afford the full fee of $8.00 a visit. The Cardiology Clinic in the Outpatient Department is staffed by the same cardiology fellows and residents, medical students and their instructors as serve in the CCD clinic. However, the nursing personnel, pediatric interns and residents assigned to the Outpatient Clinic work exclusively in the Clinic and are not assigned to CCD. From a review of Outpatient Clinic Records from September, 1973, to March, 1974, the investigator estimated that an average of 19 children are seen each month. The ratio of staff personnel to patients is usually 2:1. Againteaching should be feasible.

The pediatric wards and the cardiac recovery room of the Medical School Hospital served as the third source of subjects for this investigation. An examination of the 1973 University of Oregon Medical School Hospital census[1] revealed that an average of 32 children per month were seen for problems connected with congenital heart defects. These children were usually referred to the hospital from Congenital Heart Clinic at CCD or Cardiology Clinic of the Outpatient Clinic to undergo diagnostic tests or to receive medical or surgical treatment. The medical team in the pediatric wards includes the identical cardiology fellows, residents, interns, and medical students with their instructors that work in the cardiology clinics of CCD and Outpatient Department. However, the pediatricians, residents, interns, nursing staff and nursing students work exclusively on the wards and do not cross over into the CCD or Outpatient Clinic. The surgery team consists of senior thoracic surgeons, residents, interns, and fellows.

In all three facilities -- the Congenital Heart Clinic of CCD, the Outpatient Cardiology Clinic, and the Medical School Hospital -- staff stresses the teaching function. This teaching emphasis is, however, restricted to students in a variety of health disciplines, and is rarely generalized to include instruction of patients and their families.

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[1] The author wishes to express her gratitude to Susan Severin of the Record Room for collecting this information.

Nevertheless, the teaching goal does have an effect on patients, through the proliferation of staff personnel involved in each patient's care. Consequently, the patient and his family are frequently bewildered, and uncertain as to whom to turn to for help or information.

## Staff Sample

The entire professional staff currently attending children with congenital heart defects in the three facilities described above was asked to participate in this study. Each professional was asked to complete a questionnaire regarding his or her opinions of the importance of specific items of information for parents of children with congenital heart defects.

## Sample of Mothers

The sample of mothers was a convenience sample. For a period of four weeks every mother was contacted who arrived at any of the three facilities with a child under treatment for congenital heart defect. The purpose of the study was explained to her by the investigator and she was asked to complete a questionnaire. This process was repeated until a total of 100 mothers agreed to participate. No mother who was asked refused to participate.

## Data-gathering Instrument

The major data-gathering instrument for this study was a questionnaire, the items of which were derived from a search of the literature and from the investigator's interviews of mothers and staff. In these interviews, mothers were asked three open-ended questions: (1) what kinds of information do you think are important for parents to have regarding congenital heart defects? (2) what still puzzles you? and (3) what surprised you during the course of your child's treatment? In the phase of questionnaire construction, three mothers were contacted in the waiting room at CCD, two mothers were telephoned at home, and one was visited in her home.

Open-ended interviews with two staff members were conducted in their offices, and with three staff members during clinic times. They were asked: (1) what kinds of information do parents frequently askyoufor regarding congenital heart defects? (2) what do you think important to tell them? A preliminary questionnaire was then constructed from the items which had been mentioned at least twice in the interviews or in the literature (see Appendix B for information as to the sources of each item). Lastly, four experts in the field of heart defects and pediatrics (one physician, three nurse clinicians) were asked to review the questionnaire in its preliminary form in order to add or delete items. The questionnaire in this draft was then administered to five subjects for pretesting, resulting in a number of changes in the wording and placement of specific items.

In its final form, the instrument consisted of 50 items, each of which was rated by the subject on a 5-point scale, with respect to its importance for parents of children with congenital heart defects. Ratings could vary from "Not Important" (score of 1), "Slightly Important (score of 2), "Moderately Important" (score of 3), "Very Important" (score of 4), to "Extremely Important" (score of 5).

The items included in the questionnaire covered three main areas: knowledge, emotional needs, and techniques for presenting information. Thus, items 1 through 34 referred to such cognitive areas as knowledge of the functioning of the normal heart (items 1 to 3), diagnosis (item 4), etiology (items 5-7), tests and procedures (items 8-13), instructions (items 14-19), surgery (items 20-27), post surgery (items 28-30), and prognosis (items 31-34).

Emotional needs of both parents and children were placed under items 35-39. As examples, item 36 questions how important it is for the parent to be told, "How to help a child with his worries", and item 39 asks how important it is "To talk with someone regarding the financial cost". Such items were included in the instrument since the literature review indicated their close relation to parents' understanding of cognitive statements (Cooper, 1959; Peay, 1960;

Maxwell and Gane, 1962; Glaser et al., 1964; Schwartz, 1966; Hellmuth et al., 1966; Thomas, 1970; Linde et al., 1971; Roberts, 1972).

Thirdly, items 40 to 50 concerned the importance of specific techniques for presenting information or giving support, such as "To be shown a drawing of the heart defect" (Item 45). These items were included since they were frequently mentioned in the interviews or in the literature as helpful in the transmission or assimilation of information. (See Appendix B for copy of the final questionnaire.)

In addition to her rating of the importance of these 50 items, each mother was asked to provide information as to (1) her own age; (2) age of her child; (3) her own education; (4) her husband's education; (5) her own occupation; (6) her husband's occupation; (7) the date of the first diagnosis of her child's heart defect; and (8) her child's form of treatment, whether medical or surgical. Such information was sought so that the effects of their variations on the mothers' responses might be analyzed.

In order to determine whether systematic variations also existed in the responses of staff according to background, each staff member was requested to provide information on the questionnaire regarding: (1) age; (2) health discipline (e.g. nursing, pediatrics, etc.) and (3) status (e.g. student, fellow, charge nurse, etc.).

## Design and Procedure

The research design of this study was nonexperimental and correlational, and restricted to one point in time. The questionnaire was administered to the 100 mothers during the four weeks in April 1974, and their responses were compared to those of staff during this same time period.

The names of patients were obtained from the clinic or hospital staff. The study was explained to each mother and she indicated her willingness to participate by signing a permit. The questionnaire was then administered in the clinic area or pediatric ward. The instructions were read to her and any of her questions answered. Since a question regarding the marital status of the mother had been inadvertently omitted, the investigator verbally asked for this information. If she reported she was not currently married, she was told to omit items 7 and 9 regarding husband's occupation and education. The average time needed to complete the questionnaire was from 10 to 15 minutes. When the mother had returned the form, it was examined for completeness by the investigator and responses were solicited for any omitted questions. Confidentiality was ensured by removing the signed permit from the questionnaire and subsequently identifying the questionnaire by number alone.

Staff members were contacted in a variety of settings: in classes, in discussion periods, conferences, clinics, offices, and on the wards. The study was explained to them, their questions answered, and their returned forms were checked for completeness by the investigator. The questionnaires were not signed by the staff. This procedure guaranteed anonymity.

## Analysis of Data

The basic analytic tasks of this investigation were: (1) to determine the extent to which staff as a group and mothers as a group agreed or disagreed on the relative importance of specific items of information; (2) to ascertain whether or not these agreements and disagreements clustered around certain broad topics; (3) to determine the extent to which staff and mothers rank-ordered similarly the importance of the various items; (4) to determine which items appeared to command consensus among members of a given role group, and which items appeared to generate dissensus; and (5) to examine and analyze systematic variations in responses within each role group, mothers and staff.

For these tasks, relatively simple statistical techniques appeared adequate. The t-test was selected in order to determine the significance of the difference between the mean ratings of mothers and staff for each of the fifty items; and also to assess the significance of the difference between mean ratings of subsets of mothers, or of subsets of staff. The use of this statistic might be challenged on the basis of the ordinal nature of the data. However, convincing arguments have been advanced in recent years in support of the use of parametric statistics under such circumstances. The utility of assigning numbers to ordinal data and then applying interval statistics has been repeatedly demonstrated, especially when analysis requires the use of means, disperison measures, or correlation techniques (see, for example, Labovitz, 1967).

To arrive at an estimate of the extent of consensus within staff as a group, or among mothers as a group, regarding the importance of specific items, the variances of the items were compared. Thus, items with smaller variances were viewed as representing areas of consensus for the group, whereas items with larger variance represented areas in which group consensus was lacking.

Finally, Spearman's rho was selected as the appropriate statistic by which the similarity of rank-orderings of the items with reference to their importance might be measured across role groups.

## Chapter III.

# RESULTS

## Characteristics of the Samples and Respondents

Before an analysis of the results of the investigation proper is attempted, the questions of the representativeness of the samples and of the adequacy of the response rates must be considered.

### Staff Sample

As stated earlier, all staff members were contacted who were currently involved in treating children with congenital heart defects in any of the three designated facilities. Of the 139 staff questionnaires distributed, 117 or 84% were returned. As may be seen from Table 1, the participants differed somewhat in discipline and status from the overall staff sample. First, proportionately fewer nurses than medical personnel responded. The response rate of the medical personnel was extremely high (97%), with only one individual failing to respond. The response rate of the nursing group was considerably lower, although still a respectable 79%. Second, the lower return rate of the nurses was attributable entirely to the failure of

## TABLE 1

## DISCIPLINE, STATUS, AND MEAN AGE OF TOTAL STAFF IN FACILITIES STUDIED, AND OF STAFF PARTICIPATING IN THIS STUDY.

| Discipline | Status | Total Staff | N | Percent Responding | Mean Age |
|---|---|---|---|---|---|
| Medicine: | | 39 | 38 | 97 | 35.1 |
| Cardiology | Senior | 9 | 9 | 100 | |
| | Fellow | 3 | 3 | | |
| | Intern | 1 | 1 | | |
| Pediatrics | Senior | 3 | 3 | 100 | |
| | Resident | 6 | 6 | | |
| | Intern | 2 | 2 | | |
| Surgery | Senior | 4 | 3 | 85.7 | |
| | Fellow | 3 | 3 | | |
| | Students | 8 | 8 | 100 | 24.9 |
| Nursing: | | 99 | 78 | 79 | 26.9 |
| | RN | 56 | 45 | 80 | |
| | (Charge) | (20) | (20) | (100) | (28.0) |
| | (Staff) | (36) | (25) | ( 70) | (24.7) |
| | LPN | 31 | 21 | 68 | 32.4 |
| | Students | 12 | 12 | 100 | 22.2 |
| Social Work: | Senior | 1 | 1 | 100 | 52.0 |
| Total | | 139 | 117 | 84.1 | 29.3 |

lower-status members to respond: for while 100% of the higher-status charge nurses participated, only 70% and 68% respectively, of the staff nurses and the licensed practical nurses responded. This slight bias of our subjects in the direction of medical personnel and of higher status nurses should be kept in mind in generalizing the results of the study.

From the investigator's observation, the composition of the staff in April, 1974, appeared basically similar to the composition of the staff at the same facilities throughout the year. However, no data existed for determining how representative the present sample was of all staffs attending children with congenital heart defects throughout the United States. Possibly the staff studied was slightly younger than the average staff. The present respondents ranged in age from 20-65 years, with a mean of 29. 3 years. It appears reasonable to assume that medical staff in nonuniversity settings might be older, in the absence of a student component. However, the youthfulness of the nursing staff of this sample may simply reflect the youthfulness of nursing staffs generally in Oregon hospitals. Thus, the majority of RNs in Oregon hospitals were under forty years of age, according to a report of June 10, 1974, of the Oregon State Licensing and Examining Board.

These considerations lead to two conclusions. First, the present staff sample may be somewhat younger than other staffs in Oregon and the United States, but other aspects of similarity or dissimilarity remain unknown. Caution must be exercised, then, in generalizing the findings regarding the staff in this study to other staffs in other settings. Second, in view of the low attrition rate of our sample, it would appear justifiable to generalize the findings from the respondents to the total staff sample, always keeping in mind a possible bias produced by the slightly higher proportion of medical personnel and higher status persons among the respondents than in the original sample.

## Sample of Mothers

Attrition was not a problem here, since every mother approached did in fact complete a questionnaire. The question that does arise is how representative this particular group of mothers was of (1) all mothers whose children underwent treatment for congenital heart defects at the institution under study, and (2) of the total universe of mothers whose children were treated at other institutions.

From the responses to the questionnaire, certain facts were ascertained regarding the mothers' characteristics and those of their husbands and children. In age, the mothers ranged from 17 to 65 years, with a mean of 33.4 years. Their educational level was high, averaging 12.52 years, and ranging from no formal schooling at all to postgraduate college work. Seventeen obtained less than a high school education, 57 graduated from high school, and 26 received some college training. Most (91) were married and living with their husbands.

Of their husbands, 28 obtained less than a high school education, 37 graduated from high school, and 26 received some college training. Eight of the husbands were unemployed. Of the remaining, 59% were engaged in manual occupations (e.g. carpenter, truck driver), 18% were in nonmanual occupations (e.g. salesman), 8% owned a small business (e.g. barber, store owner), 7% were in service occupations (e.g. police, fireman), and 7% practiced a profession (e.g. teacher, dentist). It would appear, then, that the majority of families in this study were blue collar families.

Since complete data concerning the age, education, occupation, and marital status of their parents are not routinely entered into the records of child patients, there was no way to check how representative this sample was of all mothers bringing children to the designated facilities for treatment throughout the year. And nothing can be directly inferred regarding the sample's representativeness of the total universe of mothers throughout the country whose children are undergoing treatment for heart defects.

Some comparisons, however, can be made between the children covered by this investigation and the child patient population seen in the hospital and in the Crippled Children's Division over a six-month period. (No figures were available for the Outpatient Department.) The children of the mothers in the present sample ranged in age from newborn to 21 years of age, with a mean of 7.9 years. The children were treated by medical management in 59 cases and by surgery in the remaining 41 instances. Length of time since initial diagnosis varied from one month to 19 years, with a mean of 5.9 years. The diagnosed problems of the children are enumerated in Table 2. From this table, it is clear that the patients considered in this study are similar to all children seen in these same facilities over a six-month time span with reference to age (mean ages of the two groups were 7.8 and 7.9) and with reference to treatment (62.2% and 59% of the two groups were treated by medical means and 38% and 41% by surgical means).

With reference to diagnosis, some differences are apparent. The study group contained greater proportions of children with ventricular septal defect, with pulmonary artery stenosis, and coarctation of aorta; and smaller proportions of children with patent ductus arteriosus and anomalies of the heart valves. Probably these differences are attributable to chance alone, although the two distributions of the sample and of the six-month patient load might prove more similar were records available from the Outpatient Department.

## TABLE 2

## DIAGNOSIS, AGE, AND FORM OF TREATMENT, OF CHILDREN IN THE STUDY AS COMPARED TO THE TOTAL CHILD PATIENT POPULATION SEEN IN A SIX-MONTH TIME SPAN IN THE SAME FACILITIES.

| | Frequency of Diagnoses Among Children in Two Facilities for 6-Month Period (N = 765)[a] | | | Frequency of Diagnoses Among Children in Study (N = 100) | Percentage Distribution of Diagnoses Among Children with Congenital Heart Defects in U. S. (N = 1017)[b] |
|---|---|---|---|---|---|
| Diagnosis: | Hosp. | CCD | Total | | |
| Ventricular Septal Defect | 39 | 154 | 193 | 36 | 35% |
| Atrial Septal Defect | 30 | 58 | 88 | 12 | 8% |
| Anomalies of Heart Valve | 12 | 137 | 149 | 10 | 11% |
| Tetralogy of Fallot | 17 | 44 | 61 | 8 | 6% |
| Patent Ductus Arteriosus | 29 | 52 | 81 | 6 | 12.5% |
| Coarctation of Aorta | 9 | 34 | 43 | 9 | 8% |
| Pulmonary Artery Stenosis | 25 | 11 | 36 | 10 | 7.5% |
| Other | 32 | 82 | 114 | 9 | 12% |
| Age: | | | | | |
| Range | Newborn to 21 | | | | |
| Mean | 5 | 8.64 | 7.8 | 7.9 | --- |
| Mode of Treatment: | | | | | |
| Medical | 40 | 436[c] | 476 | 59 | --- |
| Surgical | 153 | 136 | 289 | 41 | --- |

---

[a] Outpatient Clinic numbers not included, past records not kept. [b] Nadas and Fyler (1972). [c] Some of these children may have had surgery, statistical breakdown unavailable.

Do these differences in diagnosis imply that the results of this study are not generalizable to the universe of patients attending the facilities named? It is the contention of the author that the results can be so generalized. The differing diagnostic conditions demand much the same management of children by mothers, and present many of the same problems for mothers. One exception would be heart defects accompanied by cyanosis (e. g. tetralogy of fallot), which may create more apprehension and some unique problems for parents. But the proportion of children with such cyanotic heart defects was approximately the same in our study population (13%) and in the six-month caseload (16%). Hence, it is argued here that the mothers of our study faced much the same problems as mothers of the total caseload, and might be expected to react similarly to questions of the relative importance of specific items of information. On this reasoning, the conclusions of this investigation might be extended beyond the immediate respondents to other mothers seen in the same facilities.

## Importance of Information as Perceived by Mothers

Analysis of the data revealed a skewing of the distribution of mothers' responses toward the high (or important) end of the scale rather than toward the low (or unimportant) end. The mean ratings for the fifty items varied from 2. 82 to 4. 85, with an overall mean of 4. 21. (The means for each item are reported in Appendix A, Table A.)

## TABLE 3

## MEAN RATINGS FOR FIFTY INFORMATION ITEMS, BY MOTHERS AND BY STAFF AND BY SUB-CATEGORIES OF MOTHERS AND STAFF.

| Categories of Respondents | Number of Respondents | Mean Ratings For 50 Items |
|---|---|---|
| All Mothers: | 100 | 4.21 |
| A. By Education: | | |
| 1) Less than high school education | 17 | 4.20 |
| 2) High school education | 57 | 4.23 |
| 3) Some college education | 26 | 4.16 |
| B. By Mode of Treatment of Child: | | |
| 1) Surgical | 41 | 4.31 |
| 2) Medical | 59 | 4.14 |
| C. By Time Since Diagnosis | | |
| 1) Six-months or less | 18 | 4.29 |
| 2) Over six-months | 82 | 4.19 |
| All Staff: | 117 | 3.92 |
| A. By Discipline: | | |
| 1) All Medical Staff: | 38 | 3.65 |
| a) All Physicians | 30 | 3.70 |
| (1) Senior physicians | (14) | (3.73) |
| (2) Interns, residents, fellows | (16) | (3.68) |
| b) Medical students | 8 | 3.64 |
| 2) All Nursing Staff: | 79[a] | 4.04 |
| a) All RNs | 45 | 4.06 |
| (1) Charge nurses | (20) | (4.05) |
| (2) Staff nurses | (25) | (4.07) |
| b) LPNs | 21 | 3.89 |
| c) Nursing students | 12 | 4.23 |
| B. By Status: | | |
| 1) All Senior Staff (Physicians and Charge Nurses) | 35[a] | 3.91 |
| 2) All students (Medical and Nursing) | 20 | 3.92 |

[a] Includes one Social Worker.

The mothers attributed the greatest importance to the following items:

| | | Mean rating |
|---|---|---|
| Item 4 | Being told what is wrong with child's heart, | 4.85 |
| Item 29 | Care parents will give at home after surgery, | 4.79 |
| Item 34 | What signs and symptoms to watch for, | 4.77 |
| Item 40 | Surgeon to talk to parent before and after surgery, | 4.77 |
| Item 24 | Whether surgery is a complete or partial correction, | 4.76 |
| Item 50 | To have the name of someone to call in case of an emergency, | 4.76 |

The five items judged least important were:

| | | |
|---|---|---|
| Item 27 | Where the parents could stay while the child is in the hospital, | 3.38 |
| Item 42 | To talk with another parent whose child has a similar defect, | 3.11 |
| Item 7 | To be told how many children are born with heart defects, | 3.08 |
| Item 44 | To see a model of the heart, | 3.05 |
| Item 43 | To have a nurse call at home to discuss condition and/or problems. | 2.82 |

Thus, the most important item of information turned out, in the mothers' opinion, to be a matter of diagnosis (4), and the least important items concerned techniques (43, 44).

## Consensus Among Mothers

The extent to which mothers as a group expressed consensus on the importance of a specific item was estimated by the distribution of their responses to that item over the five point scale of importance. If the responses to the item clustered closely together, the item was considered to possess higher consensus than if responses were widely and equally distributed over all points of the scale of importance. The measure of consensus used here was the variance ($s^2$) of responses for that item, with larger variances implying lesser consensus, and smaller variances implying greater consensus.

The range of these variances was from .10 to 1.62 with a mean variance of .72 and a standard deviation of .41. The following items were considered to command the greatest consensus since their variances were all less than .31 (one standard deviation below the mean variance of .72):

| | | |
|---|---|---|
| Item 25 | If parents should find blood donors, | $s^2 = .10$ |
| Item 31 | Why the child may be small for age, | $s^2 = .12$ |
| Item 40 | Surgeon to talk to parent before and after surgery, | $s^2 = .17$ |
| Item 27 | Where the parents could stay when child is in the hospital, | $s^2 = .17$ |
| Item 4 | What is wrong with the child's heart, | $s^2 = .17$ |
| Item 34 | What signs and symptoms to watch for, | $s^2 = .20$ |
| Item 24 | Whether the surgery is a complete or partial correction, | $s^2 = .20$ |
| Item 32 | Whether child will live a normal life, | $s^2 = .27$ |
| Item 50 | To have the name of someone to call in case of an emergency, | $s^2 = .28$ |

At the other end of the distribution of variances were the following eight items, exhibiting the least consensus. The variances of these items all exceeded 1.13 (one standard deviation above the mean variance of .72):

| | | |
|---|---|---|
| Item 7 | How many children are born with heart defects, | $s^2 = 1.21$ |

| | | |
|---|---|---|
| Item 49 | To keep parents informed of the progress during the surgery, | $s^2 = 1.29$ |
| Item 37 | How to discipline child, | $s^2 = 1.32$ |
| Item 42 | To talk with another parent whose child has a similar condition, | $s^2 = 1.35$ |
| Item 46 | To be told the medical term for the defect, | $s^2 = 1.40$ |
| Item 44 | To see a model of the heart, | $s^2 = 1.40$ |
| Item 43 | To have the nurse call at home to discuss condition and/or problems, | $s^2 = 1.56$ |
| Item 48 | Parents to visit the intensive care room before surgery, | $s^2 = 1.62$ |

The question arose whether a significant relation existed between consensus and the judged importance of items. When the items were trichotomized according to importance, and again according to degree of consensus, it was found that items rated as highly important tended to command high consensus, those rated as moderately important tended to command moderate consensus, and those least important received the least consensus. This association proved statistically significant at the .01 level (chi square = 21.25, df = 4). An exception to this finding was item 27 (where the parents could stay when child is in the hospital). The mothers apparently agreed that this was a matter of little importance.

## Systematic Variations Among Mothers Concerning Importance of Items

The responses of the mothers were examined to determine whether systematic differences occurred by (1) level of education, (2) mode of child's treatment (whether by medical management or by surgery), and (3) length of time elapsed since diagnosis.

Education. According to the first hypothesis, better educated mothers should tend to place more importance on the items than should less well educated mothers. From Table 3, it may be seen that the mean ratings for the fifty items varied from 4.20 for mothers with less than a high school education, through 4.23 for mothers who had graduated from high school, to 4.16 for mothers with some college education. These small differences probably represent chance fluctuations. On the surface no support would appear to exist for the postulated linear relation between education and importance assigned to the information. When the two extreme groups were considered, it was found that the mothers with some college education rated 32 of the items as more important than did the mothers with less than a high school education; but only three of these differences in ratings proved significant at the .05 level, according to the t-test. These findings generally indicate that the mothers did not differ substantially in their responses according to educational level achieved. The first hypothesis is not, then, upheld by the evidence.

The basic similarity of the two groups is further indicated by the strong correspondence of their rankings of the items in order of importance (Spearman's rho = .81). However, it might be mentioned that mothers with less than a high school education appeared to place the following items higher on their own scale of priorities than did

## TABLE 4

## CORRESPONDENCE OF RANK-ORDERING OF IMPORTANCE OF FIFTY ITEMS OF INFORMATION, AMONG VARIOUS SUBCATEGORIES OF RESPONDENTS: AS MEASURED BY SPEARMAN'S RHO.

| | Pair of Categories | Spearman's Rho* |
|---|---|---|
| I | All Mothers (N = 100) and All Staff (N = 117) | 0.89 |
| | All Mothers (N = 100) and All Senior Staff (N = 35) | 0.86 |
| | All Mothers (N = 100) and All Nursing Staff (N = 79) | 0.83 |
| | All Mothers (N = 100) and All Medical Staff (N = 38) | 0.88 |
| | All Mothers (N = 100) and All Physicians (N = 30) | 0.92 |
| | All Mothers (N = 100) and All Students (N = 20) | 0.86 |
| II | Between Subcategories of Mothers: | |
| | Mothers of children with surgical treatment (N = 41) and Mothers of children under medical management (N = 59) | 0.92 |
| | Mothers with some college education (N = 26) and Mothers with less than high school education (N = 17) | 0.81 |
| | Mothers of children diagnosed within six-months (N = 18) and Mothers of children diagnosed earlier (N = 82) | 0.85 |
| III | Between Subcategories of Staff: | |
| | All medical Staff (N = 38) and All Nursing Staff (N = 79)[a] | 0.80 |
| | All senior physicians (N = 14) and All junior physicians (interns, residents, fellows) (N = 16) | 0.89 |
| | All senior staff (senior physicians and charge nurses) (N = 35)[a] and All students (medical and nursing) (N = 20) | 0.66 |
| | Charge RNs (N = 20) and Staff RNs (N = 25) | 0.90 |

[a] Includes one Social Worker.

*All rho's listed are significant at .05 level or better.

the college educated mothers on their scale of priorities: being kept informed of progress during surgery (49); how to discipline the child (37); wanting an explanation of the medical terms used (1); what may have caused the defect (5); and having information on the financial cost (39). (Complete rank-ordering may be found in Appendix A, Table D.)

On the other hand, the mothers with some college education placed the following items of information higher on their own scale of priorities than did the mothers with less than a high school education: restrictions on the diet (18); the medical word for the defect, instructions, and treatment written down and given to them (47); what is done in a cardiac catheterization (12); what to expect in a clinic visit (13); and why antibiotics are to be taken before dental care (17).

With respect to the matter of consensus, mothers with some college education appeared to exhibit strong consensus on a number of items and also to exhibit a marked lack of consensus on other items. By comparison, mothers with less than high school education tended to concentrate in the moderate consensus range. In other words they neither strongly agree nor disagree among themselves. This finding may indicate that the better educated mothers are able to discriminate among items better and to demonstrate less of a response set by distributing their responses more widely over the five-point scale of importance.

Mode of Child's Treatment (Whether by Medical Management or Surgery. The second hypothesis stated that mothers of children undergoing surgery would place greater emphasis on items regarding surgery and postsurgery than they would place on other items. The third hypothesis stated that mothers whose children had been treated by medical management would place greater emphasis on areas of instruction and knowledge of medication than on other areas. These two hypotheses imply that the ranking of the items in order of importance should differ as between the two groups of mothers. But in fact the rank orderings were very similar for the two groups (Spearman's rho = .92). And upon analysis of the responses of the mothers whose children had undergone surgery, it was found that the eleven items regarding surgery and postsurgery (items 20-30) were not rated as more important than the six items on instructions (14-19). The mean ratings were respectively 4.44 and 4.63. Both these categories (surgery-postsurgery, and instructions) received higher mean ratings of importance than the remaining 33 items (4.19). However, since the area of instructions received the highest mean ratings of importance from the mothers of children who had surgery, the second hypothesis is not upheld.

Analysis of the responses of the mothers whose children were under medical management revealed that those mothers failed to rate the six items concerning instruction and medication (14-19) as more important than other items. The mean rating for items of instruction was 4. 37 in comparison with the mean of 4. 40 for the items of surgery and postsurgery. The mean rating for the remaining 33 items calculated from the responses of the mothers of children under medical management was 4. 02. So although the items of instruction had a higher rating of importance in comparison to the mean of all the remaining items, the area of surgery-postsurgery had a mean rating of greater importance. Again these results do not support the third hypothesis.

Finally in comparing the responses of the two groups of mothers, the mothers whose children had surgery tended to rate all 50 items higher (4. 31) than did the mothers of children under medical management (4. 14) (see Table 3).

Length of Time Elapsed Since Diagnosis. The fourth hypothesis stated that the mothers of children more recently diagnosed would place greater importance on the items regarding tests (8-13) than items of general information such as items on function, etiology, and prognosis (1-3, 5-7, 31-34). To test this hypothesis, the sample of mothers was divided into two groups: those whose children were diagnosed within the past six-months, and those whose children were diagnosed over six-months before. Hamburg and Adams' study (1967) reported that "over a span of several weeks or months, the families sought information pertinent to diagnosis". On this basis the present author postulated that mothers of children diagnosed with congenital heart defects might desire more detailed evaluation to confirm the diagnosis in the few months immediately following their child's diagnosis. Therefore it was hypothesized that mothers of the newly diagnosed children would rate tests as more important than the other items of general information.

Hamburg and Adams did not state how long "several" months were. The present study, a six-month time span since diagnosis seemed a natural cutting point in that 18 children were diagnosed within the previous six-months and the others were diagnosed at least 15 months earlier.

In analyzing the responses of the mothers of the more newly diagnosed children, the items regarding tests received a mean rating of 4. 13. The items regarding general information received a mean rating of 4. 32. These results do not confirm the fourth hypothesis (see Table 3).

Mothers of the newly diagnosed children tended to assign greater overall importance to the fifty items than did mothers of children diagnosed earlier (4. 29 to 4. 19). Lastly, the two groups ranked the items in about the same order of importance (Spearman's rho = . 85).

## Importance of Information as Perceived by Staff

The distribution of the staff's responses was skewed toward the high (or important) end of the five-point scale. The importance of the fifty items ranged from 2.93 to 4.67, with an overall mean of 3.92 (see Appendix A, Table A-1).

The staff ascribed the greatest importance to the following items:

| | | Mean rating |
|---|---|---|
| Item 4 | What is wrong with the child's heart, | 4.67 |
| Item 40 | Surgeon to talk with parents before and after surgery, | 4.61 |
| Item 34 | What signs and symptoms to watch for, | 4.56 |
| Item 50 | To have a name of someone to call in case of an emergency, | 4.54 |
| Item 23 | What are the risks during surgery, | 4.50 |
| Item 24 | Whether the surgery is a complete or partial correction, | 4.50 |

The staff classified the following five items as least important:

| | | |
|---|---|---|
| Item 46 | To be told the medical term for the defect | 3.26 |
| Item 42 | To talk with another parent whose child has a similar condition, | 3.03 |
| Item 44 | To see a model of the heart, | 3.03 |
| Item 7 | How many children are born with heart defects, | 2.94 |
| Item 43 | To have a nurse call at home to discuss condition and/or problems. | 2.93 |

Consequently, in the staff's opinion, the most important item of information was the diagnosis (4), and the least important items dealt with techniques to impart information (43, 44) and incidence (7).

## Consensus Among Staff

The consensus among the staff was determined in the same manner as was the consensus among the mothers. The range of the staff variances was from .10 to 1.62 with a mean variance of .79, and a standard deviation of .32. The staff appeared to have the greatest consensus on the following eight items, the variance of which were all less than .47 (one standard deviation below the mean variance of .79).

| | | |
|---|---|---|
| Item 27 | Where the parents could stay when child is in the hospital, | $s^2$ = .10 |
| Item 25 | If parents should find blood donors, | $s^2$ = .12 |
| Item 34 | What signs and symptoms to watch for, | $s^2$ = .30 |
| Item 4 | What is wrong with child's heart, | $s^2$ = .33 |
| Item 50 | To have the name of someone to call in case of an emergency, | $s^2$ = .40 |
| Item 30 | What activities to allow after surgery, | $s^2$ = .41 |
| Item 32 | Whether the child will live a normal life, | $s^2$ = .42 |
| Item 40 | Surgeon to talk to parents before and after surgery, | $s^2$ = .43 |

The following eight items elicited the least consensus in that their variances were above 1.11 (one standard deviation above the mean variance of .79):

| | | |
|---|---|---|
| Item 5 | What caused the defect, | $s^2$ = 1.15 |
| Item 46 | To be told the medical term for defect, | $s^2$ = 1.16 |
| Item 7 | How many children are born with heart defect, | $s^2$ = 1.25 |
| Item 42 | To talk to another parent whose child had a similar condition, | $s^2$ = 1.26 |
| Item 48 | Parent to visit the intensive care room before surgery, | $s^2$ = 1.34 |

| | | |
|---|---|---|
| Item 47 | To have the medical word for the defect, instructions, and treatments written down and given to parent, | $s^2 = 1.37$ |
| Item 49 | To keep parents informed of the progress during surgery, | $s^2 = 1.54$ |
| Item 37 | How to discipline child, | $s^2 = 1.62$ |

To determine whether a significant relation existed between the degree of consensus and relative importance of items, the items were trichotomized according to importance and again according to degree of consensus and the chi-square measure of association was calculated. This association failed to reach statistical significance at the .05 level (Chi-square = 9.128, df = 4).

## Systematic Variations Among Staff Concerning Importance of Items

The responses of the staff were analyzed to determine whether systematic differences occurred by (1) discipline (nurses vs. physicians), and (2) status (senior staff vs. students; senior medical staff vs. interns-fellows-residents; charge nurses vs. staff nurses).

*Differences Between Disciplines.* The fifth hypotheses predicted that nurses would classify items as more important than would medical staff. And although members of the two disciplines reacted somewhat alike in rank-ordering the fifty items (Spearman's rho = .80), nurses consistently accorded more importance to the items than did the medical staff. Thus, the nurses (RNs, LPNs, and nursing students) gave an average rating of 4.04 to the items, whereas medical staff (physicians, interns, residents, fellows, and medical students) gave an average rating of 3.65. The nurses' ratings of importance were higher than the medical staff's on 45 items, and on 29 of these the differences were statistically significant. Medical staff placed more importance than nursing staff on only five items, and in no instance was the difference a significant one. These findings uphold the hypothesis.

Specifically, the items which most significantly differentiated the two disciplines were:

| | |
|---|---|
| Item 28 | What to expect in the intensive care room, (t=4.32). |
| Item 9 | How to prepare child for tests, (t=4.63). |
| Item 48 | Parent to visit intensive care room before surgery (t=5.25). |
| Item 20 | How to prepare child for hospitalization, (t=5.75). |
| Item 21 | How to prepare child for the operation, (t=5.96). |

(See Appendix A, Table B for complete listing of t-tests.)

In an additional analysis, it was noted that the nurses placed the following items considerably higher in their rank-ordering of importance than the medical staff placed them in their own ordering:

| | |
|---|---|
| Item 9 | Preparing the child for tests. |
| Item 20 | Preparing the child for hospitalization. |
| Item 21 | Preparing the child for surgery. |
| Item 28 | What to expect in the intensive care room. |
| Item 48 | Parents to visit the intensive care room. |
| Item 49 | Keeping the parents informed during the surgery. |

In contrast, the medical staff placed the following items relatively higher in their order of priority than did the nurses:

| | |
|---|---|
| Item 5 | What caused the defect. |

| | |
|---|---|
| Item 14 | Telling the parents the name of the medicine. |
| Item 16 | What activity to allow before surgery. |
| Item 17 | The reason anitbiotics are given before dental care. |
| Item 25 | If the parents should find blood donors. |

These items at least on the surface appear to some extent to reflect the customary roles of the two groups with both medical and nursing staff members stressing the importance of their respective activities.

*Differences Between Status Categories.* The sixth, seventh, and eighth hypotheses concerned the effect of status within the staff group on the differing importance attributed to the several items of information by their status categories. The sixth hypothesis specifying that higher status staff would rate the items generally as more important to communicate to parents than would the lower status staff was not upheld by the data. Thus, the higher status group (defined as senior physicians and charge nurses) ranked the items in approximately the same order of importance (Spearman's rho = .88) as did the lower status staff (defined here as medical and nursing students). Additionally, the two status groups gave almost identical average ratings to the items, 3.91 and 3.92.

The seventh hypothesis stated that the senior medical staff would rate items as more important to communicate to parents than would the junior staff of interns, residents, and fellows. Again the two groups ranked the items in the same general order of importance (Spearman's rho = .89), and again the mean ratings of the two groups were close, 3.73 for the senior staff and 3.68 for the junior staff. The seventh hypothesis was then not upheld.

The last of the hypotheses concerning status specified that charge nurses would rate items as more important to communicate to parents than would staff nurses. These two groups of nurses rank-ordered the items similarly (Spearman's rho = .90), and assigned virtually identical ratings of importance (4.05 and 4.07) to the items. The eighth hypothesis fails to be supported by these data.

## Comparison of Responses of Mothers and Staff

According to the ninth hypothesis, mothers should judge items generally as more important than should staff members. And indeed, mothers assigned an average importance rating of 4.21 in contrast to the average rating of 3.92 by staff. Mothers considered 47 of the items to be more important than did the staff, and in 33 of these instances, the differences in their ratings were statistically significant according to the t-test. The most significant differences marked responses to the following five items:

| | |
|---|---|
| Item 29 | What care parents will give at home after surgery (t=5.18). |
| Item 25 | If parents should find blood donors (t=5.71). |
| Item 22 | What will be done in surgery (t=5.67). |
| Item 33 | That child would not outgrow defect (t=5.51). |
| Item 32 | Whether child would live a normal life (t=6.42). |

(A complete listing of the means and t-test scores may be found in Appendix A, Table A-C.)

Despite the large number of significant t-test scores, the two groups ranked the items in much the same order of importance (Spearman's rho = .89). And the single most important item of information was the same for both mothers and staff, namely, diagnosis (4), whereas the least important items for both groups were those concerning the methods of presenting information (43, 44).

## Consensus Between Mothers and Staff

With few exceptions, the items on which mothers expressed the greatest agreement were also the same items as those on which the staff expressed greatest agreement. The Spearman's rho of item variances for the mothers' responses compared to the item variances for the staff's responses was .87. The items eliciting the least consensus from the mothers also elicited the least consensus from the staff. For example, the following four items commanded the greatest consensus from both the mothers and staff:

Item 25 If parents should find blood donors.
Item 27 Where the parents could stay when child is in the hospital.
Item 34 What signs and symptoms to watch for.
Item 4 What is wrong with the child's heart.

These four items held the least consensus for both groups:

Item 7 How many children are born with heart defects.
Item 46 To be told the medical term for the defect.
Item 42 To talk with another parent whose child has a similar condition.
Item 49 To keep parents informed of the progress during the surgery.

## Relative Correspondence of Ratings of Nursing and Medical Staffs to Those of Mothers

The tenth hypothesis held that the correspondence between mothers' and nurses' opinions regarding communications should be closer than the correspondence between mothers' opinions and those of the medical staff. From Table 3, it may be seem that the mean item received a rating of 4.21 from the mothers, 4.04 from all nursing staff, and 3.65 from all medical staff. Second, for 45 items, the ratings of nurses were closer to those of mothers than were the ratings of the medical staff. These data support the tenth hypothesis. However, the ranking of the fifty items in order of importance was closer between mothers and medical staff (Spearman's rho = .88) than between mothers and nurses (Spearman's rho = .83). Apparently the mothers and nurses are more alike in the high importance they attach to all information generally, but the mothers and medical staff are more alike in their rank-ordering of items in terms of importance.

In further comparison, it was noted that the differences in the ratings of mothers and nurses were significant according to the t-test in 22 instances. The most significant of these differences were in:

| | |
|---|---|
| Item 33 | That child will not outgrow defect (t=4.30). |
| Item 5 | What caused the defect (t=4.75). |
| Item 22 | What will be done during the surgery (t=4.91). |
| Item 25 | If parents should find blood donors (t=5.06). |
| Item 32 | If the child will have a normal life (t=5.08). |

(See Appendix A, Table C for complete listing of the mean ratings of mothers and medical staff and t-test values.)

Finally the differences in the ratings of mothers and medical staff were significant in 40 instances. The most significant differences were:

| | |
|---|---|
| Item 21 | How to prepare child for the operation, (t=5.65). |
| Item 41 | To have factual information to read on congenital heart defects, (t=5.70). |
| Item 32 | Whether child will live a normal life, (t=6.11). |
| Item 37 | How to discipline child, (t=6.29). |
| Item 29 | What care parents will give at home after surgery, (t=6.92). |

(See Appendix A, Table C for complete listing of the mean ratings of mothers and medical staff, and for t-test values.)

## Relative Correspondence of Ratings of Senior and Junior Status Staffs to Those of Mothers

The eleventh hypothesis predicted the staff members with higher status would express opinions more closely aligned to those of mothers than would staff members of lower status. As may be seen in Table 3, the mean ratings of the fifty items by the three senior status groups were very nearly the same as those of junior status groups (senior staff vs. students, 3.91 and 3.92; senior physicians vs. interns-fellows-residents, 3.73 and 3.68; and charge nurses vs. staff nurses, 4.05 and 4.07). These data indicate no difference between senior and junior status staff in regard to their rating of importance of the items. Hence there could be no significant difference in the extent to which their views corresponded to the mothers' opinions, and therefore no support for the eleventh hypothesis.

## Summary of Findings

Mothers tended to consider the specified items of information as very important. Most importance was attached to the child's diagnosis and least to the various methods by which the desired information was imported. Staff members expressed similar opinions, although they did not rate the importance of the information quite so highly as did the mothers. This finding of the greater importance of information for mothers than staff supports the ninth hypothesis.

Mothers tended to agree as to which items were most important. Less consensus existed as to which items were least important. For staff, no significant association was found between the perceived importance of the information item and the degree of consensus regarding that item.

Systematic variations among mothers were largely absent. No support was found for the first four hypothesis stipulating systematic differences among mothers according to the three variables of educational level of the mother, mode of treatment of the child, or length of time since child's diagnosis. Mothers with more education did not attribute greater importance to the information than did mothers with less education. However, some differences were found regarding the relative ranking of the items, with some items consistently given higher priority by better educated mothers. Mothers of children treated by surgical means did not place the greatest emphasis on surgery and postsurgery information, judging instruction to be more important. However, their ratings of the importance of the surgical and postsurgical items did exceed the mean rating for all fifty items combined. The mothers of children under medical management did not place the greatest emphasis on instructions and medication but believed surgical items of greater importance. However, their ratings of the importance of the instructional and medication items still exceeded the mean rating for all the fifty items combined. Mothers of children recently diagnosed did not place less importance on general information than on information regarding the immediate situation they faced.

Some systematic variations in responses were found for differing categories of staff. Nurses generally rated the information as more important than did the medical staff, a finding in keeping with the fifth hypothesis. Nursing staff also tended to perceive as most important those areas of information which they customarily controlled, whereas medical staff stressed the information they ordinarily transmitted to patients. Status did not appear to have a marked effect on opinions of staff members. There were no differences in the rated importance of the items by senior staff (medical and nursing staff) and by students, by senior medical staff and junior medical staff, or by charge nurses and staff nurses.

Finally, the opinions of nurses and mothers tended to coincide more closely than the opinions of medical staff and mothers with regard to the average importance of all items. However, the opinions of medical staff and mothers tended to coincide more closely than the opinions of nursing staff and mothers with regard to which items were relatively more important and which items were relatively less important. The opinions of mothers and lower status staff members and students coincided just as closely as the opinions of mothers and higher status staff members. No status group appeared to demonstrate perceptions closer to the mothers' than any other status group. Thus there was no support for the sixth, seventh, eighth, tenth, and eleventh hypothesis.

# Chapter IV.

# DISCUSSION

## The Importance of Information as Perceived by Mothers

As mentioned in the previous chapter, the first finding was that the responses of mothers to the questionnaire items were skewed toward the high or important end of the five-point scale. That this was so should not be surprising in view of the criteria used for selecting the items for the instrument; namely, that the item should have been mentioned at least twice in the literature or in the interviews as being "important". Hindsight tells us that it might have been better, then, not to offer alternatives such as "not important" or "slightly important" which few respondents might be expected to check. Rather alternatives should have been restricted to several gradations of importance between the "moderately important" and the "extremely important" points of the continuum. Yet another procedure to circumvent a response set among respondents might have been to force a spread of choices as by a Q-sort.

According to the mothers in this study, the single most important item of information was the diagnosis of the child's condition. Dodge (1969; 1972) also reported that patients assigned top importance to diagnosis, and the present finding thus replicates hers. The mothers in this study also rated as highly important specific information regarding their children's condition. As one mother wrote on her questionnaire, "I find it extremely important that parents be told the truth to the fullest extent about their child's condition and what to expect in any case".

Of lesser importance than the information itself were the techniques by which information might be transmitted. However, the spirit in which the information was imparted was of some significance to mothers, for, as one mother wrote, "The information should be given freely . . . Parents are angry when they feel as if every little nugget of information has to be chased all over the hospital and pried loose. A shuffled-around feeling is produced easily in parents who aren't used to what's going on - a dehumanization feeling."

Least importance was attributed to visitation by a nurse in the home to discuss the conditions or problems. Here mothers may have been reacting to the phrase "visit in the home". Perhaps mothers feel ambivalent to such visits (as do welfare clients) as a slight invasion of privacy or somewhat of a bother; and may believe problems might just as well be discussed elsewhere as in the clinic or hospital, or via telephone. On the other hand, the mothers might have been responding to the term "discuss". This investigator wonders: If the word "discuss" had been changed to read "teach" regarding heart defects, would the parents have rated this item as more important? Perhaps mothers do not want general "discussion" from the nurse, but specific details to help them plan for the care of their child. One mother wrote, "A public health nurse called on me a few times and because there were no practical suggestions or help she could give and because our family is mutually supportive, I could see no reason for her continued visits."

## Consensus Among the Mothers

For the group of mothers as a whole a significant relationship was found between the degree of consensus and the judged importance of items. The important items were also those on which most mothers expressed agreement and the items held to be least important were also least agreed upon. So. in discussing the items here classified as important, the health communicator can be assured that the majority of parents agree on this information as being important. In so far as items rated of lesser importance are concerned, there is no certainty that all parents classify the information as negligible. Some may indeed desire the information while others do not. Under such circumstances the staff member may need to inquire of the parent whether he would like such information, e.g., the incidence of heart defects (item #7), or whether he would find it helpful to see a model of the heart (item #44), or to talk with another parent whose child has a heart defect (item #42).

## Systematic Variations Among Mothers Concerning Importance of Items

Contrary to expectation, the responses of mothers showed few systematic variations according to the mother's education, the mode of treatment for her child, and the length of time elapsed since first diagnosis of the child.

Education. The first hypothesis of this study stated that mothers with more education would tend to attribute greater importance to information than would mothers with less education. This hypothesis was based on Dodge's (1969) findings. Dodge utilized as her measure of importance, the mean rating accorded all items; and observed that the mean ratings of patients with most education (e.g. some college training) tended to exceed the mean ratings of the items by patients with high school education and the mean ratings of high school graduates exceeded those of less than high school graduation. However, the present data ran counter to Dodge's, with no significant difference noted between the mean ratings of the three educational categories. Consequently the first hypothesis was not upheld. However, the variable, educational level, did seem to make some differences in the responses of mothers. First, the better educated mothers demonstrated a wider spread in their responses. Apparently, the mothers with some college education discriminated more among items, and exhibited less of a response set in the distribution of their responses over the five-point continuum. Mothers with less than a high school education tended to show less discrimination among items, and tended to classify all items in a more or less uniform manner. Thus the variances of the better educated mothers' responses to the fifty items were spread more widely than the variances of the less well educated mothers' responses.

Second, the areas of information ranked as most important differed as between the better and less well educated mothers. The less well educated mothers indicated they wanted more general information on cause and incidence of heart defects, and an explanation of terms. They also desired more emotional support. However, complex information requiring detailed instruction was not so highly valued.

Well educated mothers indicated they would like more detailed information on how they could actively participate in their children's care as by controlling diets or obtaining antibiotics before dental work. These mothers also would like instructions written down.

Seemingly, these mothers with more education want a more active involvement in their children's care. A comment from one mother exemplifies this idea, "Anything dealing with how to care for child or what will happen to child (procedures and tests) should be explained in detail, and some written information provided or referred. The strain of dealing with a heart defect can be intensified unbelievably by having answers to questions evaded, glossed over, or avoided in any way." As Voysey (1972) found in her work with parents of disabled children, parents who can participate in their child's care, feel less helpless. Of the mothers in this study, well educated mothers appeared to want more power to control the outcome, while the less well educated mothers put somewhat less importance on becoming actively involved in the details of their children's care. Rather they relied on the "medical experts" more heavily.

These findings were similar to Dodge's (1969). She found the more poorly educated patients desired nontechnical information and stressed the personal, emotionally-charged aspects of their care, whereas well educated patients valued the kind of information which required a greater degree of intellectual sophistication. They did not want vague comments, but rather information that would enable them to plan more effectively for their immediate and long-term futures. Well educated patients exhibited greater objectivity and less need for a dependent relationship on the staff. In all these respects the findings are in accordance with past research which has demonstrated that white collar workers (or better educated individuals) tend to stress mastery of the environment, independence, and autonomy to a greater extent than do members of the blue collar occupations (or less well educated individuals).

### Mode of Child's Treatment (Whether by Medical Management or Surgery)

Dodge (1969) reported that surgical patients manifested more interest in learning about matters pertaining to surgery than other matters, and medical patients placed more emphasis on knowledge regarding instructions and medication. The second and third hypotheses of this study were based on her findings. However, the present data do not support the hypotheses. Mothers of children who had surgery actually rated instructions as somewhat more important than surgery or postsurgery items. Mothers of children under medical management rated surgery and postsurgery items as more important than instructions.

Two possible explanations for the failure to obtain results congruent with those of Dodge lie in certain differences in procedure and samples of the two studies. Thus, Dodge interviewed patients in the immediate postsurgery phase of hospitalization. For her patients, then, questions on surgery might have been uppermost in their minds. The children of the mothers participating in this study were, for the most part, not hospitalized, but had undergone surgery weeks or even years earlier. The importance of surgery then may have receded for these mothers, and currently they may have been more concerned with problems of the general management of their children. Hence, they felt a greater need for instructions than for more information regarding past surgery.

Secondly, Dodge's sample of surgical patients were "short-term" with recovery usually complete. The present sample differed substantially, consisting of "long-term" patients who must live with their condition for an extended period of time. Problems of care and medication remain continuous. In dealing with a congenital heart defect the parents' involvement is not short-termed. A high degree of apprehension is aroused when the functioning of the heart is threatened. Even after surgery may have corrected the child's heart defect, parents frequently continue to feel apprehensive, and to treat their child as still experiencing heart trouble. Hence in this study, we must consider both groups of children, those who had surgery and those under medical management, as long-term cases. This difference in the nature of the two samples may also have contributed to the difference in results of our study and Dodge's.

A third explanation is possible for the present findings (although not an explanation which reconciles our findings with those of Dodge). Many mothers of medically managed children anticipated surgery in the future and may want information regarding that contingency: whereas mothers of surgically treated children already possessed information regarding surgery and now may feel greater need for information concerning the maintenance and continuing medical management of their children.

## Length of Time Elapsed Since Diagnosis

As reported in the previous chapter, the responses of mothers of children diagnosed within six months, and of mothers of children diagnosed over six months previously were basically similar. Thus the fourth hypothesis was not supported.

The fourth hypothesis was derived from the research of Hamburg and Adams (1967). Those authors found that parents of children with leukemia went through four distinct information seeking time periods. They desired information pertinent to (1) diagnosis, (2) their responsibility, (3) treatment, and (4) coming to terms with the expected loss. Hence, the existence of various time phases in the progress of the illness appeared marked by differing expressions of need.

The reason for the present failure to corroborate the findings of the above authors lies perhaps in the two time divisions selected or perhaps in the two different groups studied. If different periods of time had been selected, or if the length of time since diagnosis had been divided into several time periods, possibly changes over time might have become apparent. However, possibly parents of children with leukemia would react quite differently over a period of time than would parents of children with congenital heart defects due to the difference in diagnosis and prognoses attached to these illnesses.

However, mothers of the more newly diagnosed children placed more importance than did mothers of children diagnosed earlier, on the items "having a nurse visit at home" and "to discuss financial worries with someone." These findings may be indicative of the desire of mothers of recently diagnosed children for more contact with staff and more emotional support. As Henning (1968) has pointed out, the most effective time to assist a family through a crisis (e. g. the diagnosis of congenital heart defect) is during that crisis. One way a nurse may help is to visit the family of the newly diagnosed child and give that family the support and instructions needed at that time.

## The Importance of Information as Perceived by Staff

The responses of the staff were found to be skewed toward the high or important end of the continuum. The criteria for item selection would appear to account for this finding, as for the similar finding in regard to the mothers' responses.

In this investigation, just as in Dodge's (1972) study, staff designated diagnosis as the most important item of information. Next in importance were a number of items regarding surgery. Staff members may stress such information in the belief that parents need it; or they may stress such information due to their own need to ventilate their anxiety regarding heart surgery.

The items to which staff attributed the least importance were the incidence of the defect and the various techniques for presenting information. The greater importance assigned to information on diagnosis and surgery than to information of disease and techniques of communication is understandable in the light of medical and nursing training. Such training tends to stress arriving at a diagnosis, treating a disease, and making the patient physically comfortable. The need to provide information on other areas and the need to use a variety of techniques has not been emphasized to date. The concept of total patient care may not become a reality until communication between staff and patients is increased (Brown, 1965).

The item obtaining the lowest mean rating from the staff was "to have a nurse visit at home to discuss problems". First, the low rating may have been due in part to the use of the term "discuss" rather than "teach". A second possible reason for the low priority of this item may have been the fact that the staff under study was oriented to a hospital facility. Aftercare of patients was accomplished through office or clinic visits and referral to a community nurse for follow-up was uncommon.

Regarding the item "to talk with another parent whose child has a similar condition", one physician wrote, "Very bad, as no two cases are alike." However, this form of communication occurs commonly in the clinic and in the hospital. Hamburg and Adams (1967) found in their study, that parents frequently exchanged information. In this study also, parents were frequently observed discussing their child's condition with other parents and ventilating their worries. In this informal manner, parents pass on information, both correct and incorrect. At times they provide emotional support for one another; at times they may create additional worries for one another. This investigator believes this sharing among parents could be better structured for constructive use. Perhaps a parent who has made this "passage through crisis" can provide more effective emotional support for a frightened parent just entering the treatment cycle than can a staff member (Meadow, 1968). To maximize the benefits and counteract any harm, staff may take advantage of an on-the-spot informal discussion between two or more parents to introduce some health teaching. The time is opportune to ask one parent her solution to a particular problem in order to give another parent some fresh ideas. This also may be a propitious time to correct misinformation or to clarify statements passed between parents.

## Consensus Among Staff

There was a lack of a significant relationship between the staff's degree of consensus on the item and the relative importance of that item. This wider diversity on the items may be due to the staff's varied education, areas of expertise, and roles they perform. The lack of relationship between consensus and importance on items for staff may result in confusion for parents, since differing staff members may stress differing items. This would indicate there is a need for unifying instruction or at least for recording what information has been discussed (Weed, 1969) so additional areas may be covered or previous areas supplemented.

## Systematic Differences in Opinions Associated With Differences in Disciplines

In accordance with the fifth hypothesis, nurses in this study attributed more importance to the imparting of information to mothers than did the medical staff. This finding replicates that of Dodge (1963), and corroborates Skipper's (1965) observation that nurses desire to communicate more with patients than do physicians.

In speculating as to why this was so, two reasons come to mind. First, nurses spend more time with patients, hear more questions, and may therefore feel more pressed to produce answers. Second, health teaching has been explicitly designated by professional nurses as part of the nurse's role.

Although nurses may set a higher value on health teaching than do physicians, nevertheless it remains the physicians' prerogative to determine the kind and amount of knowledge to be delivered in the medical setting (Linehan, 1966; Katz, 1969; Redman, 1974). This fact may accord the nurse a comforting type of immunity from the responsibility of explaining difficult and threatening events. Perhaps the nurse has exercised this immunity too well and needs now to accept a more active role in health instruction (Aasterud, 1963). Some nursing leaders suggest the nurse should become the patient's advocate in seeing to it that the patient's need for health instruction is adequately met.

A second difference between the disciplines noted in the present research was the difference in their rankings of the importance of information. Each discipline tended to give priority to the activities it performed, and to the information which it controlled and could disseminate. Thus, physicians stressed the importance of informing parents about medication and the results of surgery, information which the doctor commands. Nurses stressed informing parents about diet, care at home, preparing the child for various hospital procedures, facilitating events between doctor and parent, and so on, areas in which nurses are likely to be particularly involved.

## Systematic Differences in Opinions Associated With Difference in Status

It was anticipated that higher status staff members would place more stress on communicating information to parents than would lower status staff members. This expectation was based both on Dodge's (1963) empirical findings, and on her argument that higher status individuals, since they feel more adequate and secure in their positions are more willing to communicate openly and fully with others.

However, on analysis, the expected relation did not materialize between any of the pairs of status groups compared, not between the senior staff (physicians and charge nurses) and students (both nursing and medical), nor between senior physicians and junior staff (interns, residents, fellows), nor yet between charge RNs and staff RNs. Thus, the sixth, seventh, eighth, and eleventh hypotheses were not upheld. The reasons for these findings which were contrary to those anticipated may lie in social changes occurring during the past decade to which many younger staff became exposed. These changes emphasized civil rights, including the patient's right to know and the worth of the individual. In addition, a changing of education policies with a free and more open relationship may have resulted in a decrease in status groupings.

## Comparison of Responses of Mothers and Staff

In this investigation, mothers placed higher value on receiving information than the staff did on imparting it. This finding was consistent with that of Dodge (1963) who reported that patients attributed more importance to medical information than did either physicians or nurses.

The reasons for this phenomenon can only be guessed at. While the professional schools may recognize the need for educating patients or clients, in the clinical areas, planning for such may not be allotted for its implementation. As Redman (1974) has suggested this situation will probably change in the future, with patient teaching being accorded more equal status with medication or other treatment considered as vital for patient welfare; and the time will come when the omission of health teaching, may be defined as malpractice.

Any long term health problem involves basic teaching tasks for the health professional in that knowledge often exists which is essential for the patient's proper regulation of his condition. In this teaching, the health professional should not only transmit factual information, but provide emotional support in the process. When children are the patients, their parents become the pupils, and must learn the facts and procedures necessary for carrying out their responsibility to monitor and treat their children. Parents of children with congenital heart defects face formidable problems and a heavy emotional burden in caring for their children. Their need for instruction and emotional support is clear.

## Relative Correspondence of Ratings of Nursing and Medical Staffs to Those of Mothers

Analysis revealed a difference of opinion between nurses and mothers as to the importance of some of the specific items of information. Dodge (1963; 1972) found that nurses ranked as the most important communications those which explained hospital routines, treatments and test procedures, and listed activity and diet restrictions for the post-hospital period. The findings of the present study were similar. Nurses gave high priority to information regarding their own tasks, information which they are customarily permitted to give; but mothers attached somewhat less importance to these items. This investigator does not suggest that nurses should omit giving this information to parents. Indeed, the information appears valuable in that it has been found to, (1) reduce complications during or after procedures (Ryan, 1967; Helberg, 1972; Boegli, 1972; Lindeman, 1973), (2) increase the satisfaction of the staff in performing their tasks, and (3) relieve patients' anxiety about the unknown.

The results of this study would suggest, however, that the nursing staff should become aware of the whole picture regarding health instruction. If nurses are to assume the major burden of patient teaching in the future, then it would seem advisable for nurses to become thoroughly acquainted with the areas of knowledge that patients want. Thus Redman (1974) has pointed out that one of the tasks facing nurses is to provide health teaching, without forcing their own values on patients.

As stated previously, physicians placed less importance on the information generally than did the mothers. This may be attributable in part to the greater tendency of physicians to discriminate among items, and in part to their basic ambivalence about the worth of patient teaching. While considered important, such teaching may still be judged less crucial than other professional activities. Finally, physicians may in some degree guard information from the general public in the interest of maintaining expertise. (It is commonly regarded as a characteristic of a profession to carefully restrict access to its specialized body of knowledge to protect the profession's position.).

Although the overall importance attached to the information by physicians was lower than that of mothers and of nurses, the physicians' ranking of the items in order of importance was in closer harmony with the mothers' ranking than was the nurses'. We may conclude that, paradoxically, the doctors, if they would only increase the priority they attach to patient teaching, might cover areas desired by the mothers, while the nurses who sympathize with the need for instruction might stress areas considered less important by the mothers.

## Content of Educational Program

The findings of this study may be of assistance in development of an educational program. An effective health instructional program includes content which meets the perceived needs of the mother and incorporates basic information that the staff has found essential. This study found mothers and staff agree on many areas as being important to communicate, e. g. information on diagnosis, what signs and symptoms to watch for, and information concerning surgery. Any instructional plan should cover these specific topics.

However, this investigation found mothers and staff did not agree on other areas as being equally important to communicate. First, mothers considered certain items as more important than did staff, e. g., what is done in surgery, and whether or not the child will outgrow the defect. Such items which mothers wish to know should be included in the educational content. The staff needs to recognize these differences of opinions and search out the areas in which mothers desire information. Secondly, disagreement was found in that staff ranked some areas of information as more important than did mothers, e.g., medication and diet instructions. The staff may need to evaluate anew the importance of these various items for an educational program. If then the staff continues to view these items as essential, while cognizant of their lesser significance in the view of parents, new strategies of teaching may need to be employed to ensure their being learned. For example, the order of instructions might be altered, so as to begin with the challenged items (Ley, 1965; Ley, 1972); or the parent might be asked to paraphrase the information in order to facilitate longer retention of the item.

In this research, a few systematic variations were found in the opinions of differing categories of mothers. These suggest the desirability of altering the emphases in content or approach in working with various types of mothers. For example, mothers with less education appeared to be less able to discriminate among items with relation to their greater or lesser importance. Such less well educated mothers present a challenge to the health communicator in that he must (1) identify specific areas in which less educated mothers need special clarification; (2) present information in nontechnical terms so that it will not be ignored or rejected; and (3) exhibit patience in repeating instructions. As a second example, mothers of children under medical management manifested considerable interest in the surgical process, a finding suggesting that this topic should be discussed with such mothers. And finally, because mothers of children more recently diagnosed appeared to desire more emotional support and contact with staff, this fact might be taken into account by staff members.

In this investigation, systematic differences were found among categories of staff members concerning what they thought important to communicate. This fact may lead staff members to neglect mentioning certain topics when instructing patients. In considering the content for an instructional program, staff needs to be aware of their biases and tailor the plan to ensure the inclusion of such topics which they might otherwise be inclined to overlook.

## Chapter V

## SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

The purpose of this investigation was to determine the areas and extent of agreement and disagreement between professional staff and mothers of children with congenital heart defects, regarding the importance of specific communications. The sample of mothers was selected on the basis of convenience, and consisted of the first 100 mothers who brought their children to any of three facilities of the University of Oregon Medical School Hospital for examination or treatment during the month of April, 1974. The entire staff attending these children was asked to participate in the study. Of the 139 members, 117 or 84% responded.

Each subject completed a questionnaire, in which he or she rated the importance of 50 items of communication on a five-point scale. These items covered three areas: knowledge, emotional needs, and techniques for presenting information. In addition, the questionnaire provided data on the background characteristics of each respondent.

Eleven hypotheses were formulated. Four concerned differences in opinion among mothers with differing background characteristics; four concerned differences in opinions among subcategories of staff; and three concerned the relative similarity of the responses of mothers and differing subcategories of staff.

On analysis of the data, three of these hypotheses were confirmed at least in part.

| | |
|---|---|
| Hypothesis # 5. | Nurses tend to consider information generally as more important than do medical staff. |
| Hypothesis # 9. | Mothers tend to consider information generally as more important than do staff members. |
| Hypothesis #10. | Nurses tend to express opinions about the importance of information more like those of mothers than do medical staff. |

The eight hypotheses not supported by the findings included:

| | |
|---|---|
| Hypothesis # 1. | Mothers with more education tend to consider items of information generally as more important than do mothers with less education. |
| Hypothesis # 2. | Mothers of children who undergo surgery tend to consider items of information regarding surgery and postsurgery as more important than other items. |
| Hypothesis # 3. | Mothers of children treated by medical means tend to consider items regarding instructions and knowledge of medication as more important than other items of information. |

| | |
|---|---|
| Hypothesis # 4. | Mothers of children more recently diagnosed tend to consider items of information concerning tests and examinations as more important than other items, such as those concerning incidence, prognosis, and the physiological functioning of the heart. |
| Hypothesis # 6. #7, #8. | Senior status groups tend to consider information generally as more important than do junior status groups (senior staff vs. students, senior physicians vs. interns-fellows-residents, and charge nurses vs. staff nurses). |
| Hypothesis #11. | Staff members of higher status tend to express opinions about the importance of information more like those of mothers than do staff members of lower status. |

The general conclusion to be reached from these findings is that indeed areas of agreement and disagreement exist between staff and mothers as to what is important to communicate, and also between various subcategories of mothers, and various subcategories of staff. More specifically, the major findings are as follows. First, both mothers and staff attached the greatest importance to diagnosis and the least to various methods of presenting information. Second, mothers judged items generally as more important than did the staff. Third, both mothers and staff tended to rank-order the importance of the items similarly. Fourth, mothers' responses as to the overall importance of the fifty items did not vary systematically according to mother's level of education, child's mode of treatment (whether surgical or medical), or length of time since first diagnosis of the child. However, less well educated mothers tended to discriminate less among the items; and mothers of children recently diagnosed appeared to need more emotional support and staff contact than mothers of children diagnosed longer ago. Fifth, staff judgments varied according to discipline, with nurses tending to judge information generally as more important than did the medical staff. Sixth, the status of the staff member did not appear to influence judgments of the importance of items. Seventh, nurses' responses accorded more closely with those of mothers than did the responses of the medical staff, in that both nurses and mothers assigned greater importance to the items than did the medical staff. Eighth, the responses of medical staff resembled those of mothers to a greater degree than did the responses of nursing staff, with respect to the rank-ordering of the items in terms of their relative importance.

Certain problems encountered by the author during the course of this investigation led to the following recommendations for further research into the area of staff-client communication. To circumvent the problem of the skewed distribution of responses, and to force finer discriminations among items, either the rating scale might be expanded from five to seven or nine points, or the number of items assigned to any given category might be specified and limited by a technique such as a Q-sort. Second, the present instrument needs reworking, with the possible elimination of some items and the addition of others; and a factor analysis of the items would appear desirable to determine the clustering of items and the underlying dimensions being measured. It is probable that differing role groups stress differing areas of communication, and it would seem useful to take such tendencies into account in setting up any instructional program. Third, each of the problems touched upon in this research might be examined in depth and an explanation sought for each of the findings. For example, why do there seem to be no differences among status groups? Are these findings a result of the unique characteristics of the setting in which the investigation was conducted, of the peculiarities of the samples chosen? Fourth, the relation between what staff says is important to communicate and what the staff in fact communicates need to be explicated, as does the relation between what parents claim they want to know and what they are told.

Finally, the results of this study would appear to have practical value in suggesting content for an instructional program for mothers of children with congenital heart defects. This content should include both what mothers perceive as important and what staff members have found vital to share. It would suggest variations of the content depending on the differing characteristics of the mothers concerned. Finally it is hoped the study will serve to make staff members more aware of their biases in the process of their explanations.

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# APPENDICES

# APPENDIX A

# TABLES

# TABLE A

## MEAN VALUES OF IMPORTANCE OF INDIVIDUAL ITEMS, CALCULATED FROM RATINGS OF 100 MOTHERS: t-TEST STATISTICS FOR DIFFERENCES OF MEAN VALUES OF ITEMS AS BETWEEN SPECIFIED SUBCATEGORIES OF MOTHERS

| Categories of Items[a] | All Mothers N=100 | Less Than High School N=17 | More Than High School N=26 | t-Test Value | "Surgical" Mothers N=41 | "Medical" Mothers N=59 | t-Test Value | 6 Months or Less Since DX N=18 | More than 6 Months Since DX N=82 | t-Test Value |
|---|---|---|---|---|---|---|---|---|---|---|
| Function: | | | | | | | | | | |
| 1. Explain terms | 4.13 | 4.29 | 3.96 | 1.28 | 4.19 | 4.08 | 0.63 | 4.22 | 4.11 | 0.51 |
| 2. How heart works | 3.87 | 3.88 | 3.80 | 0.26 | 4.05 | 3.74 | 1.56 | 3.83 | 3.87 | 0.17 |
| 3. Normal circulation | 3.79 | 4.00 | 3.58 | 1.44 | 4.02 | 3.62 | 2.13* | 3.89 | 3.76 | 0.49 |
| Diagnosis: | | | | | | | | | | |
| 4. What is wrong | 4.85 | 4.71 | 4.88 | 1.28 | 4.90 | 4.81 | 1.06 | 4.89 | 4.84 | 0.44 |
| Etiology: | | | | | | | | | | |
| 5. Cause of defect | 4.50 | 4.59 | 4.42 | 0.71 | 4.51 | 4.49 | 0.14 | 4.78 | 4.44 | 1.76 |
| 6. Reoccurence of defect | 4.52 | 4.59 | 4.46 | 0.38 | 4.75 | 4.35 | 2.04* | 4.61 | 4.50 | 0.43 |
| 7. Incidence | 3.08 | 3.47 | 2.69 | 2.53* | 3.21 | 2.98 | 1.06 | 3.44 | 3.00 | 1.56 |
| Tests: | | | | | | | | | | |
| 8. Why tests done | 4.14 | 4.06 | 4.23 | 0.67 | 4.29 | 4.03 | 1.44 | 4.27 | 4.11 | 0.73 |
| 9. Prepare child-tests | 4.11 | 3.94 | 4.27 | 1.09 | 4.34 | 3.94 | 1.91 | 3.94 | 4.15 | 0.75 |
| 10. Meaning of tests | 4.25 | 4.06 | 4.35 | 0.92 | 4.21 | 4.27 | 0.27 | 4.11 | 4.28 | 0.68 |

TABLE A continued

| Categories of Items[a] | All Mothers N=100 | Less Than High School N=17 | More Than High School N=26 | t-Test Value | "Surgical" Mothers N=41 | "Medical" Mothers N=59 | t-Test Value | 6 Months or Less Since DX N=18 | More Than 6 Months Since DX N=82 | t-Test Value |
|---|---|---|---|---|---|---|---|---|---|---|
| 11. If painful | 4.19 | 4.00 | 4.15 | 0.49 | 4.31 | 4.10 | 1.12 | 4.17 | 4.19 | 0.11 |
| 12. Cardiac cath. | 4.47 | 4.23 | 4.69 | 1.89 | 4.70 | 4.30 | 2.29* | 4.44 | 4.47 | 0.13 |
| 13. Clinic visits | 3.90 | 3.82 | 4.11 | 0.95 | 4.02 | 3.81 | 0.98 | 4.22 | 3.83 | 1.43 |
| Instructions: | | | | | | | | | | |
| 14. Medicine name | 4.38 | 4.23 | 4.23 | 0.01 | 4.60 | 4.22 | 1.92 | 4.39 | 4.37 | 0.04 |
| 15. Medicine action | 4.52 | 4.41 | 4.54 | 0.43 | 4.63 | 4.44 | 1.08 | 4.61 | 4.50 | 0.48 |
| 16. Activities | 4.72 | 4.59 | 4.77 | 1.04 | 4.75 | 4.69 | 0.50 | 4.89 | 4.68 | 1.31 |
| 17. Antibiotics | 4.31 | 4.00 | 4.35 | 1.19 | 4.53 | 4.15 | 2.18* | 3.83 | 4.41 | 2.60 |
| 18. Diet restrictions | 4.45 | 3.88 | 4.58 | 2.37* | 4.63 | 4.32 | 1.89 | 4.39 | 4.45 | 0.34 |
| 19. Effects of colds | 4.49 | 4.35 | 4.50 | 0.61 | 4.60 | 4.40 | 1.52 | 4.39 | 4.51 | 0.72 |
| Surgery: | | | | | | | | | | |
| 20. Prepare child-hosp. | 4.23 | 4.29 | 4.38 | 0.38 | 4.35 | 4.13 | 1.47 | 4.22 | 4.23 | 0.05 |
| 21. Prepare child-surgery | 4.55 | 4.47 | 4.69 | 1.15 | 4.65 | 4.47 | 1.32 | 4.50 | 4.56 | 0.34 |
| 22. What done in surgery | 4.63 | 4.65 | 4.69 | 0.27 | 4.60 | 4.64 | 0.27 | 4.83 | 4.58 | 1.56 |
| 23. Surgical risks | 4.73 | 4.59 | 4.77 | 1.04 | 4.65 | 4.77 | 1.05 | 4.83 | 4.71 | 0.85 |
| 24. Complete or partial | 4.76 | 4.65 | 4.81 | 1.17 | 4.70 | 4.79 | 0.97 | 4.89 | 4.73 | 1.34 |
| 25. Blood donors | 4.20 | 4.18 | 4.27 | 0.30 | 4.14 | 4.23 | 0.44 | 4.05 | 4.23 | 0.67 |
| 26. Time in hospital | 4.09 | 4.29 | 4.15 | 0.52 | 4.04 | 4.11 | 0.38 | 4.50 | 4.00 | 2.17* |
| 27. Where parents stay | 3.38 | 3.35 | 3.50 | 0.35 | 3.41 | 3.35 | 0.22 | 3.00 | 3.46 | 1.37 |
| Post-surgery: | | | | | | | | | | |
| 28. Intensive care | 4.45 | 4.35 | 4.42 | 0.25 | 4.48 | 4.42 | 0.42 | 4.50 | 4.44 | 0.31 |

TABLE A continued

| Categories of Items[a] | All Mothers N=100 | Less Than High School N=17 | More Than High School N=26 | t-Test Value | "Surgical" Mothers N=41 | "Medical" Mothers N=59 | t-Test Value | 6 Months or Less Since DX N=18 | More Than 6 Months Since DX N=82 | t-Test Value |
|---|---|---|---|---|---|---|---|---|---|---|
| 29. Care at home | 4.79 | 4.71 | 4.85 | 0.87 | 4.85 | 4.74 | 0.99 | 4.94 | 4.76 | 1.35 |
| 30. Activities to allow | 4.70 | 4.59 | 4.73 | 0.58 | 4.78 | 4.64 | 0.99 | 4.78 | 4.68 | 0.53 |
| Prognosis: | | | | | | | | | | |
| 31. Small for age | 3.82 | 4.06 | 3.81 | 0.71 | 3.92 | 3.74 | 0.79 | 4.11 | 3.76 | 1.21 |
| 32. Normal life | 4.73 | 4.59 | 4.69 | 0.58 | 4.70 | 4.74 | 0.36 | 4.78 | 4.72 | 0.42 |
| 33. Not outgrow | 4.70 | 4.59 | 4.85 | 1.72 | 4.68 | 4.71 | 0.26 | 4.72 | 4.70 | 0.19 |
| 34. Signs and symptoms | 4.77 | 4.70 | 4.88 | 1.48 | 4.78 | 4.76 | 0.19 | 4.78 | 4.77 | 0.08 |
| Emotional: | | | | | | | | | | |
| 35. What to tell child | 4.29 | 4.24 | 4.23 | 0.02 | 4.39 | 4.22 | 0.95 | 4.27 | 4.29 | 0.06 |
| 36. Child and his worries | 4.34 | 4.12 | 4.35 | 0.81 | 4.41 | 4.28 | 0.69 | 4.05 | 4.40 | 1.49 |
| 37. Discipline child | 3.97 | 4.23 | 3.69 | 1.50 | 4.19 | 3.81 | 1.65 | 3.61 | 4.05 | 1.47 |
| 38. Parents talk to someone | 4.40 | 4.35 | 4.46 | 0.43 | 4.44 | 4.37 | 0.38 | 4.39 | 4.40 | 0.06 |
| 39. Financial cost | 4.08 | 4.35 | 4.00 | 1.03 | 4.29 | 3.93 | 1.69 | 4.55 | 3.97 | 2.14* |
| Techniques: | | | | | | | | | | |
| 40. Talk to surgeon | 4.77 | 4.71 | 4.81 | 0.76 | 4.83 | 4.73 | 1.70 | 4.78 | 4.76 | 0.09 |
| 41. Information to read | 4.11 | 4.06 | 4.00 | 0.19 | 4.24 | 4.01 | 1.32 | 4.22 | 4.08 | 0.62 |
| 42. Talk to other parent | 3.11 | 3.35 | 3.04 | 0.90 | 3.12 | 3.10 | 0.08 | 3.33 | 3.06 | 0.90 |
| 43. Nurse call at home | 2.82 | 3.12 | 2.96 | 0.39 | 2.90 | 2.76 | 0.55 | 3.44 | 2.68 | 2.39* |
| 44. Model of heart | 3.05 | 3.00 | 3.12 | 0.29 | 3.29 | 2.88 | 1.73 | 3.11 | 3.03 | 0.24 |

TABLE A continued

| Categories of Items[a] | All mothers N=100 | Less than High School N=17 | More Than High School N=26 | t-Test Value | "Surgical" Mothers N=41 | "Medical" Mothers N=59 | t-Test Value | 6 Months or Less Since DX N=18 | More Than 6 Months Since DX N=82 | t-Test Value |
|---|---|---|---|---|---|---|---|---|---|---|
| 45. Drawing of heart | 3.99 | 4.00 | 3.81 | 0.56 | 4.14 | 3.88 | 1.29 | 4.11 | 3.96 | 0.56 |
| 46. Told medical term | 3.75 | 3.82 | 3.92 | 0.26 | 4.00 | 3.57 | 1.78 | 3.89 | 3.72 | 0.55 |
| 47. Infor. written down | 4.17 | 4.06 | 4.50 | 1.73 | 4.19 | 4.15 | 0.20 | 4.33 | 4.13 | 0.74 |
| 48. Visit intensive care | 3.55 | 3.88 | 3.38 | 1.39 | 3.78 | 3.38 | 1.52 | 4.05 | 3.43 | 1.88 |
| 49. Progress during surgery | 4.08 | 4.59 | 3.73 | 2.25* | 4.00 | 4.13 | 0.58 | 4.50 | 3.99 | 1.75 |
| 50. Name to call | 4.76 | 4.71 | 4.88 | 1.28 | 4.87 | 4.67 | 1.86 | 4.94 | 4.71 | 1.63 |

[a] Exact wording for the items may be found in Appendix B.

*Significant at .05 level.

TABLE B

MEAN VALUES OF IMPORTANCE OF INDIVIDUAL ITEMS, CALCULATED FROM RATINGS OF 117 STAFF MEMBERS: t-TEST STATISTICS FOR DIFFERENCES OF MEANS OF ITEMS AS BETWEEN SPECIFIED SUBCATEGORIES OF STAFF

| Categories of Items[a] | Nurses N=79 | Physicians N=38 | t-Test Value Sign. at 1.98 | Charge RNs N=20 | Staff RNs N=25 | t-Test Value Sign. at 2.02 | Senior Physicians N=14 | Intern-Fellows Residents N=16 | t-Test Value Sign. at 2.04 | Senior Staff N=35 | Students N=20 | t-Test Value Sign. at 2.00 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Function: | | | | | | | | | | | | |
| 1. Explain terms | 3.70 | 3.36 | 1.64 | 3.90 | 3.64 | 0.90 | 3.64 | 3.22 | 1.44 | 3.77 | 3.70 | 0.28 |
| 2. How heart works | 4.04 | 3.50 | 3.18* | 4.15 | 3.92 | 0.88 | 3.50 | 3.37 | 0.36 | 3.86 | 3.95 | 0.38 |
| 3. Normal circulation | 3.48 | 3.24 | 1.22 | 3.35 | 3.60 | 0.88 | 3.36 | 3.19 | 0.48 | 3.31 | 3.30 | 0.05 |
| Diagnosis: | | | | | | | | | | | | |
| 4. What is wrong | 4.70 | 4.61 | 0.80 | 4.70 | 4.68 | 0.11 | 4.71 | 4.50 | 0.94 | 4.68 | 4.80 | 0.73 |
| Etiology: | | | | | | | | | | | | |
| 5. Cause of defect | 3.82 | 3.95 | 0.59 | 3.65 | 3.72 | 0.20 | 4.07 | 3.87 | 0.60 | 3.77 | 4.10 | 1.08 |
| 6. Reoccurance of defect | 4.32 | 4.24 | 0.46 | 4.15 | 4.52 | 1.41 | 4.21 | 3.94 | 0.83 | 4.17 | 4.75 | 2.63* |
| 7. Incidence | 2.96 | 2.89 | 0.30 | 3.00 | 2.80 | 0.58 | 2.86 | 2.94 | 0.21 | 2.88 | 3.05 | 0.64 |
| Tests: | | | | | | | | | | | | |
| 8. Why tests done | 4.15 | 3.58 | 3.45* | 4.10 | 4.12 | 0.09 | 3.36 | 3.87 | 1.44 | 3.77 | 3.95 | 0.72 |
| 9. Prepare child-tests | 4.47 | 3.66 | 4.63* | 4.65 | 4.40 | 1.15 | 3.57 | 3.44 | 0.32 | 4.23 | 4.55 | 1.37 |
| 10. Meaning of tests | 4.04 | 3.66 | 2.05* | 3.90 | 4.12 | 0.90 | 3.93 | 3.44 | 1.14 | 3.91 | 4.00 | 0.33 |
| 11. If painful | 4.05 | 3.76 | 1.64 | 4.25 | 4.08 | 0.89 | 3.93 | 3.94 | 0.02 | 4.11 | 3.90 | 0.87 |
| 12. Cardiac cath. | 4.15 | 3.84 | 1.94 | 4.00 | 4.20 | 0.86 | 3.78 | 4.12 | 1.09 | 3.91 | 3.85 | 0.25 |
| 13. Clinic visits | 3.87 | 3.18 | 3.66* | 3.70 | 3.88 | 0.76 | 3.50 | 2.87 | 1.73 | 3.66 | 3.80 | 0.53 |
| Instructions: | | | | | | | | | | | | |
| 14. Medicine name | 4.29 | 4.47 | 1.09 | 4.25 | 4.52 | 1.26 | 4.93 | 4.37 | 2.72* | 4.51 | 4.20 | 1.32 |
| 15. Medicine action | 4.44 | 3.84 | 3.68* | 4.30 | 4.64 | 2.15* | 4.14 | 3.75 | 1.02 | 4.23 | 4.10 | 0.57 |
| 16. Activities | 4.27 | 4.18 | 0.58 | 4.35 | 4.40 | 0.22 | 4.07 | 4.19 | 0.36 | 4.26 | 4.40 | 0.66 |
| 17. Antibiotics | 4.05 | 4.66 | 3.59* | 4.10 | 4.04 | 0.22 | 4.93 | 4.50 | 2.07* | 4.46 | 4.35 | 0.51 |

TABLE B continued

| Categories of Items[a] | Nurses N=79 | Physicians N=38 | t-Test Value Sign. at 1.98 | Charge RNs N=20 | Staff RNs N=25 | t-Test Value Sign. at 2.02 | Senior Physicians N=14 | Intern-Fellows Residents N=16 | t-Test Value Sign. at 2.04 | Senior Staff N=35 | Students N=20 | t-Test Value Sign. at 2.00 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 18. Diet restrictions | 4.58 | 4.10 | 3.38* | 4.50 | 4.64 | 0.71 | 4.28 | 4.00 | 0.90 | 4.43 | 4.50 | 0.35 |
| 19. Effects of colds | 4.30 | 3.81 | 3.30* | 4.25 | 4.28 | 0.14 | 3.78 | 3.87 | 0.27 | 4.08 | 4.25 | 0.75 |
| Surgery: | | | | | | | | | | | | |
| 20. Prepare child-hosp. | 4.43 | 3.55 | 5.75* | 4.55 | 4.40 | 0.85 | 3.57 | 3.56 | 0.03 | 4.17 | 4.20 | 0.12 |
| 21. Prepare child-surgery | 4.58 | 3.71 | 5.96* | 4.60 | 4.60 | 0.00 | 3.93 | 3.75 | 0.49 | 4.34 | 4.15 | 0.78 |
| 22. What done in surgery | 4.13 | 3.84 | 1.61 | 4.15 | 4.04 | 0.48 | 3.64 | 4.19 | 1.32 | 3.94 | 3.95 | 0.03 |
| 23. Surgical risks | 4.46 | 4.58 | 0.79 | 4.40 | 4.56 | 0.67 | 4.78 | 4.50 | 1.28 | 4.54 | 4.50 | 0.22 |
| 24. Complete or partial | 4.46 | 4.61 | 1.06 | 4.45 | 4.52 | 0.33 | 4.64 | 4.75 | 0.62 | 4.51 | 4.45 | 0.36 |
| 25. Blood donors | 3.39 | 3.37 | 0.11 | 3.15 | 3.56 | 1.48 | 3.71 | 3.31 | 1.02 | 3.40 | 3.45 | 0.18 |
| 26. Time in hospital | 3.72 | 3.37 | 1.95 | 3.80 | 3.72 | 0.35 | 3.50 | 3.37 | 0.39 | 3.68 | 3.90 | 0.91 |
| 27. Where parents stay | 3.53 | 2.87 | 3.40* | 3.75 | 3.60 | 0.65 | 2.86 | 3.19 | 0.97 | 3.34 | 3.15 | 0.69 |
| Post-surgery: | | | | | | | | | | | | |
| 28. Intensive care | 4.42 | 3.71 | 4.32* | 4.45 | 4.52 | 0.35 | 3.86 | 4.00 | 0.49 | 4.32 | 3.80 | 1.65 |
| 29. Care at home | 4.49 | 4.03 | 3.37* | 4.35 | 4.60 | 1.27 | 4.14 | 4.00 | 0.56 | 4.28 | 4.40 | 0.56 |
| 30. Activities to allow | 4.49 | 4.13 | 2.96* | 4.40 | 4.60 | 1.07 | 4.28 | 4.06 | 1.03 | 4.37 | 4.40 | 0.16 |
| Prognosis: | | | | | | | | | | | | |
| 31. Small for age | 3.59 | 3.23 | 2.20* | 3.60 | 3.56 | 0.16 | 3.00 | 3.25 | 0.83 | 3.31 | 3.70 | 1.63 |
| 32. Normal life | 4.28 | 4.08 | 1.55 | 4.20 | 4.52 | 1.78 | 3.93 | 4.31 | 1.58 | 4.06 | 4.15 | 0.51 |
| 33. Not outgrow | 4.27 | 4.10 | 1.20 | 4.45 | 4.40 | 0.22 | 4.00 | 4.31 | 1.33 | 4.26 | 4.15 | 0.51 |
| 34. Signs and symptoms | 4.64 | 4.37 | 2.62* | 4.60 | 4.60 | 0.00 | 4.36 | 4.37 | 0.08 | 4.51 | 4.50 | 0.09 |
| Emotional: | | | | | | | | | | | | |
| 35. What to tell child | 4.16 | 3.81 | 2.25* | 4.35 | 4.12 | 1.15 | 3.71 | 3.87 | 0.49 | 4.11 | 4.10 | 0.07 |
| 36. Child and his worries | 4.12 | 3.76 | 1.96 | 4.35 | 4.08 | 0.98 | 3.93 | 3.75 | 0.51 | 4.20 | 4.00 | 0.82 |
| 37. Discipline child | 3.61 | 2.63 | 4.14* | 4.05 | 3.72 | 1.00 | 3.00 | 2.50 | 1.32 | 3.60 | 2.55 | 3.10* |

TABLE B continued

| Categories of Items[a] | Nurses N=79 | Physicians N=38 | t-Test Value Sign. at 1.98 | Charge RNs N=20 | Staff RNs N=25 | t-Test Value Sign. at 2.02 | Senior Physicians N=14 | Intern-Fellows Residents N=16 | t-Test Value Sign. at 2.04 | Senior Staff N=35 | Students N=20 | t-Test Value Sign. at 2.00 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 38. Parents talk to someone | 4.35 | 3.79 | 3.38* | 4.30 | 4.36 | 0.27 | 4.07 | 3.63 | 1.25 | 4.33 | 4.10 | 0.51 |
| 39. Financial cost | 4.07 | 3.58 | 3.08* | 3.35 | 4.04 | 0.82 | 3.71 | 3.50 | 0.68 | 3.83 | 4.05 | 0.87 |
| Techniques: | | | | | | | | | | | | |
| 40. Talk to surgeon | 4.72 | 4.37 | 2.81* | 4.95 | 4.64 | 2.30* | 4.57 | 4.37 | 0.78 | 4.80 | 4.45 | 1.91 |
| 41. Infor. to read | 3.76 | 3.31 | 3.30* | 3.65 | 3.52 | 0.43 | 3.07 | 3.31 | 0.59 | 3.40 | 3.70 | 1.07 |
| 42. Talk to other parents | 3.29 | 2.50 | 3.77* | 3.40 | 3.24 | 0.52 | 2.00 | 2.94 | 2.44* | 2.80 | 3.35 | 1.73 |
| 43. Nurse call at home | 3.15 | 2.47 | 3.43* | 3.10 | 3.28 | 0.62 | 2.21 | 2.75 | 1.68 | 2.74 | 3.25 | 1.89 |
| 44. Model of heart | 3.26 | 2.55 | 3.94* | 3.25 | 3.12 | 0.50 | 2.43 | 2.56 | 0.44 | 2.88 | 3.30 | 1.56 |
| 45. Drawing of heart | 3.56 | 3.08 | 2.59* | 3.60 | 3.56 | 0.15 | 2.86 | 3.31 | 1.22 | 3.26 | 3.45 | 0.69 |
| 46. Told medical term | 3.28 | 3.21 | 0.32 | 3.55 | 3.28 | 0.96 | 3.36 | 3.19 | 0.37 | 3.43 | 3.10 | 1.14 |
| 47. Infor. written down | 3.73 | 3.39 | 1.47 | 3.65 | 3.96 | 1.03 | 3.57 | 3.63 | 0.12 | 3.57 | 3.25 | 0.96 |
| 48. Visit intensive care | 4.26 | 3.18 | 5.25* | 4.40 | 4.32 | 0.37 | 3.36 | 3.37 | 0.04 | 4.00 | 3.65 | 1.21 |
| 49. Progress during surgery | 3.75 | 2.84 | 3.91* | 3.90 | 3.60 | 0.89 | 3.43 | 2.81 | 1.29 | 3.68 | 3.00 | 1.93 |
| 50. Name to call | 4.63 | 4.34 | 2.36* | 4.60 | 4.52 | 0.40 | 4.36 | 4.44 | 0.32 | 4.51 | 4.55 | 0.22 |

*Significant at .05 level.

[a] Exact wording for the items may be found in the Appendix B.

# TABLE C

MEAN VALUES OF IMPORTANCE OF INDIVIDUAL ITEMS, CALCULATED FROM RATINGS OF 100 MOTHERS AND 117 STAFF MEMBERS: t-TEST STATISTICS FOR DIFFERENCES OF MEANS OF ITEMS AS BETWEEN MOTHERS AND SPECIFIED SUBCATEGORIES OF STAFF.

| Categories of Items[a] | All Mothers N=100 | All Staff N=117 | t-Test Value Sign. at 1.96 | Nurses N=79 | Mothers N N=100 | t-Test Value Sign. at 1.96 | Medical Staff N=38 | Mothers N=100 | t-Test Value Sign. at 1.96 |
|---|---|---|---|---|---|---|---|---|---|
| Function: | | | | | | | | | |
| 1. Explain terms | 4.13 | 3.59 | 4.26* | 3.70 | 4.13 | 3.07* | 3.37 | 4.13 | 4.57* |
| 2. How heart works | 3.87 | 3.86 | 0.05 | 4.04 | 3.87 | 1.23 | 3.50 | 3.87 | 2.06* |
| 3. Normal circulation | 3.79 | 3.40 | 2.93* | 3.48 | 3.79 | 2.09* | 3.24 | 3.79 | 3.07* |
| Diagnosis: | | | | | | | | | |
| 4. What is wrong | 4.85 | 4.67 | 2.74* | 4.70 | 4.85 | 2.11* | 4.60 | 4.85 | 2.74* |
| Etiology: | | | | | | | | | |
| 5. Cause of defect | 4.50 | 3.86 | 5.13* | 3.82 | 4.50 | 4.75* | 3.95 | 4.50 | 3.67* |
| 6. Reoccurance of defect | 4.52 | 4.29 | 1.80 | 4.52 | 4.52 | 1.44 | 4.24 | 4.52 | 1.56 |
| 7. Incidence | 3.08 | 2.94 | 0.93 | 2.96 | 3.08 | 0.69 | 2.89 | 3.08 | 0.91 |
| Tests: | | | | | | | | | |
| 8. Why tests done | 4.14 | 3.97 | 1.45 | 4.15 | 4.14 | 0.09 | 3.58 | 4.14 | 3.20* |
| 9. Prepare child-tests | 4.11 | 4.21 | 0.70 | 4.47 | 4.11 | 2.59* | 3.66 | 4.11 | 2.27* |
| 10. Meaning of tests | 4.25 | 3.91 | 2.60* | 4.04 | 4.25 | 1.56 | 3.66 | 4.25 | 3.11* |
| 11. If painful | 4.19 | 3.96 | 1.85 | 4.05 | 4.19 | 1.04 | 3.76 | 4.19 | 2.31* |
| 12. Cardiac cath. | 4.47 | 4.05 | 3.60* | 4.15 | 4.47 | 2.55* | 3.84 | 4.47 | 3.70* |
| 13. Clinic visits | 3.90 | 3.65 | 1.78 | 3.87 | 3.90 | 0.18 | 3.18 | 3.90 | 3.59* |

TABLE C continued

| Categories of Items[a] | All Mothers N=100 | All Staff N=117 | t-Test Value Sign. at 1.96 | Nurses N=79 | Mothers N N=100 | t-Test Value Sign. at 1.96 | Medical Staff N=38 | Mothers N=100 | t-Test Value Sign. at 1.96 |
|---|---|---|---|---|---|---|---|---|---|
| Instructions: | | | | | | | | | |
| 14. Medicine name | 4.38 | 4.35 | 0.23 | 4.29 | 4.38 | 0.63 | 4.47 | 4.38 | 0.50 |
| 15. Medicine action | 4.52 | 4.24 | 2.28* | 4.44 | 4.52 | 0.63 | 3.84 | 4.52 | 3.85* |
| 16. Activities | 4.72 | 4.25 | 4.84* | 4.28 | 4.72 | 4.11* | 4.18 | 4.72 | 4.17* |
| 17. Antibiotics | 4.31 | 4.25 | 0.51 | 4.05 | 4.31 | 1.88 | 4.66 | 4.31 | 2.24* |
| 18. Diet restrictions | 4.45 | 4.43 | 0.21 | 4.58 | 4.45 | 1.16 | 4.10 | 4.45 | 2.22* |
| 19. Effects of colds | 4.49 | 4.15 | 3.53* | 4.30 | 4.49 | 1.80 | 3.81 | 4.49 | 5.05* |
| Surgery: | | | | | | | | | |
| 20. Prepare child-hosp. | 4.23 | 4.15 | 0.76 | 4.43 | 4.23 | 1.80 | 3.55 | 4.23 | 4.34* |
| 21. Prepare child-surgery | 4.55 | 4.30 | 2.41* | 4.58 | 4.55 | 0.33 | 3.71 | 4.55 | 5.65* |
| 22. What done in surgery | 4.63 | 4.03 | 5.76* | 4.13 | 4.63 | 4.91* | 3.84 | 4.63 | 5.25* |
| 23. Surgical risks | 4.73 | 4.50 | 2.55* | 4.45 | 4.73 | 3.56* | 4.58 | 4.73 | 1.38 |
| 24. Complete or partial | 4.76 | 4.50 | 3.19* | 4.45 | 4.76 | 3.22* | 4.60 | 4.76 | 1.75 |
| 25. Blood donors | 4.20 | 3.38 | 5.71* | 3.39 | 4.20 | 5.06* | 3.37 | 4.20 | 4.29* |
| 26. Time in hospital | 4.09 | 3.61 | 3.89* | 3.72 | 4.09 | 2.66* | 3.37 | 4.09 | 4.27* |
| 27. Where parents stay | 3.38 | 3.32 | 0.39 | 3.53 | 3.38 | 0.86 | 2.87 | 3.38 | 2.20* |
| Post-surgery: | | | | | | | | | |
| 28. Intensive care | 4.45 | 4.19 | 2.36* | 4.42 | 4.45 | 0.28 | 3.71 | 4.45 | 4.81* |
| 29. Care at home | 4.79 | 4.34 | 5.18* | 4.49 | 4.79 | 3.17* | 4.03 | 4.79 | 6.92* |
| 30. Activities to allow | 4.70 | 4.38 | 3.61* | 4.49 | 4.70 | 2.08* | 4.13 | 4.70 | 4.59* |

TABLE C continued

| Categories of Items[a] | All Mothers N=100 | All Staff N=117 | t-Test Value Sign. at 1.96 | Nurses N=79 | Mothers N N=100 | t-Test Value Sign. at 1.96 | Medical Staff N=38 | Mothers N=100 | t-Test Value Sign. at 1.96 |
|---|---|---|---|---|---|---|---|---|---|
| Prognosis: | | | | | | | | | |
| 31. Small for age | 3.82 | 3.48 | 2.50* | 3.59 | 3.82 | 1.48 | 3.24 | 3.82 | 2.94* |
| 32. Normal life | 4.73 | 4.21 | 6.42* | 4.28 | 4.73 | 5.08* | 4.08 | 4.73 | 6.11* |
| 33. Not outgrow | 4.70 | 4.22 | 5.51* | 4.28 | 4.70 | 4.30* | 4.10 | 4.70 | 5.45* |
| 34. Signs and symptoms | 4.77 | 4.56 | 3.18* | 4.64 | 4.77 | 1.79 | 4.37 | 4.77 | 4.18* |
| Emotional: | | | | | | | | | |
| 35. What to tell child | 4.29 | 4.05 | 2.08* | 4.16 | 4.29 | 1.01 | 3.81 | 4.29 | 2.87* |
| 36. Child and his worries | 4.34 | 4.00 | 2.83* | 4.13 | 4.34 | 1.53 | 3.76 | 4.34 | 3.34* |
| 37. Discipline child | 3.97 | 3.29 | 4.13* | 3.61 | 3.97 | 2.00* | 2.63 | 3.97 | 6.29* |
| 38. Parents to talk | 4.40 | 4.17 | 1.95 | 4.35 | 4.40 | 0.38 | 3.79 | 4.40 | 3.59* |
| 39. Financial cost | 4.08 | 3.91 | 1.26 | 4.07 | 4.08 | 0.03 | 3.58 | 4.08 | 2.60* |
| Techniques: | | | | | | | | | |
| 40. Talk to surgeon | 4.77 | 4.61 | 2.21* | 4.72 | 4.77 | 0.66 | 4.37 | 4.77 | 3.86* |
| 41. Infor. to read | 4.11 | 3.55 | 4.40* | 3.76 | 4.11 | 2.62* | 3.13 | 4.11 | 5.70* |
| 42. Talk to other parents | 3.11 | 3.03 | 0.49 | 3.29 | 3.11 | 1.08 | 2.50 | 3.11 | 2.79* |
| 43. Nurse call at home | 2.82 | 2.93 | 0.71 | 3.15 | 2.82 | 1.88 | 2.47 | 2.82 | 1.57 |
| 44. Model of heart | 3.05 | 3.03 | 0.11 | 3.26 | 3.05 | 1.33 | 2.55 | 3.05 | 2.35 |
| 45. Drawing of heart | 3.99 | 3.40 | 4.33* | 3.56 | 3.99 | 2.95* | 3.08 | 3.99 | 4.72 |
| 46. Told medical term | 3.75 | 3.26 | 3.19* | 3.28 | 3.75 | 2.84* | 3.21 | 3.75 | 2.35 |
| 47. Infor. written down | 4.17 | 3.62 | 3.66* | 3.73 | 4.17 | 2.69* | 3.39 | 4.17 | 3.76* |

TABLE C continued

| Categories of Items[a] | | All Mothers N=100 | All Staff N=117 | t-Test Value Sign. at 1.96 | Nurses N=79 | Mothers N N=100 | t-Test Value Sign. at 1.96 | Medical Staff N=38 | Mothers N=100 | t-Test Value Sign. at 1.96 |
|---|---|---|---|---|---|---|---|---|---|---|
| 48. | Visit intensive care | 3.55 | 3.91 | 2.19* | 4.26 | 3.55 | 4.21* | 3.18 | 3.55 | 1.51 |
| 49. | Progress during surgery | 4.08 | 3.45 | 3.88* | 3.75 | 4.08 | 2.00* | 2.84 | 4.08 | 5.40* |
| 50. | Name to call | 4.76 | 4.54 | 2.79* | 4.63 | 4.76 | 1.49 | 4.34 | 4.76 | 3.82* |

*Significant at .05 level.

[a] Exact wording for the items may be found in Appendix B.

## TABLE D

## RANK-ORDERING OF IMPORTANCE OF FIFTY ITEMS, BASED ON MEAN VALUES OF ITEMS CALCULATED FROM RATINGS OF 100 MOTHERS, FROM RATINGS OF DIFFERING SUB-CATEGORIES OF MOTHERS, AND FROM RATINGS OF 117 STAFF MEMBERS.

| | Rank-Ordering by Specified Categories of Subjects | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Categories of Items[a] | Mothers N=100 | Staff N=117 | Less Than High School N=17 | More Than High School N=26 | "Surgical" Mothers N=41 | "Medical" Mothers N=59 | 6 Months or less Since Dx N=18 | More than 6 Months Since DX N=82 |
| Diagnosis: | | | | | | | | |
| 4. What is wrong | 1 | 1 | 2.5 | 2 | 1 | 1 | 4 | 1 |
| Post-surgery: | | | | | | | | |
| 28. Intensive care | 19.5 | 19 | 19.5 | 21.5 | 22 | 16 | 18.5 | 19.5 |
| 29. Home care | 2 | 10 | 2.5 | 4.5 | 3 | 5.5 | 1.5 | 3.5 |
| 30. Activities | 10.5 | 8 | 11.5 | 10 | 5.5 | 11.5 | 10 | 10.5 |
| Prognosis: | | | | | | | | |
| 31. Small for age | 42 | 39 | 33 | 39.5 | 44 | 41.5 | 35 | 42.5 |
| 32. Normal life | 7.5 | 17.5 | 11.5 | 12.5 | 10 | 5.5 | 10 | 6 |
| 33. Not outgrow | 10.5 | 16 | 11.5 | 4.5 | 12 | 8 | 13 | 9 |
| 34. Signs and symptoms | 3.5 | 3 | 5 | 2 | 5.5 | 4 | 10 | 2 |
| Surgery: | | | | | | | | |
| 20. Preparing child-hosp. | 27 | 21.5 | 23 | 23 | 26 | 29.5 | 30.5 | 27.5 |
| 21. Prepare child-surgery | 13 | 11 | 16 | 12.5 | 13.5 | 14 | 18.5 | 13 |
| 22. What done in surgery | 12 | 25 | 6.5 | 12.5 | 18 | 11.5 | 6.5 | 12 |

TABLE D continued

| Categories of Items[a] | Mothers N=100 | Staff N=117 | Less Than High School N=17 | More Than High School N=26 | "Surgical" Mothers N=41 | "Medical" Mothers N=59 | 6 Months or less Since DX N=18 | More than 6 Months Since DX N=82 |
|---|---|---|---|---|---|---|---|---|
| | Rank-Ordering by Specified Categories of Subjects | | | | | | | |
| 23. Surgical risks | 7.5 | 5.5 | 11.5 | 8.5 | 13.5 | 3 | 6.5 | 7.5 |
| 24. Complete or partial | 5.5 | 5.5 | 6.5 | 6.5 | 10 | 2 | 4 | 5 |
| 25. Blood donors | 28 | 43 | 29 | 27.5 | 36.5 | 24 | 38 | 27.5 |
| 26. Time in hospital | 35 | 36 | 23 | 32.5 | 39 | 37 | 18.5 | 36 |
| 27. Where parents stay | 46 | 44 | 47.5 | 45 | 46 | 46 | 50 | 45 |
| Instructions: | | | | | | | | |
| 14. Medicine name | 22 | 9 | 25.5 | 30 | 18 | 25.5 | 23.5 | 24 |
| 15. Medicine action | 14.5 | 15 | 17 | 16 | 15.5 | 15 | 14.5 | 15.5 |
| 16. Activities | 9 | 13.5 | 11.5 | 8.5 | 7.5 | 9 | 4 | 10.5 |
| 17. Antibiotics | 24 | 13.5 | 37.5 | 25 | 20 | 27.5 | 43.5 | 21 |
| 18. Diet restrictions | 19.5 | 7 | 42 | 15 | 15.5 | 20 | 23.5 | 18 |
| 19. Effects of colds | 17 | 21.5 | 19.5 | 17.5 | 18 | 17 | 23.5 | 14 |
| Etiology: | | | | | | | | |
| 5. Cause of defect | 16 | 32.5 | 11.5 | 21.5 | 21 | 13 | 10 | 19.5 |
| 6. Reoccurance of defect | 14.5 | 12 | 11.5 | 19.5 | 7.5 | 19 | 14.5 | 15.5 |
| 7. Incidence | 48 | 49 | 46 | 50 | 48 | 48 | 46.5 | 49 |
| Tests: | | | | | | | | |
| 8. Why tests done | 31 | 27 | 33 | 30 | 29.5 | 34 | 27.5 | 32.5 |
| 9. Prepare child-tests | 33.5 | 17.5 | 40 | 27.5 | 27 | 36 | 40 | 30 |

TABLE D continued

| | Rank-Ordering by Specified Categories of Subjects | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Categories of Items[a] | Mothers N=100 | Staff N=117 | Less Than High School N=17 | More Than High School N=26 | "Surgical" Mothers N=41 | "Medical" Mothers N=59 | 6 Months or less Since DX N=18 | More than 6 Months Since DX N=82 |
| 10. Meaning of tests | 26 | 30 | 33 | 25 | 32 | 23 | 35 | 26 |
| 11. If painful | 29 | 28 | 37.5 | 32.5 | 28 | 32 | 33 | 29 |
| 12. Cardiac cath. | 18 | 23.5 | 27.5 | 12.5 | 10 | 21 | 21 | 17 |
| 13. Clinic visits | 40 | 34 | 44.5 | 34 | 40.5 | 39.5 | 30.5 | 41 |
| Emotional: | | | | | | | | |
| 35. What to tell child | 25 | 23.5 | 25.5 | 30 | 25 | 25.5 | 27.5 | 25 |
| 36. Child and his worries | 23 | 26 | 30 | 25 | 24 | 22 | 38 | 22.5 |
| 37. Discipline child | 39 | 45 | 27.5 | 43 | 34 | 39.5 | 45 | 35 |
| 38. Parents talk to someone | 21 | 20 | 19.5 | 19.5 | 23 | 18 | 23.5 | 22.5 |
| 39. Financial cost | 36.5 | 30 | 19.5 | 35.5 | 29.5 | 37 | 16 | 38 |
| Function: | | | | | | | | |
| 1. Explain terms | 32 | 37 | 23 | 37 | 34 | 33 | 30.5 | 32.5 |
| 2. How heart works | 41 | 32.5 | 42 | 41 | 38 | 41.5 | 43.5 | 40 |
| 3. Normal circulation | 43 | 41.5 | 37.5 | 44 | 40.5 | 43 | 41.5 | 42.5 |
| Techniques: | | | | | | | | |
| 40. Talk to surgeon | 3.5 | 2 | 2.5 | 6.5 | 4 | 7 | 10 | 3.5 |
| 41. Infor. to read | 33.5 | 38 | 33 | 35.5 | 31 | 35 | 30.5 | 34 |
| 42. Talk to other parent | 47 | 47.5 | 47.5 | 48 | 49 | 47 | 48 | 47 |
| 43. Nurse call at home | 50 | 50 | 49 | 49 | 50 | 50 | 46.5 | 50 |

## TABLE D continued

|  |  | Rank-Ordering by Specified Categories of Subjects |  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|---|---|---|
|  | Categories of Items[a] | Mothers N=100 | Staff N=117 | Less Than High School N=17 | More Than High School N=26 | "Surgical" Mothers N=41 | "Medical" Mothers N=59 | 6 Months or less Since DX N=18 | More than 6 Months Since DX N=82 |
| 44. | Model of heart | 49 | 47.5 | 50 | 47 | 47 | 49 | 49 | 48 |
| 45. | Drawing of heart | 38 | 41.5 | 37.5 | 39.5 | 36.5 | 38 | 35 | 39 |
| 46. | Told medical term | 44 | 47.5 | 44.5 | 38 | 42.5 | 44 | 41.5 | 44 |
| 47. | Infor. written down | 30 | 35 | 33 | 17.5 | 34 | 27.5 | 26 | 31 |
| 48. | Visit intensive care | 45 | 30 | 42 | 46 | 45 | 45 | 39 | 46 |
| 49. | Progress during surgery | 36.5 | 40 | 45 | 42 | 42.5 | 29.5 | 18.5 | 37 |
| 50. | Name to call | 5.5 | 4 | 2.5 | 2 | 2 | 10 | 1.5 | 7.5 |

[a] See questionnaire in Appendix B for complete wording of items.

## TABLE E

## RANK-ORDERING OF IMPORTANCE OF FIFTY ITEMS, BASED ON MEAN VALUES OF ITEMS CALCULATED FROM RATINGS OF 117 STAFF MEMBERS, AND FROM RATINGS OF SPECIFIED SUBCATEGORIES OF STAFF

| | Rank-Ordering by Specified Staff Category | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Categories of Items[a] | Doctors N=38 | Nurses N=79 | Senior Staff N=35 | Students N=20 | Charge RNs N=20 | Staff RNs N=25 | Senior Doctors N=14 | Interns-Fellows-Residents N=16 |
| Diagnosis: | | | | | | | | |
| 4. What is wrong | 3 | 2 | 2 | 1 | 2 | 1 | 4 | 3 |
| Post-surgery: | | | | | | | | |
| 28. Intensive care | 25.5 | 14 | 16.5 | 33.5 | 10 | 12.5 | 23 | 16 |
| 29. Home care | 15 | 7.5 | 12 | 11 | 16.5 | 6.5 | 12.5 | 16 |
| 30. Activities | 11 | 7.5 | 10 | 11 | 13 | 6.5 | 9.5 | 14 |
| Prognosis: | | | | | | | | |
| 31. Small for age | 39 | 41 | 44.5 | 36 | 42.5 | 43 | 43.5 | 39 |
| 32. Normal life | 14 | 19 | 25 | 18 | 24 | 12.5 | 20 | 9.5 |
| 33. Not outgrow | 12.5 | 20.5 | 13.5 | 18 | 10 | 17.5 | 17 | 9.5 |
| 34. Signs and symptoms | 6.5 | 3 | 5.5 | 6 | 5 | 6.5 | 7.5 | 7 |
| Surgery: | | | | | | | | |
| 20. Preparing child-hosp. | 31 | 13 | 20.5 | 15.5 | 7 | 17.5 | 32 | 29 |
| 21. Prepare child-surgery | 25.5 | 5.5 | 11 | 18 | 5 | 6.5 | 20 | 25 |
| 22. What done in surgery | 18 | 26 | 27 | 28 | 26 | 30 | 29.5 | 11.5 |

TABLE E continued

| Categories of Items[a] | Rank-Ordering by Specified Staff Category | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | Doctors N=38 | Nurses N=79 | Senior Staff N=35 | Students N=20 | Charge RNs N=20 | Staff RNs N=25 | Senior Doctors N=14 | Interns-Fellows-Residents N=16 |
| 23. Surgical risks | 4 | 10.5 | 3 | 6 | 13 | 9 | 3 | 3 |
| 24. Complete or partial | 2 | 10.5 | 5.5 | 8.5 | 10 | 12.5 | 5 | 1 |
| 25. Blood donors | 34.5 | 45 | 41.5 | 39.5 | 48 | 43 | 27 | 37 |
| 26. Time in hospital | 34.5 | 38 | 35.5 | 30.5 | 36 | 36 | 35 | 34 |
| 27. Where parents stay | 45 | 43 | 43 | 46 | 37 | 40 | 46 | 41 |
| Instructions: | | | | | | | | |
| 14. Medicine name | 5 | 18 | 5.5 | 15.5 | 22 | 12.5 | 1.5 | 7 |
| 15. Medicine action | 18 | 12 | 16.5 | 21.5 | 19.5 | 3 | 12.5 | 25 |
| 16. Activities | 10 | 20.5 | 13.5 | 11 | 16.5 | 17.5 | 15 | 11.5 |
| 17. Antibiotics | 1 | 29.5 | 8 | 13 | 28.5 | 30 | 1.5 | 3 |
| 18. Diet restrictions | 12.5 | 5.5 | 9 | 6 | 8 | 3 | 9.5 | 16 |
| 19. Effects of colds | 20.5 | 17 | 24 | 14 | 22 | 22 | 24.5 | 21.5 |
| Etiology: | | | | | | | | |
| 5. Cause of defect | 16 | 34 | 33 | 21.5 | 40 | 36 | 15 | 21.5 |
| 6. Reoccurance of defect | 9 | 16 | 20.5 | 2 | 26 | 12.5 | 11 | 18.5 |
| 7. Incidence | 44 | 50 | 47.5 | 48 | 50 | 50 | 46 | 44.5 |
| Tests: | | | | | | | | |
| 8. Why tests done | 29.5 | 24.5 | 33 | 28 | 28.5 | 25 | 39.5 | 21.5 |

TABLE E continued

| | Rank-Ordering by Specified Staff Category | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Categories of Items[a] | Doctors N=38 | Nurses N=79 | Senior Staff N=35 | Students N=20 | Charge RNs N=20 | Staff RNs N=25 | Senior Doctors N=14 | Interns-Fellows-Residents N=16 |
| 9. Prepare child-tests | 37 | 9 | 16.5 | 3.5 | 3 | 17.5 | 32 | 31.5 |
| 10. Meaning of tests | 28 | 31.5 | 28.5 | 25.5 | 33 | 25 | 20 | 31.5 |
| 11. If painful | 23.5 | 29.5 | 22.5 | 30.5 | 22 | 27.5 | 20 | 18.5 |
| 12. Cardiac cath. | 18 | 24.5 | 28.5 | 32 | 31 | 23 | 24.5 | 13 |
| 13. Clinic visits | 41.5 | 33 | 37 | 33.5 | 38 | 34 | 35 | 46 |
| Emotional: | | | | | | | | |
| 35. What to tell child | 20.5 | 23 | 22.5 | 21.5 | 16.5 | 25 | 27 | 21.5 |
| 36. Child and his worries | 23.5 | 27 | 19 | 25.5 | 16.5 | 27.5 | 20 | 25 |
| 37. Discipline child | 47 | 40 | 38 | 50 | 30 | 36 | 43.5 | 50 |
| 38. Parents talk to someone | 22 | 15 | 16.5 | 21.5 | 19.5 | 20 | 15 | 27.5 |
| 39. Financial cost | 29.5 | 28 | 31 | 24 | 35 | 30 | 27 | 30 |
| Function: | | | | | | | | |
| 1. Explain terms | 36 | 39 | 33 | 36 | 33 | 38 | 29.5 | 43 |
| 2. How heart works | 32 | 31.5 | 30 | 28 | 26 | 33 | 35 | 34 |
| 3. Normal circulation | 38 | 44 | 44.5 | 42.5 | 50 | 40 | 39.5 | 41 |
| Techniques: | | | | | | | | |
| 40. Talk to surgeon | 6.5 | 1 | 1 | 8.5 | 1 | 3 | 6 | 7 |
| 41. Infor. to read | 37 | 35 | 41.5 | 36 | 40 | 45 | 42 | 37 |

TABLE E continued

| Categories of Items[a] | Rank-Ordering by Specified Staff Category | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | Doctors N=38 | Nurses N=79 | Senior Staff N=35 | Students N=20 | Charge RNs N=20 | Staff RNs N=25 | Senior Doctors N=14 | Interns-Fellows-Residents N=16 |
| 42. Talk to other parent | 49 | 46 | 49 | 41 | 45 | 48 | 50 | 44.5 |
| 43. Nurse call at home | 50 | 49 | 50 | 44 | 49 | 46.5 | 49 | 48 |
| 44. Model of heart | 48 | 48 | 47.5 | 42.5 | 47 | 49 | 48 | 49 |
| 45. Drawing of heart | 43 | 42 | 46 | 39.5 | 42.5 | 43 | 46 | 37 |
| 46. Told medical term | 40 | 47 | 40 | 47 | 44 | 46.5 | 39.5 | 41 |
| 47. Infor. written down | 33 | 37 | 39 | 44.5 | 40 | 32 | 32 | 27.5 |
| 48. Visit intensive care | 41.5 | 22 | 26 | 38 | 13 | 21 | 39.5 | 34 |
| 49. Progress during surgery | 46 | 36 | 35.5 | 49 | 33 | 40 | 37 | 47 |
| 50. Name to call | 8 | 4 | 5.5 | 3.5 | 5 | 12.5 | 7.5 | 5 |

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[a] See questionnaire in Appendix B for complete wording of items.

# APPENDIX B

# QUESTIONNAIRES

Copy of questionnaire with notation of sources for each item.

Please give an opinion on every item.

| Not Important | Slightly Important | Moderately Important | Very Important | Extremely Important | |
|---|---|---|---|---|---|
| | | | | | 1. To explain medical terms used (e.g., chambers of heart, valves, etc.). (Am. Heart Assoc., 1970; Glazer, 1964) |
| | | | | | 2. To explain how the heart works. (Maxwell & Gane, 1962; Glazer, 1964; Amer. Heart Assoc., 1970) |
| | | | | | 3. To explain what normal circulation is. (Maxwell & Gane, 1962; Am. Heart Assoc. 1970; Interview) |
| | | | | | 4. What is wrong with child's heart. (Maxwell & Gane, 1962; Glazer, 1964; Mellish, 1969; Am. Heart Assoc. 1970; Interviews) |
| | | | | | 5. What caused the defect.(Cooper, 1959; Maxwell & Gane, 1962; Meadows, 1968; Mellish, 1969) |
| | | | | | 6. The possibility this same defect may occur in other children in the family. (Reiss, 1972; Interviews) |
| | | | | | 7. How many children are born with heart defects. (Maxwell & Gane, 1962; Am. Heart Assoc., 1970) |
| | | | | | 8. Why tests are done (Blood test, x-ray, EKG-electrocardiogram). (Glazer, 1964; Am. Heart Assoc., 1970) |
| | | | | | 9. How to prepare child for tests. (Peay, 1960; Am. Heart Assoc., 1970) |
| | | | | | 10. The meaning (interpretation) of the tests. (Glaser, 1964; Bartsch, 1967) |
| | | | | | 11. If the various tests will be painful. (Am. Heart Assoc., 1970; Roberts, 1972) |
| | | | | | 12. What is done in a cardiac catheterization. (Carter, 1959; Maxwell & Gane, 1962; Glaser, 1964) |
| | | | | | 13. What to expect in a clinic visit (length of time, what will be done, etc.). (Glaser, 1964; Interviews) |
| | | | | | 14. The name of the medicine child is taking. (Bartsch, 1967; Interviews) |
| | | | | | 15. The action of the medicine child is taking. (Bartsch, 1967; Tisza, 1962) |
| | | | | | 16. What physical activities to allow before surgery. (Tisza, 1962; Bartsch, 1967) |
| | | | | | 17. Why antibiotics are to be taken before dental care. (Am. Heart Assoc., 1970; Interviews) |
| | | | | | 18. Any restrictions on diet.(Tisza, 1962; Bartsch, 1967; Roberts, 1972) |

| Not Important | Slightly Important | Moderately Important | Very Important | Extremely Important | |
|---|---|---|---|---|---|
| | | | | | 19. Effects of colds and illness on child. (Maxwell & Gane, 1962; Glaser, 1964; Bartsch, 1967) |
| | | | | | 20. How to prepare child for hospitalization. (Peay, 1960; Glaser, 1964; Mellish, 1969) |
| | | | | | 21. How to prepare child for the operation. (Cooper, 1959; Peay, 1960; Glaser, 1964) |
| | | | | | 22. What will be done during the surgery. (Tisza, 1962; Brambilla, 1968; Interviews) |
| | | | | | 23. What risks will there be during surgery. (Peay, 1960; Mellish, 1969) |
| | | | | | 24. Whether the surgery is a complete or partial correction. (Maxwell & Gane, 1962; Am. Heart Assoc., 1970) |
| | | | | | 25. If parents should find blood donors. (Am. Heart Assoc., 1970; Interviews) |
| | | | | | 26. How long will child be in the hospital. (Peay, 1960; Interviews) |
| | | | | | 27. Where the parents could stay when child is in the hospital. (Children's Orthopedic Hosp-Seattle, 1973; Interviews) |
| | | | | | 28. What to expect in the intensive care room. (Cooper, 1959; Peay, 1960; Brambilla, 1968) |
| | | | | | 29. What care parents will give at home after surgery. (Tisza, 1962; Bartsch, 1967) |
| | | | | | 30. What activities to allow after surgery. (Brambilla, 1968; Am. Heart Assoc., 1970; Interviews) |
| | | | | | 31. Why the child may be small for age. (Maxwell & Gane, 1962; Bartsch, 1967; Glaser, 1964) |
| | | | | | 32. Whether child will live a normal life. (Pickett, 1969; Roberts, 1972; Interviews) |
| | | | | | 33. That child will not "outgrow" defect. (Tisza, 1962; Am. Heart Assoc., 1970) |
| | | | | | 34. What signs and symptoms to watch for. (Bartsch, 1967; Roberts, 1972) |
| | | | | | 35. What to tell your child about his condition. (Cooper, 1959; Lewis, 1962) |
| | | | | | 36. How to help child with his worries. (Cooper, 1959; Lewis, 1962; Am. Heart Assoc., 1970; Roberts, 1972) |
| | | | | | 37. How to discipline child. (Maxwell & Gane, 1962; Glaser, 1964; Roberts, 1972) |

| Not Important | Slightly Important | Moderately Important | Very Important | Extremely Important | |
|---|---|---|---|---|---|
| | | | | | 38. The parent have a chance to talk with someone regarding child. (Cooper, 1959; Peay, 1960; Lewis, 1962; Bartsch, 1967; Mellish, 1969) |
| | | | | | 39. To talk with someone regarding the financial cost. (Bartsch, 1967; Roberts, 1972) |
| | | | | | 40. Surgeon to talk to parent before and after surgery. (Cooper, 1959; Lewis, 1962; Tisza, 1962) |
| | | | | | 41. To have factual information to read on congenital heart defects. (Carter, 1959; Redman, 1971; Interviews) |
| | | | | | 42. To talk with another parent whose child has a similar condition. (Meadows, 1968; Peay, 1960; Interviews) |
| | | | | | 43. To have a nurse call at home to discuss condition and/or problems. (Glaser, 1964; Bartsch, 1967; Interviews) |
| | | | | | 44. To see a model of the heart. (Redman, 1971; Interviews) |
| | | | | | 45. To be shown a drawing of the heart defect. (Bartsch, 1967; Mellish, 1969; Am. Heart Assoc., 1970) |
| | | | | | 46. To be told the medical term for the defect. (Mellish, 1969; Reiss, 1972) |
| | | | | | 47. To have the medical word for the defect, instructions, and treatment written down and given to parents. (Gofman et al., 1957; Hill, 1962; Neal, 1962; Reiss, 1972) |
| | | | | | 48. Parent to visit the intensive care room before surgery. (Lisboa, 1972; Interviews) |
| | | | | | 49. To keep parents informed of the progress during surgery. (Tisza, 1962; Interviews) |
| | | | | | 50. To have the name of someone to call in case of an emergency. (Children's Orth. Hosp.-Seattle, 1973; Interviews) |

Add any comments or other areas of information you think important for parents to be told.

Copy of questionnaire as administered to mothers with distributions of mothers' responses.

# PERMIT

Yes, I am willing to participate in this study about what information parents want regarding heart defects of their children. I realize my answers will be kept confidential, and my participation in no way changes the care or treatment we will receive from the University of Oregon Medical teams.

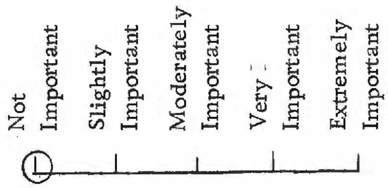
________________________________________

Dear Parent,

We are conducting a study to find out what parents think it is important they be told about heart defects. We are not asking you whether or not you know this information, only whether or not you think the information is important for you to be told.

Please circle a mark on each line to indicate how important you think that item of information is. You may circle a mark under one of the following: "Not important", "Slightly Important", "Moderately Important", "Very Important", or "Extremely Important".

EXAMPLE



5. What caused the defect.
If you think it makes no difference whether you be told this or not, then you should circle the mark at the extreme left hand position, under "Not Important".

5. What caused the defect.
If you think this item is essential for you, circle the mark under "Extremely Important", at the right hand end of the line.

Otherwise circle one of the other positions. "Slightly Important", "Moderately Important", or "Very Important", according to your opinion.

Please give an opinion on every item.

| Not Important | Slightly Important | Moderately Important | Very Important | Extremely Important | Please give an opinion on every item. |
|---|---|---|---|---|---|
| | 3 | 21 | 36 | 40 | 1. To explain medical terms used (e.g., chambers of heart, valves, etc.). |
| 2 | 4 | 29 | 35 | 30 | 2. To explain how the heart works. |
| 3 | 3 | 29 | 42 | 23 | 3. To explain what normal circulation is. |
| | | 2 | 11 | 87 | 4. What is wrong with child's heart. |
| | | 15 | 20 | 65 | 5. What caused the defect. |
| 4 | 1 | 8 | 13 | 74 | 6. The possibility this same defect may occur in other children in the family. |
| 9 | 18 | 40 | 22 | 11 | 7. How many children are born with heart defects. |
| 2 | 1 | 18 | 39 | 40 | 8. Why tests are done (blood test, x-ray, EKG-electrocardiogram). |
| 3 | 4 | 17 | 31 | 45 | 9. How to prepare child for the tests. |
| 1 | 5 | 14 | 28 | 52 | 10. The meaning (interpretation) of the tests. |
| 2 | 5 | 10 | 38 | 45 | 11. If the various tests will be painful. |
| 2 | 2 | 8 | 23 | 65 | 12. What is done in a cardiac catheterization. |
| 3 | 8 | 19 | 36 | 34 | 13. What to expect in a clinic visit (length of time, what will be done, etc.). |
| 3 | 5 | 6 | 23 | 63 | 14. The name of the medicine child is taking. |
| 2 | 3 | 5 | 21 | 69 | 15. The action of the medicine child is taking. |
| 1 | | 2 | 20 | 77 | 16. What physical activities to allow before surgery. |
| 1 | 4 | 10 | 33 | 52 | 17. Why antibiotics are to be taken before dental care. |
| 2 | 2 | 3 | 35 | 58 | 18. Any restrictions on diet. |
| | 1 | 6 | 36 | 57 | 19. Effects of colds and illness on child. |
| | 3 | 12 | 44 | 44 | 20. How to prepare child for hospitalization. |
| | 1 | 8 | 26 | 65 | 21. How to prepare child for the operation. |
| | 1 | 4 | 26 | 69 | 22. What will be done during the surgery. |
| | | 6 | 15 | 79 | 23. What risks will there be during surgery. |
| | | 1 | 22 | 77 | 24. Whether the surgery is a complete or partial correction. |
| 2 | 5 | 15 | 27 | 51 | 25. If parents should find blood donors. |
| | 4 | 24 | 31 | 41 | 26. How long will child be in the hospital. |
| 11 | 15 | 23 | 27 | 24 | 27. Where the parents could stay when child is in the hospital. |
| 1 | 1 | 6 | 36 | 56 | 28. What to expect in the intensive care room. |

| Not Important | Slightly Important | Moderately Important | Very Important | Extremely Important | |
|---|---|---|---|---|---|
| | 1 | 3 | 12 | 84 | 29. What care parents will give at home after surgery. |
| 1 | 1 | 3 | 17 | 78 | 30. What activities to allow after surgery. |
| 5 | 7 | 22 | 33 | 33 | 31. Why the child may be small for age. |
| | | 4 | 19 | 77 | 32. Whether child will live a "normal life". |
| | | 4 | 22 | 74 | 33. That child will not "out grow" defect. |
| | | 1 | 21 | 78 | 34. What signs and symptoms to watch for. |
| 1 | 4 | 10 | 35 | 50 | 35. What to tell your child about his condition. |
| 2 | 3 | 8 | 33 | 54 | 36. How to help child with his worries. |
| 7 | 3 | 16 | 34 | 40 | 37. How to discipline child. |
| 1 | 1 | 14 | 25 | 59 | 38. The parent have a chance to talk with someone regarding child. |
| 4 | 4 | 16 | 32 | 44 | 39. To talk with someone regarding the financial cost. |
| | | | 23 | 77 | 40. Surgeon to talk to parent before and after surgery. |
| 1 | 3 | 16 | 54 | 36 | 41. To have factual information to read on congenital heart defects. |
| 13 | 13 | 34 | 30 | 10 | 42. To talk with another parent whose child has a similar condition. |
| 20 | 18 | 32 | 20 | 10 | 43. To have a nurse call at home to discuss condition and/or problems. |
| 10 | 23 | 33 | 20 | 14 | 44. To see a model of the heart. |
| 2 | 6 | 21 | 33 | 38 | 45. To be shown a drawing of the heart defect. |
| 6 | 11 | 16 | 36 | 31 | 46. To be told the medical term for the defect. |
| 2 | 6 | 15 | 27 | 50 | 47. To have the medical word for the defect, instructions, and treatment written down and given to parent. |
| 10 | 10 | 23 | 29 | 28 | 48. Parent to visit the intensive care room before surgery. |
| 6 | 3 | 15 | 29 | 47 | 49. To keep parents informed of the progress during surgery. |
| | | 5 | 14 | 81 | 50. To have the name of someone to call in case of an emergency. |

Add any comments or other areas of information you think important for parents to be told.

Please complete the following information also. We need this information to find out if parents with different backgrounds want different information.

1. Your child's age: ____________________.

2. When did you first learn your child had a heart problem

   ___________________.
   month/year

3. Has your child had surgery for the heart defect? Yes-No

   If yes, when did he have surgery? _________________________

4. If no surgery has been done, is it planned? (circle) Yes-No-Don't Know

5. Your age: _____________.

6. Your occupation ____________________________________________

7. Your husband's occupation (be specific as to his duties, state the type of work and company he works for): _______________

8. Circle the last year you completed in school: 1 2 3 4 5 6 7 8 9 10 11 12 Graduated from high school. College: 1 2 3 4 Graduated from college. Post Graduate work.

9. Circle the last year your husband completed: 1 2 3 4 5 6 7 8 9 10 11 12 Graduated from high school. College: 1 2 3 4 Graduated from college. Post graduate work.

Thank you for your help with

this study.

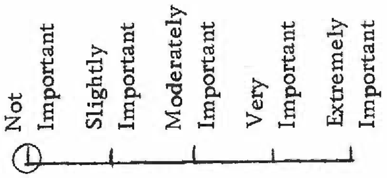
Copy of questionnaire as administered to staff with distribution of staff's responses.

Dear Staff,

We are conducting a study of what the medical staff thinks is important to tell parents of children with congenital heart defects. We are not asking if you do tell parents, but whether or not you think the information is important to tell parents.

Please make a circle around the appropriate mark to show how important you think that item is for parents to be told. You may indicate the item as "Not Important", "Slightly Important", "Moderately Important", "Very Important", or "Extremely Important".

EXAMPLE



5. What caused the defect.
If you think it makes no difference whether the parent be told this or not, then you should place a circle around the mark at the extreme left hand position, under "Not Important".

5. What caused the defect.
If you think this item is essential for parents to be told, make a circle around the mark under "Extremely Important" at the right hand end of the line.

Otherwise indicate one of the other positions, "Slightly Important", "Moderately Important", or "Very Important" according to your opinion.

Please give an opinion on every item.

Staff, please complete:

1. Your age ______________.

2. Your discipline in medicine or nursing (be specific - surgery, pediatrics, cardiology, pediatric nurse, clinic nurse, etc.)
______________________________

3. Your status (e.g. senior staff, fellow, 3rd year medical or nursing student, charge R.N., staff ward R.N. or L.P.N.)
______________________________

| Not Important | Slightly Important | Moderately Important | Very Important | Extremely Important | | Please give an opinion on every item. |
|---|---|---|---|---|---|---|
| 5 | 10 | 34 | 47 | 21 | 1 | To explain medical terms used (e.g., chambers of heart, valves, etc.). |
| | 8 | 31 | 47 | 31 | 2. | To explain how the heart works. |
| 3 | 21 | 35 | 42 | 16 | 3. | To explain what normal circulation is. |
| | | 6 | 27 | 84 | 4. | What is wrong with child's heart. |
| 1 | 15 | 26 | 34 | 42 | 5. | What caused the defect. |
| 1 | 4 | 15 | 37 | 60 | 6. | The possibility this same defect may occur in other children in the family. |
| 11 | 31 | 41 | 22 | 12 | 7. | How many children are born with heart defects. |
| | 8 | 23 | 51 | 35 | 8. | Why tests are done (blood test, x-ray, EKG-electrocardiogram). |
| 1 | 7 | 19 | 34 | 7 | 9. | How to prepare child for the tests. |
| 2 | 7 | 25 | 48 | 35 | 10. | The meaning (interpretation) of the tests. |
| 1 | 6 | 23 | 52 | 35 | 11. | If the various tests will be painful. |
| | 6 | 20 | 55 | 36 | 12. | What is done in a cardiac catheterization. |
| 1 | 15 | 35 | 39 | 27 | 13. | What to expect in a clinic visit (length of time, what will be done, etc.). |
| 1 | 2 | 16 | 34 | 64 | 14. | The name of the medicine child is taking. |
| | 5 | 13 | 44 | 55 | 15. | The action of the medicine child is taking. |
| | 4 | 17 | 42 | 54 | 16. | What physical activities to allow before surgery. |
| 2 | 2 | 18 | 38 | 57 | 17. | Why antibiotics are to be taken before dental care. |
| | 2 | 10 | 40 | 65 | 18. | Any restrictions on diet. |
| | 3 | 19 | 53 | 42 | 19. | Effects of colds and illness on child. |
| | 7 | 16 | 47 | 47 | 20. | How to prepare child for hospitalization. |
| | 5 | 14 | 39 | 59 | 21. | How to prepare child for the operation. |
| 2 | 3 | 24 | 48 | 40 | 22. | What will be done during the surgery. |
| 1 | 3 | 6 | 34 | 73 | 23. | What risks will there be during surgery. |
| 1 | 2 | 3 | 42 | 69 | 24. | Whether the surgery is a complete or partial correction. |
| 8 | 13 | 41 | 36 | 19 | 25. | If parents should find blood donors. |
| 2 | 11 | 37 | 48 | 19 | 26. | How long will child be in the hospital. |
| 4 | 24 | 35 | 40 | 14 | 27. | Where the parents could stay when child is in the hospital. |
| 1 | 6 | 15 | 43 | 52 | 28. | What to expect in the intensive care room. |
| | 1 | 15 | 44 | 57 | 29. | What care parents will give at home after surgery. |

| Not Important | Slightly Important | Moderately Important | Very Important | Extremely Important | |
|---|---|---|---|---|---|
| | | 10 | 53 | 54 | 30. What activities to allow after surgery. |
| 1 | 13 | 42 | 51 | 10 | 31. Why the child may be small for age. |
| | | 15 | 62 | 40 | 32. Whether child will live a "normal life". |
| | 3 | 14 | 55 | 45 | 33. That child will not "out grow" defect. |
| | | 3 | 46 | 68 | 34. What signs and symptoms to watch for. |
| | 6 | 16 | 61 | 34 | 35. What to tell your child about his condition. |
| 2 | 9 | 15 | 52 | 39 | 36. How to help child with his worries. |
| 14 | 15 | 36 | 27 | 25 | 37. How to discipline child. |
| 1 | 3 | 22 | 40 | 51 | 38. The parent have a chance to talk with someone regarding child. |
| | 5 | 36 | 44 | 32 | 39. To talk with someone regarding the financial cost. |
| | 2 | 5 | 30 | 80 | 40. Surgeon to talk to parent before and after surgery. |
| 3 | 11 | 45 | 34 | 24 | 41. To have factual information to read on congenital heart defects. |
| 11 | 29 | 31 | 37 | 9 | 42. To talk with another parent whose child has a similar condition. |
| 10 | 31 | 40 | 29 | 7 | 43. To have a nurse call at home to discuss condition and/or problems. |
| 5 | 31 | 43 | 31 | 7 | 44. To see a model of the heart. |
| 3 | 18 | 40 | 41 | 15 | 45. To be shown a drawing of the heart defect. |
| 7 | 21 | 38 | 37 | 14 | 46. To be told the medical term for the defect. |
| 5 | 20 | 25 | 35 | 32 | 47. To have the medical word for the defect, instructions, and treatment written down and given to parent. |
| 7 | 8 | 17 | 41 | 44 | 48. Parent to visit the intensive care room before surgery. |
| 11 | 16 | 27 | 36 | 27 | 49. To keep parents informed of the progress during surgery. |
| | 1 | 6 | 39 | 71 | 50. To have the name of someone to call in case of an emergency. |

Add any comments or other areas of information you think important for parents to be told.

# AN ABSTRACT OF THE FIELD STUDY OF

## AUDREY OLSON LEIGHTON

For the degree of MASTERS IN NURSING

Date of receiving this degree: June 13, 1975

Title: IMPORTANCE OF INFORMATION RELEVANT TO THE
CARE OF CHILD CARDIAC PATIENTS, AS PERCEIVED
BY MOTHERS AND STAFF

Approved: [redacted]
Julia Brown, Ph. D., Associate Professor, Field
Study Advisor

The purpose of the present study was to investigate the areas and extent of agreement as to the importance of specific communications between staff and parents of children cardiac patients. To this end, a questionnaire was administered to 100 mothers of children with congenital heart defects, and to 117 staff members attending these children at three facilities within a university teaching hospital. The respondents were requested to rate the importance of fifty items, covering knowledge, emotional needs, and preferred techniques for communication.

The major findings follow. (1) Both mothers and staff attached greatest importance to diagnosis and least to the various methods of presenting information. (2) Mothers judged the items generally as more important than did the staff. (3) Both mothers and staff

tended to rank-order the items similarly with respect to their importance. (4) Mothers' responses as to the overall importance of the items did not vary systematically according to mother's level of education, child's mode of treatment (whether surgical or medical), or length of time since first diagnosis of the child. (5) Staff judgments varied according to discipline, with nurses tending to judge information generally as more important than did the medical staff. (6) The status of the staff member did not appear to influence judgments of the importance of items. (7) Nurses' responses accorded more closely with those of mothers than did the responses of the medical staff, in that both nurses and mothers assigned greater importance to the items than did the medical staff. (8) The responses of medical staff resembled those of mothers to a greater degree than did the responses of nursing staff, with respect to the rank-ordering of the items in terms of their relative importance.

Since parents clearly desire information and emotional support in caring for their children with congenital heart defects, and since staff working with these children also acknowledges the necessity of educating parents on health matters, such health instruction should be explicitly formulated and implemented. It is hoped that the findings of this study can be used in developing the content for this instructional plan, a content including both what the mothers indicated they considered as important to know, and what staff members in their experience have found vital to share.