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ISBN 0-315-55400-2

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THE UNIVERSITY OF ALBERTA

THE EFFECT OF CONTEXT ON INFORMATION GIVING FOR PARENTS OF SCHIZOPHRENIC CHILDREN

by

KEVYN NOBLE ROSENTHAL

A THESIS SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND
RESEARCH IN PARTIAL FULFILMENT OF THE
REQUIREMENTS FOR THE DEGREE OF
MASTER OF NURSING

FACULTY OF NURSING

EDMONTON, ALBERTA
(FALL, 1989)

THE UNIVERSITY OF ALBERTA

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NAME OF AUTHOR: Kevyn Noble Rosenthal

TITLE OF THESIS: The Effect of Context on Information Giving for Parents of Schizophrenic Children

DEGREE: Master of Nursing

YEAR THIS DEGREE GRANTED: Fall, 1989

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research, for acceptance, a thesis entitled The Effect of Context on Information Giving for Parents of Schizophrenic Children submitted by Kevyn Noble Rosenthal in partial fulfilment of the requirements for the degree of Master of Nursing.

Supervisor

Rose C. Day

Date: October 2, 1989

To

the children and their families

who have taught me the most

Abstract

Emphasis on deinstitutionalization and community based treatment has inadvertantly created an increase in distress and demand for coping in the families of the chronically mentally ill. While work has begun to alleviate this problem in families of adult patients, the difficulties faced by chronically mentally ill children and their families are only beginning to be recognized. Available literature supports the effectiveness of information giving for families of adult patients; however, the reported intervention programs have varied greatly in composition and context and none have been attempted with families of schizophrenic children. The purpose of this study was to design, implement, and evaluate an information program for parents of schizophrenic children.

An experimental post-test only comparison group design was used in which twelve sets of parents of schizophrenic children were randomly assigned to one of two groups. Group 1 received the information in a group format while Group 2 received the information by mail. The information provided was developed as part of the study. Data were analysed using the Mann-Whitney U Test and the effect of these two contexts on post-test measures of parents' distress, knowledge, and beliefs, fear, and worry revealed no statistically significant differences between groups. However, responses to open-ended questions and ratings by parents in both groups indicated that the group format was more satisfactory to the parents. Results are discussed in light of the small sample size and the lack of previous research with children with schizophrenia.

ACKNOWLEDGEMENTS

This study would not have taken place without the support, encouragement, and input of many people. First, I would like to thank Dr. Terry Davis for her enthusiastic and knowledgeable support for intervention research; and her understanding, guidance and personal support through the hard times.

The two nurses who helped me develop the information packages and run the group, Marilyn Malthouse, R.N. and Sandy Lenz, R.P.N., shared with me their wisdom and experience generously always. Their friendship is warmly appreciated.

I would also like to thank the physicians who provided me access to the families and gave me their support and encouragement: Dr. Alan Carroll, Dr. Sarah Matthews, Dr. Judith Ustina, and Dr. Gordon King.

The other members of my thesis committee provided me with valuable input along the way: Dr. Alan Carroll helped me with clinical matters, Dr. Rene Day with clarifying my thinking, and Dr. Tom Maguire with design and statistical issues.

Dr. Sheila Cantor who pioneered the study of schizophrenic children, also shared her expertise and encouragement. Dr. Cantor died during this study and she will be sadly missed.

The patience, support, and love of Jay, David, and Shelley Rosenthal keeps me going.

Funding assistance was provided by a student research bursary from the Alberta Foundation for Nursing Research.*

Most of all, I would like to thank all the children and families over the years from whom I have learned so much.

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* Such funding does not necessarily constitute support of any part of the study by the Alberta Foundation for Nursing Research.

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CHAPTER I

THE PROBLEM

Background

In the past, families, especially parents, of schizophrenic people have been accused of being overprotective, neglectful, overintrusive or unavailable, of disconfirming, scapegoating, pseudomutuality, and double-binding in their family ralationships (Bateson, Jackson, Haley, & Weakland, 1956; Lidz, Cornelison, Fleck, & Terry, 1957; Wynne, Ryhoff, Day, & Hirsh, 1958; Bell & Vogel, 1968; Schopler, 1971). In spite of (and because of) misguided professional efforts to help, many of these families have remained distressed, guilt-ridden, ashamed; desperately trying to cope, to understand and to help their schizophrenic family member. Recently, in an attempt to address these problems, clinicians have developed psycho-educational interventions for families of <u>adult</u> schizophrenic patients (Anderson, Hogarty, & Reiss, 1980; Plummer, Thornton, Seeman, & Littmann, 1981; Leff, Kuipers, Berkowitz, Eberlein-Vries, & Sturgeon, 1982; Falloon, Boyd, & McGill, 1985; Anderson, Reiss, & Hogarty, 1986). However, such interventions with families with schizophrenic <u>children</u> have not been reported in the literature, and personal communication with authorities in the field indicates that this application has not been made.

Psychoeducational interventions have been defined by Kinney as

> typically a series of didactic presentations that follow a structured lesson plan which provides information on and facilitates insight into the nature of schizophrenia in order to develop more adaptive perceptions/feelings, behavior, and communication" (1985, p.47).

The fact that such interventions have not yet been developed and utilized with families of schizophrenic children is understandable considering the previous lack of clarity of diagnostic criteria for schizophrenia in children (Rutter, 1972) and the reluctance of many physicians to label a child with this chronic psychopathology (S. Cantor, personal communication, December 23, 1987). Currently, with greater diagnostic clarity being provided by DSM-III (American Psychiatric Association, 1980) and DSM-III-R (American Psychiatric Association, 1987), children are now diagnosed as schizophrenic using the same criteria as for adults. Unfortunately, however, no reliable estimate of the current prevalence of schizophrenia in children is available (Cantor, 1982; S. Cantor, personal communication, December 23, 1987). But, it is common clinical knowledge that a small but very underserved population of children with schizophrenia exists.

I became acutely aware of the need for some form of psychoeducational intervention with the parents of schizophrenic children as a result of my nursing experience with these stressed and distressed families. Along with other members of a multi-disciplinary team, I began to notice that these parents asked the same questions over and over: they asked for basic information about schizophrenia, its cause, treatment, management, and prognosis; but most of all, they wanted to know how to help their children. It was evident from observing these parents interact with their children that they often did not connect their child's behavior and difficulties with the symptoms we had discussed. Somehow, the information we were giving these parents was not being heard, or not being understood, or not being remembered. Further, it seemed the often hurried atmosphere of the physician's office, the inpatient ward, or an outpatient telephone call were not conducive to giving parents information that they could understand and use.

Hence, my interest in developing and evaluating an information-giving intervention for these parents. This interest was verbally supported by a number of clinicians who specialize in working with schizophrenic adults and children: Judith Waugh, PhD., Western Psychiatric Institute in Pittsburgh; Elizabeth Plummer, R.N., Clarke Institute of Psychiatry in Toronto; Richard Fischer, MSW, Western

Psychiatric Institute; Sheila Cantor, M.D., (now deceased, formerly at the Schizophrenia Treatment and Research Foundation, University of Manitoba); and Alan Carroll, M.D., Glenrose School Hospital, Edmonton, Alberta.

Purpose of the Study

The purpose of this study was to develop, implement, and evaluate an information package for parents of schizophrenic children. It was reasoned that by increasing parents' knowledge of the illness, its causes, treatment, and management, it would be possible to alter their beliefs, worries, fear, and distress; thereby, benefitting both parent and child. Given the current level of knowledge in treatment of schizophrenia, information-giving interventions appear to make a positive contribution to the course of the patients' illness and to the family's ability to cope. However, as noted earlier, these reports pertain only to interventions with families of adult patients. It was reasoned that information giving might also be an effective intervention with families of schizophrenic children in helping to decrease distress and to increase ability to cope. Moreover, parents ask clinicians for information about schizophrenia and its treatment such as has been presented in the above programs, but little is known about the role context plays in effective interventions. It was with this in mind that this study was designed to develop and implement an information program for parents of schizophrenic children and to evaluate the program's effectiveness in light of two different contexts of information presentation which could easily and realistically be put into place in clinical practice.

CHAPTER II

LITERATURE REVIEW

This literature review will focus on three areas: first, the rationale for information provision to families of schizophrenics; second, the anticipated outcomes of information provision; and third, the information provision outcome literature.

Rationale

In a thorough review of the literature on the evaluation of treatment methods for schizophrenic patients, May (1975) concluded that it is the combination of vigorous outpatient aftercare programs plus drug treatment that is most effective in maintaining adult schizophrenic patients in the community. This conclusion was supported by Hogarty and Ulrich (1977) who reported that although antipsychotic drug treatment alone is capable of inducing remission of psychotic symptoms in most patients, as many as 40% subsequently relapse within a year of hospital discharge even when medication compliance is assured by depot administration. Thus, it is recognized that effective treatment for schizophrenic patients requires a comprehensive approach using biological, psychosocial, and environmental intervention strategies (Cf. Falloon, Boyd, & McGill, 1985).

An unintended effect of the emphasis on community treatment and deinstitutionalization has been an increase in stress and related adjustment problems for both the chronically mentally ill and their families (Bryant, 1978). A number of studies show that great difficulties exist for these families. For example, in a British study examining the burdens for families of mental patients, Grad and Sainsbury (1963, 1968) found 20% of the families they studied reported "additional burden." Hoenig and Hamilton (1969) reported 56% of their families of mental patients were experiencing stress and disruption in their lives. Herz, Endicott, and Gibbon (1976) found moderate to severe stress in 32 of their families of newly discharged mentally ill patients. Hatfield (1978) and Kriesman, Simmens, and Joy (1979) also report emotional stress and unhappiness in families of discharged mental patients.

As the foregoing studies indicate, families of the chronically <u>mentally ill</u> experience severe stress and burden; however, the explicit nature of these stresses and burdens have not been delineated. Similarly, clinicians and researchers working with the families of <u>developmentally disabled</u> children have recognized the stresses and burdens present in these families (Carver & Carver, 1972; Gath, 1977; Reed & Reed, 1965). Consequently, it is important to recognize that since schizophrenic children are both chronically mentally ill <u>and</u> developmentally disabled, they and their families are doubly at risk for experiencing distress, burden, and poor prognosis. Therefore, it is understandable that these parents ask the same questions over and over and have difficulty understanding how to help themselves and their children.

Anticipated Outcome of Information Provision

Information giving interventions for families with a schizophrenic member have been designed to provide the patient and/or his or her family with information about the biological, psychological, and environmental factors which are believed to play a part in the course of schizophrenic illness. While these factors and their relationships are poorly understood, information is given at the level of current knowledge and is aimed at preventing or postponing relapse in patients, at decreasing the subjective feelings of stress and distress reported by family members, and at assisting patients and their families to cope more effectively. The literature on psychoeducational interventions supports the effectiveness of information giving for families of schizophrenic patients. The rationale for this intervention is based on the belief that environmental stimuli (e.g., family reactions to the ill member) are capable of being modified so that the hypothesized information processing deficits in schizophrenia can be adapted to minimize psychotic symptomatology. This modification will have direct beneficial effects for the family and also indirect beneficial effects for the patient (see Anderson et al., 1986 for a detailed account of this theory). The model on which this intervention is based may be seen in Figure 1. This model is congruent with the goals of information giving: to provide information about the illness, its treatment, and management to help the family prevent or postpone relapse in patients, to decrease the subjective feelings of distress reported by family members, and to assist patients and their families to cope more effectively.

Because of the distortions in stimuli processing inherent in the illness, any stress, upset, or turmoil in the family environment can lead to an increase in symptoms and a decrease in level of functioning for the patient. In turn, the behavior of the patient is, in itself, often a stressor to the family. In order to break this cycle of bizarre behavior--family stress--bizarre behavior--family stress, parents can be helped to understand the illness and its management by providing them with information. Information giving then becomes one aspect of treatment along with medication, special educational and vocational training, social skills training, and behavior management.

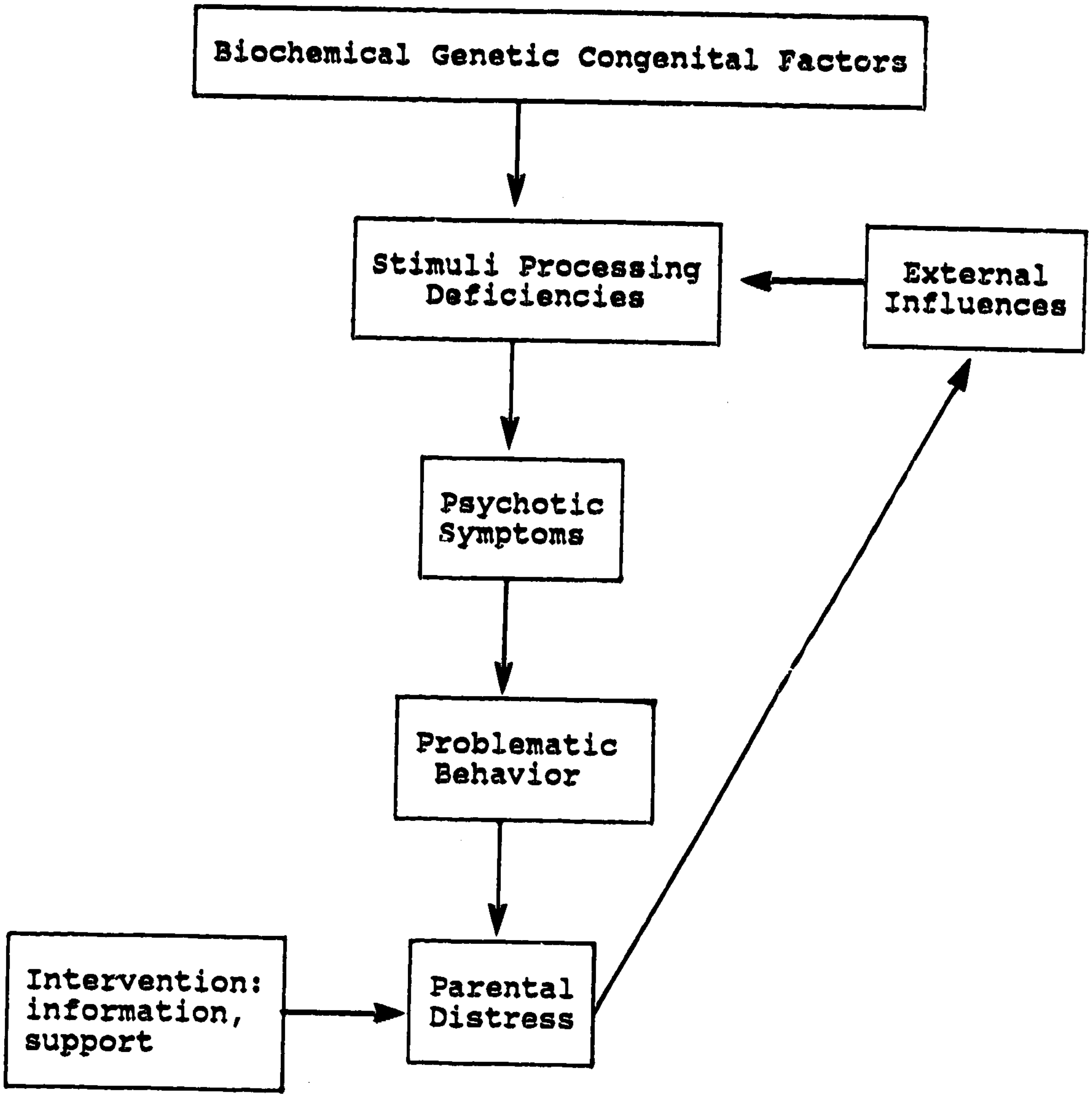

Figure 1. Conceptualization of Model for the Study

Information Provision Outcome Literature

The research literature on information provision for families of schizophrenic patients takes two forms: (1) clinical reports and (2) empirical studies.

Clinical reports. A summary of the clinical reports on information provision is presented in Table 1. These clinical reports provide a descriptive account of the information provision strategies and subjective clinical impressions of their effectiveness. For example, Atwood and Williams (1978) offered a support group for relatives living with psychiatric patients of a community mental health centre in suburban Boston. This family group consisted of twelve parents of "mostly schizophrenic patients" and lasted for a pre-determined eight week period. The group process involved "expression of affect" and resulted in "growth in cognitive understanding" and "reporting of behavioral change." Atwood and Williams reported success based on feedback from the relatives and on high group attendance rates.

Similarly Zelitch (1980) and Plummer, Thornton, Seeman, and Littmann (1981) also developed informational groups for families of adult schizophrenic patients and reported efficacy based on high attendance rates and on comments expressed by group participants in interviews (Zelitch) and changes in topics of concern (Plummer et al.). In summary, all three of these clinical investigators found positive results for families receiving the information.

Table 1

Summary of Clinical Reports of Psychoeducational Family Interventions

Author(s)	Group Size & membership[a]	Type of Intervention	Outcome Measure(s)	Results[b]
Atwood & Williams (1978) Boston	12 parents of "mostly schizo-prhenic patients"	multi-family group, 8 weekly sessions	participant reports, group attendance rates	+
Plummer et al. (1981) Toronto	8 sets of relatives of adult schizophrenic patients	multi-family group, weekly for 6 months	therapist impressions changes in group's topics	+
Zelitch (1980) Pennsylvania	14 relatives all living with schizophrenic family member	multi-family groups, 2 sets of 8 weekly sessions	feedback from relatives, follow-up interviews, group discussions	+

[a] relative = any person related to the patient; parent = mother and/or father; family = mother, father, spouse, child, or sibling of patient.

[b] + = subjective reports of participants and/or clinicians were positive.

Empirical studies. A summary of these studies may be seen in Table 2. In a more rigorous British study, which included information provision, Leff, Kuipers, Berkowitz, Eberlein-Vries, and Sturgeon (1982) studied families of 24 schizophrenic patients determined to be at high risk for relapse. One half of the families were assigned to routine outpatient care, while the other half received a package of social interventions consisting of a four-week in-home individual family education programme, a nine month multi-family relatives group, and individual family sessions. Additionally, all patients were maintained on depot neuroleptics. These researchers reported a relapse rate of 50% in the control group compared with 9% in the experimental group (p=0.04). The explanation offered by the authors for this difference is that the amount of face-to-face contact and/or level of expressed emotion was decreased in the experimental group. However, they stated they were unable to specify which aspect of their program was responsible for these changes in family environment.

Anderson, Reiss, and Hogarty (1986) in Pittsburgh developed a similar package for the families of a total of 90 patients with similar results. Their patients were also maintained on depot neuroleptics. The information provision component consisted of a one day "Survival Skills Workshop" for family members. The researchers reported no relapses at nine month follow-up in the group of patients who received

Table 2

Summary of Empirical Studies of Psychoeducational Interventions

Author(s)	Group size, Membership[a]	Control Group(s)[b]	Type of Intervention	Outcome Measures	Results
Anderson et al. (1980) Pennsylvania	90 (total) relatives of adult schizophrenic patients	RA 1:family therapy only 2:behavior therapy 3:chemotherapy + support	multi-family group, 1 day workshop	relapse rate	19% of family therapy group, 20% of behavior therapy group, 41% of chemotherapy + support group, 0% of combined treatment (experimental) group
Leff et al. (1982) Britain	12 families in treatment group, 12 families in control group	RA routine outpatient care	individual family program of education about Sz. + relatives group + family sessions	relapse rate	50% in control group, 9% in treatment group
McGill et al. (1983) California	18 families in treatment, 18 families in control group	RA individual treatment	individual program of family education	scores on knowledge questions, relapse rate	knowledge: treatment group significantly higher relapse 6% for treatment group, 44% for control
Smith & Birchwood (1987) Britain	20 families of adult Sz. patients in "group" and 20 in "postal" conditions	RA "group" treatment or "postal" treatment	"group"- multi-family education group, "postal"- mailed packets of information. Both weekly for 4 weeks.	specific: knowledge questions non-specific: specific: family distress, stress, fear, worry, beliefs, burden, patient behaviors	Both groups significant increase in decreased distress burden. No significant between groups differences.

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[a] relative = any person related to the patient; patient = mother and/or father; family = mother, father, spouse, child, or sibling of patient.

[b] RA = random assignment

both problem-oriented family therapy and information provisions interventions, a relapse rate of 20% for the group who received individual behavioral therapy, and 41% for the group of patients who received only chemotherapy plus support ($p<.01$). The authors explained these results by stating that the family approach (information provision plus problem-oriented family therapy) "appears to buy time for patients, permitting them to recover more fully by decreasing family distress and helping them to understand the illness that reduces their expectations, and otherwise promotes the development of new coping strategies" (p.25).

McGill, Falloon, Boyd, and Wood-Siverio (1983) in California developed a family education intervention in which information provision was carried out with individual families in their own homes. Patients were randomly assigned either to the family treatment group or to a group in which patients and family members were seen individually. All patients were maintained on neuroleptic medication and both groups were seen on the same schedule: weekly for the first three months, biweekly for the next six months, and monthly thereafter to two years. A total of 36 patients completed nine months of treatment. These researchers reported that patients and families in the family treatment program acquired and retained information about schizophrenia more readily than patients and families who received individual treatment. They also reported that this knowledge helped families to become "more effective in aftercare and to surmount problems associated with post-hospital adjustment" (p.934).

Smith and Birchwood (1987) conducted a study in which forty schizophrenic patients known to their hospital were randomly assigned to one of two groups. The same information package was delivered to both groups at identical time intervals over a four week period either in a group setting or via mailed packets of information. The "group" condition also included the use of audiovisual aids as well as the opportunity to interact with the primary therapist and with other families in the group. The results of this study were that both groups of relatives significantly increased their level of knowledge from baseline (p<.05), but the "group" relatives acquired significantly more knowledge than the "postal" relatives (p<.05). "Group" relatives tended to be more optimistic concerning the family's role in treatment. Worry, fear, stress, and distress scores all showed a significant decrease from pre- to post-test in both groups but there were no significant differences between groups. These authors concluded that information provision seemed to play an important role in decreasing family stress and burden. They also noted idiosyncratic effects which may have greatly helped individual families (such as one family who did not understand the relationship between the patient talking to himself and hearing voices). They discussed these effects as having clinical significance but not statistical significance in their study.

In summary, clinical reports have provided description and subjective evaluation of information-giving interventions as helpful to families of schizophrenic patients. Research reports have provided more rigor but have been lax in defining variables such as "relapse" and "family distress" and the effect of the educational component has been confounded because it comprised only a part of the treatment plan in most studies. Two studies (Anderson et al., 1986; Smith & Birchwood, 1987) described the intervention in detail. While Smith and Birchwood (1987) found that families in their "group" condition acquired significantly more knowledge, non-significant results in the non-specific effects do not allow conclusions to be drawn concerning the importance of this increase in knowledge.

The question of the contribution of "context" vs. "content" relative to these information provision outcomes remains unanswered. The authors pointed out the importance of separating out "content" from "context" factors of knowledge acquisition. They noted that while pure information content common to both groups is clearly the crucial element in knowledge acquisition <u>per se</u>,

> contextual factors would appear to have a role in further enhancing knowledge assimilation conceivably through the combined efforts of repetition and clarification of information - and the opportunity to listen to and discuss views with the therapist and other group members (Smith and Birchwood, 1986, p.650).

Research Questions

In order to explore the relative importance of content and context, the following research questions were formulated:

1. What effect, if any, does the context in which information is given have on the amount of knowledge gained by parents of a schizophrenic child?

2. What effect, if any, does the context in which information is given have on parents' beliefs, worries, and fears regarding their schizophrenic child?

3. What difference, if any, does the context in which information is given make to the parents' distress levels regarding their schizophrenic child?

CHAPTER III

THE INFORMATION PACKAGE

The content for the information package was developed by the researcher and the two nurses who co-led the group because with the exception of Dr. Cantor's book The Schizophrenic Child (1983), there is a dearth of information available for parents. The information which is available for families of adult patients is not truly helpful or appropriate for the families of child patients because it does not address the interplay between child development and schizophrenia.

The content for the information package was developed by: (1) reviewing the literature to see what other clinicians/researchers had included in their information for families of adult patients; (2) reviewing handouts and pamphlets from the National Institute of Mental Health and various pharmaceutical companies; (3) consulting physicians, nurses, social workers, and child care workers working in Child Psychiatry for input about the questions that parents ask repeatedly; (4) consulting representatives from a local family support group for families of adult patients, Friends of Schizophrenics.

The content identified was then reviewed for accuracy and adequacy by mental health professionals experienced with psychotic children. The handouts were given to various friends and relatives with no knowledge of psychiatry who were asked to comment on readability and ease of understanding. The handouts were then revised and the materials were determined to be at the Grade 10 reading level by the SMOG Readability Formula (McLaughlin, 1969). The comments of the lay people (who had Grade 8-12 education) judged the handouts to be easily read. The SMOG Readability rating may have been artificially inflated because the formula takes into consideration the number of words with greater than three syllables. Many of the words in the handouts (eg. schizophrenia) had more than three syllables, but they were used in the context of being explained.

A summary of the content of these packages may be seen in Table 3 and the complete information packages are included in Appendix A.

The topics covered in Package I included an introduction and overview of the sessions (or information packets) to follow. A Glossary of Terms frequently used by mental health professionals was presented first. Then followed information on what schizophrenia is, its history, epidemiology, and etiology. Specific information on schizophrenia in children, the world of the schizophrenic child, and how parents can tell if their child has schizophrenia completed Package I.

Table 3

Summary of Content of Information for Parents

Package	Topics Covered
I.	Introduction and overview of sessions. Glossary of terms frequently used by mental health professionals. Schizophrenia: what is it?, history, who gets it?, schizophrenia in children, the world of the schizophrenic child, how can I tell if my child has schizophrenia? What causes schizophrenia?
II.	Treatment. Medications: how they work, positive and negative symptoms, side effects, drugs to relieve side effects, how can the family help with drug treatment. Information sheet about phenothiazines.
III.	The family and schizophrenia. Why families need to help. Common behaviors of families. What the family can do to help. Summary of guidelines for parents.
IV.	Common problems that patients and families face. General effects on the parents. Siblings. Dealing with "others". Difficult to accept. Expectations for the future. Family support groups.
V.	Managing symptoms. Symptoms. How to behave toward a person suffering from schizophrenia. Parents' responsibilities towards themselves. Vocational and educational issues. Using professionals.
VI.	Where do we go from here? Questionnaires. Friends of Schizophrenics, the future of the parent group. Good books about schizophrenia and where they are available.

Package II explained treatment with medications. The topics of how medications work, what their side effects may be, and the drugs given to relieve side effects were covered. An information sheet about phenothiazines and information about how the family can help with drug treatment were included.

Package III dealt with family related issues such as why professionals need the families to help, common coping behaviors of families, and some guidelines to help families cope more easily.

Package IV discussed common problems that patients and families face. This section discussed the effect of having a schizophrenic child on the family as a whole, and on parents and siblings specifically. Suggestions were given concerning how parents can deal with extended family, friends, and the community who do not understand schizophrenia. The difficulty parents have in accepting the diagnosis was discussed as well as the expectations that the parents might have for their child's future. The value of family support groups was also addressed.

Package V discussed managing symptoms by giving specific examples of common problem situations. Tips on how to behave toward a person suffering from schizophrenia were included as well as parents' responsiblities toward themselves. Vocational and educational issues were addressed and suggestions on how to effectively use professionals were included.

Package VI consisted of the study questionnaires to be completed by the parents, a book list of good books about schizophrenia for further information, and a list of local stores which either carry or will order these books.

CHAPTER IV

METHOD

Design

A posttest-only comparison group design (Gottman & Markman, 1978) was used to determine 1) what effect, if any, the context in which information is given has on the amount of knowledge gained by the parents of a schizophrenic child; 2) what effect, if any, the context has on the parents' beliefs, worries, and fears regarding their schizophrenic child; and 3) what effect, if any, the context has on the parents' levels of distress regarding their schizophrenic child. The two comparison groups consisted of parent volunteers, who were randomized into either Group 1 (Group context) or Group 2 (Mailout context) using the schizophrenic child as an index so that two parents of one child would not be split into different groups. Parents in both groups completed questionnaires at the end of the six week study period.

This comparative outcome design -- which involved a comparison between two alternative forms of intervention rather than an intervention and no-intervention control comparison -- was chosen because it was a viable and ethical clinical evaluation research strategy. Specifically, the researcher felt that no-intervention, wait-list, or placebo control prodedures raised ethical issues because a reasonable intervention would be withheld or postponed (O'Leary & Borkovic, 1978), thereby causing possible harm to participants. Further, this design allowed for a viable intervention for a given problem and at the same time for evaluation of questions of theoretical and clinical significance (Kazdin, 1986).

Definitions

1. "Parents of a schizophrenic child" was defined as the mothers and/or fathers of a child less than 15 years old at the beginning of the study who had been diagnosed as schizophrenic by a child psychiatrist and who met the DSM-III criteria for schizophrenia. Parents who volunteered for the study could have been biological, adoptive, foster, and/or step-parents and the child must have been living with them most of the time. The parents must have been able to speak and read English.

2. "Context" was defined as the circumstances in which the information was disseminated. The group context was defined as a weekly group meeting of parents who met and shared a common experience. The group provided its members with moral support, opportunity for group problem solving, and empathy as well as with ideas for resources. The mail-out context was defined as information packets mailed out each week to the parents' homes.

3. "Parents' distress" was defined as self-reports of burden, discomfort, and stress directly relating to the experience of having a schizophrenic family member as measured by the Family Distress Scale (Pasamanick, Scarpitti, & Dinitz, 1967, see Appendix B).

4. "Parents' knowledge about schizophrenia" was defined as their score on the Knowledge of Schizophrenia questionnaire as adapted from Smith & Birchwood, 1987 (see Appendix C).

5. "Parents' beliefs, fears, and worries about their schizophrenic child" was defined as their responses to the seven direct questions concerning these areas as measured by the Belief, Worry, and Fear Scales (see Appendix D).

Recruitment of Parents and Randomization

The recruitment of parents occurred as follows. First, copies of a letter to prospective parent volunteers describing the study and requesting their participation was forwarded to four child psychiatrists who work with such families and who had agreed to assist in this manner (see Appendix H). The psychiatrists, in turn, forwarded the letters to parents who met the inclusion criteria. Second, parents who wished to volunteer then phoned the researcher directly to discuss participation. After verbal agreement to participate was obtained, participants all signed written consents (see Appendix I). After the referring psychiatrists informed the researcher of the total number of letters sent out, corresponding "contact" numbers were randomly drawn. As each parent contacted the researcher to volunteer, they were assigned to a group according to the number of their contact. Specifically, the first parent to phone was placed in the group in which the number 1 fell, the second parent to phone was placed in the group in which the number 2 fell, and so on.

Description of the Contexts

Group 1 (Group Context). The intervention for Group 1 consisted of six 1 and 1/2 hour weekly evening sessions in a group format. The sessions took place in a room provided by a local hospital. The atmosphere was kept as informal as possible with refreshments being served and participants sitting around a table. This group was led by three nurses, one of whom was the researcher. Each specialize in Child Psychiatry and have extensive experience working with psychotic children and their families. The presence of three leaders also provided increased credibility and allowed for explanations to be given in many ways when parents had questions. The researcher presented four of the sessions while the other two nurses each presented one session.

The group sessions were conducted as follows. The information was read from the hand-outs and questions and discussion were dealt with as they arose. The parents in Group 1 also were given copies of the information packets to take home. Besides the basic information packets, parents received feedback from the group leaders and from each other.

Group 2 (Mail-out Context). The information hand-outs were mailed out to the homes of the Group 2 parents each week so that they would be received on approximately the same day as Group 1 met. There was no other contact with the researcher or other group leaders during the course of the study.

Dependent Measures

Five measures were used with both groups. Also, four open-ended questions were asked of both groups. Additionally, four Likert scale items were asked of Group 1 (Group context).

Family Distress Scale. At the end of the six week intervention period, parents in both groups were asked to complete the Family Distress Scale (Pasamanick, Scarpitti, & Dinitz, 1967). This is a 22 item scale which measures the impact of having a schizophrenic relative in the family in terms of the extent of disruption on family life, embarrassment, and the concern of self and others. This scale was developed by Pasamanick et al. as part of a large study on the community adjustment of schizophrenic patients and their families. The items were identified from the larger questionnaire by factor analysis. Smith and Birchwood (1987) reported a Cronbach's alpha of 0.91 for this scale as used in their study. Although the scale was developed and used with the families of adult patients, it has been judged by experts in child psychiatry to be applicable to the families of child patients as well. A copy of the scale may be found in Appendix B.

Knowledge Scale. A 20-item knowledge of schizophrenia questionnaire as adapted by the researcher with permission from Smith and Birchwood (1987) was also administered. This questionnaire consists of multiple choice and true false questions and measures specific knowledge about schizophrenia, its etiology, symptoms, and treatment (see Appendix C).

Beliefs, Worry, and Fear Scales. A seven item questionnaire to measure parents' beliefs, worries, and fears specific to their schizophrenic family member (Smith & Birchwood, 1987) asked parents directly to rate the degree to which they felt a given statement applied to them (see Appendix D).

<u>Satisfaction with Intervention Questions.</u> In order to solicit parents' input about what was helpful/unhelpful and valuable/not valuable in both groups, four open-ended questions were also included (see Appendices E and F).

<u>Satisfaction with Group Scale.</u> Four Likert scale items were also asked of Group 1 to facilitate description of the parents' perceptions of the group context (see Table 6).

CHAPTER V

FINDINGS

This chapter is divided into two sections: a description and summary of the biographical data collected and a description and summary of the analysis of the data from the Scales and the open-ended questions.

Biographical Data

Six families per group who met the selection criteria were originally recruited for the two comparison groups. These parents were a mixture of biological, adoptive, foster, and step parents and a mixture of single and two parent families. A summary of the biographical data for the parents may be seen in Table 4. All parents who volunteered were placed in the study and all completed the study with one exception. One parent in Group 2 (Mail-out context) received and read all information packets but did not complete the questionnaires. This parent was a foster parent who had given up custody of the child during the study. Her reasons for giving up the child were complex and not related to the study.

Group 1 (Group context) contained one family with a set of twin boys both diagnosed schizophrenic. This group also contained more parents who were both able to

Table 4

Summary of Parent and Family Biological Data

	Group 1 (Group)	Group 2 (Mail Out)
Sex of parent reporting:		
female	50%	67%
male	50%	33%
Parents:		
single parents	10%	17%
two parents	90	83
other relatives in household	0	0
Mean number of children in family	2.6	2.3
Years of school completed by parent reporting:		
less than grade 8	0%	0%
grade 9	0	0
grade 10	10	17
grade 11	20	0
grade 12	10	50
more than grade 12	60	33
Time diagnosis known to parents:		
less than 3 months	40%	34%
3 - 6 months	30	17
7 - 12 months	20	17
longer than 12 months	10	33

participate. In Group 2, two fathers were working out of town during the time of the study and were unable to participate and one step-parent was unwilling to participate. Due to these factors there were a total of ten parents (seven children) in Group 1 and six parents (five children) in Group 2.

It is important to note that biographical data revealed that the two groups were different on two aspects which have clinical significance. The number of patients having medication changes during the study and the number of patients who were inpatients during or within 30 days prior to the study was higher in Group 1. These two factors indicate that the children in Group 1 may have been more acutely ill than those in Group 2. The implications of this difference will be discussed below. The two groups were not significantly different on any other biographic variable. A summary of the child biographic data may be seen in Table 5.

Summary of Data and Data Analysis

<u>Summary.</u> Both groups scored high on the Knowledge of Schizophrenia scale (Xgrp1=85.7%, Xgrp2=83.2%). Both groups had low to moderate scores on the Family Distress Scale (Xgrp1=18.58, Xgrp2=16.5, with a possible high score of 66). Belief Scale scores were moderately positive in both groups (Xgrp1=10, Xgrp2=10.67, with a possible high score of 20) with a higher score representing a more

Table 5

Summary of Child Biological Data

<u>Variable</u>	Group 1 (Group)	Group 2 (Mail out)
Age: (Mean in years)	10.58	11.16
Sex of child:		
female	14%	0%
male	76%	100%
Percentage of children whose parents reported medication changes in last six weeks	86%	20%
Inpatient status during study or within 30 days prior	86%	20%

positive outlook toward the hopefulness of the future for the ill child and the ability of the family to contribute positively to his/her treatment. Worry Scale scores were moderate in both groups (Xgrp1=2.5, Xgrp2=2.33 with a possible high score of 4) indicating that these parents are moderately worried about their children most of the time. Fear Scale scores were low in both groups (Xgrp1=0.92, Xgrp2=0.67, with a possible high score of 4) indicating that these parents have little fear for the safety of themselves or others in regards to their child's behaviour.

__Analysis.__ Because of the small number of parent subjects, uneven number of respondants in each group, and non-precise intervals of the data, the Mann-Whitney U Test was performed on the data. No statistically significant differences were found on the Knowledge, Family Distress, Beliefs, Worry, or Fear Scales. Further analysis showed that the variance in the scores in both groups was also not statistically different. These data are summarized in Table 6.

As can be seen in Table 7, the Satisfaction with Group Scale scores show that parents rated the group as providing moral support "quite a lot" (5 parents) or "very much" (5 parents). Nine parents rated the group as helping them to understand their child's illness and treatment "quite a lot" or "very much". All 10 parents rated the group as making them feel they are not alone in their concerns and experiences "very much". There was less agreement on whether the group provided an opportunity for problem-solving with others with 3 parents rating this category "somewhat", 3 parents "quite a lot" and 4 parents "very much".

Table 6

Summary of Data from Dependent Measures

Scale		Group 1 (Group)	Group 2 (Mail out)
Knowledge	$\bar{X}$	85.70	83.17
	s.d.	4.62	5.67
	Mann-Whitney	U'obt=39 *	Uobt=21*
	Critical U	≥46	≤14
Family Distress	$\bar{X}$	18.58	16.50
	s.d.	10.35	8.53
	Mann-Whitney	U'obt=34*	Uobt=38*
	Critical U	≤14	≥58
Beliefs	$\bar{X}$	10.0	10.67
	s.d.	1.95	2.88
	Mann-Whitney	U'obt=43.5*	Uobt=16.5*
	Critical U	≥46	≤14
Worry	$\bar{X}$	2.5	2.33
	s.d.	0.67	0.52
	Mann-Whitney	U'obt=33*	Uobt=27*
	Critical U	≥46	≤14
Fear	$\bar{X}$	0.92	0.67
	s.d.	1.16	0.82
	Mann-Whitney	U'obt=24.5*	Uobt=35.5*
	Critical U	≤14	≥46

* non-significant at p=.05.

Table 7

Summary of Satisfaction with Group Context Scores*

	Not At all	Very Little	Some-what	Quite a Lot	Very Much
To what extent did the group...					
1. Provide you with "moral support"				5	5
2. Provide you with opportunity for problem-solving with others			3	3	4
3. Help you understand your child's illness and treatment			1	3	6
4. Make you feel you are not alone in your concerns and experiences					10

*numbers represent the numbers of subjects responding in each category.

On the open-ended Satisfaction with Intervention Questions, parents in Group 1 (Group context) rated their experience very positively. Parents in Group 2 (Mail-Out Context) also reported satisfaction with the intervention but expressed the desire to have been in the "support" group (see Appendix G for a summary of these comments).

CHAPTER VI

DISCUSSION

The purpose of this study was to develop, implement, and evaluate an information-giving intervention for parents of schizophrenic children. The specific research questions were:

1) What effect, if any, does the context in which information is given to parents of schizophrenic children have on the amount of knowledge about schizophrenia gained by the parents?

2) What effect, if any, does the context in which the information is given have on parents' beliefs, worries, and fears regarding their schizophrenic child?

3) What difference, if any, does the context in which information is given make to the parents' distress levels regarding their schizophrenic child?

In answer to the research questions, it cannot be concluded from this study that the two contexts used made any appreciable difference on the amount of knowledge gained by these parents or on the level of parents' distress, beliefs, worries, or fears regarding their schizophrenic child.

The findings from this study leave us with two possible conclusions: (1) that the non-significance is false and a difference does truly exist that is not shown by these data or (2) that the non-significant results are true and there is really no difference between the two contexts. Each of these possible conclusions will be discussed.

If a difference between the groups did exist but was not demonstrated in this study, there are four possible explanations. First, since both groups received an "active" intervention there was an expectancy for change on the part of the parents and we might expect that some change did take place in both groups. In fact, it may be that both groups did receive some support. Information is, in itself, a kind of support and it is part of what these parents were asking for. Parents in both groups stated that they received information about the things they wanted to know and that the hand-outs were clear and easy to read. Both groups also received the time and interest of mental health professionals. While the effect size between pre- and post-intervention might be large, the effect size between groups is likely small. Therefore, many replications of the study to increase the total number of parents reporting in each context to approximately 100 would be needed to increase the likelihood of detecting a significant difference to a reasonable level.

Second, the tools used may not completely tap what it is that is most important to these parents. For example, the concept of family distress may need further clarification in the context of families with chronically mentally ill children. Parents' comments about relief of guilt suggests that personal distress be an additional concept to measure. Personal distress might be high (resulting in the "kick the cat" phenomenon) while Family Distress were only low or moderate. The group of parents who have already participated in this study could be used to further validate the Distress tool.

Third, these two groups appear to have been non-equivalent on a clinically significant characteristic. For example, it is interesting to note that Group 1 (Group context) had a higher mean Family Distress Score, though not statistically significant. This difference may reflect the higher acuity of the children in Group 1, as suggested by the higher number of inpatients and medication changes in this group, or it may have occurred by chance. The level of Family Distress may have actually been much higher in this group pre-intervention than that of Group 2. Unfortunately, no pre-intervention measures were taken to allow for pre- and post-intervention comparisons. Again, it is not possible to tell from this study whether the less positive outlook of the parents in Group 1 (as represented by the Belief Scale scores) reflects the degree of illness of their children or chance. Because Group 1 contained more children who were or who had recently been inpatients, it was also possible that those parents might have been receiving more support from other professionals than Group 2. Even if this were true, it seemed to be either not enough or not the kind of support that parents wanted. They still expressed a need for information and peer contact.

In future replications of this study, it would be advantageous (if possible) to block for the factor of acuity of illness and then randomize the members of each pair of subjects to eliminate this difficulty. Such a blocking procedure for the variable of acuity of illness of the child was considered in this study and decided against for two reasons. First, clinical experience indicates that it is not how ill the child is <u>per se</u> that distresses a family, so much as the perception the family has of the child and his/her behaviors. An attempt to measure perceptions of family members is extremely complex and outside the scope of this study. Second, severity of symptoms can vary greatly and rapidly, being influenced by growth, physical illness, and environment so that a child deemed to be "acute" and matched accordingly prior to randomization might actually be "less acute" at commencement of the intervention. Acuity is such an unstable concept over time that it would be difficult to use as a blocking variable.

Fourth, it is possible that the strength of the intervention was attenuated by being too short in duration of group sessions or too short in total length. It might be that if the group sessions had lasted longer than the 1 and 1/2 hours or that the sessions had continued longer than six weeks, there might have been more of a difference between groups. Both time periods made sense in terms of the amount of information to be conveyed and the duration of other groups described in the literature. That parents expressed a desire to continue the group in the Fall indicates that perhaps the group's full value was not reached within the six weeks of the study.

If non-significant differences observed in this study reflect no true difference, then the information package could be readily given out to parents who request such information. This finding may be important for families in outlying areas who would not have access to a support group but could receive the information by mail. Further, if through replication, significant differences are not found between groups, busy clinicians could be assured that the information could be given out to parents without the time and resources required to run a group. At this point in time, I would suggest that the information package could be used but used with the guidance of careful clinical judgement. Any parent who received the information should have access to follow-up clarification and support at least by telephone.

There was no indication that parents who received the information by mail became more distressed or confused. While one parent in this group made the comment that he/she "became depressed for awhile" after reading the information, all parents in both groups stated they found the information helpful. On the other hand, if because of the limitations of sample size, study design, validity of tools, or inaccurate concepts, true differences do exist between the two contexts which are not evident in these data, information might be given out without some arrangements for professional guidance and/or support leaving parents and families in more distress than before. Only further research will clarify these issues.

Conclusion

The findings of this research must be placed within the context of the beginning point of an ongoing course of enquiry. Research in a clinical area in which the number of available subjects will always be small must be carried out as repeated replications by many reasearchers in order to have sufficient numbers for statistically valid conclusions. It was in the spirit of offering such a beginning point that this project was undertaken.

The value of this study lies in two areas: clinical practice and research. From a clinical standpoint, as yet, there is no standard procedure or measurement strategy to assess clinical significance. While outcome measures are commonly used, Kazdin (1986) points out the importance of other measures as well, in particular, client reaction to and evaluation of the intervention and participation rates. In this study, all participants had asked for the kind of information which they were given; all wanted to be in the "group" but accepted randomization because as one parent said , "it's better than nothing." As the information was presented to the parents in Group 1, heads nodded in recognition of their child's behavior with many "Aha!" experiences as they connected deficits and symptoms of the illness with their child's behavior. At one point, one mother said, "But my son looks so normal...do your kids all look normal?" The parents then passed around school pictures of their children who do, indeed, look normal. This group offered parents a temporary personal community of others with similar problems. When one of the referring psychiatrists came to Session 5 as an observer (with the group's prior approval), the atmosphere was noticeably more restrained and the parents spoke less freely. The change with the addition of an "outsider" was taken as indication that the group had developed a sense of community and cohesion. The atmosphere in all sessions was one of fostering mutual aid and warm, supportive, nonconfrontive participant interactions.

Comments on the open-ended questions reflected the parents' desire for some sort of group support. Parents in Group 1 indicated their pleasure and benefit from that context both in their responses to the Likert scale (see Table 6) and to the open-ended questions. These parents organized a family picnic which took place after the study ended in order to continue contact with each other. Attendance was very high at all sessions with one set of parents even coming to a group meeting on the evening of their twenty-fifth wedding anniversary. Parents have asked that the group continue to meet in the Fall. A summary of the comments which participants wrote in response to the open-ended questions may be seen in Appendix G. Parents in Group 2 wrote that they benefitted from the information packets but wished they had been in the group.

Clinically, this study provided a valuable service to parents. An information package was developed that can be used by other clinicians and researchers. The researcher and the other two nurses who co-led the groups found the groups in themselves a most rewarding experience. The parents were eager, receptive, and shared the warmth and humor that helps them manage their burdens. Parents expressed their satisfaction with the group and their hope that the group would continue. Parents themselves began to ask why there is so little research in the area of schizophrenic children. They wanted to know what they can do to get research started that will at least provide more knowledge about these children and hopefully lead to effective interventions.

The research value of this study is that it provides a starting point for research into ways to help parents of schizophrenic children and to help those parents help their children. Little will ever be known about this population or effective interventions for them if research in this area is avoided because of the difficulties inherent in small group research. If other researchers with other similar groups of parents can replicate this study, perhaps more definitive statistical conclusions can be drawn. It is recommended that tools be further validated, concepts refined, and larger numbers gathered. Further, pre-intervention measures need to be assessed so that changes in levels of knowledge, distress, beliefs, worry, and fear can be monitored. As well, follow-up studies need be done to see if these levels change over time.

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Appendix A

PARENT INFORMATION SCHEDULE

Date	Topic
April 25	I. Introduction and overview of sessions. Schizophrenia: history, causes, jargon. The world of the schizophrenic child.
May 2	II. Treatment of schizophrenia: use of medications, other treatments.
May 9	III. The family and schizophrenia - the needs of the patient, the needs of the family.
May 16	IV. Common problems that patients and families face, school and community resources.
May 23	V. What the family can do to help - behavior management, routines, using professionals.
May 30	VI. Where do we go from here? Questions, evaluation of sessions, fill out questionnaires. Further resources. Friends of Schizophrenics.

Package I

GLOSSARY

AFFECT.	How a person feels (mood), such as angry, sad, happy.
AMBIVALENCE.	Holding two opposing ideas or feelings at the same time which keep a person from making reasonable decisions.
ATTENTION.	The ability to concentrate on a task.
AUTISTIC.	Thinking that completely disregards the environment and views the world from internal fantasies rather than on external realities.
BLOCKING.	Unexpected disruption of a person's train of thought.
CATATONIA.	This can be either a state of extreme agitation and overactivity referred to as catatonic excitement or motionless behavior called catatonic negativism.
CLANGING.	A form of communication where the sound of the word triggers the next words rather than the meaning. For example, "money, honey, funny...."
COMPULSIONS.	Repeated, senseless performance of actions accompanied by the feeling of not being able to stop the behaviors.
CONCRETE THINKING.	The tendency to take words literally and to attach limited meaning to language. Abstract or hypothetical reasoning is misunderstood and metaphors and jokes are misinterpreted or missed.
CONFABULATION.	Inventing facts or stories to cover up impairments in thinking or performance.
DELUSIONS.	These are fixed, false beliefs or ideas that are made from incorrect inferences from reality. They are maintained despite evidence to the contrary.

DEPERSONALIZATION.	The perception that something has happened to a person's body that results in feelings of change or sensations in body parts.
DISORIENTATION.	The inability to accurately identify the time, place, and name of the person being interviewed.
DISTRACTIBILITY.	The person's mind is easily diverted from the conversation by unimportant detail.
DYSTONIA.	Acute muscle spasms, often of the tongue, jaw, eyes, neck. These can be associated with the use of some psychoactive medications and can be relieved by medication prescribed for this.
ECHOLALIA.	The mimicking repetition of words.
ECHOPRAXIA.	Mimicking another person's movements.
EUPHORIA.	Exaggerated sense of well-being.
EXTRAPYRAMIDAL SYMPTOMS (EPS).	A variety of symptoms including muscle rigidity, tremors, drooling, shuffling gait, restlessness, muscle spasms.
FANTASY.	Imagined thoughts, wishful thinking.
FLIGHT OF IDEAS.	Thoughts and speech that occur in rapid succession and may be incoherent.
GRANDIOSITY.	Unrealistic feelings of great importance, exaggerated euphoria, and delusions of grandeur.
HALLUCINATION.	A false perception of the senses, not based on reality. The person experiencing these sensations believes they are real. a) Auditory hallucinations - hearing sounds or voices that are not there. b) Visual hallucinations - seeing things that are not there. c) Olfactory hallucinations - smelling odors that are not there.

d) Gustatory hallucinations - tasting things that are not there.
e) Tactile hallucinations - feeling something that is not there.
f) Somatic hallucinations - falsely feeling that something is happening to one's body.

HYPERACTIVITY.	Excessive physical activity.
IDEAS OF REFERENCE.	This occurs when a person feels that special events such as TV shows are referring to or have special meaning for him.
ILLUSIONS.	Misinterpretations of real sensory stimuli.
LABILE.	Unstable emotions.
LOOSE ASSOCIATIONS.	Speech in which ideas have very little or no relation to each other.
MAGICAL THINKING.	Thinking that indicates that a person's thoughts or actions will result in outcomes that defy logic or reality.
NEOLOGISMS.	Using words in a distorted manner, creating new words, or giving special meaning to standard words.
NEUROLEPTIC.	Medications which act on the nervous system and are used to treat mental disorders.
OBSESSIONS.	Ideas or thoughts or images that persistently intrude into consciousness.
PARANOIA.	Mental disorder featuring delusions of persecution and suspiciousness. The person may feel that others are "out to get" him or her.
PSYCHOTROPIC DRUGS.	Drugs that are intended to have an effect on mood, behavior, or experience.
PSYCHOSIS.	This term refers to a state in which a person is out of touch with reality and cannot distinguish real from unreal.

REALITY TESTING.	The ability to accurately distinguish the real from the unreal, to make sense of one's environment.
SCHIZOPHRENIA.	A major psychiatric disorder, probably with multiple causes, characterized by disturbances in content and form of thought, perception, affect, sense of self, willful action, relationship to the external world, and psychomotor behavior.
STEREOTYPY.	Purposeless movements which are repetitive and odd.
TANGENTIALITY.	A disturbance in interpersonal communication characterized by the person bringing up a point, getting off the track, and never making the original point.

SCHIZOPHRENIA

What Is It?

Schizophrenia is a brain disease which causes a disorder in thinking, feeling, and relating to others. "Schizophrenia" is a term used to describe a complex and extremely puzzling condition - it may be one disorder or it may be many disorders with different causes. Because of the disorder's complexity, few generalizations hold true for all people who are diagnosed "schizophrenic."

History

The term "schizophrenia" was first used early in the 20th century by a German psychiatrist named Eugen Bleuler. The name comes from a Greek word, meaning "split mind." It does NOT mean split personality. It describes a group of patients whose emotions and thoughts were often incongruent, for example laughter while describing a tragic event or smiling while speaking angry words. Bleuler described four major symptoms of schizophrenia:

1) Autism - a preoccupation with inner stimuli

2) Ambivalence - constantly conflicting emotions and ideas, for example "I love you, I hate you."

3) Loose Associations - constant switching from one subject to another which may be only very remotely related.

4) Disturbed Affect - emotions which are either blunted (flat) or inappropriate to the situation.
Symptoms such as delusions and hallucinations came to be emphasized later. They are often present early in the illness or during acute episodes and are called "positive symptoms" of schizophrenia because they are added to the person's usual range of feelings and behavior. "Negative symptoms" are subtractions from the person's normal range of feelings and behavior such as loss of interest, energy, warmth, or humour.

"Psychotic" means out of touch with reality, or unable to separate real from unreal experiences. Some people (especially adults) have only one such episode. Others have many episodes during a lifetime but lead relatively normal lives in between. The person with chronic (continuous or recurring) schizophrenia often does not fully recover normal functioning and typically requires long-term treatment, usually including medication to control the symptoms.

Who Gets It?

Approximately 1% (or 1 out of every 100) people develop schizophrenia during their lives. This means that approximately 20,000 Albertans will develop the disorder some time in their life. It occurs rarely in young children, perhaps 3 out of every thousand children under the age of 16 years. It is more common in male children but in adults it occurs equally among men and women. It occurs in all social classes. It is more common in families who already have a member with schizophrenia. The chances of a person developing schizophrenia are higher if one of their parents have schizophrenia, even higher if both parents have it or if the person has an identical twin who has it.

Schizophrenia in Children

Schizophrenia in children has been the subject of much professional debate and confusion. Some of the confusion came about because early psychiatrists used Bleuler's term "autism" and used it to describe some infants. There has been controversy ever since about the relationship of "infantile autism" to adult forms of schizophrenia. Only children with symptoms like those seen in adults are currently diagnosed as "schizophrenic." The schizophrenic child may resemble the "autistic" child during the first few years of life. But after the age of 5-7 years, the behavior of the schizophrenic child is more complex than that of the autistic child.

The diagnosis of schizophrenia at any age relies upon observing disordered thought and emotion. A positive diagnosis can only be made when language allows the presence of abnormal thought content (delusions or hallucinations) or abnormal thought processes (fragmentation of incoming information and loose associations) to be noticed. As a result of delayed and impoverished language development, a diagnosis in childhood can rarely be made before the age of 5 or 6 years. Males are far more likely to develop schizophrenia before puberty than females. The reasons for this are unknown.

The World of the Schizophrenic Child

Childhood is the period in life when schizophrenia can do the most harm. The earlier the onset, the more the illness can interfere with normal growth and development. The illness will have the most damaging effects if it comes on either before or shortly after speech develops. Young children who have learned a few words seem unable to learn more and often forget the ones they have already learned.

Schizophrenic children have many of their senses altered. The world of the schizophrenic child is not at all like ours. He or she may suffer distortions in perception of time, space, seeing, hearing, and of his or her own body. The intense hyperactivity of some young schizophrenic children may be the result of their distorted way of experiencing time. The repetitive questionning seen in almost all schizophrenic children may also be due to this distortion in time perception. Even though only seconds may have gone by, the child may experience the brief interval like the passage of many hours without his question being answered. The distortions in space relationships frequently produce strange ways of walking. The child may walk in a zig-zag pattern or with his legs high and wide. The child is often clumsy and has poor balance. Due to all these difficulties, these children often touch the walls as they walk along.

The schizophrenic child appears to be disoriented, confused, and anxious and often realizes he is confused. This can be more easily understood if you think of the brain in terms of a telephone operator sitting at an old plug type switchboard in the middle of your head. The switchboard operator receives all of the sensory input, thoughts, emotions, ideas, and memories coming in, sorts them and puts together appropriate combinations. Normally our brain would work to take the words of a sentence and sort them automatically into a pattern of thought. With a schizophrenic person, the switchboard operator may not put the proper combinations together, or she may not receive all the messages. The result may be that the child with schizophrenia will misunderstand what we see and hear very clearly. He may, therefore, have trouble recognizing people. When his hearing is distorted and disturbed, he may be unable to locate the sources of sounds and may, therfore, pay no attention to them. He is most often overly sensitive to sounds, yet at times may not even respond to loud sounds.

While the schizophrenic child can pay attention and be involved, he is usually inattentive and incapable of putting out effort over a long period of time. He may also show decreased reaction to painful situations or be overly fearful of everyday situations.

Schizophrenic children do have hallucinations. While these are often difficult to detect in children, they may report that pictures look real and may be afraid to be left alone because of this. Real people may look small or flat to the child. Their own body perceptions are also distorted; for example, children may report they feel like a stuffed animal or think that their legs disappear when they are in the swimming pool.

How Can I Tell If My Child Has Schizophrenia?

In order for a child to be diagnosed as having schizophrenia, he or she must have the following (check the Glossary for unfamiliar words):

A. The presence of (1), (2), or (3) over a period of time:
  (1) Two of the following:
    a. Delusions
    b. Hallucinations
    c. Incoherence

d. Catatonic behavior

e. Inappropriate affect or actions

(2) Bizarre delusions (for example believing he is being controlled by someone else, or someone is sending him thought messages)

(3) Prominent hallucinations

He or she must also have:

B. Significantly impaired functioning in normal life spheres (school, play, friends, family)

C. No other mental illness

D. Signs of the disturbance for at least 6 months with an active phase of at least one week and with or without a prodromal (before the active phase) or residual (after the active phase) phase.

Prodromal phase: A clear deterioration in functioning (or in children, failure to achieve the expected level of functioning) before the active phase (not due to mood disturbance or drug abuse). He or she may wander about the house, get little sleep, or have difficulty remembering what he or she was planning to do.

Residual phase: Following the active phase, persistence of at least 2 of the symptoms below:

1) Very noticeable isolation and withdrawal from other people.
2) Very noticeable impairment in functioning
3) Noticeably peculiar behavior
4) Deterioration in personal hygiene or grooming
5) Blunted or inappropriate affect
6) Strange speech patterns
7) Odd beliefs or magical superstitions influencing behavior
8) Recurrent illusions
9) Very noticeable lack of initiative, interests, or energy

E. No organic cause for this disease can be found.

What Causes Schizophrenia?

No one knows for sure what causes schizophrenia. There are a number of differing theories. Some of these are:

1. Genetic. Research shows that there is a genetic (inherited) component to schizophrenia. It is likely that a vulnerability of the brain may be inherited, but there is no proof that the disease itself is inherited.
2. Biochemical. People with schizophrenia appear to have brains which show structural and functional differences from normal. They particularly have abnormalities in the level of some brain chemicals called neurotransmitters.
3. Nutritional. There is no evidence that food, vitamin, or mineral deficiencies cause schizophrenia.

4. Infectious Disease. Schizophrenia is more common among people born in the winter months when viruses are common. More research is needed in this area.
5. Psychoanalytical and Family Interaction. There is NO support for theories that parent-child interactions cause schizophrenia. Modern studies have come up with a great deal of evidence that parents are NOT to blame for their children's illness.
6. Stress. There is no evidence that stress causes schizophrenia, although it can make symptoms worse as it can for many diseases.
7. Drug Abuse. There is no evidence that drugs can cause schizophrenia, but drug and alcohol use can make it worse. Psychosis caused by street drugs is not the same as schizophrenia but some of the symptoms are the same.

The most likey explanation is that some combination of genetic, biochemical, viral, and environmental factors must happen together for a person to become schizophrenic.

Package 2

TREATMENT

Information regarding treatment of schizophrenic children has been collected from a variety of sources and adopted from the literature on adult schizophrenics as there is a scarcity of information pertaining to children. While professionals working in the area of child psychiatry have made great strides in appreciating the course of the disease, treatment of schizophrenia focuses on the use of antipsychotic medications and on management of the child's psychosocial and educational environment.

The management of a schizophrenic child is a complicated and taxing undertaking for one is dealing with a family in which one member has a potentially lifelong disease. While many children with a psychotic disorder are admitted to hospital for either inpatient or daypatient treatment, the lifelong caretaking of the psychotic child is done by the child's parent or parents at home and interacting with community resources.

Often by the time the child is formally diagnosed by a child psychiatrist, the parents have had severe misgivings and worries regarding the lack of or erratic progress the child has made in his development. Frequently as a parent, you have sought consultation with professionals who in previous meetings may have given you a variety of diagnoses or interpretations of your child's behaviors. Included may have been hyperactive, mildly retarded, learning delayed -- labels which may have conferred more favorable connotations and outcomes. Some parents, mothers especially, will have felt something was wrong with their child as early as infancy and in presenting to doctors and other professionals were reassured the child will outgrow the presenting problems or were referred to a variety of agencies who were often not helpful. It is necessary to view symptoms within a holistic concept which considers the child's biological, intellectual, social, family, and academic attributes.

Treatment of the schizophrenic child must be tailored to individual needs. Strengths should be identified and whenever possible built upon to improve the child's self-esteem and to provide the child with a common base for interactions with other children.

Medications

One of the most important discoveries of this century was the finding of the antipsychotic drug known as Chlorpromazine or Largactil. Modifications of this chemical have led to the development of a number of similar antipsychotic drugs. For our purposes, the words "antipsychotic", "neuroleptics", and "phenothiazines" will be used to refer to the same group of medications.

How They Work

Antipsychotic medications are the most important and effective treatment for schizophrenia. Antipsychotic drugs exert their action by blocking the action of certain naturally occurring neurotransmitters, particularly dopamine, at receptor surfaces, limiting nerve impulse transmission. All antipsychotic medications interfere with dopamine in some way, but each different medication has different properties. They differ in their effect on other brain chemicals such as noradrenaline which may cause a sedative effect. First, effective receptor blockade results in a normalizing of brain arousal (where excited unfocused children can be calmed down and underactive children can be livened up a bit) and the correct focusing of attention to relavent environmental cues. Second, they also influence emotions in which there is a reduction in such symptoms as withdrawal, anger, paranoid ideas or depression. The third area influenced by antipsychotic medication is cognitive, in which there is restoration of perceptual functioning with a decrease in hallucinations, delusions, and disorganized thinking. Use of antipsychotic medication <u>influences</u> (rather than cures) a disease process as does the use of insulin in the treatment of diabetes.

There is currently little scientific evidence which predicts which schizophrenic child will respond best to which drug. Generally antipsychotic medication is prescribed by identifying target symptoms like disordered thinking, paranoid ideas, or hallucinations which will be diminished by a particular medication.

The type and dose of antipsychotic medication a child will respond to depend upon a variety of factors indicated over a period of time. Frequently, a doctor will chose on the basis of the side effects that a medication usually produces. Sometimes "depot" or long-acting medicines are used and are given weekly or every two weeks injected deep into the muscle and absorbed slowly over time. These long-acting medications are usually used in older teens and adults. Whether given as a liquid, a pill, or an injection, these medications must be taken for several days or weeks before the full benefit may be noticed. They must be administered regularly, as prescribed, in order to accurately determine their effectiveness.

The following are medications commonly prescribed to control some of the symptoms which interfere with the functioning of schizophrenic children: Stelazine, Largactil, Haldol, Mellaril, Trilafon, Neuleptil, and Orap. Generally, the medication's main action will be on the arousal level of the brain by producing a quieting effect in an excited psychotic child or conversely, a stimulating effect for unmotivated, withdrawn children, or to reassign attention to relevant stimuli in the environment, or for disturbances or distortions of emotions such as anxiety, apprehension, fears, anger, and suspicion which are interfering with the child's ability to function.

Antipsychotic medications such as Stelazine, Trilafon, and Haldol dissolve easily in the body fats and therefore doses can be low. Two milligrams of Haldol can have the same therepeutic potency as 100 milligrams of Largactil or 100 milligrams of Mellaril. Individual responses are variable and each person's medication type and dose have to be individually tailored and monitored if the child remains on medication over a period of time. The purpose of antipsychotic medication is not to cure the disease but to cause disruptive and troublesome symptoms to decrease or to go away all together and to allow the child to learn and grow to their best potential.

Positive and Negative Symptoms

One way of looking at the signs and symptoms of schizophrenia is to label them "positive" or "negative" symptoms. "Positive" symptoms are symptoms such as the hearing of voices (auditory hallucinations), severe agitation or bizarre behavior and aggressiveness and the symptoms having to do with overacuteness of the senses. Positive symptoms are more effectively diminished with medication than are negative symptoms. "Negative" symptoms are losses or absences, such as lack of interest in activities of others, lack of persistence, diminished ability to derive pleasure from peer interactions and limited range of emotional expression. These symptoms are less effectively treated with antipsychotic medications. Some success has been noted using antipsychotic medication which has a stimulating effect such as Orap.

Side Effects

Some common and minor side effects from treatment with antipsychotic medication include: tiredness, dry mouth, constipation, change in appetite, and fine tremors. Often these side effects are temporary and not distressing to the child. Usually supportive care such as increasing water consumption and attention to bowel routine and diet are sufficient to ease any discomfort. Common side effects that require informing the physician include: persistent oversedation, "extrapyramidal symptoms" such as mask-like face, tremor while at rest, drooling, shuffling walk, akathisia (extreme restlessness), pacing, feeling of jitteriness, continuous movements, dystonia (severe muscle spasms, difficulty swallowing, stiff neck, rotation of eyes upward, facial grimacing or protrusion of tongue), akinesia - immobility, weakness, decreased spontaneity of speech or gesture. Often it is difficult to determine if a side effect is being observed or if a symptom of the disorder itself is being manifested. If a side effect is evident, the doctor must be informed to determine if the medication dose needs adjusting or if a different antipsychotic medication might produce fewer side effects in a particular child. Photosensitivity, or hypersensitivity to sunlight, is troublesome especially if the child is on Largactil. Your child should wear a sunscreen and a hat to protect him or her from sunburn when outdoors. Urinary retention, if it persists, requires immediate medical attention and is more common early in treatment.

Tardive dyskinesia is a late appearing extrapyramidal effect which does not respond to antiparkinson drug treatment. These symptoms involve loss of coordination and are frequently grouped as follows:

1) Lingual - facial movements including tongue tremors, blinking of eyes, smacking and licking of lips, chewing and sucking motions of the mouth and tongue, facial grimacing. 2) Neck and Trunk - neck spasms, twisting movements of the trunk, hip-rocking movements.

3) Choreoathetoid Movements of Extremities - slow irregular movements of the hands and arms, peculiar and awkward walk.

Drugs to Relieve Side Effects

An antiparkinsonism drug (Cogentin or Artane) is often used to counteract some of the side effects of the antipsychotic drugs. Antiparkinson drugs are prescribed only when indicated and the doctor may wish to discontinue it if the side effects do not persist after treatment. This medication as well may have side effects, although not frequently, including agitation and confusion.

The decision to implement medication therapy is made by the child psychiatrist in consultation with the child's parents and often considering information from others involved in the child's life such as teachers. The weighing of potential risks with gains expected or realized must be considered. Abnormal movements are often present in schizophrenic children prior to drug treatment and must be differentiated from any that develop after treatment. In general, the lowest possible effective dose is prescribed for ongoing treatment. Some doctors may consider taking a child off antipsychotic medications for periods of time although there are also risks associated with this.

How Can the Family Help with Drug Treatment?

Compliance with taking the medication as it is prescribed is important. Not all children or adolescents take their medications willingly. Families are wise to have a firm but positive approach to a resistant child. Reasons for resisting vary from the child believing that the medication does not help (or perceiving it as harming him or her) to believing that it has helped so much that the child is "well" and no longer needs to take the medication. If families have concerns about the effectiveness of their child's medication or adverse effects from it, their doctor should be contacted. Families should understand the "target behaviors" that the medication is prescribed to alter, such as loose thinking, sociability, emotional lability, or preoccupation with inner stimuli, and collect information through daily observations and talking with the child's teacher or others involved about changes noticed in the child's behavior and functioning.

Learn about the medication your child is taking and what the dose is. Be aware of potential and actual side effects. Be alert to symptoms which may indicate antiparkinsonism side effects.

Not everyone on antipsychotic medications experiences side effects. Some side effects like constipation and drowsiness are temporary and will diminish or disappear with time. Other side effects are more serious and must be brought to the attention of the doctor right away. Prevention is the key here with the emphasis on ongoing monitoring which minimizes the risk of these important and beneficial medications.

PHENOTHIAZINES

Common Brand Names:

Largactil, Thorazine, Modecate, Moditen, Prolixin, Trilafon, Mellaril, Orap, Stelazine, Haldol

Used for:

These drugs are used to treat medical and emotional conditions.

Remember:

- KEEP ALL MEDICATIONS OUT OF THE REACH OF CHILDREN.
- Do not change the dosage or stop giving your child this medication without talking to your doctor.
- Sometimes this medication must be taken for several weeks before the full benefit is reached.
- If you miss giving a dose and the regular dosing schedule is one dose:

  Once a day
    - give the missed dose as soon as possible. Return to the regular schedule the next day.

  Two times a day
    - take the missed dose as soon as possible. If it is almost time for the next dose, skip the missed dose and return to the regular schedule.

  More than two times a day
    - if you remember within an hour or so of the missed dose, give it right away. If you do not remember until later, skip the missed dose and go back to the regular schedule.

  DO NOT double dose.

Side Effects which are common:

(Check with your doctor if these are bothersome)

- dry mouth may be relieved by sugarless candy or gum
- dizziness or drowsiness
- constipation or difficulty urinating
- blurred vision
- sensitivity to sunlight - be sure to put a good sunscreen on your child prior to exposure to sunshine.

Side Effects which are rare - Notify your doctor of these as soon as possible:

- difficulty in speaking or swallowing
- chewing movements of the mouth
- fainting
- loss of balance
- muscle spasms (especially of face, neck, back)
- stiffness of arms or legs
- skin rash
- unexplained sore throat or fever
- yellowing of eyes or skin

Drugs to avoid with this medication:

- Alcohol, including some cough and cold medications
- Over-the-counter sleep medications
- Antihistmaines (cold and hay-fever pills)
- Sedatives or tranquilizers (sleep medications or nerve pills)
- Prior to surgery (including dental procedures), notify the doctor or dentist that your child is taking this medication
- Discuss the use of ANY other medications with your doctor or pharmacist.

Name of your child's medication ____________________

Dose ____________________

Package 3

The Family and Schizophrenia

Schizophrenia is a serious illness that is likely to be chronic. It has "ups and downs", getting better or worse at different times but it does not usually go away. While it is fine to hope that your child will outgrow the illness, you must also realize that he or she probably will not. While no one knows the cause of schizophrenia, the best current explanation suggests a disturbance in brain function of unknown origin which leaves patients vulnerable to internal and environmental stimulation. Thus, they may react "badly" to any situation involving intensity (both positive and negative); in other words, most situations which are common in family life. Neither the positive symptoms (hallucinations, delusions) nor the negative symptoms (withdrawal, lethargy, lack of motivation) are willful misbehaviors, but are manifestations of the illness. There is NO evidence that families cause schizophrenia. While there is no cure for schizophrenia, it is possible to control symptoms making it possible for patients to learn and grow.

Why Families Need to Help

Schizophrenia, like any long term illness has an impact on everyone in the family. Schizophrenia is even more difficult for families to live with because its symptoms show up as behaviors which are difficult to live with and difficult to understand, and because society is still so ignorant about mental illness that it may often be regarded as embarrassing. When a family experiences the severe and chronic stress associated with living with this illness without help and support, its members will be less able to help the child effectively. They may also develop problems of their own -- such as marital conflict, acting out in siblings, and depression and/or physical symptoms in everybody in the family.

We (professionals who work with children who have schizophrenia and their families) have some understanding of what parents and families go through as they learn to live with and understand their children. The following are some common emotional responses that families have told us they experienced:

1. Anxiety and fear: This includes the feeling that something is NOT right with your child even before any diagnosis is made. Watching the sometimes strange and unexplainable behaviors of your child causes fear and anxiety about what is wrong and what will become of the child.

2. Guilt: Most parents lack knowledge about what causes the illness. They ask themselves what they have done "wrong". The guilt is often made worse by professionals who tell them that their child's problems are the result of ineffective parenting.

3. Stigma and embarrassment: These children often do have behavior which causes embarrassment in public situations. The situation is not much relieved when the diagnosis is finally made, because society has such an ignorant view of mental illness.

4. Frustration: Parents try everything they can think of to help their child and to understand his or her difficulties, while also trying to keep family life going day to day. Enormous amounts of energy are used up but nothing works consistently.

5. Anger: Anger is a normal response to chronic frustration. You begin to believe "this kid does this on purpose." You become angry at behaviors that are thoughtless, irritating, and perhaps dangerous. You may feel that your child does not "give back" to you what most children do.

6. Sadness: The pain and the plight of your child at times causes you great sadness.

7. Worry: You worry greatly over the future of your child who you know is not growing and developing as he or she should.

Common Behaviors of Families:

In trying to cope with the emotions that were just listed, familes often respond with the following behaviors:

1. Adapting and normalizing the situation: Families adapt their routine to accomodate the child's quirks. They constantly adjust the environment so that the child will be able to manage. They say to themselves and others that this is "just a stage" that the child is going through and that he or she will outgrow it.

2. Coaxing and reasoning: Parents try to convince their child that his or her unusual behaviors or ideas are unreasonable. Parents try to persuade their child to try things and to "act normal." Since there is no physical disability or readily identifiable reason, parents believe that the child's behavior must be in his or her control.

3. Making Sense out of Nonsense: Families try to guess what their child needs, wants, is afraid of, and make sense of his or her odd behavior.

4. Ignoring: Parents deny the significance and unusualness of the behavior. They hope the child will grow out of it and focus on other aspects of the child's life. Some parents delay taking the child to a psychiatrist for this reason.

5. Doing For: Parents take over responsibility for things the child should be able to do.

6. Providing Constant Supervision: Parents constantly watch to make sure the child does not do anything strange or embarrassing or get into a situation which the parent knows will cause difficulty.

7. Curtailing their own activities to care for their child: Parents begin to plan their life around their ill child. They give up their own activities because of difficulties finding babysitters, being too tired, etc.

8. Ignoring the needs of other family members: The ill child becomes the focus of the whole family's attention and energy. Siblings take responsibility for the ill child even when they are younger. Relationships deteriorate.

What the Family Can Do To Help

There are specific things that the family can do that will make things better for themselves and for the ill child. While professionals may be "experts" on schizophrenia and on patients and families in general, YOU are the expert on your family and your child. The coping techniques which follow have been found to be helpful by other families; however, some may not be appropriate or possible for you. You must be the final judge of what you should do.

1. Revise expectations. What you expect from your child can be temporarily modified -- decreased or increased to follow the ebb and flow of your child's illness. As stressors in other areas (eg. school) increase, expectations may be temporarily lowered at home.
For example, if your child is drowsy from a new medication, he or she might be allowed to sleep more. Change is slow. Use an "internal yardstick" -- compare behaviors this month to last month (not last year or next year or to other children). Improvement comes in inches not miles.

2. Create barriers to overstimulation. Where possible, decrease stimulation and stress. Minimize conflict and criticism between family members in general and toward the ill child in particular. Modulate the highs and lows of family interactions. Professionals refer to the amount of "expressed emotion" in families. Too much expressed emotion is difficult for people with schizophrenia to understand. Minimize nagging, rejection, fights and conflicts, but also the expression of extreme concern, encouragement, and enthusiasm. Avoid overinvolvement with the patient in either a positive or negative way. Overly praising the child is as stimulating for him or her as criticism. Your child still needs praise as do all children, but overdoing it confuses the child and leaves him feeling that he or she can never live up to the praise. Increase the involvement with each family member's own social network or sources of support or pleasure.

3. Set limits. Create reasonable rules. Low stimulation is NOT permissiveness. Because kids are ill does not mean you can or should do whatever they ask. Decide what minimal rules are necessary in your family. Priorize -- decide what is intolerable and what is only irritating. Never tolerate abuse. Set limits clearly without detailed discussion. Avoid the "why's". Use direct statements such as "That's not acceptable." Keep requests specific. Don't ask the

child to abstract or generalize from one situation to another. Don't give multiple requests or directions simultaneously. For example say "Your job is to take out the garbage on Monday and Wednesday" not "Why don't you help out more." Set limits before tension builds. Excessive anger is much less helpful to the child than calm limit setting. Don't go by the child's chronological age -- go by what you know the child is capable of. Avoid threats. Expect limits to be tested over and over. Sometimes schizophrenic children have to begin each situation like it was brand new. Feel free to admit that some limits are set for the needs of other family members. You have needs and rights too.

4. Selectively ignore. Never ignore violence. If other behaviors are only irritating rather than intolerable in your family, ignore the smaller things.

5. Keep communication simple. Encourage all family members to speak for themselves. Avoid assuming anyone knows what anyone else wants or needs without being told. Wait for your child to respond for himself even if it takes a while. Keep communication specific but avoid too many details or abstractions. Focus on and reward small positive behaviors.

6. Support the child's medication regime. Children will pick up your attitudes toward medications. Tell the child that "these pills will help you with your thinking ...or temper ...or voices" - whatever the medication is supposed to be helping. Explain to the child that the medication is still needed when he or she is feeling well in order to stay well.

7. Normalize the family routine. Try to avoid centering your life entirely around your ill child. Good parenting begins by taking care of yourselves. Maintain a support system for yourself, especially one that is outside your immediate family. Social contacts are useful as distractions from day to day stresses and also provide general support and recreation. Social contacts also makes it easier to divert the concentration of too much time and energy on your ill child. Social contacts can also help in times of crisis by providing practical support.

8. Learn to recognize signals of increasing stress in your child. By recognizing signals early you can avoid situations getting too overwhelming for your child.

9. Use professionals when you have questions or concerns.

Summary of Guidelines for Parents:

Do what you can to improve things.

Look for your own strengths.

Don't feel guilty about what you can't do.

Strive for good physical health -- good diet, regular exercise, pleasing environment.

Watch your own stress level --play cards, watch TV, take a hot bath, run, meditate, work in the garden, do whatever relaxes you.

Maintain social contacts.

Seek out the support of others who understand.

Continue to pursue your own interests.

Share what you've learned with others...there's a world of ignorance about schizophrenia out there.

Package 4

Common Problems That Patients and Families Face

Cognitive, perceptual, and behavioral characteristics, when viewed from a developmental disabilities perspective, overlap strikingly with conditions such as learning disabilities, sensory defects, mental retardation, and minimal brain dysfunction. Thus all parents have had a variety of professionals see their child by the time a diagnosis of schizophrenia has been made.

General Effects on the Parents

In addition to constant worry and anxiety, parents, in an attempt to cope, try not to think too far ahead but take each day as it comes. They experience many levels of sorrow and it is critical not to remain at the deepest level for too long. The tendency to be apprehensive of one's child forces the uncertain parent to do little, to live one's life around the child, not intruding or disrupting for fear of triggering an upset.

The fine line between burden and responsibility is reflected in the ambivalent feelings of wanting to be free and the sense of being needed.

Parents are hesitant to have more children once the illness has been diagnosed. Fear of having another ill child or of the amount of attention the ill child will need to receive, do not make decision making any easier.

Parents considering a move to a new area must have reassurance that appropriate services are available.

Parents often neglect their own lives in the time consuming role of raising a schizophrenic child. Parents, struggling by themselves, often blame each other for contributing to the problem or argue over the best discipline technique. In the early stages, they may argue over whether a problem even exists.

Siblings

The disproportionate amount of time given to the schizophrenic child increases the rivalrous feelings normally expressed by brothers and sisters. Unprepared siblings are at times burdened with caretaking responsibilities and have to develop a level of tolerance that may be unfair and unrealistic.

The brother or sister may have guilt over possibly being the cause or aggravating the illness. They may feel guilty that they have escaped the disease and are able to lead normal lives. They may worry that they will come down with it themselves. Embarrassment is another common and understandable feeling, especially prominent in the teen years when peer pressure and social concerns are at their peak.

Dealing With "Others"

For all families, dealing with the public means confronting ignorance or callousness, having to explain unexplainable behavior, suppressing anger and eventually developing a "thick skin," a sense of humor, or casual indifference.

Perhaps more stressful than the general public is the criticism and lack of understanding of relatives. These relatives, usually from good intentions, fully express opinions that often contribute to the parents' feelings of guilt and inadequacy. They underestimate the significance of the problem, impose their own attitudes and experiences freely, without accounting for the different circumstances and are usually not available when needed!

Parents of a schizophrenic child have or will become sensitive to the lack of services and inadequate community resources. Classrooms often reject their child because "he does not fit in."

The response from the "professional community" is sometimes less than adequate. In the search for a "cause," professionals have contributed to the parents sense of confusion and guilt by asking relentless questions and offering few answers.

Difficult To Accept

The most painful aspect of living with a schizophrenic child is perhaps that of the absence of normal human relatedness. These youngsters are often out of touch with the needs and feelings of others. For some parents, confusing and unnatural feelings develop towards the child. Warmth and affection are artificially maintained where detachment or cynical objectivity are more natural replacements. Parents are at a loss to interpret their child's attitudes and feelings and although certain they exist, it is impossible to determine what they are.

One of the saddest hallmarks of schizophrenia is the loss of pleasure. This means that joy, affection, desire, pride, humor -- all emotions that keep us going in life -- can become lessened, sometimes to such a degree so as to appear absent altogether. This will be difficult for parents to observe over time.

The most difficult symptom to treat is that of lack of initiative or motivation. All families experience the weight of responsibility for deciding how much of their child's life they must program. The tendency toward passivity, helplessness, and general non-interest on the part of the ill family member is an enormous physical and emotional burden that will not ease up over time.

The most common dilemma parents of a schizophrenic child find themselves in is that of discipline. Verbal warnings and reasoning -- techniques that work well with their other children seem to fall on deaf ears with the ill child. Parents vacillate between permissiveness and strictness more than usual. They worry that as difficult as it may be now when the child is young -- what will it be like when the child is older and physically bigger.

Expectations for the Future

The hardest task parents of a schizophrenic child must face is accepting the reality of the illness and modifying their expectations for the future.

There would be nothing the schizophrenic child could do to please the family more than to get well but that is beyond their control. Families will find it more helpful to lower their expectations. This is the first step in cutting the problem down to a manageable size.

For those parents who, through daily experiences, come to realize the seriousness of their youngster's cognitive and communicative impairments, the sadness and disappointment is often lightened by a sense of relief from the burden of over-expectations. A new-found pleasure can be found in observing accomplishments, however small.

With the decreased expectations come the parents' ability to change their roles somewhat. They become advocates for their child, seeking out more information, becoming more directed in their planning for the future.

Family Support Groups

The biggest single advance in coping with schizophrenia since the introduction of antipsychotic medications, has been the advent of family support groups. The group should include mutual support and education. The sharing of common experiences and problems is reportedly the most useful function. While many are available for adult schizophrenics -- there were none for the parents of schizophrenic children. This is an attempt to start such a group.

Package 5

Using Professionals

Parenting, at the best of times, is a difficult job. For all of us, it is full of frustrations, disappointments, and worries as well as pleasures and joys. These characteristics of parenthood are magnified when you are the parent of a schizophrenic child. Your child seems more vulnerable, the worries and uncertainties greater, and the emotions more intense. But just as becoming a parent of any child is an acquired skill, so too is parenting a schizophrenic child. In the process of acquiring this skill, nothing is quite as valuable as the support of knowledgeable, caring professionals. They can help you to keep things in perspective, help you to manage your child and deal with the "system," and give you reassurance that you are doing the right thing. They can share information and knowledge to help you understand. Learning how to use professionals is one of the skills you need in parenting your child.

Guidelines

1. Keep appointments. Keep all appointments with your doctor even if your child is doing well. Ongoing monitoring is important so that the doctor can see your child when he or she is doing well and not only when there are problems.

2. Phoning the doctor. When problems and questions come up in between scheduled appointments, you may need to phone your doctor. Many parents have difficulty deciding whether or not their worries are important enough to bother with. Follow your instincts --you know your child best and you have good judgement.

3. Notice how your child is functioning. If you think things are not going as well as they were, phone your doctor. Try to notice how things affect your child (eg. illness, holidays, family changes, medication changes).

4. Make connections with other knowledgeable professionals besides your doctor. Find a nurse or other professional who is knowledgeable about childhood schizophrenia with whom you feel comfortable to talk. This person can often answer questions and provide support more readily than can your doctor.

5. Write things down. Write down questions and observations that you want to ask your doctor about and write down the answers that he or she gives you. This helps you to collect your thoughts and lets you review what was said later.

6. Selecting professionals.

-Professionals should be a resource to you, your child, and your family. If you feel they are not, look for someone new. Select professionals who demonstrate through their actions a concern for you, your child, and your family.

-If a professional uses technical terms you don't understand, ask them to explain in simple English or ask them to give you an example. It is their job to help you understand.

-Professionals are people too. Be aware that they may feel threatened or defensive. Try to find ways to ask your questions that will minimize this problem, but don't hesitate to ask them. You have a right to have your questions answered. There will be questions which no one knows the answer to. Professionals should be able to say "I don't know." in these cases. If you ask your questions several different ways and you still do not feel they have been answered, consider changing professionals.

7. Know the "system."

-Discover sources of information and keep informed.

-Be persistent in your efforts to make the system respond to your child's and your family's needs.

-You are your own best advocate. In order to look after your own interests, be well-informed, stay involved, participate.

-Seek out and explore support groups and publications related to your child's needs.

-When gathering information, begin by talking to people you know --both professionals and non-professionals. Find out about support groups and information sources in your community and use them.

While there are limits to the influence that any of us will have on our children, you can make a difference: a difference in the services your child receives; a difference in their feelings about themselves and their place and importance in this world. Whether any of us end up making such a difference depends upon our skills, our knowledge, and our attitudes. The information shared with you over these last five weeks is an attempt to help us all make a difference.

Managing Symptoms

Schizophrenia, is for the most part, a relapsing condition. It makes good sense, therefore, to anticipate and plan for a return of symptoms. The time to be worried is when the person begins to behave in a way that first brought the illness to your attention or the way the person was in the acute phase of the illness. Each person has his or her own set of early warning signs. Some of these are increased irritability, uncontrollable moods, diminished ability to concentrate, difficulties in thinking, social withdrawal, increasing suspiciousness of others, and sleep disturbances. An acute phase of the illness can sometimes be precipitated by physical illness, stress, over-stimulation, or too many life changes. Recognized early, the progression of the illness can be stopped by a medication increase or change of medication, lowered expectations for a period of time, more rest, and increased structure in daily routines.

Schizophrenic children may hear, see, smell, taste, and feel things differently. These are often greatly distorted from the way they actually are. These symptoms are "real" for your child and one should not deny them or give the impression they are silly.

Symptoms

1. Delusions - management of delusions involves knowing not to argue about the logic or truth of the delusion, but to quietly repeat reality to the child. Accept the child's belief as his but let him or her know it is not true for you. Help the child feel comfortable and safe.

2. Visual Hallucinations - In children these are more troublesome at night with television and movies seeming to stimulate visual hallucinations. Children can be taught to ignore or look away. This is especially more successful toward adolescence.

3. Auditory Hallucinations - Sometimes a Walkman with soothing music or music the child likes helps to interfere with the thoughts and voices troubling the child. This sometimes helps at bedtime to encourage sleep.

4. Odd Behavior - Laughing out loud at nothing, talking to no-one in particular, and excessive silliness - probably caused by misperceptions of thought and feeling - can be managed simply by stating to the child to "Stop it!" They often can, though many may need to be reminded several times.

5. Depression - Symptoms of depression may be expressed as feelings of helplessness and hopelessness, listlessness, insomnia, lack of appetite, and perhaps lack

of desire to do anything at all. Thoughts of suicide are common and should not be ignored.

6. Anger - Anger is related to depression, unhappiness and fears. Try to be calm, clear, explicit, and predictable. Offer privacy for a period of time. Talk if you get a positive response - learn to be quiet if you don't. Threats of violence are unacceptable and should not be ignored.

7. Sleep Disturbances - These are common and should be monitored. Ask the child to go back and lay on the bed even if he or she cannot sleep. Try leaving on a light. The child should not be allowed to disturb others.

How To Behave Toward a Person Suffering From Schizophrenia

Kindly! In conversation be brief, practical, and nonjudgemental. Be patient. Expectations must be realistic and in keeping with the capabilities of the child. The ill child should be treated like everyone else in the family with modifications given during a difficult phase of the illness. If preferential treatment lasts too long, the ill child prefers it and the burdens of being well are just not worth it for them.

Keep routines simple and successful. Include regular and healthy meals, exercise, chores or responsibilities and a time away from home (ie. school and activities). Lack of motivation makes this simple statement difficult to put into practice, draining the energy of the caregiver. The strain of conversation sometimes panics these children and sometimes accepting their "just listening" is ok.

Parents' Responsibilities To Themselves

1. Accept what is happening. With acceptance comes a certain repose - a rest from doctor chasing, a rest from getting your hopes dashed again and again. Give up the secret search for the mistake you believe you must have made that caused your child to have schizophrenia.

2. Keep up your social life. Friends are good medicine. Get involved in support groups so you have people to talk to who understand.

3. It _is_ possible to be happy. Freedom from triviality is one great gift given to those who have suffered a lot. Incurable does not mean untreatable! Take care of yourself.

Vocational and Educational Issues

The decision to tell or not to tell your child's teacher of a diagnosis of schizophrenia may confront you at some point during your child's school years. You probably will have mixed feelings about this, realizing the lack of accurate information available to school personnel and the misperceptions which may be attributed to your child's illness. There is no one correct way to handle this dillemma. With fluctuations which naturally occur with the schizophrenic child affecting his or her abilities and possible hospitalizations, it is most likely that the child's diagnosis will need to be made known to your child's teacher and other personnel in the school. The diagnosis of schizophrenia must be accompanied with information so school personnel are not overwhelmed and may approach your child in an informed, helpful manner. In some situations, a change of school may be necessary.

Parents of a schizophrenic child probably have established a relationship with personnel in their child's school born out of concern for the child and his erratic performance at school. It is essential to convey an attitude of constructive concern and one of working with your child's teacher for the child's well-being. You are your child's best and most powerful advocate. You know your child and how he or she responds to emotional, social, and academic situations. Knowledgeable teachers know how your child fits into the classroom, relates peers and authority figures, responds to group situations, follows instructions and achieves academically. Your child will do better when the teacher and parents work together to provide and respond to the varying needs of your child.

Most schizophrenic children will require a small classroom placement and some classrooms may require an aide to provide the structure needed. Resources continue to dwindle and may not be available in smaller communities.

In discussing classroom expectations and management with your child's teacher, the following may be useful:

1. Common problems of the schizophrenic child in the classroom. Often this child is lacking in social awareness and this gets him or her into trouble with peers. He or she may ignore peers or he may incorporate them into his grandiose schemes and attempt to order them around. Such a child finds it harder than most to keep his workspace organized. A schizophrenic child may be "too talkative" or "too quiet." Clear feedback or efforts to "draw the child out" may alleviate this. Whenever possible, identify and work on strengths which the child has. Pair the child up with another child in the classroom who is capable or tolerant.

2. Fluctuations - expect "good and bad days". It is essential for both the welfare of the child and the salvation of the teacher, that it is recognized that a schizophrenic child goes through certain phases. For example, he or she may be able to work industriously for long blocks of time - 9:00 - 10:30 for 4 or 5 days and then, without any apparent reason, it all becomes too much for him and he will resort to tears, or simply look into space and do nothing. After a period of time with this youngster, the teacher will know when he has one of these down days. Remove the pressure by giving him a task that is not demanding but will enable him to continue working along with his classmates.

3. Teaching Strategies.

-Schizophrenic children need structure.

-Daily schedules should be as consistent as possible.

-Seatwork should be organized in a binder so that it can be contained.

-Do not overload the child with 20 questions when you can find out desired information using only 10. eg. Math - 10 problems will tell you what you need to reteach - 20 will only tell you that he is too tired to function at top level.

-The child may have both a short attention span and a tendency to perseverate or become stuck on an activity. Switching from one activity to another may be easier if the child is given advance warning, "In 10 minutes we will do...."

-Because a child demonstrates good ability to read, do not assume he understands the content. Ask questions related to content to assure he understands and is able to use the information he reads. He will find it difficult to do abstract tasks or make inferences.

4. Home/School Issues

-Before the child begins each part of his homework, ask him to tell you what he is expected to do. If instructions are obviously incorrect, do not argue with him. This only agitates him. Inform the teacher of the problem and perhaps a homewrok plan could be devised wherein the instructions rarely vary.

-Inform the teacher if the child is experiencing great difficulty, either in sleeping, eating, playing, or doing homework.

-If the child is not feeling well his performance will not keep pace with his usual abilities.

-The child may experience difficulty keeping up with his peer group in sports due to motor and perceptual problems.

5. Future Educational/Vocational Concerns

-If the child demonstrates a specific skill, eg.working in the garden, art, cooking, computers, etc. then encourage this and seek information from special schools regarding their expectations and opportunities for students.

-Usually such children find it almost impossible to concentrate in a large setting and with a frequent change of caretakers - so check out school placements and find out how many children are in the class and how many different teachers he or she will have to work with.

6. What Can Parents Expect Academically or Vocationally From Their Schizophrenic Child?

It is not possible to predict academic abilities in the future. The child who is stabilized on medication and manages to achieve at or about grade level throughout school generally has a better chance of post secondary education. Motivation is often a problem. The lack of structure, large size of classes, and abstract nature of learning material of post secondary facilities is often difficult for a schizophrenic adolescent or young adult to manage.

Vocationally, the young adult usually does better in a small or isolated work environment. The schizophrenic adult may work better with machines, like computers, which respond in a predictable and consistent manner. The need for human interaction is greatly reduced and the schizophrenic adult is less stressed when around as few as possible people. He or she will not cope well with deadlines or competition.

Many schizophrenic adults are never able to enter the competetive work force and for these people a sheltered work setting may be required.

If parents of schizophrenic children seek out other parents within their community they may give each other much needed support and as a group they are more likely to succeed in their efforts to establish community based vocational programs for their schizophrenic children. Collectively parents can join other mental health interest groups to lobby government bodies for funding for residences and vocational opportunities.

Package 6
Good Books About Schizophrenia

Anderson, C., Reiss, D., & Hogarty, G. (1986) Schizophrenia and theFamily. New York: Guilford Press.

Andreason, N. (1984) The Broken Brain. New York: Harper & Row.

Birchwood, M., Hallett, S., & Preston, M. (1988). Schizophrenia:An Integrated Approach to Research and Treatment. New York: Longman.

Cantor, S. (1982). The Schizophrenic Child. Montreal: Eden Press.

Families of the Mentally Ill Collective, (1986). Families HelpingFamilies: Living with Schizophrenia. New York: Avon.

Fuller Torrey, E. (1988). Surviving Schizophrenia: A Family Manual. (Revised edition). New York: Harper and Row.

McElroy, E. (Ed.) (1988). Children and Adolescents with Mental Illness: A Parents Guide. Woodbine House.

Seeman, M., Littman, S., Plummer, E., Thornton, J. & Jeffries, J. (1982). Living and Working with Schizophrenia. Toronto: University of Toronto Press.

Tsuang, M. ( ). Schizophrenia: The Facts. Toronto: Oxford University Press.

Tsuang, M. & Vandermey, R. (1980). Genes and the Mind: Inheritance of Mental Illness. Toronto: Oxford University Press.

Walsh, M. ( ). Schizophrenia: Straight Talk for Families and Friends. William Morrow Co.

These books may be available from or may be ordered from:

University Hospital Bookstore
Wm. MacKenzie Health Sciences Centre

Le Bookstore
7 Perron St.
St. Albert
459-2525

Audrey's Books
10702 Jasper Ave
423-3487

Greenwood's Bookshoppe
10355 Whyte Ave.
439-2005

Most of these books are available in paperback.

Appendix B

Family Distress Scale

Regarding (your child) __________'s behaviour today or in the past few weeks:

	Not at all	Sometimes	Often	Almost Always	Does not Apply
1. How much trouble has ______ been at night (being noisy, wandering about, etc.)?	☐	☐	☐	☐	☐
2. Has ______ been a nursing problem (i.e. bedridden, incontinent, needing to be bed or bathed)?	☐	☐	☐	☐	☐
3. Has ______'s safety been a source of worry (for example wandering off by himself, using the car, etc.)?	☐	☐	☐	☐	☐
4. Has ______'s behaviour caused you to fear for the safety of others?	☐	☐	☐	☐	☐
5. Has ______caused any difficulty by being unco-operative?	☐	☐	☐	☐	☐
6. Does ______ represent a strain by relying and depending on you or people in the home too much?	☐	☐	☐	☐	☐
7. Has ______'s constant restlessness, noisiness or talking been upsetting to you or the family?	☐	☐	☐	☐	☐
8. Has ______'s frequent body symptoms or complaints worried you?	☐	☐	☐	☐	☐
9. Has ______ been a problem because of sexual, rude, or objectional behaviour?	☐	☐	☐	☐	☐

	Not at all	Sometimes	Often	Almost Always	Does not Apply
10. Has _____'s behaviour caused you any embarrassment because he speaks or behaves oddly?	☐	☐	☐	☐	☐
11. Has _____ caused any trouble with the neighbours?	☐	☐	☐	☐	☐
12. Is your household work or routine upset by _____?	☐	☐	☐	☐	☐
13. Are the social or leisure time activities of the family interfered with because of _____?	☐	☐	☐	☐	☐
14. Has anyone in the household had to stay away from work because of _____?	☐	☐	☐	☐	☐
15. Has anyone in the household had to stay away from school because of _____?	☐	☐	☐	☐	☐
16. Has _____'s behaviour caused you much worry? (overall)	☐	☐	☐	☐	☐
17. Has _____ been a physical strain on you?	☐	☐	☐	☐	☐
18. Does _____ require excessive amounts of attention or companionship?	☐	☐	☐	☐	☐
19. Are the children ashamed because of _____?	☐	☐	☐	☐	☐
20. Are the children afraid of _____?	☐	☐	☐	☐	☐

	Not at all	Sometimes	Often	Almost Always	Does not Apply
21. Do you feel ashamed because of _____?	☐	☐	☐	☐	☐
22. Are you afraid of _____?	☐	☐	☐	☐	☐

Appendix C

Knowledge Questionnaire

Please check the appropriate box or boxes. There may be more than one appropriate answer.

1. Who can become schizophrenic?
    - a) anyone
    - b) only adults
    - c)only people with personality disorders
    - d) only pgople with rejecting mothers
    - e) dont't know

2. Schizophrenia in children is:
    - a) unheard of
    - b) rare
    - c) more common than in adults
    - d) very common
    - e) don't know

3. I you are a child of someone who has schizophrenia, the chances of you also having schizophrenia are:
    - a) the same as onyone else
    - b) higher than anyone else
    - c) lower than anyone else
    - d) 100% definite
    - e) don't know

4. Symptoms of schizophrenia may be made worse by:
    - a) physical illness
    - b) stress
    - c) overstimulation
    - d) stopping prescribed medications
    - e) don't know

5. Which of the following are common symptoms of schizophrenia?
    - a) hearing voices
    - b) lack of energy
    - c) incontinence
    - d) delusions
    - e) headaches
    - f) irritability
    - g) loss of appetite
    - h) lack of or inappropriate emotions
    - i) sleep problems
    - j) overactivity
    - k) withdrawal
    - l) difficulties with thinking
    - m) don't know

6. Which of the following are <u>negative</u> symptoms of schizophrenia?
   a) hearing voices
   b) withdrawal
   c) lack of emotion
   d) lack of energy
   e) thought disorder
   f) delusions
   g) irritability
   h) don't know

7. A <u>positive</u> symptom of schizophrenia is:
   a) A symptom that is definitely due to schizophrenia and not due to anything else.
   b) A symptom that is used to diagnose schizophrenia.
   c) When something is added to a person's normal behavior.
   d) When there is a loss from a person's normal behavior.
   e) don't know

8. When schizophrenic symptoms reappear and/or get worse this is called:
   a) relapse
   b) omission
   c) remission
   d) prolapse
   e) don't know

9. Medications help most for what kind of symptoms:
   a) positive
   b) negative
   c) neutral
   d) both positive and negative
   e) don't know

10. The main medications given to remove schizophrenic symptoms are called:
    a) antihistamines
    b) narcotics
    c) neuroleptics
    d) tranquilizers
    e) don't know

11. If a schizophrenic patient is taking his medications he should:
    a) Take them only until symptoms disappear.
    b) Take them until advised otherwise by his doctor.
    c) Take them only when he feels he needs them.
    d) don't know.

12. Which of the following may be associated with the onset of schizophrenic symptoms:
    a) too much stress
    b) poor diet
    c) inability to get angry and express feelings directly
    d) runs in the family (genetic)
    e) biological problems, body chemicals
    f) personality type - just that kind of person
    g) a split in the personality
    h) family problems when the patient was a child
    i) an upsetting experience, loss of an important person
    j) don't know

13. To help the person recover from schizophrenia, the family should try to:
    a) leave the person alone.
    b) try to get him to do things for himself.
    c) do as much for the person as possible.
    d) encourage him to do whatever he can.
    e) let the patient do whatever he wants.
    f) not burden the patient with any household tasks.
    g) ensure that he takes his medication.
    h) decrease stimulation in the environment if necessary.
    i) don't know

14. To help themselves, the family should:
    a) leave the person alone.
    b) talk about their difficulties with friends.
    c) try to forget about their problems and difficulties.
    d) get out doing things and seeing friends.
    e) help the patient as much as possible but make sure to keep their own hobbies and interests.
    f) put all their time and effort into helping the patient.
    g) ignore the patient and get on with their lives.
    h) don't know.

15. If you notice side-effects of the medication that your child is taking, you should:
    a) wait to see if the side-effects go away.
    b) ask the doctor's advice.
    c) stop the medication altogether.
    d) take a lower dose of the medication than prescribed.
    e) don't know.

16. The cause of schizophrenia is probably:
    a) genetic
    b) birth problems
    c) virus
    d) stress
    e) some combination of the above factors
    f) don't know

17. Schizophrenia in children is the same as autism.
    a) true
    b) false
    c) don't know

18. An accurate diagnosis of schizophrenia can only be made after children's language has developed enough to allow the presence of disordered thought (age 6-7 years).
    a) true
    b) false
    c) don't know

19. Females are more likely than males to develop schizophrenia as children.
    a) true
    b) false
    c) don't know

20. Approaches which have been found to be helpful for patients with schizophrenia include:
    a) medications
    b) psychoanalysis
    c) special education
    d) vocational training
    e) family support and education
    f) behavior management
    g) don't know

Appendix D

Beliefs, Worry, Fear Scale

Please place an X in the blank which applies for you. Where the question says <u>(Child)</u> imagine your child's name.

	Not al all	A little	A moderate amount	A considerable amount	A great deal
1. The family can help the patient to get better.	____	____	____	____	____
2. Treatments for schizophrenia are effective.	____	____	____	____	____
3. <u>(Child)</u> will improve in the future.	____	____	____	____	____
4. The control that <u>(Child)</u> has over his symptoms is	____	____	____	____	____

	Never	Rarely	Somet-times	Most of the time	All of the time
5. I feel I have cause to point out or criticise <u>(Child's)</u> faults or behavior	____	____	____	____	____
6. I find myself thinking and worrying about <u>(Child)</u> during the day	____	____	____	____	____
7. Regarding <u>(Child's)</u> behavior at home, to what extent do you feel afraid? (for you or your family's safety or property?)	____	____	____	____	____

Appendix E

Evaluation Form

In order to provide better service to parents, your answers to the following questions would be most valuable.

To what extent did the group...	Not at all	Very Little	Somewhat	Quite a Lot	Very Much
1. Provide you with "moral support"	☐	☐	☐	☐	☐
2. Provide you with opportunity for problem solving with others	☐	☐	☐	☐	☐
3. Help you understand your child's illness and treatment	☐	☐	☐	☐	☐
4. Make you feel you are not alone in your concerns and experiences	☐	☐	☐	☐	☐

Regarding this group:

1. The aspect(s) that has (have) been most helpful to me was:

2. Something(s) I would like to see changed is (are):

3. In general, this group can help parents by:

4. Any additional comments you would like to make:

5. Do you wish to be contacted by the nurse-researcher regarding any questions or concerns you have?
yes no
If yes, please write in your name and phone number:

Appendix F

Evaluation Form

In order to provide better service to parents, your answers to these questions would be most helpful.

Regarding these information packets:

1. The aspect(s) that has (have) been most helpful to me was:

2. Some thing(s) I would like to see changed is (are):

3. In general these information packets can help parents by:

4. Any additional comments you would like to make:

5. Do you wish to be contacted by the nurse-researcher about any questions or concerns you have?
   yes   no
   If yes, please write in your name and phone number:

Appendix G

Summary of Comments to Open-Ended Questions

Comments from Group 1 (Group):

1. What did you find most helpful about this program...

   - "moral support of others - knowing we are not alone"
   - "knowledge of the disorder"
   - "learning about the disease - I know now what I'll be facing in the future and I think I'll be able to deal with it"
   - "hand-outs are very good - can be re-read... discussions help to know you're not alone"
   - "communication between nurses and parents and each other"
   - "having and learning the material, learning we are not alone and there are ways of helping our son by hearing what other parents have tried. I've also enjoyed the company of the nurses and their support and understanding"
   - "parents could share their feelings and problems"

2. What thing(s) would you like to see changed about this program...

   - "nothing"
   - "longer, on-going program"
   - "public perception of schizophrenia"
   - "more time for interchange of problems and solutions"
   - "more hospitals so they're there when needed"
   - "to see films or videos"
   - "involve other family members"

3. In general, this group can help parents by...

   - "providing education to the public - government and school boards"
   - "understanding what parents are going through"
   - "fight the government for more money for the things these children need"
   - "good support"
   - "more of these types of get-togethers"
   - "letting people know they are not alone and there is help"
   - "providing information and a place to ask questions and get resources"
   - "being there with information and someone knowledgeable to talk to"
   - "discussing problems"

Comments from Group 1 (Group) continued

4. <u>Additional comments...</u>

   - "more interaction with the doctors would be good"
   - "hospital or other body should organize meetings on an on-going basis"
   - "I'm very glad to have been a part of this group. It has helped me move through the grieving process toward acceptance"
   - "I am thankful I was in the group rather than receiving the information by mail"
   - "would like to see the group continue"
   - "We enjoyed the sessions and look forward to continuing"

Comments from Group 2 (Mail-Out):

1. The aspect of these information packets that was most helpful to me was...

   - "overview in plain language"
   - "Nice to have something in writing to go back to at one's convenience"
   - "in-depth information"
   - "information on how to behave around the sick child"
   - "having the reports to give relatives to read"
   - "very informative and easy to read"

2. Some thing(s) I would like to see changed are:

   - "group meetings would have been better...to provide support"
   - "after reading, I became depressed for awhile...more emphasis on the positive"
   - "a monthly meeting along with pre-read information so parents could clear up questions and doubts"
   - "more support groups"

3. In general these packets can help parents by...

   - "overview of problems so effective management can be developed"
   - "helping parents to understand the disease process and how to deal with the child"
   - "learning how to cope with the problems"
   - "easing guilt and prepare them for helping other people understand the child"
   - "giving information which is often not done in a doctor's office...I feel hurried when the waiting room is full"

4. Any additional comments...

   - "information packets are very suited for giving parents just after their child is diagnosed - this would be a good place to start"
   - "good program - keep it up"
   - "the hardest hurdle parents have is overcoming guilt and learning to stop asking why us? Learning there is no one to blame and only positive action will improve homelife so we don't hide ourselves from life, which will only hinder the total family"
   - "the information helped to relieve a lot of worries - I wish there were more support services"

Appendix H

Letter Sent to Prospective Subjects

Dear Parent:

My name is Kevyn Rosenthal. I am a nurse working in Child Psychiatry and am currently enrolled in the Masters in Nursing Program at the University of Alberta. As my thesis research, I conducting a project entitled "The Effect of Context on Information Giving for Parents of Schizophrenic Children" to look at two ways which information about schizophrenia and its treatment can be given to parents of schizophrenic children.

I have asked four child psychiatrists to contact parents of their patients for me. I am looking for parents of schizophrenic children aged 14 years or less in September. If you would be interested in helping me by volunteering to participate in my study, you would be randomly assigned (like in a lottery) to receive information by one of two methods.

Method One would consist of meeting with myself and other parents once a week for six weeks for about 1 and 1/2 hours in the evening. During this time basic information about schizophrenia and its management and treatment would be discussed and parents could also offer support and information to each other.

Method Two would consist of parents receiving the same information by pamphlets mailed to their homes once a week for six weeks.

At the end of the six weeks, you will be asked to fill out an evaluation of the method you received and its effect, if any, on your family. The questions are written and would require 30 - 45 minutes of your time. All information will be kept completely confidential. You may phone me during or after the study with any questions or concerns you have. At the end of the study you will be asked if you wish to be contacted regarding any questions or concerns you might have at that time.

If you agree to participate, you will not be able to choose which group you are in; this will be determined by chance alone. However, participants of both groups will receive information which they will likely find helpful. Many of the parents I have worked with over the years as a nurse in Child Psychiatry have asked for information like this.

Your participation is voluntary and parents in either group who wish to drop out of the project at any time may, of course, do so freely.

If you would be willing to participate and/or if you have any questions regarding this study, please contact me. You may feel free to phone me at work at 477-4636 during the day or at home at 458-2127 evenings. My supervisor at the University is Dr. Terry Davis, R.N. and you may also contact her with any questions or concerns at 432-8167.

Thank you very much for your help. Your participation in this study will contribute to a better understanding of how to provide helpful information to other parents in similar situations.

Kindest regards,

Kevyn Rosenthal,
R.N., B.Sc.N.
University of Alberta

Appendix I

Informed Consent

PROJECT TITLE: The Effect of Context on Information Giving for Parents of Schizophrenic Child

RESEARCHER: Kevyn Rosenthal, R.N., B.Sc.N., M.N. candidate
Faculty of Nursing, University of Alberta

PHONE: 477-4636 (work) 458-2127 (home)

SUPERVISOR: Dr. Terry Davis, R.N., Ph.D.

PHONE: 492-8167

PURPOSE OF THE STUDY:

We know that parents of schizophrenic children ask for information about schizophrenia and its treatment. We don't know what the most helpful ways are to give them this information. I will be studying two ways of giving this information to parents.

PROCEDURES:

Method One will consist of parents meeting with myself, another nurse, and other parents for six weeks for about 1 and 1/2 hours in the evening. During this time basic information about schizophrenia and its management and treatment will be discussed and parents can also offer support and information to each other.

Method Two will consist of parents receiving the same information by pamphlets mailed to their homes once a week for six weeks.

At the end of the six weeks, you will be asked to fill out an evaluation of the method you received and its effect, if any, on your family. You will also be asked to answer multiple choice questions about the information you learned. The questions are written and will require 30 - 45 minutes of your time.

If you agree to participate, you will not be able to choose which group you are in; this has been determined by chance alone. Participants of both groups will receive information which they will likely find helpful.

PARTICPANT'S STATEMENT:

RISK:

I understand that there will be no known health risk to me resulting from my participation in this research.

CONFIDENTIALITY:

I understand that the information which results from this research will be kept completely confidential. I understand that the information may be published or presented in talks, but my name will not be associated in any way with the research.

VOLUNTARY PARTICIPATION:

I understand that my participation is voluntary and that if I wish to withdraw at any time, I may do so freely.

I have been given the opportunity to ask whatever questions about this research I desire, and all such questions have been answered to my satisfaction. I understand that if I have any questions or concerns during the research project I may contact either the researcher or her supervisor.

THIS IS TO CERTIFY THAT I,____________________________
HEREBY AGREE TO PARTICIPATE AS A VOLUNTEER IN THE ABOVE NAMED PROJECT.

____________________________ Participant

____________________________ Researcher

____________________________ Date