

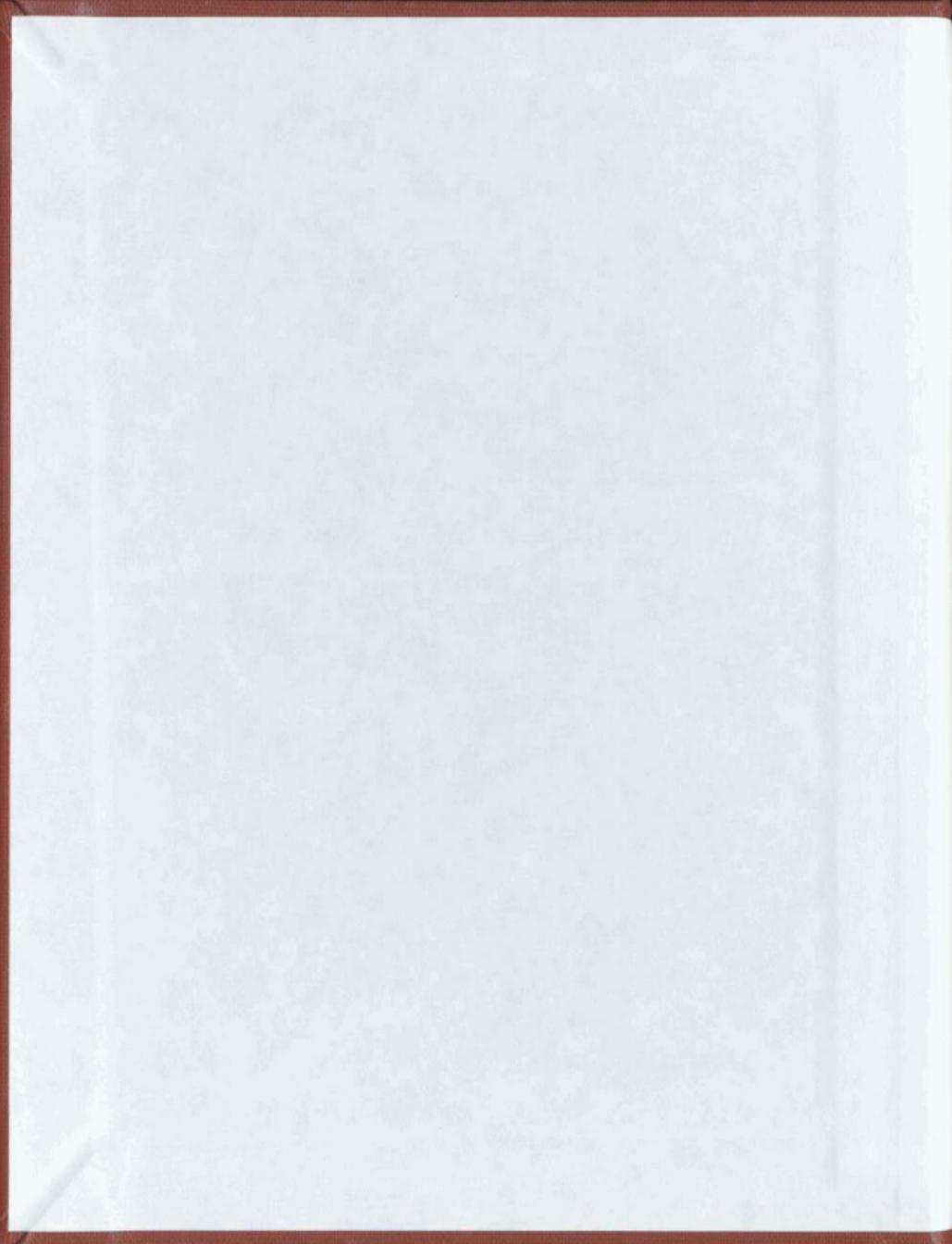
PSYCHIATRISTS' AND SOCIAL WORKERS' DISCLOSURE  
PRACTICES WITH REGARDS TO THE  
DIAGNOSIS OF SCHIZOPHRENIA

CENTRE FOR NEWFOUNDLAND STUDIES

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Psychiatrists' and Social Workers' Disclosure Practices with Regards to  
the Diagnosis of Schizophrenia

BY

© Mary A. Smyth, B. A. , B. S. W.

A thesis submitted to the School of Graduate Studies in partial fulfillment  
of the requirements for the degree of the Master of Social Work

Department of Social Work  
Memorial University of Newfoundland  
May 1989

St. John's

Newfoundland



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## ABSTRACT

Psychiatrists' decisions regarding disclosure of the diagnosis of schizophrenia have implications for social work practice as well as for patient and family treatment. Ongoing controversy still exists on how disclosure of this diagnosis should be handled.

This descriptive study examines Newfoundland psychiatrists and social workers who work in psychiatry as to what they report on their practices of disclosure, their opinions, and the various factors that influence them in this area. Sixty-three respondents representative of both populations were given personal interviews utilizing an open-ended semi-structured questionnaire. There was one hundred per cent participation.

The study reveals that the practice of disclosure is not uniform among psychiatrists and social workers. Some psychiatrists generally disclose to all of their patients, some to a portion, and a few are refraining from revealing the diagnosis. Similarly, not all social workers disclose the diagnosis of schizophrenia to patients. Over half of the workers require participation in relation to disclosure from psychiatrists when working with uninformed schizophrenic patients.

Some notable examples of the many factors which influence psychiatrists and social workers include: the certainty of the diagnosis, patients requests for the diagnoses, the degree of social stigma, the activity of the psychosis, the patient's ability to understand, and individual

patient characteristics.

A diversity of issues were raised relating to disclosure; some of these include: the patient has a right to know his/her diagnosis, there is more than one illness lumped under the classification of schizophrenia, some patients prefer euphemisms to the term schizophrenia, knowledge of diagnosis allows patients and their families to increase their educational and therapeutic opportunities, social work's role is affected when patients do not know, it is important, when revealing, to consider "where one's client is at", revealing often reduces the blame for patients and their families, and revealing can at certain times be countertherapeutic.

Overall, the psychiatrists and the majority of social workers believed that under most circumstances the psychiatrist should be the individual who reveals the diagnosis of schizophrenia but that this does not preclude other trusted individuals (including social workers) revealing or being present when disclosure occurs.

This study concludes that disclosure is a complex phenomenon and is only a small part of educating patients about their schizophrenic illnesses. Ultimately, each case needs to be examined individually as to whether disclosure should occur, how it should be handled, and who is the most appropriate person to disclose the diagnosis and follow up the disclosure.

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This thesis would not have been as interesting nor as rich with quotes if it was not for the willingness and candidness of the Newfoundland psychiatrists and social workers who work in psychiatry.

My warmest love and appreciation is held for my devoted husband, Dr. Brian Robert Mirtle, for his encouragement in completing this thesis.

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## FORWARD

Whether or not psychiatrists disclose the diagnosis of schizophrenia to patients has implications for social work practice and intervention. This study explores Newfoundland psychiatrists' decisions to disclose and how their decisions affect the practice of social work.

Psychiatrists' disclosure of the diagnosis of schizophrenia has been observed as not being uniform. Certain schizophrenics are not being told their diagnoses of schizophrenia (Green, January 1984; & Appleton, 1972). (For the sake of clarity and readability, the term "schizophrenic" has been used as a noun even though the author has discomfort with this usage.) There has been controversy over the subject of disclosure in the profession of psychiatry (Kudler, 1984), and there have been no specific guidelines for revealing the diagnosis of schizophrenia in Mellor's (1980) explanations and elaborations of the Canadian Medical Association Code of Ethics for psychiatrists.

The decision to disclose the diagnosis of schizophrenia has implications for patient treatment. Having psychiatric patients believe they are suffering from "bad nerves", or "nervous breakdowns", for example, may result in keeping them unaware of their diagnoses. If patients are unaware and social workers do not disclose the diagnoses then the opportunity for the social workers to engage in patient education is diminished. Knowledge of diagnoses can also be essential for

individuals who require certain resources (Green, January, 1984), for example, 'Friends of Schizophrenics'. The decision to disclose the diagnoses also has implications for the treatment team, including social workers. If psychiatrists do not tell patients of their diagnoses then the entire treatment team that is involved with the patient may be required to engage in this nondisclosure. Nondisclosure could entail social workers having to engage in much circumlocution in discussing problems symptomatic of the syndrome. At times, with more confrontational patients, this can be a difficult task. It is also possible that dealing with patients who are unaware of their diagnoses at times requires special skills.

Dilemmas exist within the decision to disclose the diagnosis of schizophrenia. Schizophrenic patients' diagnoses can be shared with community agencies at the time of the referral into programs. If patients are unaware of their diagnoses then this situation raises ethical issues and places social workers in a dilemma. Other dilemmas arise when social workers attempt to "foster maximum self-determination on the part of their clients" (Canadian Association of Social Workers, 1983, p. 108); nondisclosure runs contrary to this value. (The term psychiatric social workers is not being utilized in this study since not all social workers interviewed had received specialized academic training in psychiatry.)

In deciding whether or not to disclose the diagnosis of schizophrenia, psychiatrists could be faced with various treatment-

related, legal, cultural, ethical, and situational questions. For example, Will patients understand the diagnosis? Is the diagnosis of schizophrenia always clear? Will disclosure be traumatic to some patients? Will the patient suffer additional distress from the stigma associated with the disorder? Should the therapeutic privilege be exercised? Could the diagnosis at a later date be proven inaccurate? Do patients have a right not to know? Will the diagnosis convey hopelessness to the patient? Will not revealing deny patients access to resources, deny them the ability to be self determining, and diminish their trust in psychiatrists? Based on the above considerations, psychiatrists make decisions regarding disclosure. While psychiatrists' disclosures impose certain constraints on social workers' interventions with patients, psychiatrists' nondisclosure necessitates a decision by social workers as to whether or not they should disclose. Their decisions regarding disclosure also have associated constraints on their interventions.

How individual psychiatrists resolve the issue of disclosure has implications not only for themselves but for the profession of psychiatry, the patients concerned, their families, and the other professions and agencies who deal with people with schizophrenic illnesses. Knowing how psychiatrists have resolved this issue may enable social workers and psychiatrists to better work together and to provide more effective service to schizophrenic individuals and their families.

## LITERATURE REVIEW

### Background Information

#### Epidemiology of Schizophrenia

Schizophrenia is a mental disorder from which one out of every one hundred individuals will suffer at some point in time (Seeman, Littman, Plummer, Thornton, & Jeffries, 1982). In 1986, the global estimate of the number of individuals with schizophrenia was 40 million (Confronting Myths, 1986). In Canada in 1978, the prevalence of schizophrenia was 200,760 (8.55/1000 population); the prevalence for males was 120,941 (10.36/1000 population) and for females was 79,819 (6.76/1000 population) (Bland, 1984). The Health Research and Statistics Division of the Department of Health, Government of Newfoundland and Labrador, has collected data on the numbers of patients discharged from all hospitals in Newfoundland and Labrador who were given the primary diagnosis of schizophrenia. The classification system on which this data is based is the World Health Organization's International Classification of Disease, Ninth Edition (ICD-9). At the time of this study in the one year period of 1986 - 1987 there were 540 patients discharged with the primary diagnosis of schizophrenia of which 362 were males and 178 were females. Included

within these figures were 2 female residents of Newfoundland who were treated and discharged outside of the province. <sup>1</sup>

The illness occurs in both sexes and makes its appearance most commonly when individuals are in their early twenties (Seeman, Littman, Plummer, Thornton, & Jeffries, 1982). The illness occurs in all walks of life and has shown itself through symptoms that may be acute or may remain for long periods (Seeman, Littman, Plummer, Thornton, & Jeffries, 1982). Schizophrenia shows cultural variability in its manifestations. There is considerable variability in the outcome of this illness.

Schizophrenia: about one-quarter of all persons having a schizophrenic first episode recover and never have a recurrence (despite careful diagnosis) and an additional quarter have a favorable outcome: thus about half do quite well. About 10-20% have a "very unfavorable" outcome and an additional 10-20% have an "unfavorable" outcome for a total of about 30% with an "unfavorable" to "very unfavorable" outcome (Bland, 1984, p. 244).

Schizophrenia is a costly illness both in terms of health care expenses and the enormous loss of wage-earning capacity in affected individuals. For example, the appraised costs of persons with this illness living in the United States in terms of hospitalizations, loss of income, expenditures on welfare benefits, et cetera lie somewhere between ten to twenty billion dollars per annum (Torrey, 1983). It consumes "more hospital beds than cancer, heart disease, diabetes, and arthritis combined" (Walsh, M. 1985, p. 39). Demographically it is the most expensive out of any of the chronic diseases, since the individual

remains well throughout the years of rearing and education, then becomes ill and often dependent on society just at the point where he/she would become a contributing wage earner" (Torrey,1983, p.3).

This illness presents no small health problem, is the source of a great deal of suffering for afflicted individuals and their loved ones, and is of great significance for professionals working in the field.

#### Diagnostic Criteria Used to Define Schizophrenia

The definitions of and diagnostic criteria for schizophrenia have been numerous; examples are: Schneider's First-Rank Symptoms, Feighner's Criteria, and Research Diagnostic Criteria. The most highly recommended classification system was that of the "Diagnostic and Statistical Manual of Mental Disorders (DSM-III)" (Mezzich & Slayton,1984). DSM III has now been revised to DSM-III-R which has been in circulation since 1987. Junek (1983) conducted a study of the diagnostic classifications chosen by psychiatrists and found that 42% of psychiatrists chose DSM III as a system that should be used in the future while 16.3% chose the International Classification of Diseases, Ninth Edition (ICD 9). At the time of Junek's (1983) research the Canadian Psychiatric Association had not chosen any particular classification system for psychiatrists in Canada to use. A variety of classification systems have been in use in Canada for diagnosing schizophrenia. Newfoundland, according to Junek , has authorized the use of the ICD-9.

### Knowledge and Theories Pertaining to Schizophrenia

Over the years there have been numerous theories and hypotheses generated about this very enigmatic illness. Knowledge about schizophrenia has been growing and in recent years it has not been uncommon to find some professionals falling behind this knowledge (Torrey ,1983).

Torrey (1983) summarized the current state of knowledge on schizophrenia, stating that it is a brain disease(s), that there are qualitative differences in the brains of those individuals suffering from schizophrenia as compared with normals, that the limbic system and its connections in the brain appear to be the areas affected, that there is a familial trend to the illness, and that the insult(s) responsible in some cases may be followed by a lag period of several years before symptoms appear. In recent years, it has become more apparent that schizophrenia represents several diseases with varied causes, manifestations, courses, and outcomes (Torrey, 1983) which are herein for convenience' sake subsumed under 'schizophrenia'.

Etiologic explanations of this illness have produced a spectrum of often overlapping theories; these include: psychoanalytical, family- interactional, social, diathesis-stress, biochemical (dopamine and nutritional theories), genetic, infectious disease (viral), and structural (hypofrontality) theories (Torrey, 1983). In addition, a current theory which has particular relevance to this study has been that of Expressed

Emotions (EE). This theory operates from the viewpoint that schizophrenic patients have deficits which result in their being sensitive to particular environmental stresses. High levels of certain expressed emotions in families have been shown to increase relapse rates of recently discharged schizophrenic patients (Kanter, Lamb, and Loeper, 1987). (For more information on the theory of Expressed Emotions, refer to Appendix A).

With the recent advances in radiologic imaging techniques and other research tools such as the CAT Scan (Computerized Axial Tomography), MRI (Magnetic Resonance Imaging), CBF (regional Cerebral Blood Flow), PET scan (Positron Emission Tomography), and BEAM (Brain Electrical Activity Mapping), there has been a corresponding increase in the understanding of abnormal brain functions in schizophrenia and a strengthening of the position that it represents a biological entity (Taylor, 1987). Thus, psychiatrists' and social workers have shifted away from the viewpoint of schizophrenia as a problem in patients' psychosexual developments or as an outcome of family systems. Rather than providing "psychotherapeutic treatments for the victims" (Taylor, 1987, p.118) and therapy for the families, mental health workers have been providing rehabilitation for afflicted individuals, with the assumption that others cannot be talked out of physical infirmities, only supported with information (Taylor, 1987). With the present theories and factual information about schizophrenia, it is possible that more

information is currently shared with patients and their families by professionals and that this includes patients' diagnoses. Schizophrenia's etiology is not clearly known but is thought to include a "variable combination of genetic predisposition, biochemical dysfunction, and psychosocial stress" (Bellack, 1984, p. ix). Despite controversy about the etiology of schizophrenia, some agreement exists about two aspects pertaining to its etiology: that it is probably not a single clinical entity and that it is highly unlikely there will ever be one method of treatment for the disorder.

#### Treatment Approaches for Schizophrenia

As various etiological views about the disorder evolved so did various ways to treat the disorder. The many treatment approaches for schizophrenic patients include: 'psychopharmacology', inpatient treatment and 'community support programs' (drop-in centers, transitional living programs), 'social skills training', 'problem solving training', 'psychotherapy', 'group therapy', and 'family therapy' (Bellack, 1984), 'psychoeducation', and 'vocational rehabilitation', (Anderson, Reiss & Hogarty, 1986), or a combination of some or all of these.

The psychoeducational approach is a model for intervention with patients and families which has been somewhat successful in reducing relapse rates by providing more education, support, and partnership with the families and patients than other forms of family therapy. The

approach aims to educate families on the best ways to interact with ill family members (Hatfield, Spanoil, & Zipple, 1987). They are taught the theories and known factual information about the causes of schizophrenia, the signs and symptoms of the illness, the various treatments, and practical suggestions for coping with the disorder (Kanter, Lamb, Loeper, 1987). Because all individuals providing care are subject to similar emotions, some professionals are using the psychoeducational approach with care-providers in residential settings such as group homes, jails, et cetera (Drake & Oscher, 1987).

The psychoeducational approach of Leff and associates (1982), attempts to directly reduce families' high levels of Expressed Emotions (EE); that of Falloon and associates (1985), indirectly tackles families' levels of EE, provides education, support, and other interventions with the aim of facilitating a better understanding, less criticism and frustration (cited in Kanter, Lamb, & Loeper, 1987). The psychoeducational approaches have demonstrated comparable results (Kanter, Lamb, & Loeper, 1987) and have been provided by a range of professionals working in the field of mental health, including psychiatrists and social workers.

Work with schizophrenics and their families has now taken the form of providing "psychosocial education, social skills training, the resolution of grief and guilt, community assessments, advocacy, and the acquisition of resources, all of which constitute the rehabilitation model"

(Taylor, 1987, p. 118).

In summary, there is a wide range of available treatment approaches for schizophrenic individuals with a potential for multiprofessional involvement.

### Psychiatrists' Responsibilities

A comprehensive treatment approach for schizophrenia requires multidisciplinary collaboration of the various mental health professions (Bellack, 1984). Patients initially may come to the attention of various professionals and be referred to a psychiatrist with admitting privileges in a general and/or a psychiatric hospital. Most psychiatrists operate from the medical model, diagnosing the patient so as to guide their therapeutic approach (Appleton, 1972).

According to Eliot Freidson, within the health care system the medical profession has been "dominant" and the other professions have not been allowed, without medical approval, "to communicate anything of significance to the patient about what his illness is, how it will be treated, and what the chances are for improvement" (Freidson, 1970, p. 141). The ancillary team members have handled patients' questions about their illnesses by suggesting that they approach their physicians. Physicians, for various reasons, have not always given their patients extensive information either about their illnesses (Freidson, 1970) or about their diagnoses (Appleton, 1972; Anderson, Reiss & Hogarty, 1986). However,

in the researcher's review of the literature, a trend has appeared over the past ten to fifteen years indicating that physicians have been giving increasing consideration to the release of information pertaining to patients' diagnoses, including disclosure of the diagnosis of schizophrenia.

#### No Specific Guidelines

In deciding whether or not to disclose the diagnosis of schizophrenia, psychiatrists have no specific established guidelines for disclosure of this and other diagnoses; authorities in this matter have been the World Psychiatric Association's ethical guidelines, the "Declaration of Hawaii" (British Medical Journal, 1977), the Canadian Medical Association Code of Ethics (Canadian Medical Association, 1982), or Mellor's explanations and elaborations of the Canadian Medical Association Code of Ethics for psychiatrists (Mellor, 1980).

Bleich (1983), in a "Letter to the Editor", maintained that psychiatrists are supposed to share all of the facts about patients' illnesses but that this does not include confronting patients with diagnoses if these are not specifically requested. He advocated physician discretion in these matters because different cases need different approaches and thus different decisions as to whether or not to tell diagnoses. While psychiatrists have resolved this issue to suit the situation, there are several factors, namely: consent, therapeutic

privilege, and patients' right to know, all of which play an important role in decisions about disclosure of diagnoses.

### Consent

Consent is an issue in situations involving a 'fiduciary' relationship where a contract for professional service exists (Culver, & Gert, 1982). A patient's consent to any treatment given by a doctor is a very basic human and legal right. Various aspects of consent applicable to the area of disclosure of diagnosis must ideally be present in order that the consent can be considered valid: " [it] must be voluntary" (with exceptions), "the patient must be told the nature and risks of the treatment, of not having treatment and of any alternative treatments [if, in fact, any do exist]" (informed consent), and "the patient must have the mental capacity" (competent and able to understand the outlined treatment) (Rozovsky, 1980, p. 34-36).

The cases that have been presented before the Canadian courts where consent has been questioned have operated on the premise that the doctor should have told the patient what 'a reasonable person', defined by the judge, would want to know (Rozovsky, 1980). What this implies is that the patient must be informed of anything a rational individual would want to know and as well of anything that might affect his/her personal decisions (Culver, & Gert, 1982).

Patients are not seen as incompetent solely on the grounds of

mental illness (Litz, Meisel, & Roth, 1977). Culver & Gert (1982) maintained that the overwhelming majority of psychiatric patients, even if psychotic, are quite competent to give informed consent, can appreciate that there is something wrong with them, and are capable of understanding the nature of their illnesses and available treatment alternatives.

#### Therapeutic Privilege

An exception to the complete disclosure of information that is required by informed consent laws has been the legal doctrine of physicians' 'therapeutic privilege'. This privilege has allowed physicians to disclose or underdisclose based on what they consider "sound medical judgment" (Beauchamp, 1983). Thus, psychiatrists have decided whether or not to reveal schizophrenic patients' diagnoses based on how they felt their patients would react to this information and hence what was best for patients' welfare.

#### Patients' Right to Know

This is the "age of consumerism" (Hoffman, 1981) and an important principle in medicine is the patient's right to know about his/her illness including his/her diagnosis (Green, Jan, 1984). This right to know is an ethical, moral, and, in certain circumstances, a legal right, although the latter is difficult to enforce. Canadians have been advocating for a

document similar to 'The [American] Patient's Bill of Rights' which is supposed to act only as a guide but uses legal jargon and could be enforced in a court of law (Rozovsky, 1980). The American bill recognizes that a personal relationship between the patient and his/her psychiatrist is essential for the provision of "good care"; it specifies that the patient or, when indicated, "an appropriate person on his behalf" has a right to receive from his/her physician understandable, updated information pertaining to all aspects of his/her illness, including his/her diagnosis before any diagnostic or therapeutic intervention (Rozovsky, 1980, p. 2)

Given the medical and psychiatric codes of ethics, the consent laws, the physician's therapeutic privilege, and the 'Patient's Bill of Rights', the psychiatrist can use discretion based on his/her medical judgment in determining whether or not to disclose the diagnosis of schizophrenia to the patient. If the patient is incompetent or temporarily incompetent then, according to the (American) 'Patient's Bill of Rights', the psychiatrist must disclose the patient's diagnosis to "appropriate [people] on his behalf" (Rozovsky, 1980, p. 2).

#### Responsibilities of Social Workers who work in Psychiatry

Social workers who work in psychiatry often function as members of multidisciplinary teams within general and psychiatric hospitals. In 1905, Dr. Richard Cabot, a Boston physician, first assigned a social worker to work in a hospital. The duties of the early social workers

corresponded to what physicians believed patients required (Adelson & Leader, 1980). Thus, hospital social work had its beginnings by having to rely completely upon the acceptance and support of physicians (Adelson & Leader, 1980). This fact "has created a significant legacy which actively affects current practice [of social work]" (Mizrahi & Abramson, 1985).

The Second World War reduced the numbers of psychologists and psychiatrists, giving social workers the opportunity to provide psychotherapy. Social workers in large numbers practiced in psychiatric hospitals beginning in the early 1940's. "Their analytically-oriented graduate school training was acceptable to the psychiatric profession and their proven competence as practitioners in the private family agencies underscored their value to psychiatric hospitals" (Adelson & Leader, 1980, p. 777). After the war, social workers emerged as necessary members of the multidisciplinary team, of which the psychiatrist was the leader.

Over the last few decades, psychiatrists' hesitancy to become involved with families allowed social workers to expand in this realm (Adelson & Leader, 1980).

Affecting social workers' approach with patients has been the civil rights movement (Adelson & Leader, 1980) and more recently the push for the Patient's Bill of Rights in the United States. This has led social workers and other professionals to give more acknowledgement and respect to patients' rights to be active in the decisions which affect and

influence their courses of treatment (Maluccio,1979, Proger & Tanaka 1980 cited in Grob, Eiser. & Edinburg 1983). There are other influences on the role of social workers in the hospital. For years, medical and psychiatric staff have approved and recognized social workers but a good portion of the administrative decisions in hospitals have been made outside of social work departments (Adelson & Leader, 1980; Falck,1978). This is, in part, an outcome of social workers having been employed in an "ancillary service" in a "host setting" which "creates complexities and conflicts to the social worker's role". "Therefore the social worker must function within an authority system that tends to place his/her profession in a subordinate position and forces it to constantly affirm the professional responsibilities it has a right to assume" (Chan, Ostrov & Yaji, 1976, p. 15).

Social work has accommodated to the medical setting by allowing the physician to have the primary control of the patient, by tolerating the medical model, and by functioning in a highly specialized mode utilizing crisis interventions (Mizrahi & Abramson,1985). Social work's autonomy has been affected not only by the limitations placed on workers by physicians and administrators, but by the way social workers define their functions.

Carrigan (1978) suggested taking outside forces that influence social workers' roles into consideration and accepting that it is imperative that social workers educate others as to what they are capable and

desirous of doing. Falck stressed the importance of social work clinicians having an accurate understanding of what their profession is about and hence the nature of their role, for "If one does not know his discipline, he has nothing to be interdisciplinary about!" (Falck,1978, p. 399).

The purpose of social work in the health system has been to expand the coping abilities of patients and their families as they encounter life-threatening and problematic health conditions (Caputi,1982). Social workers in hospitals, whether they work in medical or psychiatric areas, have provided the link between patients and the community (Adelson & Leader, 1980). Discharge planning has always been viewed as one of the primary roles of hospital social workers (Mailick & Jordon, 1977).

The role of social work is illuminated when it is examined against that of medicine. Falck (1978) described the difference between social work and medicine as being one of differing emphasis: social work emphasizes persons in their environments rather than their illness. Illness, from a social work perspective, is a social matter, not a medical one. Social workers are trained to perceive individuals as persons who suffer from illnesses as only one of many potential problems (Falck,1978). Social workers are to ensure that equal attention is given to social and psychological factors in patients which are influenced by illness and which influence illness. Social workers employed within psychiatry may interview patients by themselves but perceive patients in

terms of their interactions with other individuals, their family, social network, and the community; this approach is less individualistic than medicine. Psychiatry may have overlapping features with social work and medicine. Falck suggested that attending to the social situations of persons is really doing social work. The "problem formulation and interventions rest on clear understanding of social causes, social manifestations, and social intervention as group phenomena" (Falck, 1978, p. 395). Social workers maximize their patients' functioning abilities in their social situation (Falck, 1978). This can be done through advocating behalf of the patient a more rounded approach (Gerhart & Brooks, 1983).

Various authors have maintained that social work's role should include assisting patients to access the services of physicians psychiatric or otherwise. Bartlett (1961) also maintained that social workers should strengthen the patients' relationships with their physicians and the other team members. She advocated that social work should enhance what other professions have to offer. An article written by S. Blatterbauer, M. J. Kupsy, and J. Schulman (1976) suggested that consumers of the health care system need to learn how better to deal with physicians and, when physicians are inaccessible, how to access the other professions. Social workers have been seen as able to educate these consumers as to how to best utilize the system.

Caputi (1982) stated that it is social workers' role to identify problems of communication that exist in the medical model and to create a means whereby the health professions will increase patient involvement in the decision-making pertaining to treatment. Caputi put forward a "quality of life model" to be carried out by social workers working in health settings which would stress improved communication between the professions and their patients. This model assumed that patients' abilities to cope effectively may be dependent on the amount of information they receive pertaining to their medical and psychosocial conditions and the associated consequences. One of the indicators of the quality of care that patients receive is how smoothly the professions function together. Caputi maintained that the traditional medical model has created barriers to communication because physicians are the only individuals who are to divulge information relating to patients' medical conditions. Social workers under this model would communicate only medical and psychosocial information to patients. Caputi felt that her quality of life model addressed the limitations of the medical model by interceding within the traditional roles and relationships of health professionals and enhanced the care provided to patients by the entire health team.

Professionals working with the mentally ill require all the knowledge they can obtain (Falck, 1978; Gerhart & Brooks 1983). Gerhart and Brooks (1983) asserted that social workers working in the role of

advocates need to understand the mentally ill and how patients' illnesses alter their abilities to make decisions. Gerhart and Brooks (1983) also made the extreme recommendation that social workers become knowledgeable about antipsychotic medications, traditionally the realm of physician-psychiatrists, so that they can advocate on behalf of patients the types of medications patients should be receiving. These authors' view of the social work role differs from that of Bartlett (1961) who maintained that social workers should not become over-concerned with technical medical knowledge, such as symptoms, differential diagnoses, and techniques of treatment, but that they should be more concerned with aspects of the general course of illnesses, their major causes, manners of progression, prognoses, and how these aspects affect the psychosocial factors of patients' lives.

Prevailing theories of mental illness also influence the role of social workers in hospitals. The shift from the psychosocial to the biological view of schizophrenia has affected the practice of clinical social work. Taylor (1987) suggested that social workers must have up-to-date information pertaining to the practice of biological psychiatry since

This information is particularly important to social workers who must offer psychosocial education to families, participate in diagnostic workups, and develop treatment plans for families and individuals with schizophrenia. Assisting families to relieve their guilt, understand the illness, reduce the stress they experience,

and to mobilize their resources are major tasks of social workers (Taylor 1987, p. 115).

The recommendation has been made that social workers encourage families to continue to be involved with schizophrenic patients and to provide "parental" support and supervisory functions for them (Taylor, 1987). He stated that families are most often the best resources for the provision of diligent care for patients; one reason for that has been the limited community resources for schizophrenia. Furthermore, Taylor proposed that patients should reside in situations which optimize quality of life for both them and their families and which allow for necessary support from families to assist in the reduction of hospitalizations. Most families are willing to improve their adeptness in helping family members and to augment their home environments; however, Creer, a British social worker, found that mental health clinicians rarely acted upon families' appeals for detailed education to assist them with their interactions with their schizophrenic family members (cited in Taylor, 1987).

Citing the accumulating evidence against psychotherapy in schizophrenia, Taylor recommended that social workers should assist with patients' and families' rehabilitation from the illness, a component of which should be psychosocial education. The psychoeducational model discussed earlier operates on the premise that the more information families have about schizophrenia, its course, symptoms, management, long term outlook, et cetera, the better they will cope (Anderson, Hogarty,

& Reiss,1980). This model has advocated the disclosure of the diagnosis; it has been used by social workers in assisting families of schizophrenic patients to cope (Gantt & Green,1985; Anderson, Reiss, & Hogarty, 1986). Gantt and Green (1985) found that social workers had problems implementing the psychoeducational model since they were reluctant to tell diagnoses to patients and families.

Although social workers in hospitals are mainly concerned with the psychosocial aspects of patients' conditions, some work in psychiatric emergency settings where they utilize the classification system outlined in the American Psychiatric Association's Diagnostic and Statistical Manual, Third Edition (DSM III) to assess, diagnose, and arrange appropriate treatment under psychiatric supervision (Walsh, S., 1985). Because, in these situations, they are diagnosticians of the whole range of psychiatric illnesses, including schizophrenia, their role could conceivably encompass releasing diagnoses to patients. The practice of social workers revealing the diagnosis of schizophrenia when they themselves are not the principal formulators of the diagnosis raises questions regarding risks and benefits. This issue becomes contentious if social workers are to be the first professionals to ever tell patients their diagnoses. This study will attempt to provide more information on these points.

In summary, social work has evolved in the hospital system where the scope of what social workers can do for patients and their families

has been broad: assisting with discharges, ensuring that patients are not seen solely in terms of their illnesses, emphasizing psychosocial aspects of the care of patients and their families, and, in the case of schizophrenia, assisting mental health teams in educating patients and families about this illness and in some cases diagnosing the illness and giving emergency care.

The Concept of the Multidisciplinary Team in Psychiatry: Social Workers, Psychiatrists, and Disclosure

An important change in the care of psychotic patients has been the advent of the antipsychotic drugs which have enabled more patients to reside in the community and for longer periods. More areas where social workers could intervene with patients opened up as a consequence of the deinstitutionalization movement which emerged concomitantly (el-Guebaly, 1984). Team work grew out of an evolving mental health field and is a concept that, according to el-Guebaly, psychiatry borrowed from Child Guidance. Along with other developments, psychiatrists began to interact with various other professions which then began filling the demand for service. Psychiatrists had the foresight to see the demand for other health professions, enabling them to 'flourish' (Roberts, 1985). Where psychiatrists began to act as consultants, staff ratios changed with an increase of other professional groups (el-Guebaly, 1984). The leadership of the team has traditionally been assumed to be the role of

the physician (Lowe and Herranen, 1978; Bartlett,1961). Various viewpoints have existed as to the usefulness of teams; some have proposed that team work may even further discombobulate care and make its accomplishments difficult while others have countered that better use of team work is required in the face of the fragmentation of existing service (Dyer,1977; Feiger and Schmitt, 1977; Kane, 1975; Rae-Grant and Marcuse, 1968; cited in Lowe, & Herranen, 1981).

Naomi Brill defines the team as a group of people each of whom possess particular expertise; each of whom is responsible for making individual decisions; who together hold a common purpose; who meet together to communicate, collaborate, and consolidate knowledge, from which plans are made, action determined and future decisions influenced (Brill,1976, p. 22).

Teams are used differently depending on environmental factors, their leadership (Lowe and Herranen,1981), their purposes, et cetera. Psychiatrists' relationships with other professionals could be "supervisory, administrative, consultative, collaborative, or instructional" (el-Guebaly ,1984, p. 164). Psychiatry has a close association with a few professions and social work is one of those professions (el-Guebaly,1984). Team members, in order to be effective, need to deal with the problems of the patients and " not to ensure the appropriate place in the sun for various professions" (Roberts, 1985, p. 149). Effective teams must rely on the knowledge and skills of their members and must be able to orchestrate in a productive manner to set and fulfill the specific goals through good leadership. Team members must be able

to communicate effectively the knowledge they have that is not available to the other members (Roberts,1985). Clinicians are required to "step in and out of a variety of roles" (Mailick and Jordon,1979, p. 450). Within teams the roles and functions of the various professions from time to time overlap. This blurring of the division of labor can create conflict (Lowe & Herranen, 1978).

In relating to the purpose and to reach goals, team participants are influenced by their own "internal expectations" about the functions of other members and in turn they are also influenced by their team- mates' expectations as to how each group member should operate (Lowe & Herranen,1978). The different professions within health care teams view advocating on behalf of patients as their primary role although psychiatrists' choices or expectations as team leaders carry more weight (Abramson, 1984). Teams cannot function with individual members functioning independently; their efforts must be coordinated (el-Guebaly,1984).

In the "Position Paper" written for the Canadian Psychiatric Association which outlined a protocol for interacting with "allied non-medical" professionals, el-Guebaly stated that the

diagnosis of a patient's condition is a mandatory prerequisite for proper treatment. The psychiatrist through his medical education and training is the only one competent to formulate a differential diagnosis and from this to develop a protocol for the investigation, rational therapy and rehabilitation of each patient (el-Guebaly, 1984, p. 166).

The position paper went on to state that

in medical settings, such as hospitals, the physician-psychiatrist retains the primary medical responsibility, based on his training and established law and custom, for the admission, diagnosis, treatment, rehabilitation, and discharge of patients. In non-medical settings, such as social agencies, the psychiatrist retains the ultimate psychiatric and medical responsibility only for those patients whom he serves as primary caretaker (el-Guebaly, 1984, p. 166).

The position paper suggested that psychiatrists should work only with allied mental health professionals who will keep them "adequately informed" of patients' treatment and progress and also cautioned psychiatrists to trust their patients' care only to those allied professionals who demonstrate competence. Thus, psychiatrists would expect to have up-to-date information on the services other professionals provide for their patients from team meetings or through other effective channels.

Mizrahi and Abramson (1985) compared those physicians who work in internal medicine with social workers on several factors. They explored the various areas where "stress and strain" exists between the professions of medicine and social work. One area which is of relevance to this research is physicians' and social workers' approaches to the role and rights of patients. They speculated that social work and medicine function from two diverse stances. Physicians' traditional practices of disclosure of information are based on how that information or lack of information will best benefit patients while social workers attempt to facilitate patient autonomy in areas related to health. The possibility

exists at times that, if social workers are focusing their interventions towards patient autonomy, then psychiatrists may be challenged in their approaches with patients (Mizrahi & Abramson, 1985). Mizrahi (1984; cited in Mizrahi & Abramson, 1985) found residents and interns either had shallow understandings of the rights of patients or were somewhat contemptuous of the idea of patient rights. Their application of patient rights focused more around informed consent. Madison (1975), Miller & Rehr (1982), N.A.S.W. (National Association of Social Workers) in their Health Policy Statement (1979), Quinn & Somers (1974; cited in Mizrahi & Abramson, 1985) found that nurses and social workers became more involved in enforcing patient rights.

Abramson (1984) described an ethical dilemma for social workers in the area of diagnosis disclosure, namely the pull between patient autonomy versus prevention of harm. Abramson related a dilemma which has specific relevance to the diagnosis of schizophrenia:

...how much does the social worker concede to the team's decision to withhold information from a patient because the team believes that the patient might be harmed by the information, when the social worker's code of ethics says that the social worker's primary obligation is to the patient, that is the social worker's responsibility to maximize the patient's self-determination and the patient wants to know what is happening? (Abramson, 1984, p.39).

Non-disclosure of the diagnosis of schizophrenia to patients and/or families may have more ethical overtones for social workers than psychiatrists.

In summary: teams have evolved in psychiatry in which psychiatrists primarily act as leaders because they are primarily responsible for patient care in the hospital setting. Psychiatrists want competent team members who provide them with up-to-date information as to the on-going care being provided. Conflict can occur as a result of overlap of the roles of team members and with members having different expectations of their functioning. Because of the different goals and responsibilities of the team members, ethical problems can be more pronounced for one profession than another.

#### Disclosure of Diagnosis

There has been a paucity of research regarding psychiatrists and social workers' disclosure practices of the diagnosis of schizophrenia to patients and their families. It is valuable, however, to examine other disclosure practices on which there is information, as with other mental illnesses and cancer. Schizophrenia is often seen as the 'cancer of mental illness' (Green, January, 1984). In 1953, Fitts & Ravdin (cited in Green & Gantt, 1987) found 90% of physicians not revealing to patients their diagnoses of cancer. Twenty-six years later, Novack (1979) discovered 97% of doctors preferring to tell patients the diagnosis of cancer (cited in Green & Gantt, 1987).

Gantt and Green (1985) found that social workers in medical settings frequently shared diagnoses with their patients and families

whereas it was not common practice for social workers in psychiatric settings to disclose these diagnoses and their implications. In their study, these authors surveyed psychiatrists, social workers, and psychologists with regards to sharing six different psychiatric diagnoses with patients and families: manic-depression, schizophrenia, unipolar depression, borderline personality, organic brain syndrome, and obsessive compulsive personality disorder. The authors asked the professionals if they revealed the above diagnoses to their patients and/or their patients' families, and whether they approved of another profession telling the diagnoses. They found that social workers were revealing diagnoses although they were less inclined to disclose to schizophrenic, borderline, and obsessive-compulsive personality disordered patients. Psychiatrists, in general, were predictably more likely to disclose this information but also were disinclined to do so with schizophrenics, borderline individuals, and obsessive-compulsives although in absolute terms they did so more frequently than social workers. Approximately 25% of the social workers tended to tell the diagnosis of schizophrenia to families of patients whereas only 15% told it to patients. Of psychiatrists, 56% told families and 37% told patients a diagnosis of schizophrenia.

The researchers found that 53% of social workers preferred disclosure to be carried out by another professional while 59% of psychiatrists had no objection to another profession divulging this information. The professionals surveyed were disinclined to be the

"bearers of bad news" although they agreed that patients and families should have complete knowledge of the illnesses, including diagnoses (Gantt and Green, 1985, p. 108). One problem they identified was that social workers may not have the necessary information to assist patients and families in comprehending psychiatric illnesses and they would have problems in the context of the multidisciplinary team. "The overwhelming reluctance of social work staff to engage in this form of information sharing deserves further exploration" (Gantt and Green, 1985, p. 106).

There are differences of opinion between social workers and psychiatrists and within these professions as to whose role it is to reveal diagnoses to patients and families. A study of the role expectations of various health professions, including social work and medicine, revealed that, even though social workers were perceived as the professionals who work with families, all thirteen professions surveyed felt revealing the knowledge of a terminal illness to families was the responsibility of physicians. Half of the social workers surveyed believed this task was their role while the physicians saw the revealing of the illness as their role (Lister, 1980). In a similar study conducted in Hawaii, the social workers made a distinction between discussing as opposed to revealing terminal illnesses with families while the physicians did not make the same distinction (Chan, Ostrov, & Yaji, 1976).

Green & Gantt (1987) in another study surveyed 246 American psychiatrists and received a 90% response rate; they were interested in

the disclosure of schizophrenia by psychiatrists. Psychiatrists were asked if they always, usually, sometimes, rarely, or never disclosed the diagnosis of schizophrenia to patients and their families. Three-quarters (76%) of psychiatrists always or usually revealed the label to families and 58% always or usually revealed the diagnosis of schizophrenia to patients. However, 10 to 15 % "rarely or never " informed patients or their families of the diagnosis. Psychiatrists gave their various explanations for their disclosure practices. Those psychiatrists who withheld the diagnosis did so because of a lack of assurance that schizophrenia is in fact an illness, because of concern that the diagnosis further alienates patients with a stigma, and because of a feeling that patients would be incapable of understanding the illness or that disclosure would only further dishearten patients and their families. Psychiatrists' reasons for telling included: explanations of etiology reduced the families' sense of guilt; the psychoeducational model provided the patients and families with vast amounts of information about schizophrenia, increasing families' feelings of prowess with the illness and decreasing the stigmatization; revealing to families and patients enabled them to join self-help programs; patients' increased knowledge could increase compliance with treatment; finally, families who are better educated about schizophrenia could assist in reducing the recurrence of acute symptoms.

### Disclosure as a Problem

Although the disclosure practices of psychiatrists to schizophrenic patients have received little study, various letters-to-the-editor and anecdotal case discussions addressing aspects of the dilemma "to tell or not to tell" have been published. Different authors' suggestions range from telling every patient to telling only certain patients. Within psychiatry the controversial issue of disclosure of diagnosis centers around schizophrenia, the "cancer of psychiatry" (Green, Jan. 1984). For Hoffman (1981), a strong advocate of revealing to patients, it was not a matter of whether to tell but when, what, and how. Hyde (1982) implied that all schizophrenic patients should be informed of their diagnoses. Green (January, 1984) maintained that it is "good practice" to tell patients their diagnoses. Appleton (1972), Adams & Paris (1979), Bleich (1983), Green (June, 1984), Kondziela (1983), Kuder (1984), Masnik (1974), all maintained or implied that not all schizophrenic patients should be told their diagnoses. Shackle (1985) conceded that, although disclosure is associated with positive and negative aspects, patients have a right to know so they can have ... "the key to the act that has brought about this state of affairs" (Shackle, 1985, p.133).

In practice, all psychiatrists are not telling all patients their diagnoses of schizophrenia (Green, January 1984; Appleton, 1972; Anderson, Reiss & Hogarty, 1986) nor are they telling families (Anderson, Reiss, & Hogarty, 1986; Walsh, M. 1985). In a study conducted in Berlin

where 52% of the sample (85 patients) were aware of their diagnoses, 49% of these received this information from sources other than their psychiatrists (Linden & Chaskel,1981). Of the psychiatrists studied by Gantt and Green (1985), only 37% stated that they revealed the diagnosis of schizophrenia to their patients. In Green & Gantt's 1987 study, 58% "always or usually" told patients; these authors also found that 76% "always or usually" informed families. Hence, not all psychiatrists revealed the diagnosis to patients and their families. Shackle compared the revealing of the psychiatric diagnosis with a "royal baby at a christening: the good fairy is there with her blessing and the bad fairy with her curse" (Shackle,1985, p.132). The 'blessing' is the understanding rendered by disclosure possibly reducing suffering and the 'curse' is the stigma which can remain throughout the patient's life, damaging career and other life aspirations.

The arguments for and against revealing a diagnosis of schizophrenia are many and complex.

#### Arguments for Disclosure

##### Involvement of Patient In Treatment

Disclosure can help schizophrenic patients become more involved in their treatment; it can give them more information on which to base their future decisions (Masnik, 1974; Appleton,1972; Green, January

1984; Hoffman, 1981). When diagnoses are made known to patients, they can then be educated on how to watch for exacerbations or returning symptoms in order to shorten relapses (Appleton, 1972; Green, January 1984). Psychiatrists' roles include helping patients live with their illnesses just as physicians would with other chronic illnesses (Adams & Paris, 1979, de, 1982). Research completed by Hogarty, Goldberg, & Schooler in 1974 (cited in Adams & Paris, 1979) indicated that chronic schizophrenics can be given help mainly through social rehabilitation. Disclosure can allow patients to attend various programs in the community for schizophrenics and their families (Green, June 1984) which can assist with this social rehabilitation.

#### Disclosure is Therapeutic

Disclosure, according to various authors, can improve patients' therapeutic outcomes. Bebbington & Kuipers (1982) claimed that revealing can assist patients to be compliant with all forms of treatment and simplify counseling. Shackle (1985) maintained that, unless patients are told, therapeutic relationships suffer because not having access to the same knowledge about the illness puts patients in dependent roles. Shackle stated that if patients are not told their diagnoses, they are treated as objects and not as persons.

Appleton (1972) maintained that many schizophrenic patients already know their diagnoses and that revealing it to them increases trust

in their psychiatrists. Hyde (1982) proposed that lack of trust can occur when alternate terms for this illness are used as these are misleading and can make patients expect a faster recovery than is probable, thus resulting in disappointment and, consequently, a slower recovery. According to Adams & Paris (1979), many patients already know their diagnoses through what they term "middle knowledge" and as a result never ask for it to be revealed. When psychiatrists reveal all to their patients, they open up many avenues for discussion which may ultimately help build therapeutic alliances and aid treatment. Patients are then free to discuss their fears (Green, January 1984) and psychiatrists are freed from feelings of dishonesty. Hoffman (1981) suggested that one should go so far as to confront patients by asking why they have not requested their diagnoses: they may give reasons that are valuable from the point of view of treatment.

Colin Tudge (cited in Vaisrub, 1980) recounted the importance of revealing diagnoses in general to patients. Patients do not see diagnoses solely as precursors to treatment but possibly as the most important part of treatment. Patients with chronic illnesses are often satisfied with a diagnosis without elaborations, so much so that "According to Tudge much of the touted non-compliance may be due to the patient's complete satisfaction with the reassurance provided by having his disease named" (cited in Vaisrub, 1980, p. 1931). "Just as healers of the past recognized the importance of 'laying on of hands' so

may their modern counterparts appreciate the value of laying on of diagnostic labels" (cited in Vaisrub,1980, p. 1932).

Fookes (1983) found that patients recounted feelings of relief when told their diagnoses making their unusual experiences understandable and often loosening their delusional explanations for the events. Until some of Fooke's patients were told their diagnoses, they felt skeptical that professionals knew what was wrong with them.

#### Assuaging Family Guilt

Many families know very little about schizophrenia and consequently suffer from guilt (Walsh, M. 1985). Families and patients often find not knowing more difficult than knowing when something is wrong (Seeman, Littman, Plummer, Thornton, & Jeffries,1982; Hyde,1982). Sometimes, when the diagnosis is not revealed, families will seek other forms of therapy of questionable value such as megavitamin therapy (Hoffman,1981; Hyde,1982). Adams & Paris (1979) found that when psychiatrists gave the illness a label and declared a prognosis there was a reduction in the family's guilt. The Metropolitan Toronto Chapter of the Ontario Friends of Schizophrenics suggested that the diagnosis should be revealed to families as soon as possible so that they can adjust to the illness and its ramifications. They also have asserted that non-disclosure of the diagnosis adds to families' "bewilderment and fear" (McLaughin,1981).

### Diagnosis: Provides A Succinct Statement

Revealing diagnoses to schizophrenic patients can enable psychiatrists to get their thinking "channeled" (Appleton,1972). The disclosed diagnosis presents patients and families with a succinct statement of psychiatrists' understanding (Hoffman,1981).

### Arguments Against Disclosure

#### Patient Factors

Seeman, Littman, Plummer, Thornton, & Jeffries (1982), Green (June,1984), Hyde (1982) and Masnik (1974) felt that some psychiatrists were concerned that some schizophrenic patients might be deeply disturbed by the information. Kondziela (1983) maintained that with certain patients a rapid deterioration could result. Some doctors felt that a message of hopelessness would be conveyed by reporting the diagnosis to patients (Green, January 1984; Masnik,1974; Adams & Paris, 1979; Seeman, Littman, Plummer, Thornton, & Jeffries, 1982; Anderson, Reiss, & Hogarty, 1986). Appleton (1972) maintained that psychiatrists were concerned that, if they revealed the name of the illness, some patients would stop trying to cope. Bebbington & Kuipers (1982) proposed that potential for insight should be considered in making the decision to disclose the diagnosis of schizophrenia to patients.

Whether or not patients wish to know their diagnoses is a factor

some have said is worth considering. Gadow (1981) argued that patients have the right to know or not to know based on the autonomy principle; this position goes against the extremes of "traditional paternalism", in which disclosure is based on what physicians decide, and "modern paternalism/ consumerism" which dispenses information, desired or not, to patients so that they are able to make their own decisions. Others have stated that no one has the right to refuse information because this would go against deontological and utilitarian ethics (Ost, 1984).

#### Uncertainty about illness

Psychiatrists are reluctant to tell schizophrenic patients of their diagnoses where there is no absolute certainty (Seeman, Littman, Plummer, Thornton, & Jeffries, 1982; Hoffman, 1981; Adams & Paris, 1979). They feel uncomfortable with disclosure for many reasons: the knowledge base, the fact that the illness is not well understood, that its course can be unpredictable, and that the cause(s) are unknown (Seeman, Littman, Plummer, Thornton, & Jeffries, 1982; Appleton, 1972). No single diagnostic test exists to determine that what is seen is in fact schizophrenia (Torrey, 1983). There is also no one clinical feature which is present in all schizophrenics; thus the diagnosis is based on the total scenario (Torrey, 1983). The view at the National Institute of Mental Health has been that there may be as many as 12 brain diseases presently called schizophrenia (Walsh, M. 1985). According to Kudler:

DSM-III defines schizophrenia in terms of its manifestations rather than attempting to provide an integrated psychopathological understanding of schizophrenia as an illness. While DSM-III does supply some useful information on course and prognosis, the diagnosis does not convey any greater explanatory value than the simple enumeration of symptoms and associated signs. It doesn't help patients (or their therapists) to conceptualize schizophrenia as they might other kinds of illness. (Kudler, 1984, p. 732).

Some psychiatrists would prefer to be cautious about labeling patients or telling patients and their families about the diagnosis until the second bout with the illness (Atkinson, 1985). The second episode is seen as diagnostic.

Great uncertainty exists about the illness of schizophrenia which some have felt is significant enough to make them hesitant in revealing this diagnosis to patients.

### Psychiatric Model

Appleton (1972) suggested that some psychiatrists do not disclose because the psychiatric model does not focus on illness as does the medical model but rather aligns itself with the healthy parts of patients' personalities; it is then up to patients to change within the therapeutic relationships. Thus, since this model does not focus on illness, it may justify those psychiatrists who, with their schizophrenic patients, do not particularly adhere to the medical model of revealing diagnoses.

### Adverse Social Consequences of Disclosure

It is possible that psychiatrists may give great consideration to the adverse social consequences of revealing diagnoses of schizophrenia to patients and their families. Seeman, Littman, Plummer, Thornton, & Jeffries (1982) and Hyde (1982) viewed some psychiatrists as being hesitant in revealing this diagnosis because of the stigma that is attached to schizophrenia in our society. As a result, other terms are substituted for the disease: nervous breakdown, bad nerves, nerves, mental condition, nervous episode, emotional upset, depression, emotional depression, emotionally disturbed, functional psychosis, et cetera.

Social labeling theory has purported that people are labeled "ill" as a result of an interactional process between patients, doctors, families, and others which is influenced by social circumstances and the norms of society rather than solely on the signs and symptoms of the illness (Geyman, 1983). Labels are difficult to remove from people (Walsh, M. 1985) and Levene has advocated the avoidance of labels of mental illness and role assignment (Levene, 1971).

In a study of four coastal fishing villages (outports) in Newfoundland, Dinham (1977) showed how a label of mental illness has particular connotations to community members. Those studied viewed the mentally ill as "unpredictable", "violent", "disruptive", and "a potential threat". In revealing past accounts of the individuals labeled, respondents would often change the details of the stories to fit their view of the labels.

Those judged as mentally ill would probably face physical removal or being avoided or ignored by the community. Labeling individuals as mentally ill, according to this author, is a social statement about the individual's behavior. Behavior viewed as non-threatening is normalized.

There may exist a range of cultural alternative conceptions of deviant behavior between the polar concepts of normal and mentally ill. Terms such as "nervous", or "retarded" may be used to denote individuals whose behavior is unusual but still predictable from other conventional identities (Dinham, 1977, p. 77).

Persons perceived as suffering from "nerves" are viewed as relatively harmless and as more acceptable to community members than those labeled as mentally ill. Psychiatrists may in fact be concerned about this reaction.

#### Against Unconditional Disclosure

Kondziela (1983) did not want to see any rigid rules regarding the disclosure of mental illness to patients, for he believed that this would not allow consideration of individual differences. He asserted that one did not have to force diagnoses on patients in order to help them live with their illnesses. Kudler (1984) postulated that "unconditional truth telling" could, in certain situations, go against one of the basic medical principles: 'primum non nocere' (above all do no harm). Disclosure at times could be more insensitive than overlooking patients' rights to know. Kudler maintained that a complete discussion of the implications of the

illness can occur without revealing the diagnosis.

#### Disclosure Practices

Disclosure practices with schizophrenic patients are diverse. Masnik (1974, p. 457) suggested telling those patients "who have sufficiently observing egos with the motivation to achieve more insight". Kudler (1984) recommended giving answers that are geared to patients' motivation to know their diagnoses. Adams & Paris (1979) gave two indicators for disclosure: when patients specifically ask for diagnoses and when patients' denial of their illnesses is such that they need confrontation. Hoffman (1981) suggested that if doctors are only considering the diagnosis of schizophrenia they should tell patients and their families. Since the diagnosis is usually derived in stages he recommended telling patients what is known along the way beginning with broader terms. Kondziela (1983) suggested determining whether or not patients would be able to process the disclosed information regarding their diagnoses in a "constructive" or "self-destructive" manner. He advocated the use of "appropriate terminology" for certain patients whom he felt should not be told. The diagnosis of schizophrenia is incompatible with some patients' mental pictures of themselves.

Bebbington & Kuipers (1982) suggested that patients be informed of their diagnoses in a way that reduces their hopelessness. They recommended that time be spent educating families about the illness to

avoid the stigma of labeling and patient dependency on professionals.

Boverman (1982) felt physicians ought to assess the pros and cons of disclosure on the basis of factual knowledge rather than avoidance of their own uneasiness. Boverman maintained that the physicians must examine the ratio of "risks and benefit" before making their decisions. Sheldon (1982), on the other hand, rebutted Boverman by concluding that physicians should not focus too much on the risks and benefits, thereby using science as a way of avoiding an ethical decision.

It is evident that there are reasons for and against disclosure. Psychiatrists and social workers are not utilizing the same approach when intervening with patients and their families. The issues surrounding the practice of disclosure are complex and it is evident that there are numerous reasons for and against this practice. This chapter has attempted to provide background information on the subject and reasons underlying psychiatrists and social workers' disclosure practices.

## METHOD

### Overview

This chapter provides a description of the methodology employed in this study. Sections describe the setting and study populations, the operational definitions, and the procedures including the design, the instruments, the pretests, the informing of subjects, and the analysis.

### The Setting and Study Population

The setting of the study was the province of Newfoundland, Canada, and predominantly its capital city, St. John's. Most of the respondents lived and worked in St. John's. There were two professional groups and hence two populations.

The study was limited to social workers and psychiatrists who worked with adult schizophrenics. Issues relating to children and adolescents are different from those relating to adults. An example of the difference is that children and adolescents may not be seen as having the same rights to know their diagnoses as do adults.

The population of social workers included all those social workers with a Bachelor's or Master's degree in social work, who were hospital employees in Newfoundland and were functioning as social workers having regular contact with psychiatrists and with patients who were suffering from schizophrenia. Many workers functioned as psychiatric social workers without specialized training in psychiatry. Many

graduated from generic programs and obtained knowledge of psychiatry on the job. Therefore, throughout the study, when social workers are mentioned, the reference is to those social workers who work in psychiatry; for it may not be accurate to refer to all of them as psychiatric social workers. Social workers who work in psychiatry and are based in a hospital have similar constraints imposed on them because in a hospital setting they function where the physician or psychiatrist is the leader of the multidisciplinary team (Bartlett, 1961). One social worker was employed by the hospital but worked primarily in a community setting where the psychiatrist would still have been seen as the head of the multidisciplinary team. The population consisting of all social workers in such positions in Newfoundland in August 1986 numbered twenty-two. Of these 22 respondents, 73% had a Bachelor's Degree in Social Work and 27% a graduate degree in Social Work. Eighteen respondents (82%) were of female gender. The majority of respondents (82%) were employed in St. John's hospitals; eighteen per cent were employed in hospitals with psychiatric units in other parts of the province. The hospitals included in St. John's were the Waterford Hospital, the General Hospital, the Salvation Army Grace General Hospital, and the St. Clare's Mercy Hospital. Around the province the hospitals were the James Paton Memorial Hospital (Gander), the Central Newfoundland and Regional Health Centre (Grand Falls), the Western Memorial Regional Hospital (Corner Brook), and the Charles S. Curtis Memorial Hospital (St. Anthony).

Six Newfoundland hospitals (Dr. Charles A. Janeway Child Health Centre, the Miller Centre, the Carbonear General Hospital, the Twillingate Hospital, The Sir Thomas Roddick Memorial Hospital, and the Dr. Charles Legrow Centre) are excluded from this study for one or more of the following reasons: a) the hospitals did not have psychiatric units, b) the hospitals did not have visiting psychiatrists, and c) the social workers did not work with adult patients suffering from schizophrenia.

The social workers' length of experience in psychiatry working with patients who suffered from a schizophrenic illness ranged from two months to ten years, with a mean of five years. Workers' case loads of schizophrenic patients varied in size over a year period with a range from 0 to 95 and with a mean of 23.4.

The population of psychiatrists included all practicing physicians (excluding psychiatric residents) who treated schizophrenic patients and were functioning as psychiatrists in October of 1986. Thirty-one psychiatrists met these criteria and all were interviewed. Of the total number of psychiatrists' included within this study 90% are male. As can be seen from Table 1 the majority of psychiatrists (71%) were trained in foreign medical schools.

Table 1

Where Psychiatrists Graduated From Medical School

Place	Percentage of psychiatrists	n
Canada (Newfoundland & Dalhousie, Nova Scotia)	29%	9
British Isles	32%	10
India	26%	8
Other(Spain, South Africa & Philippines)	10%	3

At the time of the study the range of years since these psychiatrists graduated from medical school was from 7 to 41 years and the median was 20 years.

The psychiatrists were asked to estimate the number of patients with schizophrenic illnesses that they had treated within the last year and the range is from 3 to 150 patients with the mean of 47.2.

Table 2 shows the psychiatric qualifications of the psychiatrists within this study. The information used to construct this table was taken from the Canadian Medical Directory, 1986. Some of the psychiatrists whose psychiatric qualifications are not listed were waiting to take their fellowship examinations.

Table 2

Psychiatrists' Qualifications

Degrees	Percentage of psychiatrists	n
FRCP (C) Psych <sup>a</sup>	71%	22
Foreign psychiatric qualification	10%	3
Psychiatric qualification not listed	19%	6

<sup>a</sup>FRCP (C) Psych stands for the Fellow of the Royal College of Physicians in Canada , Psychiatry.

Both professional groups were interviewed in their offices except for one interview which was conducted in the researcher's residence because it was convenient for the social work respondent.

The fact that 100% of both populations were interviewed obviated the necessity of sampling.

### Operational Definitions

#### Schizophrenia

Schizophrenics are defined as those patients whom social workers and psychiatrists identify as persons with schizophrenia. The criteria for defining schizophrenia vary greatly. A number of classification schemes of criteria exist. Examples of the classification systems include the World Health Organization's International Classifications of Disease, Ninth Edition (ICD-9); the International Classification of Disease, Ninth Edition, with Clinical Modifications (ICD-9-CM); the Diagnostic and Statistical Manual of Mental Disorders, Second Edition (DSM-II); and the Diagnostic and Statistical Manual of Mental Disorders, Third Edition (DSM-III) (Junek, 1983). Psychiatrists are the ones that predominately diagnose schizophrenia and therefore use these criteria. The study determines which classification systems the psychiatrists in Newfoundland are using as this may have some bearing on their disclosure practices.

### Diagnosis

Another definition that requires elucidation is that of diagnosis. The Webster's Ninth New Collegiate Dictionary (1984) states that "it is the art or act of identifying a disease from its signs and symptoms". It is more than just a label, it is the conclusion reached about etiology from which treatment is guided (Appleton, 1972).

### Disclosure

Disclosure is the act of making the diagnosis known to patients and/or their families. Disclosure for the purpose of this study means revealing the diagnosis at least once. Whether patients or families understand what the diagnosis means is not the issue in terms of the definition; this study is concerned only with whether the psychiatrist and the social workers disclose the diagnosis to patients and their families. Words that will be used interchangeably for disclosure will include, revealing and telling, and will refer specifically to the diagnosis of schizophrenia.

### Non-Disclosure

Non-disclosure means not telling patients and or their families the actual diagnoses.

## Procedure

### Design

The research design was a descriptive survey using face-to-face interviews to gather data. A predetermined set of open-ended questions structured the interviews. Two instruments were used for gathering the data, one for social workers and one for psychiatrists (see Appendix B). Taping all of the interviews was possible with the exception of two social workers' and one psychiatrist's interviews; these individuals were more comfortable without the tape recorder. The study approximated a cross-sectional one for the focus was a "single time description" (Babbie, 1973). Pretesting of the instrument itself and the interview techniques occurred prior to commencing the data gathering. The reasons for the research being conducted in this manner are elaborated upon below.

A survey is a "relatively easy way to obtain data about attitudes, opinions, motivations, and other characteristics that are not directly observable" (Dijkstra, & van der Zouwen, 1982 p. 2). The survey method suited obtaining information concerning the social workers' perceptions on the effects of non-disclosure of schizophrenia on current social work practice and on the psychiatrists' perceptions, attitudes, current practices, and the situations encountered when faced with the issue of disclosure. A participant observation design was not feasible because it would have been difficult to arrange, would have required more time from the respondents than they were willing or able to give, and would also have

had ethical implications. The length of the interview was in fact predetermined by consultation with representatives of the psychiatric and social work professions and proved to be as long as feasible.

The major focus of this project was descriptive and exploratory (Babbie, 1973). The descriptive elements include the classification systems used, the types of patients treated, the types of problems encountered with the issue of disclosure to schizophrenics, the ways in which these problems are resolved, and the way in which the problems are viewed (*frame of reference*).

A face-to-face interview has several advantages over other methods, such as mailed questionnaires, self-administered questionnaires, or telephone interviews. Because the two populations in this study were small in number, face-to-face interviews with all the respondents was practical. Also, an interview survey usually has a higher response rate than a mail survey (Babbie, 1973). Mailed questionnaires are reported as having a 10 to 50% return rate (Kidder, 1981) and offered no particular advantages for this study. It is doubtful that all of the social workers and psychiatrists would have completed a mailed-out questionnaire because of the volumes of paper work they are already required daily to complete. This study had one hundred per cent participation. The advantages of the face-to-face interviews include the likelihood of obtaining a higher response rate, the opportunity of getting in-depth answers by seeking clarification and by probing, the opportunity of establishing some rapport with the psychiatrists would assist in

obtaining more accurate and complete responses, and the opportunity for correcting misunderstandings should any arise. The researcher asked for clarifications. Attempts were made not to influence the answers of the subjects. The advantage to the method employed in this study of audiotaping the interview and typing the interviews verbatim is that distortion of responses did not occur (Kidder, 1981). With the taped interviews the researcher was able to assess if any leading probes might have been asked under the pressures of the interview and to deal with them appropriately.

Open-ended questions rather than fixed alternatives were used because knowledge of the complete range of responses did not exist. Questions which are open-ended elicit salient responses from articulate respondents. Salience is useful when the full range of responses is not known and can tell the researcher what are the most important perceptions of the respondents at the time the questions are asked. Asking social workers and psychiatrists some similar questions allows for a comparison as to how they handle the matter under study. Coding was time-consuming but not problematic since there was a small number of respondents.

In order to obtain frank and complete responses from the psychiatrists and social workers the investigator attempted to display a non-judgemental attitude and employed the usual safeguards for preserving objectivity in the construction and delivery of the interviews.

### Instruments

The researcher designed two questionnaires. The questions provided rich data and were the most efficient way to obtain information due to the limitations on the length of the interview. The questions incorporated ideas from the researched literature and from the researcher's own experience as a social worker working in psychiatry.

The instruments obtained descriptive data on the respondents and their perceptions as to whether or not they disclose the diagnosis of schizophrenia and their reasons for so doing the same. Areas explored included the problems encountered in disclosing or not disclosing the diagnoses of schizophrenia, how the professionals handle the issue of disclosure, the extent of not disclosing the diagnoses of schizophrenia, data on the circumstances that come to bear on the area of disclosure, and the respondents' recommendations as to how this area could be best handled. Both questionnaires appear in Appendix B. A few questions were not reported in the results because they did not yield useful information.

### Pretests

Three social workers who had psychiatric experience but who were not part of the population of social workers working with psychiatric patients completed a pretest of the social work questionnaire. In order to improve the quality of the psychiatrists' questionnaire, implementation of pretests occurred with three general practitioners who worked in the

Waterford (psychiatric) Hospital in Newfoundland having similar duties as psychiatric residents, and with a third year psychiatric resident. Those who completed the psychiatrists' pretest were knowledgeable about the issues involved in treating schizophrenic patients. The pretests allowed an examination of a few different approaches before finally choosing one and becoming comfortable with the same. Those who participated in the pretests gave the researcher feedback on the instruments. The pretests permitted a testing of the comprehensibility of the questions, the appropriateness of the ordering of the questions, the relationship between the items, and the length of the questionnaires. The pretests also assisted the researcher to prepare for some of the subjects' responses and helped identify what probing questions were required.

#### Informing Subjects

The researcher sent a letter (see Appendix C) to all of the social work subjects formally informing them of the study and advising them that telephone contact would occur to set up individual interviews. The Director of the School of Social Work at Memorial University sent a letter of introduction to the out-of-town social workers informing them of the study (see Appendix E). Telephone contact and convenient scheduling of interviews subsequently occurred with the social work subjects. In the interview itself the researcher informed the social worker that the interview could either be taped or hand-written verbatim. The social work interviews began in August 1986 and were completed in January 1987.

Prior to commencing the scheduling of interviews with the Newfoundland psychiatrists, the investigator sent letters in advance informing the psychiatrists of the study and its objectives (see Appendix D). Sending the letters in advance gave the psychiatrists some lead time to think about the area in question. The Director of the School of Social Work also sent an introductory letter informing the psychiatrists of this study (see Appendix E). The Director sent the letter to the out-of-town psychiatrists and to those the researcher had not met. The researcher, by telephone, made appointments at the convenience of the individuals. Delays resulted from some psychiatrists being heavily booked or having arranged holidays. Weather was also sometimes a delaying factor. The psychiatrist interviews began in October 1986, and the completion of the last interview occurred in February 1987.

The social workers and psychiatrists received additional information about this study in the beginning of the interviews. The advance letters to the psychiatrists explained the researcher's preference for taping the interviews to shorten the time required. The investigator took notepaper to each interview in case the respondents were more comfortable proceeding with a handwritten interview. The researcher ended all the interviews with the psychiatrists and social workers by asking the respondents if they had any questions about the study. All the participants signed a consent form just prior to beginning their interview (see Appendix F). Confidentiality exists for the individuals who participate in this study. The investigator numbered the interviews rather

than identifying them with names and then erased the audiocassette tapes. Efforts were made to try to make participation as interesting and appealing as possible. The duration of the interviews was from 25 to 45 minutes with the social workers and from 25 to 60 minutes with the psychiatrists.

### Analysis

Qualitative analysis was appropriate for this study. The researcher typed verbatim on a word processor the psychiatrists' and social workers' responses. Analysis of the open-ended responses from the questionnaires occurred question by question, with the typing of data from each question onto a word processor so that the data could be organized into categories and then coded. Index cards were used when the questions were analyzed so that relevant data not related to the specific question could be organized and included in appropriate sections at a later date. Data written on index cards which specifically related to the questions asked of the respondents was included as addendum to the questions. Because the entire populations of psychiatrists and social workers who work in adult psychiatry are being studied, "descriptive statistics" (Nutter & Nutter, 1977) assist in describing and summarizing the data. Questions elicited respondents' reports on their behaviours, attitudes and opinions. Because of the small numbers and the nominal nature of most of the data, tests of association were not necessary. Thus, the categories from the responses will be represented

and summarized using the mode, percentages, and frequency tables. Since many of the questions allowed for numerous responses from the respondents, not all the percentages will add up to 100. The use of rounding procedures occurs in the reporting of percentages and as a result some questions do not equal 100%.

Because these are open-ended questions, the responses that social workers and psychiatrists have given to questions are what is most salient to them. Percentages are used when the researcher believed they were meaningful, and when several respondents made the same comments.

## RESULTS

The findings from the interviews with the psychiatric and social work professionals concern the practice of disclosure of the diagnosis of schizophrenia in Newfoundland, their behaviors and opinions in relation to disclosure and non-disclosure, and the circumstances they encounter which influence their disclosure practices. A comparison between psychiatrists' and social workers' behaviors, opinions, and circumstances they encounter will be made.

### Not All Patients were Being Informed

Not all schizophrenic patients were being informed of their diagnoses and the extent of this was evident through an examination of the number of informed patients on psychiatrists and social workers' caseloads, the numbers that understood their diagnoses, and how each professional group defined patient understanding of the illness.

The psychiatrists reported an estimated 759 of the combined total of 1466 treated schizophrenic patients were aware of their diagnoses; this is 52% of the total.<sup>2</sup> The social workers estimated 514 schizophrenic patients on their combined caseloads of which 285 patients knew their diagnostic labels, which is 56% of the total. Thus, an estimate from both professional populations revealed that just over half of their patients knew their diagnoses of schizophrenia.

Psychiatrists and social workers reported on the numbers of schizophrenic patients who knew their diagnoses. Psychiatrists gave an estimated range which was from all to no patients knowing; 29% were unable to specify with numbers or percentages; thus a mean statistic was not possible. The range given by social workers was also from all to no patients knowing. Social workers estimated the number of patients who knew their diagnoses and understood what their diagnoses meant as 128 which is 25% of the total number of patients in their combined caseloads.<sup>3</sup>

What constitutes an understanding of one's schizophrenic illness was defined by individual psychiatrists and social workers. Psychiatrists' definitions ranged from patients having a thorough understanding to having almost no understanding. Psychiatrists, in contrast to social workers, were unable to estimate the numbers of their patients who understood what their diagnoses meant. The range was illustrated with these comments: from "understanding is very limited", "...[patients who suffer from schizophrenia] live in a different ozone layer to the average person and they are constantly out of touch with reality", to "knowing as much as the psychiatrist knows about what constitutes the disease".

The psychiatrists' and social workers' definitions of schizophrenic patients' understanding involved knowledge of the components listed in Table 3 from most to the least frequently mentioned.

Table 3

Psychiatrists' and Social Workers' Definitions of the Knowledge Required by Patients to Understand their Schizophrenic Illnesses

Psychiatrists' definitions	Social Workers' definitions
Knowledge of signs and symptoms	Knowledge of symptoms
Able to relate the signs and symptoms to oneself	Able to relate the symptoms to oneself
Knowledge of causes of the illness	
Knowledge of the duration of the illness	
Knowledge of what is involved in the treatment process	Knowledge that one requires medication and treatment
Knowledge of the implications of the illness	
Knowledge that one is ill (insight)	Knowledge that one is ill and when one is relapsing

Psychiatrists' and Social Workers' Disclosure Practices with Various  
Psychiatric Diagnoses

Psychiatrists and social workers were asked about their revealing practices with respect to the diagnoses of manic depression, unipolar depression, borderline personality disorder, schizophrenia, and organic brain syndrome.<sup>4</sup> The percentages of psychiatrists and social workers who generally revealed the above diagnoses to patients and families is illustrated in Table 4. With regards to revealing the diagnoses to families, a good portion of psychiatrists qualified that they would need patients' consent before they release diagnoses to families.<sup>5</sup>

Table 4

Percentages of Psychiatrists and Social Workers who Generally Reveal Various Psychiatric Diagnoses to Patients and their Families

Diagnosis	Disclosure			
	Psychiatrists to patients (n=31)	Social Workers to patients (n=22)	Psychiatrists to families (n=31)	Social Workers to families (n=22)
Unipolar				
Depression	97%(30)	50%(11) 0 <sup>a</sup>	90%(28)	55%(12) 1 <sup>a</sup>
Manic				
Depression	94%(29)	55%(12) 0 <sup>a</sup>	97%(30)	64%(14) 0 <sup>a</sup>
Schizophrenia	74%(23)	45%(10) 0 <sup>a</sup>	77%(24)	68%(15) 0 <sup>a</sup>
Organic Brain Syndrome	42%(13)	27%(6) 2 <sup>a</sup>	94%(29)	50%(11) 1 <sup>a</sup>
Borderline Personality	19%(6) <sup>b</sup>	14%(3) 0 <sup>a</sup>	35(11) <sup>b</sup>	23%(5) 1 <sup>a</sup>

<sup>a</sup> These numbers indicate those social workers who could not remember what they had done, or those who worked with psychiatrists who had already informed patients and their families.

<sup>b</sup> Included within the affirmative responses for borderline personality disorder were those psychiatrists who disclosed to patients and families the words "personality disorder" rather than "borderline personality disorder".

As can be seen from this table, the two diagnostic categories where psychiatrists did not disclose as often were those of borderline personality disorder (with patients and families) and organic brain syndrome (with patients). Psychiatrists elaborated on why they answered the way they did. The most frequent reasons given by them for not revealing to patients the diagnosis of borderline personality disorder were as follows: they were not convinced of the diagnosis (19%), it was difficult to explain to patients (16%), they rarely diagnosed the disorder (16%), there were more positive terms in use to explain the condition (10%), it was too complicated for patients to understand (10%), there was little value in revealing to patients the term (10%), and consensus within psychiatry was lacking regarding this disorder (6%).<sup>6</sup> Less frequent but similar reasons were given by psychiatrists as to why they did not reveal the diagnoses of borderline personality disorder to families. The most common explanations by psychiatrists for not revealing to patients their diagnoses of organic brain syndrome were that this syndrome covered a wide range of disorders and it therefore depended on the disorder in question, that psychiatrists did not think patients would be able to understand the term, and that they preferred instead an explanation of the symptoms.

Psychiatrists revealed to schizophrenic patients 19% less often than to manic depressive patients and 23% less often than to patients with unipolar depression. They disclosed to families with schizophrenic

members 19% less frequently than to families with manic depressive members and 13% less than to families who had members with unipolar depression. It is interesting to note that two additional psychiatrists specifically mentioned that they would reveal the diagnosis of schizophrenia to patients when they were asked for that information, plus an additional four psychiatrists would reveal this diagnosis to families when asked by the families to do so; these particular practitioners generally did not disclose the diagnosis of schizophrenia to patients and their families.

Social workers more often disclose patients' diagnoses to families than to patients. Almost all social workers qualified that they would reveal to families only with patient consent to discuss these matters. The biggest discrepancy in workers revealing between patients and their families existed in the categories of schizophrenia and organic brain syndrome. It was interesting to note that social workers informed families of schizophrenics more than families of manic depressives. A few social workers specifically stated that they did not reveal to patients the five diagnostic labels because they felt it was the doctors' role to do so.

Few social workers elaborated as to why they did not disclose to patients or families the diagnoses of borderline personality disorder and organic brain syndrome.

Within each of the five diagnostic categories, some of the social

workers qualified that they would disclose to patients or families only when they had involvement with psychiatrists. This involvement included either having the psychiatrists present when individuals were informed or ensuring that doctors were in agreement with individuals being told. Without specifically being asked, 32% of the social workers qualified that they would require input from psychiatrists before they revealed the diagnosis of schizophrenia to patients and 27% stated they would need input before they revealed this diagnosis to patients' families. It is noteworthy that on the whole social workers and psychiatrists revealed the diagnosis of borderline personality disorder less often to both patients and their families than schizophrenia. Finally, it should be noted that not all patients and families were being informed of the diagnoses listed.

Psychiatrists and social workers raised a number of issues related to their decisions as to whether or not to disclose the diagnosis of schizophrenia and described great variability in their disclosure behaviors. In response to questions on the circumstances they encountered, their perceptions of the issues pertaining to disclosure, and the variability of their disclosure practices, the two groups described factors which influenced decisions to disclose or to ensure disclosure did not occur.

### **Factors Psychiatrists Perceived as Influencing their Disclosure Practices**

Psychiatrists explained that their disclosure practices to schizophrenic patients and their families were influenced by numerous variables which included: psychiatrists' conceptions of schizophrenia, their role, their opinions on the subject of informing patients, their perceptions of patients and families, the challenges faced and circumstances associated with disclosure of this diagnosis.

#### Psychiatrists' Conceptions of Schizophrenia

Physicians and psychiatric specialists are the professionals within Newfoundland who usually diagnose schizophrenia in patients. An understanding of how psychiatrists conceived the disorder of schizophrenia would hopefully add clarity to the issues surrounding disclosure of this diagnosis. Psychiatrists' conceptions of schizophrenia, including the criteria they used to diagnose the disorder, along with the degree of diagnostic certainty, and their views of the prognosis of schizophrenia influenced their disclosure practices.

#### Etiological Views of Schizophrenia

Psychiatrists professed beliefs in different etiologies of schizophrenia. A portion of psychiatrists (42%) specifically saw the main etiology of this illness as having an organic basis. Even more psychiatrists mentioned an organic basis along with other causes. The

following table presents what the psychiatrists in Newfoundland saw as the main etiologies of schizophrenia.

Table 5

Newfoundland Psychiatrists' Etiologic Viewpoints of Schizophrenia

Etiology/ies	Percentage of psychiatrists	n
Biochemical	29	9
Multiple Etiologies <sup>a</sup>	19	6
Unsure <sup>b</sup>	19	6
Genetic & Environmental	10	3
Biological	6	2
Biochemical & Environmental	6	2
Biological & Biochemical	3	1
Biological & Environmental	3	1
Genetic	3	1

<sup>a</sup>The multiple etiologies listed included the following: genetic, biochemical, biological, psychosocial, social climate, and life events.

<sup>b</sup>Those one fifth (19%) who advanced that the main etiology was unknown at the same time hypothesized multiple causes as etiologically important, namely, biochemical abnormalities, biological abnormalities, and biological and environmental stressors.

### Criteria and Classification Systems Used

Psychiatrists' conceptions of schizophrenia and how the illness is diagnosed appear to be interrelated. The psychiatrists used various criteria and classification systems to diagnose this psychotic illness. Some psychiatrists used strict criteria while others utilized a broader concept of the illness. The classification systems used were those of the Diagnostic and Statistical Manual of Mental Disorders, Third Edition (DSM III) (42%) and the International Classification of Diseases, Ninth Revision (ICD 9) (6%). Criteria used included: a combination of Schneider's First Rank Symptoms and/or Bleuler's criteria as well as various other symptoms and criteria (35%), the use of Schneider's First Rank Symptoms alone (6%), and the use of Bleuler's Criteria alone (6%).<sup>7</sup> Variation existed not only in the different criteria or classification systems utilized, but also in the number of symptoms required for the diagnosis of schizophrenia to be made, with one psychiatrist stating (s)he could make the diagnosis with a single symptom.

Psychiatrists mainly saw schizophrenia as having an organic basis, meaning that it occurs as a result of biological, biochemical, and genetic factors.

### Diagnostic Certainty

The majority of psychiatrists (65%) revealed that they would not disclose the diagnosis of schizophrenia to patients unless they were

sure of the diagnosis, while the other 35% would in some cases reveal to patients that they were considering schizophrenia as their diagnosis despite diagnostic uncertainty.

In uncertainty of the diagnosis of schizophrenia, psychiatrists who did not reveal to patients their consideration of schizophrenia as a differential diagnosis withheld because there were concerns about inducing unnecessary anxiety; it was not seen as therapeutic to disclose given the uncertainty; patients were too sick to inform initially when the diagnosis was uncertain; and when patients had recovered sufficiently some degree of certainty about the diagnosis had accrued. One psychiatrist elaborated his point with an analogy: "It would be like saying to a patient who comes in with a headache that they [sic] have a brain tumor. With anyone who has a headache that is the differential diagnosis".

Those psychiatrists who sometimes told patients their differential diagnoses did so when patients asked for the possible diagnoses, when patients were capable of accepting the information, when they were revealing the plan of therapy and they felt that the biological factors and medication were important, and as a part of the process of zeroing in or negotiating the diagnosis with patients. A few psychiatrists commented that when they gave patients the differential diagnosis of schizophrenia, they also informed them of the uncertainty of the label. In general,

psychiatrists required diagnostic certainty before they could disclose the diagnosis of schizophrenia.

Disclosure appeared to be related to the number of previous hospital admissions. Approximately half (45%) of the psychiatrists stated that they were influenced by the number of hospital admissions of patients in revealing the diagnosis of schizophrenia. These practitioners believed that they would be less likely to reveal patients' diagnoses on their first hospital admissions because they would be less certain of the diagnosis than with patients who had more than one admission. Sixteen percent stated that they were not influenced by a paucity of hospital admissions as long as they were certain of patients' diagnoses of schizophrenia.

Some diversity of disclosure practices existed in relation to the number of hospital admissions, for example, a psychiatrist claimed (s)he might even wait until after several hospital admissions before (s)he revealed the diagnosis while another respondent indicated (s)he might have revealed the diagnosis after patients were discharged from their first hospital admissions. A few psychiatrists gave further examples: it is possible that patients may have only one episode of schizophrenia or may not have a relapse for a lengthy period of time and these possibilities made a few psychiatrists reluctant to reveal the diagnosis on patients' first admissions. One psychiatrist stated that one must be "cautious about the application of diagnostic criteria with a single

episode"; another advanced that (s)he would not be influenced by the number of hospital admissions because (s)he is "negotiating the diagnosis" with patients the first day (s)he sees them and "all patients are negotiable in some ways".

The number of hospital admissions appears very much linked to the psychiatrists' certainty of patients' diagnoses and to revealing of the label schizophrenia.

### Prognosis

Newfoundland psychiatrists' opinions varied regarding what constitutes a good prognosis for patients who suffer from schizophrenia. Psychiatrists' conceptions of the prognosis of schizophrenia influenced their revealing of the diagnosis. In comments made throughout the interviews, a few psychiatrists saw those with the illness as having little hope. Some commented that schizophrenia was viewed as the "cancer of mental illness". There were a few psychiatrists in this study who maintained that those individuals with a good prognosis would not be labeled schizophrenic. A few practitioners mentioned that patients could have a good prognosis and never have another episode of schizophrenia.

While patient prognosis was a factor affecting a portion of the psychiatrists in their disclosure practices, it affected them differently. Eleven (35%) of the psychiatrists stated that their view of schizophrenic

patients' prognoses would influence their disclosure behaviors. Of those clinicians influenced, 7 (23% of population) would be more likely to reveal to those patients who had a good prognosis and 4 (13% of population) would be more likely to disclose to patients with a poor prognosis. Those psychiatrists who were more likely to disclose to good prognosis patients gave as reasons that the poor prognosis patients would not be well enough to inform and they would not be able to provide these individuals with the same degree of explanation. Those who would disclose to poor prognosis patients did so in order that patients could use available resources as part of their rehabilitation and because these patients required more education, having more symptoms over time. In addition there was a chance with those patients who had a good prognosis that the illness would not recur or would not ultimately be diagnosed as schizophrenia.

#### Psychiatrists' Roles

The settings in which psychiatrists worked and the functions they performed influenced their disclosure behaviour. Psychiatrists treated schizophrenic patients in all phases of their illnesses. They had contact with these patients in a variety of settings in hospitals, in emergency services, in their offices, in outpatient clinics, in geriatric services, in nursing homes, in consultation, on medical and surgical units and all other areas of general hospitals, as short or long term residents of the

local psychiatric hospital, in community-based programs such as community care, on the forensic unit, in police-holding facilities, in rural area clinics, and when they covered other psychiatrists' practices or clinics. In addition, some treated childhood or adolescent schizophrenics. Variation in the role of psychiatrists with schizophrenic patients depended on the setting(s). For example, providing treatment for an outpatient in a private practice was different from providing treatment for long-term patients in a psychiatric hospital. Because of the the limitations of time, psychiatrists were not specifically asked, as were the social workers, to recount their perceptions of their roles with schizophrenic patients; the information in this section was gleaned from the interviews with the psychiatrists. Psychiatrists would not engage in all the activities mentioned below with every patient and family nor would some engage in certain activities to the same extent as their psychiatric colleagues.

Psychiatrists in describing their roles made specific reference to their disclosure practices of the diagnosis of schizophrenia. They mentioned providing schizophrenic patients with neuroleptic medications, rehabilitation, hospitalization, follow-up, and supportive psychotherapy,<sup>8</sup> and family interventions to reduce stress for the patient. They made reference to functioning as leaders on a multidisciplinary team. Team involvement also included conducting joint interviews with social workers and other team members where they disclosed the diagnosis to patients and their families. A few psychiatrists mentioned

their role included developing policies on their teams on how issues like disclosure should be handled.

Some psychiatrists stated that they assess schizophrenic patients for disclosure by determining if these patients are ready to deal with the diagnosis, the extent of their psychotic symptoms, their level of functioning, their psychological sophistication, and their ability to understand and to have insight. They also considered the patients' personalities, their compliance with medications, the prognoses of their illnesses, and whether or not they wanted to know the diagnosis. Of those psychiatrists who told patients their diagnoses, some mentioned judging the timing of when to disclose based on their assessments of patients and families. Some psychiatrists also dealt with patients' and families' misconceptions about the illness and were involved in an ongoing educational process with them. Psychiatrists did not elaborate on what they did in terms of education due to the time limitations. However, some indicated that in educating patients they compare the disorder to other physical illnesses such as diabetes and hypertension; others discussed signs and symptoms with patients. A few mentioned the importance of presenting the diagnosis in a positive light as well as informing patients of the risks associated with their illnesses. The importance of establishing a therapeutic relationship and increasing patients' trust prior to informing them was emphasized by some clinicians. Before patients were told of the diagnosis of schizophrenia,

the psychiatrists had usually treated their symptoms; furthermore, 65% of psychiatrists stated that they would not reveal the diagnosis to patients unless they were certain of the diagnosis. The 42% who used DSM III criteria for diagnosis of this disorder needed to observe or recognize the presence of prodromal, active, and/or residual symptoms for six months. During this time period, psychiatrists had to treat patients' symptoms and educate them with the information about which they were certain. Thirty-five per cent of the psychiatrists sometimes told patients they were considering the diagnosis of schizophrenia even before there was certainty.

Dealing with the issue of disclosure of the diagnosis of schizophrenia was only one of a multitude of tasks psychiatrists needed to perform with schizophrenic patients and their families.

#### Psychiatrists' Opinions Related to Disclosure of the Diagnosis of Schizophrenia

Psychiatrists gave different opinions regarding disclosure: whether or not schizophrenic patients should be informed of their diagnoses and whether or not they could be adequately informed about the illness without specific knowledge of the diagnosis.

A majority of psychiatrists (58%) contended that patients should be told while 23% of the respondents placed conditions upon revealing to

schizophrenic patients. One fifth of psychiatrists (19%) generally believed that these patients should not be told their diagnoses.

Those psychiatrists who generally believed that schizophrenic patients should be told their diagnoses gave various reasons, the most frequent being that they had a right to know and that they needed to know in order to deal best with the illness, its treatment, and the impact the illness would have on their lives. One quote summarizes some psychiatrists' views:

People have a right to know what the doctor feels the problem is. Their knowing is necessary for [psychiatrists] to have a good relationship with the patient. I think it is a matter of timing. First the diagnosis of schizophrenia develops over time. It takes time for doctors to be sure. Once that has happened I don't think there is any benefit for the patient not to know. If [patients] don't understand the diagnosis they won't understand the treatment or know what to expect in the future.

Another psychiatrist commented: "It is important that the patients know their diagnoses and treatment so they can read more about it and talk to other people who have the diagnosis and in that way they know they are not the only ones with it". Two psychiatrists also made the point that they did not distinguish between psychiatric illnesses and physical illnesses.

Those psychiatric respondents who placed conditions on informing patients did so for similar reasons. They contended that patients should be considered individually when deciding whether or not to disclose. They also mentioned patients' levels of intelligence and

their abilities to understand as being important factors to assess. One psychiatrist cautioned that "it is possible that some patients may use [the label of schizophrenia] to excuse behavior that they had some control over". Another psychiatrist stated that (s)he tells patients by stressing that their illness "used to be called 'schizophrenia'".

One of the reasons given by certain psychiatrists as to why they preferred to "soft peddle" the word schizophrenia included that it can be a "pejorative", "useless", misunderstood word which creates numerous problems for patients, including problems with employment and educational opportunities. One psychiatrist said (s)he would not inform patients since there were limited programs available in St. John's, Newfoundland to help them and "people say you should always inform patients but the fact is that it is a condition in which life events can be terribly meaningful for patients and make things a lot worse; it is important to try and get across what the future holds".

The question "Can patients be adequately informed about their illness of schizophrenia without knowledge of the diagnosis?" was asked of psychiatrists. The majority of respondents 71%(22) believed patients could be adequately informed about their illnesses without knowing their diagnoses while 29% maintained that they could not be adequately informed.

Of those who held that patients could be adequately informed without knowledge of the diagnosis, 55% (17) of the total population of

psychiatrists insisted that adequate knowledge could be achieved through explanations about symptomology and what the illness would entail. Comments were made that "the diagnosis is not as important as the meaning of the diagnosis" and "[schizophrenia] is a purely descriptive label so you can do without the label". However, 16% (5) contended that not informing patients could be problematic. One psychiatrist stated: "I suppose you could [adequately inform them] if you educate them on the symptoms and give them a lot of gibberish ... but if you went along with that I think you would end up in more trouble than if you informed them".

The 29% of the respondents who believed that patients could not be adequately informed without knowing their diagnoses maintained that patients would not recognize the "grave nature" of their illnesses if they did not know their diagnoses.

Interestingly, while 58% of the psychiatrists unconditionally claimed that patients should be told their diagnoses, the vast majority (71%) believed that one could adequately inform patients of the diagnosis of schizophrenia without using the actual label. Some psychiatrists who were in favour of disclosure still believed it was possible for patients to be adequately informed without giving them the label.

### Psychiatrists' Perceptions of Patients and their Families

The psychiatrists' perceptions of various patient characteristics such as: gender, age, level of functioning, level of education, psychotic symptoms, ability for providing informed consent, personality characteristics, and desire to know the diagnosis were examined. Their perceptions of family characteristics such as family history of mental illness and families' desires to know the diagnosis were also elicited. Other relevant situations included patients' misconceptions about schizophrenia and patients' indications that they desired to know their diagnoses.

#### The Patient's Gender

None of the psychiatrists interviewed felt they would be influenced by the gender of patients in revealing the diagnosis.

#### The Patient's Age

Age was reported as influencing psychiatrists' practice of disclosure to schizophrenic patients in different ways. In general those psychiatrists who stated they were influenced by the factor of age (39%) were reluctant to reveal to afflicted adolescents but began to disclose to patients at eighteen to twenty years of age. They stated that it would be difficult to separate a drug-induced psychosis from schizophrenia and that it would take longer to be certain of the diagnosis in those patients in

their early and late teens. A few psychiatrists were reluctant to disclose to younger patients because the label of schizophrenia could affect their education, employment, and self-perception. Another expressed a greater likelihood of revealing to older patients in a forceful manner when the condition had persisted for some time.

#### The Patient's Level of Education

The majority of psychiatrists reported not being influenced by patients' levels of education but about one third (39%) suggested that the educational level of the patients influenced their disclosure of the diagnosis of schizophrenia. These psychiatrists were more likely to reveal to patients who had progressed further in the educational system than to those who had not. Patients with higher education were seen as being better able to understand and individual psychiatrists mentioned that these individuals would have greater psychological sophistication, be more likely to understand the jargon, and more capable of developing insight. A few psychiatrists gave examples of situations in which better-educated patients might be more inclined to request and guess their diagnoses, or promote discussions related to diagnosis.

Clinicians who were not affected by the educational level of their patients declared that as long as the patient was able to understand or had the intellectual capability, educational level was not an influential factor. The educational level influenced these psychiatrists only in the

manner in which disclosure was handled and the timing of the disclosure.

#### The Patient's Functional Level

Most of the psychiatrists (84%) reported that they were influenced in their decisions to reveal the diagnosis based on the level of functioning of patients. A few elaborated that it was not helpful to disclose to the lowest functioning group of patients which included those who were chronically disabled schizophrenics, those who were also mentally retarded, and those who failed to recover from their psychoses. One-quarter of the psychiatrists (25.8%) mentioned that patients' functioning specifically affected the timing of their disclosure, not whether or not they would reveal; in other words, they tended to wait until patients' functioning improved.

A low level of patient functioning was stated to be a factor by most of the psychiatrists in not revealing the diagnoses to patients.

#### The Presence of Psychotic Symptoms in the Patient

Practically all (94%) of the psychiatric interviewees reported that the presence of psychotic symptoms in afflicted individuals influenced them to withhold the diagnosis of schizophrenia from patients. Of the two psychiatrists who were not affected, one (whose practice was to not reveal) commented that active psychotic symptoms would not influence

his/her revealing practice since one "would still not give the patients the word to hide behind".

Psychiatrists influenced by the presence of psychotic symptoms stated that they altered the timing of disclosure in that they would wait for the psychotic symptoms to subside. One emphasized that the patients' psychotic symptoms can be quite disturbing to them and stated "At that stage it is my primary goal to treat the psychosis and I am not certain that at that stage one would get involved in a lengthy discussion about the possible diagnosis." Some psychiatrists mentioned that it was a waste of their time and they would wait until patients had been stabilized. The views were best summarized by one psychiatrist: "It is a general rule to not try and explain things to someone who is psychotic".

#### The Patient's Ability to give Informed Consent

Approximately half (48%) of the psychiatrists stated that whether patients were capable of providing informed consent or not affected their revealing practices. Patients' abilities to understand based on their functional levels and the extent of their psychotic symptoms, including delusions and paranoia, determined whether they were able to fulfil the requirements for informed consent. These respondents were influenced to not reveal the diagnoses to patients who could not understand. One psychiatrist who was not influenced by the factor of informed consent

stated that by the time (s)he was ready to disclose the diagnosis, patients would be capable of understanding.

#### The Patient's Personality Characteristics

Half (52%) of the clinicians reported that personality types of patients guided their disclosure. These psychiatrists would either not reveal to certain personality types or would lengthen the process of revealing to them. The personality types mentioned included patients with histrionic personalities (for these individuals might become "completely involved in the word"), patients who might act aggressively, belligerent patients, impulsive patients (who might exhibit suicidal behavior), and paranoid patients (who might include psychiatrists in their delusions of persecution).

One psychiatrist gave the example of a young man who suffered from schizophrenia and was able to function adequately with medication but, because of a personality disorder he was irresponsible and would abuse drugs. This psychiatrist felt compelled to reveal the diagnosis to this patient and similar patients in the hopes of educating them to avoid abusable substances which would deleteriously affect their illnesses.

A few of the respondents who were not influenced by patients' personalities as a factor in revealing said that it would only affect their approach to the presentation of the diagnosis to patients. The factor of

personality appeared to affect how, whether, and when the psychiatrists revealed the diagnosis.

#### The Presence of a Family History of Mental Illness

The factor of patients having positive family histories of mental illness enabled some psychiatrists to more readily disclose and others not to disclose the diagnosis. Half of the psychiatrists (48.4%) reported being influenced by a positive family history of mental illness; about half again of these would be more likely to disclose while the other half would be less likely to reveal the diagnosis. Those who were influenced to be more inclined to reveal were so for the following reasons: they were more convinced of the diagnosis because of the positive family history, they were able to use the experience of the family member(s) to aid their explanations, and, because of the assumed genetic loading, a few psychiatrists felt that patients should know more about the illness because of the higher risk of passing it on to their children. Finally, a few psychiatrists noted that some patients with ill relatives were asking at an earlier stage for their diagnoses, presumably being more aware of the word "schizophrenia".

Those who mentioned that a positive family history swayed them not to disclose or slowed them down in the process of their disclosure gave examples to explain their positions. A few psychiatrists were reluctant to disclose if family members had reacted adversely to the

knowledge of the diagnosis. Others were very cautious in their disclosure if patients had relatives who spent years in a mental hospital and died there. These few psychiatrists pointed out the difference between "then and now" and requested more information about the family member(s) and the effects that the knowledge of the diagnosis had on these individuals.

#### The Patient's Misconceptions about Schizophrenia

The majority of the psychiatric interviewees claimed they were not affected in their disclosure practices by patients' misconceptions about the illness. One quarter (25.8%) were influenced when individuals had misconceptions about schizophrenia. Some of the latter psychiatrists elaborated on their reasons. One would disclose the diagnosis promptly in order to correct patients' misconceptions. Another practitioner would not disclose if patients were affected by a sense of strong stigma as a result of their misconceptions.

The general consensus of those not affected by patients' misconceptions was that more time would have to be spent with patients in educating them. In order to correct these misunderstandings, a few psychiatrists delayed the revealing of the diagnosis. One elaborated that (s)he often asked patients what schizophrenia meant thus allowing for a subsequent exploration of any misconceptions. (S)he further stated

that "by asking about the illness one is already committed to revealing the diagnosis".

#### Patients' and Families' Desires to Know the Diagnosis

Half (48%) of the psychiatrist respondents alleged that families of schizophrenic patients wanted to know the actual diagnosis and 39% of psychiatrists stated that patients also desired this information.

Psychiatrists who believed that patients and families wanted to know the diagnosis proposed that in general everyone wants to know what is wrong with them or their family members and that people look upon doctors to provide them with a diagnosis. A psychiatrist said :

I don't think the condition [schizophrenia] is different from other conditions, whether it is cancer, heart disease, or diabetes. I think there are some people who do not want to know a lot of detail about their condition and there are some that do. I don't think there is that much that is particular to schizophrenia.

Most (81%) of the psychiatrists stated they did not have patients indicating verbally or behaviorally that they did not want to know their diagnosis. Some expounded on this further by saying that their approach encouraged openness, that they felt most people were curious to know, and they had experienced patients wanting to know as much as possible. One psychiatrist commented that:

I feel most people that have a significant illness, whether it is psychiatric or medical, by the time they come to treatment, this has had an impact on their life to the point where they realize there is a significant problem. So I don't feel that when you tell a person or

when you discuss an illness that this comes to somebody as a total shock.

The 19% of psychiatrists who had encountered patients indicating either verbally or nonverbally that they did not want to know about their illnesses gave explanation. Some respondents advanced that they observed patients on an intuitive level as not wanting to know by their not asking, their lack of curiosity in knowing, their adamantly denying bizarre behaviors described by families and staff, their asking for the diagnosis and, when told, "conveniently" forgetting the label, their being frightened by the term, and their ignoring opportunities to ask the psychiatrists about the illness. One individual elaborated that:

We do not present the details of their illness as [if] they are reading material from a book. I have never done that, so I have not faced a situation where somebody would say "I want to know nothing." It is a judgement that we have to make [as to] whether they would appreciate knowing or not; we do not ask whether they want to know it or not because, in my own beliefs, in diagnosis [sic] leave a lot of doubt in them so that I don't want to present them as dogmatic statements to my patients.

Another psychiatrist claimed that some patients prefer to refer to their diagnosis after they have been told as "my depression", or "my nervous condition" which gave the impression that they were denying their illness somewhat even though they were often compliant with treatment.

The following interesting point was made by one interviewee:

You don't get pressed for the diagnosis. It is amazing how you can treat these people for many years with the understanding that they

have to come and get their medications and get their help but very seldom do they put you on the spot as to a diagnosis.

Another pertinent remark was made: "It depends on the knowledge of the community. A lot of people do not have a clue about it so they are not wanting to know because they don't know [anything about schizophrenia]. I find that if it is something that is known about then they want to know".

#### Additional Factors

There were miscellaneous factors which more than one of the respondents identified as having an effect on their revealing of the diagnosis; these included the degree of social stigma patients encountered, the length of patients' hospitalizations, patients' compliance with treatment, and patients' abilities for insight.

Factors which individual psychiatrists identified as playing a role in their decisions regarding disclosure of the diagnosis are as follows: the psychological sophistication and perceptiveness of patients, resources for rehabilitation such as "Friends of Schizophrenics" being required, their being required to reveal the diagnosis by law, such as in forensic cases, and patients being a danger to themselves and others and needing to be told their diagnoses.

One psychiatrist expressed reluctance to diagnose and subsequently to reveal the suspected diagnosis when the patients

required citizenship or had plans to travel. Another psychiatrist stated that:

Sometimes there is a lot of pressure from the family that this person is not getting any better and you inform them to get people off your backs that this person has schizophrenia: it's chronic and that's all I can do. You are exasperated at the patient not getting any better, giving the family and yourself a very difficult time, and to relieve the pressure on yourself, you use the term schizophrenia, and this is when you say "No, he's not getting any better".

#### Challenges Psychiatrists Encountered with Disclosure

The psychiatrist population studied faced challenges in several areas surrounding the issue of disclosure to schizophrenics under their care. These challenges included problems in the process of disclosure, requests from families not to disclose the diagnosis to affected members, ethical dilemmas, situations where disclosure would be countertherapeutic, and the necessity that different techniques be utilized in treating and educating patients as a consequence of how disclosure is handled. This section begins with the problems that psychiatrists mentioned in reference to question 11 (See psychiatrists instrument, Appendix B) and will subsequently report on what the researcher believes may be challenges for some psychiatrists.

Problems Psychiatrists Mentioned in the Process of Disclosure

Most psychiatrists (74%) had had problems associated with revealing the diagnostic label of schizophrenia to patients and/or their families. The other 26%(8) had not encountered any major problems [6% (2) had faced no problems but had not disclosed]. The difficulties most frequently confronted are listed in Table 6.

Table 6

**Problems Encountered by Psychiatrists in the Process of Revealing the  
Diagnosis to Patients and/or their Families**

<b>Problems</b>	<b>Percentage of respondents</b>	<b>n</b>
Patients and/or families were not able to accept the diagnosis	19%	6
Patients and/or families had misconceptions about schizophrenia	19%	6
Patients and families had anxieties and fears about the diagnosis	19%	6
Patients and family members had adverse reactions to the revealing of the diagnosis	13%	4
Uncertainty about schizophrenia	13%	4

**Note.** More than one response was given by some interviewees.

Within the process of diagnosing, treating, and educating patients about their illnesses, some psychiatrists found misconceptions about schizophrenia problematic. The vast majority of psychiatrists mentioned encountering misconceptions from patients and their families. These included the view of schizophrenics as potential mass murderers, as suffering from split personalities (Dr. Jekyll and Mr. Hyde), as violent, paranoid, aggressive, or as suffering from a universally severe chronic illness. Approximately half of the psychiatrists specifically alluded to allotting time for educating individuals in order to aid in clearing up misconceptions.

According to respondents, the fears and anxieties about this diagnosis can be associated not only with what it means for schizophrenic patients but also with what it might mean for the families themselves in terms of interacting with afflicted individuals and whether or not they will also become ill.

One psychiatrist divulged that (s)he worried about whether the knowledge of the diagnosis would "destroy" patients, whether they were able to cope with knowing or able to understand the information, and whether they would be frightened by what (s)he [the psychiatrist - respondent] termed sensationalistic journalism. Another clinician recounted:

The major problem I have is with people who are paranoid in the lay sense of the word...sometimes it is difficult to maintain a rapport with someone if they are suspicious, and if you tell them

and you concentrate on the facts that they have these delusions and false beliefs, you could run the risk of them bolting from therapy or leaving.

In addition, one practitioner had encountered patients who would visit numerous doctors after the diagnosis had been disclosed.

The adverse reactions psychiatrists faced included panic and aggressive behaviors.

The psychiatrist respondents faced the problem of uncertainty with regards to not being sure of the label, not "knowing what schizophrenia [really] is", and not being able to give a prognosis to the illness. How psychiatrists handled this uncertainty is reported on in the present chapter under "Psychiatrists' Conception of Schizophrenia".

When asked which problems they encountered in the process of revealing the diagnosis, most of the psychiatrists complained of those which were specifically associated with patients and their families when they were in the process of being told the diagnosis.

#### Requests from the Family not to Disclose the Diagnosis to the Patient

The researcher assumed that a potential challenge psychiatrists faced (which they did not mention as a problem in the process of revealing the diagnosis) occurred when they received requests from families not to disclose the diagnosis to the ill family members. When this was investigated, the majority of psychiatrists (74%) had not had this request made of them while 26% had. Most of those who had received

the above request handled it by attempting to explain to family members the importance of patients' knowing their diagnoses. A few of these psychiatrists augmented this explanation with statements to the effect that the patient was their main concern and, if they were to deliberately lie to the patient, then this could damage the therapeutic relationship with the patient. Others felt that it would not be a case of respecting the families' wishes since psychiatrists were more interested in their assessments of patients' feelings and perceptions towards knowing their diagnoses.

### Ethical Dilemmas

Only one of the psychiatric practitioners reported facing an ethical dilemma in the revealing of the diagnosis to patients. "Because we [psychiatrists] do not have hard facts surrounding making the diagnosis and our prognosis is often wrong and subject to revision, it is difficult to know how much to tell so we don't unnecessarily harm the patient."

A few psychiatrists were perplexed by related quandries. A psychiatrist asserted that there were no ethical dilemmas in revealing the diagnosis to patients but that there were dilemmas faced in revealing the diagnosis to families when patients did not want their families to have information about the illness. Another psychiatrist confronted an ethical dilemma in the writing of medical certificates to universities and employers because individuals receiving them would often know far less than families and patients about schizophrenia.

A few of these interviewees reported not facing ethical dilemmas. One explained that patients could still be cautioned and informed about the risks related to various aspects of their lives without the psychiatrists using the word schizophrenia, for example, the possibility of having a child with similar mental health problems; another insisted that there were no ethical dilemmas involved since patients should know the diagnosis.

#### Encountering the Potential for Countertherapeutic Situations if the Diagnosis is Disclosed

Some of the psychiatrists' disclosure practices with the diagnosis of schizophrenia were influenced by the potential for disclosure to be countertherapeutic. Approximately half (45%) of the psychiatrists described pertinent countertherapeutic situations. One such situation mentioned was a panicky termination of treatment when patients were not able to accept their diagnoses. Receiving the diagnosis may have been a difficult burden for some patients thereby placing unnecessary strain upon them. Other countertherapeutic scenarios given were as follows: when patients adopted negative attitudes about what they were capable of doing or used the diagnosis to avoid taking responsibility for their actions; when individuals had knowledge of tragedies or extensive suffering occurring to similarly afflicted family members. Psychiatrists also claimed that if they revealed to patients who

were paranoid and had an externalized view of their problems too early, without establishing a relationship, they would risk being included in patients' delusions. A few psychiatrists responded that if patients were told the diagnosis at the wrong time, for example, when acutely psychotic, or if the illness was painted in a negative light, then these circumstances could be countertherapeutic for patients.

#### Necessity that Different Techniques be Utilized In Treating and Educating Patients who were Unaware of their Diagnoses

More than half of the psychiatrists (55%) reported that different techniques were not required with regards to treatment and education when schizophrenic patients did not know the diagnosis. Nineteen per cent believed different techniques were required; a further 6% claimed that different techniques were necessitated only in the area of patient education. The remaining 19% of respondents were unable to comment on this question because they regularly disclosed.

Of the 55% (17) of psychiatrists who believed that different techniques were not required for unaware patients, 48% (15 of total) interviewees believed they would do the same irrespective of whether or not they used the word 'schizophrenia'. The other 6% (2 of total) pointed out that it was not the disclosure or nondisclosure which called for different techniques but other factors such as treatment refractoriness

and patients' view of their problems as external to themselves, for example, in the presence of persecutory feelings.

Those clinicians who believed that different techniques were required when patients did not know their diagnoses gave their rationales. One declared that different techniques were necessary at various stages of "negotiating" with patients about their illnesses. Another stated that (s)he used the "kid gloves approach" in trying to elicit symptoms in the early stages of assessing and treating patients when the diagnosis was not discussed as opposed to the later stages of treatment.

#### Psychiatrists Disclosure Practices

Variability existed among psychiatrists in their proclivities towards disclosure of the diagnosis of schizophrenia. This variability was noted in many areas and included the psychiatrists' general practice of disclosure, their consultation of other disciplines with regards to this area, their utilization of euphemisms for schizophrenia, the documentation or communication as to whether or not disclosure had occurred, and the treatment psychiatrists utilized with schizophrenic patients.

#### Psychiatrists' General Practice of Disclosure to Patients and Families

When certain of the diagnosis, 74% of the psychiatrists generally disclosed to schizophrenic patients and 77% generally disclosed to families. In general, therefore, not all of this population revealed to

patients and their families; some generally disclosed to all patients all of the time (29%), some to a portion of the patients (55%), some specifically when patients asked (10%), and some did not disclose or tried to avoid revealing the diagnosis (6%).

#### Consultation of Other Disciplines Regarding Disclosure

Psychiatrists in general did not frequently consult other disciplines regarding disclosure of the diagnosis of schizophrenia to patients or their families. Sixty five per cent (20) of psychiatrists indicated that they had not consulted other disciplines. Consultation of other physicians was specifically mentioned by three of these twenty psychiatrists. Those who had discussed revealing the diagnosis with other disciplines made up 35% of the population; disciplines mentioned included: nursing, social work, and the entire multidisciplinary team.

It is possible that the degree of consultation by psychiatrists of other disciplines in dealing with this specific area may be spuriously high because, if a psychiatrist had consulted another professional on even one occasion, the psychiatrists could have answered affirmatively to this question.

#### Euphemisms Used

When speaking about the disorder schizophrenia, the psychiatrists used various terms or euphemisms. Slightly over half (58%) of the

psychiatrists claimed that they used other terms for schizophrenia while 42% reported that they did not. There were numerous substitute terms or phrases mentioned which included: "nervous illness", "nervous breakdown", "bad nerves" (used in gathering information for the family history), "unduly anxious", "psychosis", "psychotic breakdown", "psychotic illness", "acute psychotic episode", "schizoaffective psychosis", "schizophrenic reaction", "recurrent psychotic disorder", "severe depression", "panic disorder", "manic depression", "chemical imbalance", "paranoid disorder", "emotional disturbance", "serious mental illness", and "Newfoundland adaptation syndrome". One psychiatrist elaborated that "nervous breakdown" was a lay term that was used frequently in Newfoundland, although it did not differentiate psychotic illnesses from the affective disorders. To substitute for the word 'schizophrenia', psychiatrists used explanations of the concept of schizophrenia, its symptoms, or causes as well as analogies. Some of the analogies used included comparisons with physical illnesses such as diabetes or hypertension, and the following metaphors: "Look, your boat is rocky; it's no use putting up your sail or trying to protect yourself doing this or that. Just sit tight as long as you can and let the storm die out", and "The water is muddy, but once the spring is over the water will be clean again".

Psychiatrists handled the use of euphemisms differently: some acquired a feeling about patients before deciding which labels to use; others used more general terms such as "mental illness" when dealing

with patients and relatives whom they did not know well; a few psychiatrists resorted to alternate expressions when they were not certain about the diagnosis; still others used euphemisms even when they were certain. Some psychiatrists used euphemisms alongside the term 'schizophrenia'; others used them to substitute for this term.

The following table reveals psychiatrists' beliefs as to whether patients prefer other terms to the word schizophrenia. Of those who used euphemisms the majority believed patients preferred them. Those respondents who held that schizophrenic patients preferred synonyms to their actual diagnosis did so because they believed patients were more familiar and comfortable with the terms. One psychiatrist asserted that 'schizophrenia' seemed to mean madness and had connotations of incurability which one did not want to reinforce in patients. Another interviewee expressed an interesting point of view in stating that the use of the term 'schizophrenia' with patients may not always mean useful information would be received from various organizations set up to help schizophrenics and their families.

Table 7

Psychiatrists' Beliefs as to Whether Patients Preferred Euphemisms to the Schizophrenic Label

Psychiatrists' beliefs	Percentage of psychiatrists	n
Patients prefer euphemisms	42%	13
Undecided	10%	3
Patients did not prefer euphemisms	6%	2

Note. This question was asked only of the 58% (18) of psychiatrists who used euphemisms for schizophrenia.

### Documentation of Disclosure

When schizophrenic individuals were hospitalized, psychiatrists were required to document treatment plans, any progress made, and changes in treatment regimens. The vast majority of the psychiatrists had never documented why, in certain instances, they had not wanted the diagnosis of schizophrenia revealed to patients or families. Only 13% (4) of the psychiatrists had on one or more occasions written on the medical chart why they had not wanted the diagnosis revealed. Their rationale in these instances included that it was a means of informing staff that certain patients had handled the knowledge of the diagnosis poorly in the past, it was documentation that patients had not given permission to reveal the diagnosis to their families, or it was an indication of psychiatrists' lack of certainty about the diagnosis.

### The Treatments Psychiatrists Utilized with Schizophrenic Patients

There are numerous treatments and combinations of treatments available for patients suffering from schizophrenia. One way to acquire a glimpse of the psychiatrists' practice was to examine their opinions as to the best treatment they can offer their patients in Newfoundland. Almost all (87%) psychiatrists mentioned in their explanations of this "best treatment" the importance of neuroleptic (antipsychotic) medications. Three-quarters (74%) mentioned rehabilitation or some aspect of rehabilitation.<sup>9</sup> Psychotherapy or supportive psychotherapy was

mentioned by 52% of the psychiatrists as playing an integral role in the provision of treatment for their afflicted patients. To reduce the stress for patients, family interventions were mentioned by 19% of the respondents.<sup>10</sup> Of the total number of psychiatrists, approximately one third (35%) mentioned the use of all three of neuroleptic medications, some aspect of rehabilitation, and psychotherapy in their descriptions of the best treatment that they could offer their schizophrenic patients in Newfoundland.

Although variability existed within their handling of issues related to disclosure of the diagnosis of schizophrenia to patients, most Newfoundland psychiatrists had done the following: most had not written on the medical charts the reasons why they had not revealed the diagnosis, the majority generally revealed the diagnosis of schizophrenia to some patients, the majority did not consult other disciplines as to whether or not patients should be told their diagnoses, most respondents mentioned the best treatment as involving neuroleptic medications, rehabilitation, and/or supportive psychotherapy, and over half of the psychiatrists used other terms for schizophrenia.

### Factors Social Workers Perceived as Influencing their Disclosure Practices

Partly because social workers did not generally diagnose schizophrenia, their roles differed from those of psychiatrists as will be reflected in the organization of this section. The researcher therefore focused more on social workers' behaviors and problems when psychiatrists had not disclosed; social workers were not asked the criteria they used to diagnose schizophrenia since in general they were not performing this function. Social workers' conceptions of the illness, their etiological views of the disorder, and their opinions of its prognosis remain valuable areas for further research. The influences on social workers' practices regarding disclosure of the diagnosis of schizophrenia that were studied were the organization of agencies, the workers' perceptions of their role with schizophrenic patients and families, their opinions with regards to disclosure, their perceptions of these patients and families, and the challenges these social workers encounter in relation to the area of disclosure.

### The Organization of the Agency and Its Impact on the Role of the Social Worker

The organization of the agency influenced the process of how disclosure of the diagnosis was handled. The roles of social workers varied depending upon where the social workers were assigned, the

mandates of the social work departments within hospitals, how workers were organized to serve their patients, the clientele served, the geographic proximity of patients and their families to the hospitals, the availability and proximity of resources, the psychiatric clinical teams' manners of operation, social workers' relationships with the teams and psychiatrists, and the clinical teams' perceptions of the roles of the social workers. Hence, social work's role was as much defined by other professionals at the workplace as it was by social workers professionally and individually.

Workers in this study were assigned to inpatient psychiatric units which served acutely and chronically ill patients, mentally retarded individuals with coexisting psychiatric problems, and the psychogeriatric and forensic populations. They were also involved with outpatients, supervised boarding home operators, and those patients who resided in the community care setting. A few social work respondents qualified that their roles could vary depending on the functional levels of the patients, the types of schizophrenia from which their patients suffered, the wishes of the family, the needs of the patients, and the nature of the referrals requested.

One of social workers' primary roles in hospitals was discharge planning (Adelson, Leader, 1980; Davidson, 1978, cited in Abramson, 1981). Time constraints for workers whose main role was discharge planning may have limited their capacities to focus on patients' illnesses

and associated problems with all cases. Major effort was needed to expediently assist in the discharging of patients into appropriate environments. The social workers interviewed had patients with chronic schizophrenia on their caseloads and the numbers of patients with this diagnosis with whom they had contact varied from worker to worker. Some chronic schizophrenic patients had been labelled in the distant past and, if these patients were not informed, workers often questioned the value and purpose in revealing the diagnosis to them. One interviewee stated that many patients in the setting where (s)he worked had intellectual deficits as well as their illnesses; this contingency would create a significant challenge in that workers would have to assess patients' abilities to understand. Conversely, another worker cautioned against adhering to the rationalization that these patients should not be told their diagnoses because of perceived intellectual deficits.

Some patients had already been informed of their diagnoses because they had been in and out of hospitals and the mental health system for a long time. Workers could then focus more on rehabilitation with these inpatients or outpatients and thus the illness and its ramifications would become one of the issues to be discussed.

According to some of the workers in this study, social workers were often the team members who had the most contact with families.

A few social workers stated that some hospitals had the policy that, if the diagnosis was going to a community agency, physicians'

permission (or, in one setting, a physician's co-signature) was required. In these settings the idea would be reinforced that diagnoses were physicians' "property" and should be released only by them.

### Social Workers' Roles

#### Social Workers' Roles with Schizophrenic Patients

Just as the organization of the agency had an influence on the way social workers handled disclosure, so did the social workers' perceptions of their roles with patients and families. They saw their roles as extending from the more encompassing to the performing of specific concrete tasks. The roles social workers mentioned are summarized in Table 8.

#### Linkage with resources

The workers' role of linking schizophrenic patients with resources was easily categorized into assisting them in finding suitable living facilities and rehabilitation programs. The types of linkage with rehabilitation included referring patients to training programs, assisting them back into the work force, and developing structured day regimens for them.

Table 8

Social Workers' Perceptions of their Roles with Schizophrenic Patients

Roles	Percentage of social workers	n
Linkage with resources	64%	14
Psychotherapeutic interventions	59%	13
Patient education	50%	11
Assessment	32%	7

### Psychotherapeutic interventions

Psychotherapeutic interventions were mentioned by over half of the social workers with approximately one quarter emphasizing the utilization of forms of support. The types of support for schizophrenic patients included helping them throughout their hospitalizations, assisting them in coping with not knowing their diagnoses when doctors are reluctant to tell (for example, during first admissions), enabling individuals to feel comfortable with their families and in dealing with family expectations, and advocating on the patients' behalf when families are not supportive. The importance of developing a solid support system and making sure supports were in place to prevent relapse was mentioned.

Means of attempting to assist these patients to adjust through counseling included assisting them to lead a normal life, helping them function to the best of their abilities without being in an institution, restoring meaning back into their lives, integrating them into the community, assisting them with future plans, and helping them adjust to their diagnoses and illnesses. The forms of therapeutic interventions mentioned by workers included: crisis intervention, family therapy, supportive counseling, and therapy aimed at improving insight into their illnesses.

### Patient education

Education or some form of education directed towards schizophrenic patients with regards to the illness was referred to by half of the workers. Areas where social workers saw patients as needing education included the illness itself and its implications, significant behavior changes and means of dealing with them, and the time to seek treatment. Patients also have to be taught how to live with the illness, how to understand what is happening, how to live independently, and how to accept that medication is required. One worker felt that social workers could also, as part of their role, recommend that other professions teach patients about schizophrenia.

### Assessment

Assessment or components of assessment were included in the descriptions of their roles by approximately one third of the population of social workers. The components mentioned can be broken down into three areas. First, there is the social work viewpoint of the circumstances of patients and their families prior to admissions, an investigation of triggering factors for episodes and an evaluation of patients' insights into their illness <sup>11</sup>. Second, there is the patients' knowledge of their diagnoses, the degree of acceptance of their diagnoses, and their compliance with medications. The third component involves factors that impact on the patients socially: the presence of family supports, the

patients' needs in relation to community living, the availability of services, and the strengths and weaknesses within the social environment. One worker stated that she explores and differentiates "...between the illness process and the impact of the illness on the social environment or patient [and] how the social environment impacts on the illness".

These assessments enabled social workers to make recommendations for treatment plans for these patients and to assist with discharge planning. A related role that emerged was that of reporting the above information to psychiatrists and/or treatment teams so that there is an understanding of the implications for patients, and so that patients were not discharged without thought given to their environments.

The role of social workers with schizophrenics was extensive and education was a significant component specifically mentioned by one half of the social work respondents. Particularly related to disclosure were the following: assisting patients in coping with the uncertainty of their diagnoses, assessing their knowledge of their illnesses, educating them about the illness and its implications, supportive counseling aimed at insight, helping them to adjust to the illness, and integrating them into the community.

#### Social Workers' Perceptions of their Role With Families

The percentage breakdown of the roles that social workers mentioned

carrying out with families of schizophrenics can be seen in Table 9 with subsequent elaboration of the components of these roles in the text that follows.

Table 9

Social Workers' Perceptions of Their Roles With Families

Roles	Percentage of social workers	n
Therapeutic interventions	86%	19
Family education	68%	15
Linkage with resources	36%	8
Interventions into the family	18%	4
Assessment	9%	2

### Therapeutic interventions

Therapeutic interventions listed were aimed at providing support and adjustment especially for families. Supportive interventions included dealing with families' feelings--especially those of guilt, and helping families to provide nurturing and supportive environments. Interventions for the purpose of adjustment included aiding families in adjusting to the illness, assisting them in helping to improve afflicted members' levels of functioning, helping them cope when they do not know the diagnosis, dealing with their expectations, and mediating when conflict occurs. One worker stated that the role of social work with families is to "offer a supportive arena or forum for them to talk about some of the difficulties, the hardships, the frustrations, and just to ventilate some of those concerns". One worker acknowledged the importance of working with families and helping them in understanding the illness so as to not reject their ill family members.

### Family education

Education of families of schizophrenics involved the following: helping them to obtain an understanding of the illness, destroying any of their myths about schizophrenia, and teaching them to notice early signs of behavior change pointing towards the possibility of relapse.

### Linkage with resources

Linkage with resources comprised assisting the families with placements for their family members, educating families on the services available for them in the community (such as "Friends Of Schizophrenics"), and ensuring adequate supports are in place for families, and gathering outside reading materials.

### Interventions into the family

Family therapy was utilized to assist these families in rearranging and readjusting ultimately to help the patient.

### Assessment

Aspects of assessment mentioned included: determining whether families should know the diagnosis and exploring for family problems. There was overlap between assessments of patients and families since part of the assessment of patients includes an assessment of their families.

The specific roles which appear to be related to social workers' practice of disclosure of the diagnosis to families encompassed such responsibilities as the social workers' assessing whether the families

The specific roles which appear to be related to social workers' practice of disclosure of the diagnosis to families encompassed such responsibilities as the social workers' assessing whether the families should know, destroying their myths, helping them to understand the patients' illnesses, and teaching them to notice the signs of relapse. Further assistance entailed giving families reading material, dealing with their feelings of guilt, and assisting them in making the necessary adjustments so that supportive environments can be provided for patients.

Reasons given for disclosure to all or practically all patients are outlined below in Table 10.

Table 10

Reasons Given By Social Workers For Revealing the Diagnosis of Schizophrenia to Patients

Reasons	Percentage of social workers	n
Assists patient rehabilitation and coping abilities	50%	11
Patient has right to know	36%	8
Knowledge assists treatment effectiveness	23%	5
Knowledge not detrimental	18%	4
Social work roles affected with uninformed patients	18%	4
Reduces blame for patients and families	18%	4
Honesty improves communications	14%	3

Note. The total number of responses appears to exceed 100% because some individuals gave more than one reason.

Responses given by only one or two individuals who favoured disclosure involved the idea that disclosure would change societal attitude, make the illness more acceptable, and take away its mystique. Other responses included the notion that knowing lessens patients' and families' misconceptions, and the claim that revealing "makes one's job easier because there is no longer a secret in which families and workers have to organize around".

Although social workers were generally in favour of disclosure some provided qualifiers as to when this should occur. One proviso adhered to by 9% of the workers was that diagnostic certainty be present before disclosure occurs; (it is possible that more social workers would have claimed that diagnostic certainty was necessary if asked this question directly). Almost one third (32%) of social workers emphasized the importance of considering "where the client is at" in making a decision about disclosure, which encompassed an awareness of the stage of the illness, the patients' intellectual abilities, and their abilities to understand and handle the diagnosis.

Social workers gave their views as to whether patients should have knowledge of their diagnoses and most explained affirmative responses with their arguments that having knowledge about the diagnosis assisted patients' treatment regimen in some manner.

Another aspect of social workers' opinions on disclosure related to whether they believed patients could be adequately informed about their illnesses without knowing the label "schizophrenia". See Table 11.

Table 11

Social Workers' Opinions as to What Constituted Adequate Information  
for Patients

Opinions	Percentage of social workers	n
Do not require knowledge of diagnosis to be adequately informed	45%	10
Required knowledge of diagnosis to be adequately informed	36%	8
Non-committal ("It would be difficult")	14%	3
"Don't know"	5%	1

The interviewees (45%) who believed patients could be adequately informed without knowledge of their diagnostic label listed the following reasons: a label is not always as important to the patient as is an elaboration of symptoms and an explanation of what can be expected; patients understand what is happening to them whether or not they have a label applied to what they are experiencing; patients can be adequately informed from the point of view of treatment without knowledge of the diagnosis.

Those 36% who believed patients could not be adequately informed without disclosure gave the following clarifications: symptoms do not make sense on their own, patients would not be able to ask appropriate questions or read further on the subject, patients would tend to minimize their difficulties if they did not know, and it is difficult to be specific without using diagnoses. One clinician expressed that patients and their families could discuss the illness with friends and relatives who might say "that sounds like schizophrenia"; as a result, the patients would form misconceptions about the illness. Another respondent summed up his/her answer with the simile: "It is like having a puzzle with a missing piece".

Two social workers contended that it would be arduous to inform patients adequately without revealing the label. One gave an informative comment that not revealing to afflicted patients could result in hidden agendas, make patients mistrustful, and cause deterioration in

therapeutic relationships. The other felt that patients would not be able to maintain themselves in a healthy balance without knowledge of their diagnoses and stated: "If you have diabetes you would be told what the warning symptoms were for hypoglycemia; you would know what the proper diet was [and] that you would have to take insulin".

Although 45% of social work respondents believed that patients could be adequately informed about their schizophrenic illnesses without knowledge of their diagnoses, all were in agreement with the diagnosis being disclosed. Social workers mainly gave reasons in favor of disclosure of the diagnosis and very few reasons why disclosure should not occur.

#### Social Workers' Perceptions of Patients and their Families

The reasons underlying social workers' interventions in terms of disclosure or nondisclosure relate in part to their perceptions of those with whom they were involved in counseling.

#### Social Workers' Perceptions of Patients' Desires to Know the Diagnosis

Table 12 shows social workers' perceptions of unknowing schizophrenic patients' desires to learn their diagnoses.

Table 12

Social Workers' Views of Schizophrenic Patients' Desires to Know Their Diagnoses

View of social workers	Percentage of social workers	n
Want to know	55% <sup>a</sup>	12
Depends on patients	27%	6
Do not want to know	18%	4

<sup>a</sup>One social worker specifically stated that all patients want to know their diagnoses.

The explanations given by the social workers who believed patients wanted to know included curiosity, finding some resolution to pain through knowing, and their increasing recognition of patients' rights to know. One clinician's illustrated his/her point.

I do feel that people in general are becoming more aware consumers of the health care system and ... over the past few years I've noticed more assertiveness on the part of the patients and families in wanting more information and expecting to get it.

Those 18% who indicated that most patients did not want to know gave the reason that patients were content to live with what information they had and that knowing would not mean very much to them.

#### Social Workers' Perceptions of Families' Desires to Know Patients' Diagnoses

The practice of disclosure of the diagnosis of schizophrenia by social workers must also be influenced by the fact that half believed that patients want to know their diagnoses and 86% of social workers maintained that most families desire to know the diagnoses of their ill members. Half of the social workers perceived that, even if families did not ask for diagnoses, they still wanted to know and 36% held that it is individualized and that most wish to know even though they do not ask. In total, therefore, 86% believed most families want to know schizophrenic patients' diagnoses. One worker was contrasted in that (s)he claimed families would want to know only if they specifically ask.

(Non-applicable responses were received from 9% of the social workers because all of their families knew). The responses which elaborated social workers' positions varied. Those from workers who were inclined to suppose that families want to know even when they do not ask concluded that "families are often more interested to know than [patients]", that professionals pick up clues in interviews that families want to know, that "some [families] want to ask but are intimidated by the whole system", and that some families think that they "should be thankful that [families] are getting these services". Some respondents also said that families say "don't put pressure on [professionals]" and "if it is important to tell [professionals] will".

An interesting remark qualified the perception of one social worker who believed that it depended on families as to whether or not they wanted to know the diagnosis:

This is a piece of the art of social work, I suppose... trying to understand if it is "I can't bear to know" versus "you are the expert in here and I am merely a lowly member of the public and I have no right to ask". A lot of families do defer once they come into hospital as they do feel they have no rights.

#### Challenges Social Workers Encountered

Some social workers encountered problems when patients were unaware of their diagnoses of schizophrenia. During the interviews they recounted various problems that this researcher perceived as challenges in their work with patients unaware of their diagnoses. These challenges

included such things as encountering patients who lack knowledge of their diagnoses, having difficulty determining whether patients actually know their diagnoses, dealing with patients' misconceptions about the illness, encountering passive patients, having to make decisions regarding disclosure, dealing with uncertain diagnoses, managing patients who have their diagnoses revealed inadvertently, encountering scenarios where revealing the diagnosis could be potentially countertherapeutic, and confronting ethical considerations. Requests from family members not to disclose the diagnosis to patients and from patients for their diagnoses were also challenges for social workers. Being required to utilize different therapeutic interventions and/or special skills in treating afflicted patients who do not know the diagnosis and the potential of having the social work intervention altered were some challenges to the social worker role.

Problems Social Workers Encountered when Patients were Unaware of their Diagnoses.

Numerous problems that Newfoundland social workers who work in psychiatry stated they contended with when patients were unaware of their diagnoses of schizophrenia were revealed by the majority of the population (77%). Non-applicable responses were received from 14% of this population and 9% specified no special problems in dealing with

these patients.

Table 13 lists the most frequent special problems identified by respondents when patients do not have knowledge of the diagnosis with subsequent elaborations in the text.

Table 13

Problems Social Workers Encountered When Dealing With  
Schizophrenic Patients Who are Unaware of Their Diagnoses

Problems	Percentage of social workers	n
Assisting patients to deal with the implications imposed by schizophrenia	45%	10
Limitations on openness	41%	9
Therapeutic relationship affected	36%	8
Preparing patients for community resources	23%	5

Note: The responses do not add up to 100% because individuals gave more than one response.

Assisting patients to deal with the implications imposed by schizophrenia.

When patients lack knowledge of their diagnoses, social workers believe they have difficulty in getting these patients to deal with the implications imposed by the illness. Non-compliance to treatment and follow-up results because patients often do not know why they should follow their treatment.

Limitations on openness.

The reasons behind some social workers' feeling less open with their patients were that they were not convinced they could answer all of the patients' questions, that they felt restrictions on the extent of education they could provide, and that they, as social workers, were forced to contend with their feeling of not being "totally honest" with patients.

Therapeutic relationship affected.

Examples of how the therapeutic relationship was affected are illustrated by the following quotes and points: "It is difficult to contract in an effective manner if [patients] don't have all the information", that patients were basing their planning on different therapeutic assumptions, and that "there is always distance in the relationship and something that is missing [in the relationship with the patient]".

Preparing patients for community resources.

A worker noted difficulty when patients do not know their diagnoses in preparing them for attendance in programs or discharges into the community: these individuals do not adequately know why they should not discuss their delusions or act in certain inappropriate ways while attending programs. One social worker recounted:

It obviously poses a lot of difficulties: "Why shouldn't I [the patient] go back home and resume the life that I had before?", "Why should I take my pills?", "Why should I go to the doctor?", "Why can't I live in that house?", and "Why can't I just be like everybody else?" Sometimes it is: "You [the social worker] are preventing me from being like everybody else", so I [the social worker] become a piece of an enemy to be ignored and to be disregarded, tolerated while [patients] are trapped in here and then forgotten as fast as possible when they are out.

This quote highlights many of the special problems social workers encounter when dealing with patients who do not know or accept their diagnoses of schizophrenia. Their lack of understanding and insight creates a desire to terminate the therapeutic relationships upon discharge since they do not know why they need to follow the treatment regimens of hospitalization and medication. It is apparent that the patients and social workers are making plans based on different assumptions since patients do not understand their illnesses.

### Requests from Families not to Disclose the Diagnosis to Patients

Requests from family members not to release the diagnosis to schizophrenic patients were received by 9% of the social workers, whereas 68% had not encountered these requests and 18% were uncertain if they had met with such requests. (An omission occurred where one worker was not asked this question.) An example of this sort of request made by a family member to one of the respondents was paraphrased as follows, "It is fine for us to know but I think he will deteriorate even further if he knows". One worker examined very carefully the reasons for families wanting to hold back information from patients themselves to see if this was the families' way of being more powerful than patients and of "[righting] the balance; after all the patients had been more powerful in the family during the period [in which] they were getting sick". Requests of this nature were seen by the researcher as being potentially problematic.

### Encountering Passive Patients

Social workers encountered passive patients who do not appear to sense that they have the right to ask for their diagnoses or to question their therapies. The passivity of these patients and family members was mentioned as problematic by 18% of the interviewees. The workers qualified "passive" as meaning that patients either do not sense that they had the right to ask for their diagnoses or do not know their rights. One

elaborated that, if patients do not think that there is such a thing as a diagnosis for themselves, they would not think to ask. Another communicated that the psychiatrist is often viewed as "God" and accordingly patients do not question any interventions and go along with any of the suggestions for treatment.

#### Encountering Difficulty Determining if Patients Know their Diagnoses

Difficulty determining whether schizophrenic patients know their diagnoses was acknowledged as a problem by 9% of the respondents. Workers explained that denial could be so strong that, even when patients were known to have this knowledge, they either act unaware or seem to be unaware. These workers therefore found it problematic determining whether patients have knowledge of their diagnoses since they often appear to lack knowledge.

#### Encountering Diagnoses in Question

Uncertainty of diagnosis in psychotic individuals created problems for two (9%) of the social work respondents. They observed patients' diagnoses of schizophrenia being changed to schizoaffective disorder or manic-depressive illness, or otherwise being questioned.

#### Encountering Patients being Revealed their Diagnoses Inadvertently.

A few social workers noted problem situations where knowledge

of diagnoses of schizophrenia was acquired inadvertently by patients' either reading it on their own charts, hearing it discussed in conference, or learning of it through naive social workers or other professionals. These respondents believed that these were most unfortunate ways for individuals to learn their diagnoses.

#### Encountering the Potential for Countertherapeutic Situations

A few social workers were cognizant of the potential for countertherapeutic situations if this diagnosis was revealed to patients and/or families under some conditions; respondents cited three relevant situations. One stated that (s)he "would have to determine if [(s)he] would be helping or harming patients by informing them of their diagnoses of schizophrenia when they have been functioning without knowing for many years, and do not really conceptualize themselves as ill". Another described individuals going home from hospitals to small communities with little to no community supports available; (s)he believed it would not be advantageous to reveal diagnoses to patients when time is lacking and patients are not well enough to comprehend the diagnosis. In such situations, this worker recalled querying whether or not one is helping patients by giving them information which they "cannot do a heck of a lot with" as opposed to revealing to those who live in centers with adequate supports to work through the knowledge of this diagnosis. A final scenario of a potentially countertherapeutic situation

reported by a worker was:

[When] dealing with hostile, demanding, dissatisfied family members who were asking for diagnoses and one gets "a gut feeling" that they may be looking for a label to use against the patient; in these situations one would be cautious in revealing the diagnoses.

#### Encountering Patients Asking not to Know Their Diagnoses

Patients are at times curious about their diagnoses and ask for the information. Social workers in this study recalled no patients who requested not to know their diagnoses. However, non-verbal reactions of this nature were reported by 23% of the respondents. These included: denial of anything being wrong, blaming other people or things, exhibiting passive reactions, showing no interest in knowing, and simply not asking for diagnoses. One worker stated that (s)he has worked on cases where disclosure to families but not their afflicted members occurs because (s)he "[reacts] to the unspoken message that the client does not want to know what [the illness] is all about".

#### Social Workers Requiring the Use of Special Skills when Patients are Unaware of their Diagnoses

Special skills were confirmed as being necessary by 73% of the social workers when they deal with patients who do not know their diagnoses, while 9% declared that no special skills are required, and 18% gave responses which were not relevant.

Of those 16 (73%) workers who indicated that special skills were required, nine (41%) identified these as "evasiveness", "lying", "beating around the bush", and "unnecessary fiddle-faddle". Four workers (18%) described the skill of enlisting physicians to tell patients as: "[using] tact", "advocating on the patients' behalf", "negotiation", and "manipulation of the system". Knowledge of schizophrenia was mentioned as a requisite by four respondents (18% of the total) in order that patients be given information without their diagnoses.

One worker professed that special psychotherapeutic skills were required in working with individuals who had committed violent acts when they did not know their diagnosis, and did not understand, or did not accept their illnesses.

Three categories of special skills were identified by the social work interviewees for dealing with patients who do not know their diagnoses of schizophrenia. These were having special knowledge, encouraging physicians to disclose the diagnosis of schizophrenia to patients, and imparting information to patients without identifying the diagnosis.

#### Social Work Interventions can be Affected when Patients are Unaware of their Diagnoses

The majority of social workers (77%) recognized that their interventions are affected when schizophrenic patients are not imparted knowledge of their diagnoses while 14% believed that having patients

unaware of the diagnosis has practically no effect on their interventions. Nine per cent of the respondents had patients who all knew their diagnoses.

The 77% of workers who alleged that social work interventions are affected mentioned educational and psychotherapeutic activities which were affected as follows, (listed in order of most to least frequently mentioned): an altered approach is necessary ("you get the same job done but differently"); different and more careful wording and more elaborate explanations to patients are required; and increased time is needed for additional efforts expended in assisting patients in understanding what is occurring in their lives. Some of these social workers determined that they are not able to intervene at all with individuals who are uninformed. Hence, most of the social work respondents claimed that their interventions were altered when patients did not know their diagnoses of schizophrenia.

### Ethical Considerations

Without being asked, seven social workers (32%) spontaneously revealed ethical considerations or mentioned ethical dilemmas in relation to disclosure. Individual workers mentioned the following types of ethical considerations they encountered: working with patients who do not know their diagnoses, releasing information to community agencies,

and agencies needing information when patients do not know their diagnoses.

Problems were created when workers did not agree with patients not having their diagnoses disclosed to them and were working with patients who did not know their diagnoses. Not revealing to patients means that one had to be evasive with patients and this "[can be] hard to deal with professionally and personally". This dilemma comes from within since social workers are taught to be open with each other and to communicate effectively; when patients ask social workers for their diagnoses and psychiatrists are reluctant to reveal the diagnoses difficulties result.

Often when social workers were referring patients to community agencies these agencies requested information about the patient. The release of information, namely diagnoses and symptoms, to community agencies was a common situation which poses a structured ethical dilemma for social workers. Agencies requested symptoms and diagnoses from 95% of the workers. The other 5% stated that they were not certain if the agencies with which they have contact required the diagnoses but the symptoms were definitely required. The number of agencies per social worker with which there was contact and which requested the symptoms and diagnoses ranged from a few to most. The types of agencies listed included: supportive housing, programs, vocational rehabilitation programs, programs which were extensions of

the health care system, structured day programs, and some social services' programs.<sup>12</sup> There were regional differences in program requirements. Different regions were represented by 18% of the respondents.

Without being specifically asked, a few social workers volunteered information on how they deal with or are able to get around having to give out diagnoses and other confidential information on their patients to agencies. These workers indicated that they require consent from patients to release any information to agencies but this does not always mean that patients would know exactly what information is being released. A worker mentioned that some of her/his patients might not know their diagnoses even when the agencies are given them. Other workers ensured that patients knew their diagnoses if this information is to be released, while one worker mentioned showing patients application forms or letters on their behalf and asking if they agreed with the information that is being released. Other workers claimed that they would not release the diagnosis unless the attending psychiatrists agree, while another needed the co-signature of the physician before the diagnosis could be released. A few social workers avoided giving out some information by withholding, or releasing a less stigmatized diagnosis such as 'depression', or communicating information verbally in the hopes that the information would not appear in the agencies' records.

A few social workers discussed the agencies' need for information as potentially problematic when schizophrenic patients do not know their diagnoses. One worker expressed concern over agencies having knowledge of patients' diagnoses when these patients do not, while three (14%) saw the agencies' need for accurate information as a legitimate one. One interviewee elaborated on a situation where transitional supportive housing staff needed to know the extent of patients' illnesses in order to prepare to deal with them. This worker ensured that all of his/her patients were aware of their diagnoses since the transitional housing staff could not be relied upon not to reveal patients' diagnoses to the patients. Finally, another worker stated that it is only fair that agencies have knowledge about patients' diagnoses lest they be sent patients under false pretenses.

#### Social Workers' Disclosure Practice

Variation existed in social workers' behaviors with regards to revealing diagnoses to patients, the types of involvement they required from psychiatrists, handling patients' questions about their diagnoses, substitute terms they used for schizophrenia with patients, and how they handled patients families' questions about the diagnosis.

In relation to disclosure of the diagnosis of schizophrenia, 41% of the social work respondents had revealed to patients (at least once) their diagnoses of schizophrenia while over half (55%) required some

involvement from psychiatrists in dealing with patients who do not know. Of those who encountered them, only 27% directly answered questions from families about patients' illnesses. Most social workers required special skills when dealing with patients who were uninformed about their diagnoses and the majority (77%) had to alter their interventions when dealing with these patients. Thus, there was variation in social workers' behavior in the way they handled patients' and families' in terms of their lack of information about the illness of schizophrenia.

#### Social Workers Who had Disclosed

Table 14 reveals the percentage of social workers who had on at least one occasion disclosed to patients their diagnoses of schizophrenia.

Table 14

The Percentage of Social Workers Who Had Disclosed to Patients Their Diagnoses of Schizophrenia

Responses given	Percentage of social workers	n
Had disclosed	41% <sup>a</sup>	9
Had not disclosed	50% <sup>b</sup>	11
Patients all knew their diagnoses	9%	2

<sup>a</sup>Amongst those nine who had disclosed, one specifically stated (s)he did so after discussing it with the team, one did so with a psychiatrist present, and two disclosed after consulting the doctor.

<sup>b</sup>One (5%) had no reason to disclose because (s)he was always successful in getting psychiatrists to reveal to patients.

The majority of social workers have not disclosed to patients their diagnosis of schizophrenia.

#### Seeking Psychiatrists' Involvement

Social workers consulted or discussed aspects of their casework with psychiatrists with over half (55%) of the social work respondents stating that they required some form of involvement from psychiatrists when it was suspected that patients did not know their diagnoses. On the other hand, 23% of the respondents worked around patients not knowing by discussing their illnesses in a more general manner. One (5%) social work respondent indicated that (s)he requested a psychiatrist's intervention after (s)he had undertaken disclosure to a patient. (This question was not relevant to 18% of the respondents.)

The 55% of social workers who required involvement by psychiatrists when they encountered patients who did not know first asked the patients what they knew about their illnesses and, if they did not know their diagnoses, some subsequently took one or more of the following actions: (a) suggested that patients discuss their diagnoses and illnesses with their psychiatrists; (b) consulted psychiatrists as to how clear the diagnoses were and whether they felt these patients should have knowledge of their diagnoses; if so, then they encouraged psychiatrists to disclose; (c) consulted psychiatrists and encouraged them to disclose to the patients in joint interviews with themselves

present; and (d) consulted the psychiatrists to obtain their judgement as to whether the patients should know and then used the information obtained to make decisions as to whether or not disclosure should occur.

Evidence that social workers involved psychiatrists in their decisions to disclose was given by psychiatrists with 35% of the psychiatrist population claiming that they had encountered social workers questioning them about disclosure of schizophrenia. The remaining 65% had not been questioned.

The majority of social work respondents (64%) reported they had discussed the issue of disclosure versus non-disclosure of the diagnosis of schizophrenia with a psychiatrist with regards to a specific patient's treatment, whereas 36% had not.

Some social workers mentioned conferring with psychiatrists when patients asked for their diagnoses; over half (59%) of the workers had received these requests and they reported enlisting involvement from psychiatrists in some form. This involvement varied and is summarized in Table 15. Those who did not encounter patients who asked for their diagnoses comprised 32% and 9% had patients who all knew their diagnoses. As can be seen, only one social worker would initially disclose and then get the psychiatrists to follow-up the disclosure.

Table 15

Social Work Action Taken when Patients Asked for their Diagnoses

Action taken	Percentage of social workers	n
Consulted psychiatrists to see if disclosure had occurred then either:		
i) arranged for psychiatrists to see patients alone or jointly,		
ii) decided if they should reveal themselves, or		
iii) arranged for an appropriate professional to reveal to patient	27%	6
Redirected patient to psychiatrist	27%	6
Revealed the diagnosis then arranged for psychiatrists to give medical information	5%	1

### Euphemisms Used

Half of the social workers (55%) used a variety of terms other than "schizophrenia" when talking with schizophrenic patients; the following terms were mentioned: "bad nerves", "nerves", "depression", "mental illness", "your condition", "your circumstances in life", and "your illness". Social workers also made reference to the symptoms of schizophrenia rather than using the actual label; some examples given were: 'mood swings', 'strange thinking', 'hearing voices', and 'difficulty with your thoughts'. Respondents also said they used terms that the clients had previously used to describe their illnesses or terms that they knew the doctors would use or had used. Some social workers used a variety of different terms for schizophrenia with patients.

Of the 55% (12) of social workers who used other terms, 32% (7) stated that patients preferred them, 14% (3) believed that it was contingent on the patients, and 9% (2) of workers did not know. Those who held that patients preferred euphemisms based these answers on the notion that patients understood the terms better. One individual indicated that there was less of a stigma and fear response with these terms and analogized this as follows: "if you talk to someone about tumors, malignancies, and growths....it sounds a lot better than cancer". Those who presumed that it depended upon the patients as to whether or not they were partial to the euphemisms for 'schizophrenia' gave the following rationale: those who had a lower educational level seemed to

prefer these terms; some individuals wanted to know and identify with a particular "brand of mental illness"; patients' attitudes towards illness would influence whether or not they were more receptive to the euphemisms; whether or not patients had accepted their conditions affected their receptivity to various terms; finally, those individuals who were not coping well opted for other terms.

#### Social Workers Handling Families' Requests to Know the Diagnoses

The social workers under study dealt with families differently especially when approached regarding ill family members' diagnoses. Two thirds (68%) faced these questions from families. One third of the social workers (32%) did not have to contend with these queries because 23% of the respondents had not encountered families asking and 9% dealt with families who already knew the diagnosis.

The actions taken by the sixty-eight per cent of social workers who encountered families asking for diagnoses can be seen in Table 16. As is evident in the table 41% of the social workers also required that other professionals be involved when families of patients asked them about the diagnosis of schizophrenia.

Table 16

Social Workers' Actions Taken When Families Asked For Diagnoses

Action taken	Percentage of social workers	n
Discussed in general terms but referred families to psychiatrists for information about diagnoses	27%	6
Revealed diagnoses to families with patients' permission	27%	6
Consulted team and/or psychiatrists before proceeding with disclosure	14%	3

Social workers' disclosure practices vary and not all social workers have revealed the diagnosis to patients and/or their families.

#### Disclosure: Whose Role?

Both professions had views on whose role it was to disclose. How Newfoundland psychiatrists viewed social work's role in terms of disclosure had implications for the practice of social work, for the practice of psychiatry, and, ultimately, the treatment of patients and families. Similar implications resulted from social workers' views of the psychiatrists' role in this area. This section examines the views of each profession in terms of how each saw the other with respect to disclosure of the diagnosis of schizophrenia.

#### Psychiatrists' Perceptions of the Social Work Role

Psychiatrists were asked their views on the following: what is the importance of the social work role in educating patients and/or families, how social workers should handle questions from patients and their families about the diagnosis of schizophrenia, what they as psychiatrists would do in situations where social workers revealed the diagnosis to patients without it being initially discussed with themselves, and whose role they believed it was to disclose this diagnosis to patients and their families.

### Education Provided By Social Workers

Psychiatrists viewed the education of patients and their families about the illness of schizophrenia by social workers as an important part of treatment. Table 17 reveals their views in this area.

Table 17

Psychiatrists' Views About Social Workers Educating Patients and Families About Schizophrenia

Social workers' provision of education to	Views of psychiatrists			
	No conditions	□	Conditions on education	□
Patients	81 %	25	19%	6
Families	90%	28	10%	3

The 81% who placed no conditions on social workers' involvement in educating patients gave the following elaborations: education was seen as an ongoing process and those trained to do so should be involved; it would be more appropriate for social workers to be the primary educators in cases where they had the closer alliances with patients; psychiatrist respondents also mentioned that other members of the health care team could also be involved in educating patients about this illness.

Psychiatrists contended that social workers have an important role in educating patients' families about the illness of schizophrenia but there was variation among psychiatrists in their views as to how this educational role ought to be performed. One interviewee said:

I think [social workers] do have a great role to play, probably more so than the psychiatrist, in educating the families because they have the opportunities to work with the families more, to see them in the home situations. I think it is imperative, especially in chronic schizophrenic patients, that social workers play a major role [in this area].

Another practitioner commented that "[education] is a very natural part of their work with families in any field - the whole psychosocial implications of these illnesses", and another went on to say, "...people are more apt to question a social worker; they may find it easier to talk [to a social worker] than a psychiatrist". A few psychiatrists expressed the hope that social workers could provide "an even bigger role with families than they are now providing". Some psychiatrists acknowledged that

education is very important in that families historically have been blamed by various etiologic theories of schizophrenia and social workers should be educating families about the present research so as to remove much of the blame families have been feeling.

Nineteen per cent of psychiatrists placed conditions on social workers educating patients. They maintained that social workers must recognize their limits in the realm of educating patients, and that they must educate only those patients who have been informed about their diagnoses. They also indicated that social workers who educate patients should be chosen more on their personal qualifications rather than their professional qualifications, and that the unit and team must have structure to deal with such roles. One psychiatrist upheld the view that the physician is the one primarily responsible for patient education for (s)he is the professional who maintains the patient in remission and prescribes medications.

Ten per cent of the psychiatrists set down certain conditions regarding social workers educating families. For example, social workers should supplement psychiatrists' education after families are informed of the diagnosis. Also, social workers should be knowledgeable about the current views of the organic nature of the disorder so that they are not in conflict with the psychiatric profession. One specified that (s)he prefer that social workers, in educating families, avoid if possible using the label schizophrenia, this preference once

again highlights a variation in practice. All of the psychiatrists contended that social workers have a role to play in educating patients and their families about schizophrenia.

Reactions of Psychiatrists to Social Workers revealing the Diagnosis to Uninformed Patients

(The psychiatrists discussed only those scenarios where the diagnosis was not in question.)

Psychiatrists mentioned four possible courses of action they would take in dealing with social workers who told patients their diagnosis of schizophrenia without it previously having been discussed. (See Table 18.)

Table 18

Psychiatrists' Courses of Action When Social Workers Told Uninformed Patients the Diagnosis of Schizophrenia

Actions taken	Percentage of psychiatrists	n
Speak with the social worker alone about disclosure	58%	1
Talk with patient and family to discuss what was understood and to give their opinions	16%	5
Take no action	16%	5
Talk initially to patient and then speak with social worker about the disclosure	10%	3

Speak with the social worker alone.

Psychiatrists who indicated that they spoke privately with social workers who had engaged in disclosure did so for the following reasons:

a) (23%) investigated why the worker told the patient, with one going so far as to say that, after (s)he found out why the social worker took such an action, (s)he would reprimand the social worker; b) (10%) relayed to the social worker that the diagnosis should be revealed only by the physician, with two psychiatrists declaring that they would convey to social workers that they should follow a multidisciplinary approach when issues of disclosure were to be discussed; c) (6%) attempted to establish a policy with the social worker as to how these issues should be handled; and d) (6%) assessed the social worker's ability to reveal to patients and whether in a given situation it was appropriate to disclose. One psychiatrist stated (s)he would caution the social worker about the potential problems one might face when a patient is informed of this diagnosis: "Look, go easy with it , you may find they tend to hide behind that [label] and cast it back into your teeth".

Talk with the patient and then speak with the social worker.

Those psychiatrists who would have discussed with the patient their views on the illness while assessing the effect of the disclosure on him/her would then approach the social worker to either: a) tell the social worker that the patient did not know his/her diagnosis; b) ask the

social worker to consult first before revealing to patients what their diagnosis is; or c) discuss their approach to ensure that they and the social worker had the same approach and views about the illness of schizophrenia. (Percentages were not reported because the responses were from one or two psychiatrists).

Take no action.

One of the respondents who essentially took no action declared, "If it occurred I would 'fire myself' ... it would be a sign that the psychiatrist could not really communicate with the social worker" although (s)he went on to say that "it is everyone's responsibility on the team to make sure they are informed about the patient".

It was interesting that less than half of the psychiatrist population (42%) mentioned that they would be upset if they encountered a social worker who told a patient his/her diagnosis of schizophrenia without it previously having been discussed.

The actions Newfoundland psychiatrists would take if they encountered patients who had been told their diagnoses by social workers varied greatly.

Psychiatrists Recommendations for Social Workers

Psychiatrists recommended that various approaches be utilized by social workers when dealing with patients and families who have questions about the diagnosis. (See Table 19. )

Table 19

The Approaches Psychiatrists Recommended for Social Workers when Dealing with Patients and Families who have Questions about the Diagnosis of Schizophrenia

<u>Recommendations of psychiatrists</u>	<u>Percentage of psychiatrists</u>	<u>n</u>
Forthrightness	32%	10
Refer individuals back to psychiatrists or consult psychiatrists	32%	10
Work closely with the multidisciplinary team	23%	7
Other responses	13%	4

### Forthrightness

Those psychiatrists who believed social workers should be forthright in supplying patients and families with the diagnosis of schizophrenia elaborated on their responses as follows: they would caution social workers to only relay the diagnosis when it had been determined; they would advise social workers not to reveal to patients who are floridly psychotic or delusional; and they would remind them that there was no absolute certainty in the diagnosis of schizophrenia. One psychiatrist suggested that, if there was any doubt as to whether or not patients would benefit from the information, then social workers should refer them back to their psychiatrists. Another commented that the social worker should be frank only if (s)he has enough information. Another further suggested being forthright but in doing so avoiding the label if possible.

### Refer individuals back to the psychiatrists or consult the psychiatrists.

A portion of psychiatrist interviewees suggested that social workers consult with them or refer the individuals back to their psychiatrists by saying "This is an issue you should discuss with your doctor". Those psychiatrists who recommended the contact with the psychiatrists believed that social workers could still discuss the illness in general terms with those asking for the diagnosis.

One psychiatrist went so far as to suggest an anticipation that

patients and families would ask questions of this nature and recommended discussing these issues in advance of seeing them. A few clinicians mentioned the possibility of a joint interview with the psychiatrist and social worker to disclose to patients and families.

Work closely with the multidisciplinary team.

One fifth of the psychiatrists suggested that social workers should work closely with their multidisciplinary teams so that patients' diagnoses and the issue of disclosure could be discussed. As a consequence of this close involvement the social worker would know how to approach the matter of patients' and families' questions about the diagnosis. Some psychiatrists gave full reign to social workers working on teams to discuss the diagnosis as long as they were "working within the philosophy of the group". Some psychiatrists also included social workers in the process of making of the diagnosis.

One psychiatrist cautioned:

I think social workers should be able to explain some of the broad perspectives. When it comes down to medications, side effects, and chemical imbalance then that should be left to the doctor. That is because if someone is not fully aware of the general run of side effects and they open CPS [Compendium of Pharmaceuticals and Specialties] and quote side effects, then that could interfere with treatment. I think social workers should be aware of the current perspectives of schizophrenia because they are going to be asked [them] so they [had] better know [them].

Hence, social workers may be able to assist with disclosure but

psychiatric involvement is critical.

Another of the physicians stated:

If the [psychiatric] unit is working well, the social worker should be following policies that should be jointly agreed upon. If it isn't working well and the social worker has the knowledge and expertise, then [he/she] should go ahead and deal with [disclosure] and I don't necessarily think it is just the business of the psychiatrists. I think it is an area where there is groundwork to be laid in a lot of areas here. There are a lot of problem areas... Social workers who know about the preventative work, which is more than just telling people--it is actually running groups and things like this--should authoritatively challenge the psychiatrists and make sure the work gets done.

This psychiatrist recommended working closely with the team if it is functioning effectively and, when it is not, ensuring that disclosure to the patient occurs.

#### Other Responses

A miscellaneous category of psychiatrist responses to the dilemma of how social workers ought to handle questions included the interesting notion that social workers "sell a positive line" with patients and families because this individual believed that there would be patients who for years would not really understand what was wrong with them. Others suggested stalling until the team could discuss the matter or discussing the illness but avoiding the word.

Psychiatrists' Views of Whose Role it is to Reveal Psychiatric Diagnoses

In terms of whose role it is to reveal psychiatric diagnoses to patients and their families, Newfoundland psychiatrists in general viewed the revealing of the categories of manic depression, unipolar depression, borderline personality disorder, schizophrenia, and organic brain syndrome as their role. Fifty-five percent of respondents felt that social workers could reveal these diagnoses to patients and/or families in certain situations. One fifth (19%) felt the diagnoses should be revealed only by psychiatrists, another one fifth (19%) had no strong preference, while 6% gave other responses.

Of the 55% of psychiatrists who felt social workers could reveal these diagnoses, a variety of conditions and qualifying statements were placed upon this which were as follows: social workers should first discuss this issue with psychiatrists before proceeding, social workers could disclose the diagnosis in situations where it was practical for them to do so, disclosure of the diagnosis to patients is the role of the physician but social workers could share the duties of revealing to families, and, finally, one psychiatrist maintained that social workers could reveal to families of individuals with what (s)he viewed as "straightforward illnesses" such as manic depression, unipolar depression, and organic brain syndrome.

The one fifth of psychiatrist respondents who maintained that the diagnoses should be revealed only by their profession gave different

reasons for their comments, the most informative of which follow: one held that if social workers began revealing diagnoses "then all professionals would be up for grabs", another contended that social workers did not have sufficient psychiatric and medical education to comment on diagnoses, and another suggested family conferences conducted by both psychiatrists and social workers where diagnoses would be disclosed.

The one fifth of psychiatrists who voiced no strong preference as to who reveals these diagnoses saw the most appropriate person to disclose as the person in a position to do so for practical reasons rather than just on professional qualifications. What were deemed as practical reasons included: having the closest or most therapeutic relationship with patients and/or families, being present when it was appropriate that the individuals be informed, and having appropriate personal characteristics and necessary knowledge to reveal. It was believed that the individual who revealed the diagnosis should be decided after the multidisciplinary team discussed the case. These psychiatrists mentioned that often social workers were the most appropriate persons to reveal diagnoses to families. One psychiatrist professed that "Sometimes if I have very little involvement with the patients... it would be countertherapeutic if I walked into the ward and said 'Well, you have schizophrenia' ". Another psychiatrist commented:

I don't care who does the work as long as it gets done and gets

done well. I think if social workers are going to work in mental health teams then they are going to carry a proportion of the patients and they should be competent to deal with this kind of thing. I am not a believer in social workers having a particular role. Now it may be that the social workers happen to run the family support program or the psychoeducational program for families, in which case they do it, but I don't think that is a special social work task. The main thing is that we make sure [the task of disclosure] gets done. Actually, in the ethical guidelines for health practice, this is something that comes out very clear that you develop a service that meets the needs of the patients and you hire and train the people on the service according to what needs to be delivered.

For this psychiatrist the importance lay in ensuring the completion of the task of disclosure rather than in the profession that carried it out.

In general, psychiatrists viewed the role of disclosing the diagnosis to patients and their families as belonging to themselves, although over half of the psychiatrists noted that in certain situations it may be appropriate for social workers to reveal. Psychiatrists' agreement with social workers revealing to patients and families in some situations does not preclude the fact that various actions could be taken if social workers reveal without first consulting the psychiatrists or team. Even though some psychiatrists would only agree with social workers revealing the diagnosis in special situations, there was complete agreement among Newfoundland psychiatrists that social workers have an important role to play in educating patients and families about schizophrenia and the vast majority also contended that social workers unconditionally have a role to perform in educating schizophrenic patients. Psychiatrists also recommended different ways of social

workers' handling questions about diagnoses from patients and their families.

#### Social Workers' Perceptions of Psychiatrists' Role in Terms of Disclosure

Social workers' views of the psychiatrists' role in disclosure of the diagnosis of schizophrenia were discussed in terms of whose role they believed disclosure to be and their predictions of psychiatrists' reactions if they, as social workers, revealed diagnoses first.

#### Social Workers' Views of Who Should Disclose Psychiatric Diagnoses

The majority (82%) of social workers preferred that psychiatrists reveal the diagnoses of schizophrenia, manic depression, unipolar depression, borderline personality disorder, and organic brain syndrome to patients and their families. Those who preferred otherwise comprised 18%.

Numerous reasons were given by those social workers who preferred that psychiatrists reveal the diagnosis rather than themselves. The most frequent responses were that it is their area of expertise and whoever formulates the diagnosis has the responsibility to disclose to those who should know the diagnosis.

To illuminate why they believed psychiatrists were more qualified based on their expertise to reveal the diagnosis, these social workers raised the following points: members of the psychiatric profession were

better prepared to "debate" diagnoses with patients and their families; psychiatrists' expertise allowed them to give a more thorough explanation of the medical components of the illness; and a few social work respondents expressed the notion that families had more confidence in the psychiatrists' opinions and expertise.

Half of the 18% who did not prefer that psychiatrists disclose the above diagnoses asserted that the revealing should not be done in isolation but by the person who has the most contact with patients and families. The remaining workers maintained that disclosure would be most effectively handled conjointly with psychiatrists and social workers. When disclosure was handled in this manner, these workers contended that the psychosocial dynamics which result from the illness can be confronted by both professionals.

#### Expected Reactions from Psychiatrists if Social Workers Disclosed the Diagnosis of Schizophrenia to Patients and Families

Although the question was not raised with the social workers, some interviewees made comments about the reaction they would expect to receive from psychiatrists if they disclosed the diagnosis of schizophrenia to patients and their families without it previously having been discussed. One social work respondent mentioned her/his concern of a reaction from psychiatrists if (s)he did disclose to patients. A few workers expressed the importance of consulting psychiatrists on matters

of disclosure since it is professional courtesy to do so. Another worker advanced the idea that if one reveals to patients their diagnoses "behind the psychiatrists' back" then one deserves to be disciplined.

The vast majority of social workers preferred that psychiatrists revealed to patients the diagnosis of schizophrenia as well as the other four diagnostic disorders previously discussed. The main reason some social workers favoured psychiatrists revealing the diagnoses was that it was the psychiatrists' area of expertise and responsibility. A few workers asserted that psychiatrists should not disclose the diagnoses in isolation but rather in conjunction with individuals with whom patients have the longest relationships.

## DISCUSSION

While the conclusions and generalizations of this study apply only to the study population, they do have implications for social work practice. The researcher began this study because of an interest in why some patients are not being informed about their diagnoses, this posing a dilemma for practicing social workers. The researcher believes that patients have a right to and ideally should know their diagnoses, that it facilitates patient autonomy, two way communication, and frankness and honesty between clinicians and patients. The study documents that given the nature of schizophrenia, the issues of disclosure of diagnosis are very complex.

Focusing solely on disclosure of the word, schizophrenia, to patients and their families is one dimension of the problem of getting patients actively involved in their treatment and enhancing their autonomy. Specifically focusing on the label in this study the researcher has learned that the education of patients and their families about the illness schizophrenia is an interactive process involving helpers, patients, the illness, the environment, et cetera. What this study examines is a "slice" of this process. Although the researcher was aware of this interactive process it became even more clear that this issue is only one very small aspect of the education process to enhance patients' autonomy and to further rehabilitation.

With some patients the actual telling of the word 'schizophrenia'

may happen very early and the bulk of the education will follow this revelation, whereas with other patients there may be a long preparatory process before the word 'schizophrenia' is disclosed. It may not be accurate to state that some psychiatrists are not educating patients because disclosure does not occur. Psychiatrists are spending time and energy using other words to educate them. It seems probable that some psychiatrists may be doing a better job of educating patients about their schizophrenic illnesses without using the word 'schizophrenia' than some of those psychiatrists who disclose the word. However, those psychiatrists who disclose the word 'schizophrenia' often pave the way for other professionals to follow-up without having to make their own decisions surrounding disclosure.

The very fact that some psychiatrists may do a better job than others without using the word 'schizophrenia' in their education of patients does not detract from the already stated arguments that patients have the right to know their diagnoses and that, if patients know, the opportunity for more autonomous action allowing a more active and effective role in their treatment can take place. This researcher would like to stress that there are other issues and factors which may need to be considered and dealt with before, during, and after the disclosure. The primary focus of this research, however, is on the factors that lead up to the decisions to disclose. There may be patients where factors are such that disclosure should never occur. It is the researcher's belief, however, that the numbers of patients who should never know their diagnoses are

small, if there are any at all.

The importance of the label is not as important as the process of education since real understanding comes out of the process of hearing the label and its ramifications numerous times and coming to accept the label along with the experience of the illness. Education of patients and their families is a healing process and through the process of education and disclosure of the diagnoses patients becomes more self-determining. Rather than a decision to disclose or not to disclose, there is a healing process involving a process of "disclosing". The process of "disclosing" advances the patients' knowledge and yields autonomy, understanding, insight and further knowledge. The ideal result is individuals understanding themselves and their illness. The ultimate goal is for the patient to be able to function with an illness. "Disclosing" promotes optimal functioning and patients' understanding of their illness helps them to become more independent and competent. The term "disclosing" needs to be employed for it better describes than "disclosure" the educational process with the above ends in mind.

Studying one step of the process, the disclosure of the word 'schizophrenia' to patients and their families by social workers and psychiatrists has been valuable for numerous reasons; most important of which is that it shows how non-disclosure affects the practice of social work. It is one of few studies in the area; it sheds light on some aspects of "disclosing"; it examines the factors which influence whether patients are told and the timing of disclosure if it occurs, it shows that some

psychiatrists are not always using the word 'schizophrenia' and the reasons for this, and it compares the psychiatrists' and social workers' opinions on the subject and their different ways of handling the issues.

#### Not All Patients are Being Informed

Not all patients and their families have been informed about the diagnosis of schizophrenia (and about other psychiatric diagnoses). Comparison of psychiatrists' disclosure of the five diagnoses with those of social workers shows that psychiatrists consistently reveal more of other diagnoses with patients and families than do social workers. Psychiatrists report revealing to patients who suffer from manic depression and unipolar depression more than schizophrenia and suggest that this is because these illnesses often appear to be more treatable and are not seen in such bleak terms. Green & Gantt (1987) find in their study that 43.7% of psychiatrists always tell schizophrenia families of the diagnosis whereas; 70.9% always tell the diagnosis of manic depression to families, and 69.6% always tell the diagnosis of unipolar depression to families. Is it possible that social workers reveal to families the diagnosis of schizophrenia more often than they do to families who have members with manic depressive and unipolar depressive illnesses because psychiatrists are more willing to disclose to families the diagnosis of manic depression and unipolar depression and are less willing to disclose to families of schizophrenics?

Psychiatrists and social workers reveal to patients and patients'

families the diagnoses of borderline personality disorder the least of any of the diagnostic categories. A few psychiatrists give similar reasons for withholding the diagnosis of borderline personality disorder as they do for schizophrenia, and they are that the labels of schizophrenia and borderline personality disorder are too complicated to explain, that there is little value in telling patients the labels, that more positive terms could be used to describe the disorders, and that there is a lack of consensus with regard to both the disorders. In not revealing the diagnoses to patients and their families these psychiatrists could be exercising the physicians' therapeutic privilege to disclose or not based on how disclosure will best benefit patients.

A general difference between social workers' and psychiatrists' disclosure practices is that social workers disclosed to families to a greater extent than they reveal to patients for all the diagnostic categories, whereas psychiatrists focused more of their attentions on patients. It was interesting to note that more social workers mention making arrangements for themselves to be present when the psychiatrists disclose to the families (27%) versus when patients (18%) are informed. This finding is consistent with social workers' perceptions of their roles. Even though social workers disclose to more families than they would patients, of those (68%) who encounter questions from families about patients' schizophrenic illnesses, only 27% directly provide the diagnoses. Social workers are either getting psychiatrists or others to reveal to patients and/or their families or are having to work with

some patients and/or families who are uninformed.

Fifty-five per cent of social workers take steps towards disclosure of the diagnosis of schizophrenia, even when patients do not ask directly for the information and, therefore, they must view the patient's knowledge of the diagnosis as important. One worker's approach is worthy of note: this worker sums up what (s)he does; (s)he asks patients what they think is wrong with them and when they have answered (s)he "reinforces the pieces of their perceptions that are correct". (S)he concludes interviews by making arrangements for psychiatrists to see patients to discuss diagnoses.

Green & Gantt's (1987) and Gantt & Green's (1985/1986) studies, found that not all psychiatrists and social workers are revealing to schizophrenic patients and their families. Similarly, Gantt and Green (1985/1986) found that social workers report revealing the diagnosis to patients and their families less often than psychiatrists. Any further comparisons between these studies and the present one would not be meaningful because of the fact they deal with different populations. Anderson, Reiss & Hogarty (1986) also observe that many different professionals "work with schizophrenic patients for many years, yet, tragically, never say the word [schizophrenia] aloud in the presence of the patient" (Anderson, Reiss & Hogarty, 1986, p. 82).

## Conceptualization of Schizophrenia

### The Etiological View of Schizophrenia

On the whole the psychiatrists in this study view the etiology of schizophrenia as having an organic basis. Their conceptions of the etiology of schizophrenia are similar to the research findings that "biological science is close to proving empirically that schizophrenia is a neuropathological disease process" (Taylor, 1987, p.115), a biological disease.

Because our understanding of schizophrenia is changing so quickly, ... physicians trained in decades past, for example, may be completely unaware of new information. They may still be thinking in terms of what they were taught, at the time they were trained such as psychoanalytic theories and family interaction theories" (Torrey, 1983, p.73).

Even though factual information about schizophrenia is growing, there is a vast amount which is still unknown and this may affect psychiatrists' disclosure practices. With the growing information on schizophrenia professionals need to put effort into staying abreast of the information in the field.

The shift to the organic viewpoint of schizophrenia might influence psychiatrists to disclose to families the diagnoses because psychiatrists should no longer believe they were blaming families for their patients' illnesses. Having an organic view is consistent with the knowledge base behind the psychoeducational approach (Anderson, Reiss, & Hogarty, 1986).

Based on the fact that the psychiatrists mainly have a biological

view and they predominately use medication, one could assume that when they mention psychotherapy for the treatment of schizophrenia that the majority are referring to supportive psychotherapy since insight psychotherapy for schizophrenia has been found to be unproductive and possibly even harmful (Torrey, 1983). Supportive psychotherapy is of great assistance to patients suffering from schizophrenia; some constituents of supportive psychotherapy are the provision of a warm, trusting relationship, guidance, assistance with concrete matters, community supportive resources, et cetera. A range of mental health professionals provide this type of psychotherapy (Torrey, 1983).

Due to limitations on time and focus, the social workers were not asked to recount their etiological views of this disorder. In retrospect this question would have been useful to the study of this area and should be asked of social workers in further research since social workers need to have a view of schizophrenia similar to that of psychiatrists so they do not confuse the patient. If social workers believe that schizophrenia is the result of a disturbed family system then treatment chaos could ensue.

#### Criteria and Classification Systems Used to Diagnose Schizophrenia

Several criteria and classification systems are in use to diagnose schizophrenia. The most frequently used diagnostic tool is the classification system DSM III; 42% of Newfoundland psychiatrists use this system. Junek (1983) has found 42% of Canadian psychiatrists choose DSM III as a system for future use. Given the variability of criteria in use,

the paucity of scientific knowledge, and that lack of diagnostic tests for schizophrenia (Anderson, Reiss & Hogarty, 1986), one can understand why it is difficult to be certain of the diagnosis. Therefore, when psychiatrists refer to the disorder, those who utilize different criteria are referring to both broader and narrower definitions of schizophrenia. Kaplan & Sadock (1981) state that psychiatrists must be satisfied with the possibility of over-diagnosing schizophrenia when the criteria are broad and under-diagnosing the disorder when the the criteria are more stringent. It is possible that those psychiatrists who believe they use broad criteria may be reluctant to disclose because they may assume they are over-diagnosing the disorder.

Social workers have not been asked to recount their views about the criteria they use to diagnose schizophrenia for, in general, social workers are not diagnosing schizophrenia. The nature of the criteria which psychiatrists use for diagnosing schizophrenia influences social work practice, for the criteria affect the number of the patients with the label of schizophrenia and the severity of illness of the population also with the label schizophrenia, hence the social workers' view of the overall prognosis of schizophrenia.

### Diagnostic Certainty

Some psychiatrists require another criterion which is diagnostic certainty. Overall, most psychiatrists (65%) state they would require diagnostic certainty before revealing the diagnosis of schizophrenia to

patients. Fookes (1983) states that he likes to be certain of the diagnosis before discussing it with individuals. Almost half (45%) of psychiatrists mention they would be less likely to reveal the diagnosis on the patient's first admission. The number of patients' hospital admissions does not influence 16% of psychiatrists as long as they are certain of the diagnoses. Atkinson (1985) observes psychiatrists wanting to wait until the patient has the second episode with their illness before revealing the diagnosis. A total of 9% of social workers spontaneously state that diagnostic certainty is necessary before patients are informed and perhaps more would make this qualification if the question is asked directly of them. Torrey (1983) suggests that schizophrenia is a serious diagnosis and should not be applied indiscriminately to anyone with schizophrenic symptoms (Torrey, 1983, p.47). Torrey is cautioning professionals to not reveal the diagnosis unless certain. One worker also mentions that it is important to put the whole notion of the diagnosis in a light where the patient and family realize that it is not "carved in stone", in view of the dispute over what schizophrenia really is. Anderson, Reiss & Hogarty (1986) discuss the variability in the diagnosing of patients, for they found that 10% of patients' schizophrenic diagnoses changed.

What complicates the area of disclosure is that a few psychiatrists within this study believe that there may be more than one illness classified under the label schizophrenia, which probably means they do not believe that they or their profession have a clear conception of the illness. Hays (1984) maintains that schizophrenia ceases to be an entity

in its own right and that if more investigations are done there would be numerous illnesses that psychiatrists could find which are now collectively called schizophrenia. The National Institute of Mental Health maintains that there could be a dozen disorders now lumped under the classification of schizophrenia (Walsh, 1985). The illness is still shrouded in mystery since there are very few facts known about schizophrenia and what is not known about schizophrenia enters into the arena of theories (Torrey, 1983). A psychiatrist who thinks along these lines, that there are more than one illness subsumed under the label schizophrenia, mentions to patients and their families that "the illness used to be called schizophrenia".

The 42% of psychiatrists who are using DSM III criteria would not be certain or able to make the diagnosis until the symptoms of schizophrenia are present for six months. Hence, the factor of the patient's first admission influences the diagnosing of the illness and ipso facto, the practice of revealing the diagnoses.

Hence, some psychiatrists and social workers require diagnostic certainty. When the diagnosis is uncertain, supporting patients and their families through the process until the diagnosis can be ascertained becomes important. Psychiatrists, social workers, and other members of the health care field can provide support to the patients and their families until the diagnosis is certain. A different form of support may very well be required for patients and families who are told the diagnosis of schizophrenia when the diagnosis is uncertain, versus those who are

given a more global label like mental illness or psychotic illness.

#### Prognosis

There are different views of the prognosis of schizophrenia among the psychiatrists interviewed. Some view the prognosis of schizophrenia in a more optimistic light than others. The view of the prognosis of schizophrenia influences only 35% of psychiatrists to reveal to patients; of those influenced, one third revealed to poor prognosis patients their diagnosis and two thirds revealed to good prognosis patients their diagnosis. One psychiatrist elaborates on his/her view of how disclosure is affected by the psychiatrists' view of the patient's prognosis:

Whether one tells patients that they are schizophrenic or not depends on whether one feels schizophrenia is and that has been argued over the years and when I was doing my residency there were different kinds of schizophrenia but there were certainly schizophrenics who were felt to have a good prognosis and in whom the illness was very acute but it would settle down. While it may recur, there would not be the kind of personality deterioration that tends to occur in other schizophrenics. If you feel that a lot of schizophrenics are like that then you are going to be more inclined to tell them because you are not telling them they have cancer; if, on the other hand, you think that schizophrenia is a long-term chronic illness with progressive mental deterioration, which is more the idea that is coming back in now, I think you are probably going to be less inclined to tell them because you are telling them they have cancer and you have to try to keep them optimistic about their own prognosis...

The comparison by a few psychiatrists of schizophrenia to cancer, as a group of physical illnesses sustains the caretakers' image of hopelessness, the "pronouncing of a psychological death sentence" for

schizophrenic patients (Green, 1984, p. 76).

The view of Torrey (1983) and Walsh (1985) disagrees with those psychiatrists in this study who view schizophrenics as having little hope or those who made the statement that patients with a good prognosis would not be diagnosed as schizophrenic. According to Torrey (1983) many schizophrenics can regain all or almost all of their mental abilities and lead a normal life. Walsh (1985) and Bland (1984) state that 25% of schizophrenics recover completely, never to have symptoms again.

A more pessimistic view of schizophrenia is mentioned in DSM III: "A complete return to premorbid functioning is unusual--so rare, in fact, that some clinicians would question the diagnosis. However there is always the possibility of full remission or recovery although its frequency is unknown" (DSM III, 1980, p. 185).

Thus, the prognosis of schizophrenia affects which patients are told, with some psychiatrists revealing to poor prognosis patients their diagnosis and others telling good prognosis patients. One could speculate that psychiatrists' pessimistic view of schizophrenia could affect treatments that patients receive, not only from psychiatrists but also the rest of the team. The view of both the prognosis of schizophrenia and patients with schizophrenia could further complicate the treatment schizophrenics receive and the whole area of disclosure and "disclosing". In further research social workers should be asked to state their views about the prognoses of schizophrenia which likely affect their disclosure practices.

### Opinions Related to Disclosure

The vast majority of psychiatrists and approximately half of the social workers believe that patients could be adequately informed about schizophrenia without disclosure of the actual label. Believing patients can be adequately informed in this way could possibly influence disclosure. Social workers' beliefs about what is required to make patients adequately informed possibly influence whether or not they reveal diagnoses and if they consult psychiatrists regarding this matter.

While a': social workers support revealing to patients, one fifth of psychiatrists do not. Most social workers (91%) are unequivocal in their support of revealing to patients of their diagnoses compared with 58% of psychiatrists. Newfoundland psychiatrists' opinions vary as to whether patients should be informed of their diagnosis of schizophrenia, paralleling what is evident in the available literature. Although most social workers are in favour of disclosure, it is evident that psychiatrists are not revealing to patients their diagnoses of schizophrenia as often as social workers would believe necessary. Conflict could arise when social workers and psychiatrists discuss plans for disclosure for their patients. Individual social workers expressed strong arguments for telling patients; of course, one could be of the opinion that patients should be told but still not disclose as a consequence of other factors.

Psychiatrists and social workers give different reasons for their decisions to reveal to their schizophrenic patients. A reason propounded

by social workers is that revealing of the diagnosis to patients and their families has the potential for lessening patients' and families' misconceptions and absolving blame. Torrey (1983) mentions that understanding the illness "demystifies" it. When families are educated, they do not experience the sense of blame and shame that they do when they believe that they may have caused the illness. Brody (1980) did find health care professionals who feared an increase in patients' anxiety if they revealed the diagnosis, as there might be a decrease in the effectiveness of treatment (cited in Schorr & Rodin, 1982). But Brody (1980) did discover that revealing to patients in general does not lead to more anxiety than not revealing to patients (cited in Schorr & Rodin, 1982). The uncertainty of not knowing may lead to greater anguish in the end than knowing the diagnosis. Another justification social workers and psychiatrists give for disclosure is that patients have a right to know their diagnoses; one worker also comments that informed consent should exist to the same extent as it does with a physical illness. What this implies is that the mentally ill should have the same rights to information as the physically ill. The fact that the therapeutic relationship could be threatened if schizophrenic patients do not know their diagnoses is discussed by a few workers.

#### Perception of Patients and Families

Over one half (55%) of the social workers assert that most or all patients would like to know their diagnoses. A comparison with the

psychiatrists' opinion is not possible since psychiatrists responses are not complete; over one third and possibly more of the psychiatrists do believe patients want to know. Houston & Pasanen (1972); McIntosh (1974); Suchman (1972), did find that, overall, patients want to be informed about their illness (cited in Schorr & Rodin, 1982). The empirical question remains, "Are patients who wish to know, told?"

Some of the social workers suggested that patients and/or their families either do not believe they have the right to know their diagnoses or are intimidated by the physician and/or the system. A few social workers specifically acknowledged that passive patients do not believe they have the right to ask, and some patients do not question professionals treatment decisions. In addition, 32% of the social workers report that patients have never asked them for their diagnoses. One worker also maintains that patients view their doctors as "God". These social workers' views are in keeping with what Schorr & Rodin (1982) maintain: that when individuals encounter psychiatric problems, their abilities to make their own autonomous decisions and govern their lives are threatened. Within the traditional view of the physician-patient relationship, the patient surrenders his control to the physician and becomes "passive" and "dependent". Rodin & Janis in 1979 (cited in Schorr & Rodin, 1982) explain that physicians [and possibly other health care clinicians] have a sense of power over the patient with the very nature of their training, skill, and expertise related to the patient's difficulties. It is not surprising that patients and their families all too often

do not question their psychiatrists' decisions and suggestions.

A small percentage of psychiatrists (6%) disclose the diagnosis only when patients ask for their diagnoses (with 10% of the total group generally telling when patients ask). Another 13% of the psychiatrists wait for families to ask for the diagnoses. Psychiatrists, social workers, and health professionals can not always assume that patients who do not ask for their diagnoses do not want to know their diagnoses. Assuming patients and their families will ask when they want to know is too simplistic a view of human behaviour and could result in a large number of patients not getting their diagnoses revealed to them.

#### The Challenges Psychiatrists and Social Workers Encounter Related to Disclosure of the Diagnoses of Schizophrenia

Differences and similarities have been apparent between the problems the two study groups encounter concerning the disclosure of the diagnosis of schizophrenia. Psychiatrists mention problems in relation to their perceived role in making the diagnosis of schizophrenia and in providing patients with the diagnoses. This is in keeping with the majority view of psychiatrists and social workers that psychiatrists ought to be the ones who, under most circumstances, disclose diagnoses to patients and even to families. Social workers mention problems associated with their roles as discharge planners, patient advocates, rehabilitation assistants, and with their therapeutic relationships with schizophrenic clients. If social workers are to disclose the diagnosis more

frequently, they might encounter problems similar to those faced by the psychiatrists in this area.

#### Difficulty Determining What Patients Know

A challenge for social workers is determining if patients already know their diagnoses and the degree of understanding they have about their illness. The reports from psychiatrists and social workers on the range of patient understanding go from full understanding to none. Overall, social workers and psychiatrists have similar criteria as to what constitutes an understanding of the illness; however, the criteria of social workers' are less technical and possibly more realistic than those of psychiatrists. Nine per cent of the social work respondents reported difficulty determining whether or not patients knew their diagnoses. It is conceivable that certain paranoid schizophrenic or other schizophrenic patients would perceive that the symptoms they experience are real rather than their being the result of their illness. Social workers reported that half of the patients on their overall caseload knew their diagnoses of schizophrenia and half of these understood what the diagnoses meant. Based on the number of patients that do understand their illnesses and the nature of their symptoms (such as suspiciousness, disorders of thinking and attention, concrete thinking, hallucinations and delusions,) one could speculate that assisting more patients to achieve an understanding would be difficult. Some would have great difficulty comprehending their illness because of the strength of their paranoid

symptoms, delusional beliefs, and thinking disorders. Workers profess that many schizophrenics do not have much insight into their illnesses. Some psychiatrists in this study, paralleling the results of Green & Gantt (1987), maintain that some patients lack the ability to understand the term schizophrenia and that disclosure of the diagnosis would only further discourage them.

On the other hand, as one worker mentions, clinicians can fall into the trap of rationalizing their not telling patients on the basis that the patients are incapable of understanding. Assuming that these patients would not understand, or would have a lessened ability to develop insight, could result in workers being less concerned for these individuals to be informed. Patients' roles in their treatments could thus potentially be attenuated, reducing their capacities for autonomous action.

A few social workers (18%) state that some patients appear content with not knowing the specifics of their diagnoses and report that patients would discuss their illnesses using terms such as "bad nerves" or "nervous breakdown". Workers may be reluctant to confront these patients themselves or to arrange for other professionals to reveal to these patients their diagnoses because they appear to be content in not knowing.

According to Bok (1978) patients with cancer can be informed of their diagnoses but can present as if disclosure has not occurred. Bok's (1978) review of the literature uncovers that between 15% to 25% of the

time terminal patients will show a lack of awareness at being told diagnoses even when though they are repeatedly seeking the information and are being informed. This possibility of patients' being informed and yet presenting as if they do not know again adds to the complexity of the disclosure with schizophrenic patients.

#### Requests for Non-Disclosure

Approximately the same proportion of social workers (27%) as psychiatrists (19%) contend that they encounter patients' non-verbal expressions of not wanting to know their diagnoses. These non-verbal responses that social workers and psychiatrists see from patients are similar and include denial of the illness and reluctance to ask diagnoses. Psychiatrists (26%) and social workers (9%) encounter requests from families to not reveal the diagnosis to patients. These families would need to have been apprised of the diagnosis to be able to make this request. It is possible that the beliefs of these psychiatrists and social workers as to whether patients wanted to know their diagnosis or not could have been influenced by encountering patients who indicated that they did not want to know their diagnoses.

#### Schizophrenia is Perhaps More Difficult Than Other Illness To Discuss

What has been gleaned from this study is that schizophrenia is more complex and difficult for these clinicians to discuss with affected individuals than, for example, depression. The symptoms are not as clear

cut, less is known about schizophrenia, and patients' schizophrenic symptoms to a great extent impair their ability to understand their own illnesses. Also it is possibly more difficult to empathize with the psychotic experience than with depression. There certainly are patients with severe depression who would also have trouble understanding because of psychomotor retardation, depressive cognitions, and/or delusions that they are experiencing. On the other hand, most individuals can understand depression for, even though they may not have experienced a depression of clinical severity, they have usually experienced a depressed mood. It may be difficult for most people, including mental health professionals, to really identify with a psychotic illness. "How can we sympathize with a mad man or mad woman" (Torrey, 1983, p. 6). These features of a psychotic illness make it fairly unique when it comes to disclosure.

#### Encountering Misconceptions

A significant problem is the misconceptions of patients and their families about the illness of schizophrenia. Only a few social workers mention dealing with patients' and families' misconceptions, but possibly more social workers would report on these misconceptions if they had been asked a direct question as were the psychiatrists. Both study groups have perceived similar misconceptions about the illness of schizophrenia on the part of patients and their families. Psychiatrists believe that they need to deal with these misconceptions in the process

of revealing to patients and their families. The misconception that schizophrenia is a split personality is according to Torrey (1983), a "widespread but erroneous belief" (Torrey, p.2). Dinham's research illustrates how residents from Newfoundland outports do not trust those defined as mentally ill because 'you never know what they might do' (Dinham, 1972). Dinham shows how individuals prefer to be identified as having other disabilities such as "bad nerves" thus avoiding the mental illness label since some other people view the mentally ill as being "dangerous".

#### The Potential for Countertherapeutic Situations Arising out of Disclosure

While half of the psychiatrists encounter situations which make telling the patients their diagnoses countertherapeutic, one psychiatrist in this study argues that the discussion of the patient's illness and the interpretation of the patient's problems are never countertherapeutic. An analogy is used to express the point:

If I got cancer today and I have secondaries all over and I want to distribute my wealth, or I want to take my time off and travel through the world and see beautiful things....I don't want a physician to rob me of that six months of life by telling me 'there is nothing wrong with you'. .... I don't believe that schizophrenics are such a peculiar group of people [that this wanting to know would not apply to them also].

This psychiatrist is suggesting that the patient's right to the truth should outweigh the physician's right to exercise the therapeutic principle when (s)he thinks it is in the patient's best interest. Kondziela (1983)

recommends that psychiatrists find out whether or not the patients could deal with their diagnoses in constructive or destructive ways. If the patient is unable to view himself as having a chronic mental illness then Kondziela suggests the use of euphemisms for schizophrenia.

A psychiatrist reports that sometimes patients adopt a negative view of their capabilities when they are informed that they suffer from schizophrenia.

A few psychiatrists mention situations where the revealing of diagnoses of schizophrenia to patients and their employers could ruin the patients' careers. Shackle (1985) speaks about the double-edged sword where understanding evolves from disclosure, but the disclosure is accompanied by a stigmatization throughout the rest of the patient's life. Once a person is labeled a schizophrenic, the label is almost impossible to remove (Walsh, 1985).

Three potential countertherapeutic situations are reported by social workers and possibly more would have been discussed if social workers had been asked a direct questions on the subject.

Disclosure requires clinical skill to enable patients and their families to confront their fears about the illness, change their misconceptions, accept the diagnoses, and develop insight. A few social workers mention having to prepare for anger and resistance to the diagnosis and that patients need a great deal of reassurance that there is treatment for their symptoms.

Dealing with adverse reactions as a result of the patients being

informed about the diagnoses requires clinical expertise. Adverse reactions occurring frequently to an individual clinician could alter disclosure practices.

Disclosure is possibly a difficult task for social workers because they do not have the knowledge necessary to answer all the patients' and families' questions. Some handle not being able to answer all the questions by suggesting to patients and their families that they consult the psychiatrists.

A few Newfoundland psychiatrists (13%) spontaneously mention that a difficulty they encounter is the lack of resources in the community to treat their patients who suffer from schizophrenia. As a result they claim they are the sole providers of education to schizophrenic patients and their families, which is a difficult and time-consuming task that might deter these psychiatrists from revealing the diagnoses and enabling them to optimally educate patients and their families. This concern of and challenge to psychiatrists may be heightened because some social workers are also looking to psychiatrists for direction as to how they should handle their patients and families.

#### Ethical Dilemmas Reported

A few psychiatrists report ethical dilemmas related to issues of disclosure of diagnosis with their schizophrenic patients and a slightly greater proportion of social workers report ethical quandries. Psychiatrists mention ethical dilemmas relating more to how much to

disclose to patients, families, and employers. Social workers, on the other hand, relate feeling the need to be honest, and to transmit information to community agencies taking into consideration the associated ramifications. These ethical concerns of each professional group are in keeping with their perceptions of their respective roles.

The majority of the psychiatrists do not acknowledge that there are any ethical dilemmas which influence them, because they believe that patients should know their diagnoses. One psychiatrist does, however, mention the situation of not knowing how much to disclose to the patient so as not to unnecessarily harm the patient (the physician's code of *primum non nocere*: above all do no harm). Kudler brings this psychiatrist's dilemma to light when he states that:

While moral practitioners endorse the truth, a policy of unconditional truth-telling is sometimes in direct conflict with another basic value in medicine: do no harm. What are the implications of discussing the diagnosis? There may be situations in which the patient would be profoundly disturbed by being given his diagnosis. Are we obliged to tell the truth even if it means harming the patient? Is not telling the diagnosis the same as lying? It seems important not to confuse truth-telling with therapy. Telling the truth is not a panacea. (Kudler, 1984, p.732).

Some social workers mention ethical quandaries usually involving when they have to withhold or be evasive about diagnoses. Agencies asking for the diagnoses on patients when patients do not know their diagnoses is a dilemma for some social workers.

A social worker's not approving of a patient's not knowing the diagnosis involves the pull between the moral principles underlying a

social worker's personal beliefs on the one hand and duties on the other (Kentsmith, Miya, & Salladay, 1986). The moral principle in this situation is the patient's right to have information pertaining to his/her diagnosis and the 'duty' of performing the function of a social worker on a team and living with team decisions.

It is noteworthy that a few social workers reported on the ethical problem of community agencies requesting symptoms and diagnoses of patients when these patients do not know their diagnoses. A few workers mention methods that they use to circumvent agencies' requests for information, but these often appear to add additional ethical problems for the workers, including misinforming agencies, using less stigmatized labels, communicating information to agencies verbally, or asking patients for consent to release information but not informing them of the specifics of what is being released. It is quite possible that some physicians are not aware of the number of agencies that have records of the diagnoses they have made on patients, for it is social workers who are giving out this information to agencies requiring it.

One worker reports that sometimes two halved application forms are sent out to agencies by social workers and psychiatrists, and that it is possible that psychiatrists may, unbeknownst to social workers, put down less stigmatized diagnoses than the diagnosis of schizophrenia, for example, psychotic illness. The agencies would then get two different diagnoses, which could result in problems.

### Disclosure Practices

Approximately one third of social workers mention that one of the golden principles of social work is to "start where one's client is at" and this is a useful tenet in the process of disclosing. "For every patient, sensitivity to his defenses, and working within his readiness to know will guide the physician as to what to tell or what not to tell" (Paris & Adams, 1979, p. 584). An obvious example of the applicability of this guideline would be the inadvisability of discussing the diagnosis of schizophrenia with a patient who is actively psychotic. This is the only factor which psychiatrists in this study agree on. Also, a patient should not be told when he is acutely psychotic and when he is experiencing persecutory delusions in which he believes everyone is out to harm him. Appleton (1972) believes that telling a paranoid patient that what he/she is experiencing is unreal can distance the patient from the very person who can be of help. One worker suggests allowing the patient to adjust to being mentally ill before disclosing the label of schizophrenia to him/her. What (s)he is advising is a lengthening of the process. A worker suggests speaking to the patient in language which he/she could understand and with terms that he/she is familiar with or had used. Some workers suggest referring to the label schizophrenia only a few times so as to not dwell on the label. Others mention giving the patient information over a number of sessions, reviewing what has already been told, and giving him/her constant reassurance. A patient often needs to hear and relearn things many times. "It certainly is not helpful

to call someone schizophrenic and leave it at that" (Bebbington & Kuipers, 1982, p. 407). Also, as individuals hear their diagnoses or symptoms again, they see them in the light of new knowledge and experiences which add to their understanding and the relevancy of the material presented. Some psychiatrists may believe they have disclosed the diagnoses to patients by doing it once, where as, in fact, patients may not retain the information because they are too sick or not ready to hear the information.

#### Documentation of Disclosure

In hospitals there are only a few means to convey to other professionals exactly what patients do know about their illness and if need be, why they should not know their diagnoses. These routes of communication include: writing the plan in relation to disclosure in the medical chart, discussing this issue of disclosing in the team conference, or discussing the plan or work done individually with various professionals. The finding that psychiatrists are generally not writing on the medical chart as a means of communicating their plan or work done with regards to disclosure could mean that some psychiatrists are not communicating that patients are not aware of their diagnoses, or that they are conveying this information only verbally.

A psychiatrist's communication of disclosure has relevance for social workers. A social worker might not understand what the patient has been told or why the patient has not been told his/her diagnosis. On

the other hand, if a social worker is assigned to only a few psychiatrists, then (s)he might learn how these psychiatrists and the team handle this issue, and the team and psychiatrists might conversely learn the social worker's preference for dealing with this issue; thus, writing on the medical chart the plan of action may not be as critical.

Social workers were not asked how they convey their plans or practices of disclosure of the diagnosis of schizophrenia, but it is evident that the social workers do communicate with the psychiatrists. A total of 59% of workers revealed that they required psychiatric input when patients asked about their diagnoses and 55% of the social workers involve the psychiatrists when dealing with patients who do not know their diagnoses. Also, 35% of psychiatrists report social workers questioning them about their disclosure practices involving particular patients. It would be useful in further research to discover the specific means social workers use to communicate information about disclosure with psychiatrists and other team members.

When psychiatrists do not convey to social workers and the team their plan for disclosure, other disciplines are left uninformed and having to deal with the lack of information and communication in this area. As a consequence these clinicians can make any of a number of choices: ask schizophrenic patients what they know about their illnesses, speak with various colleagues to see what patients do in fact know, ultimately either avoid the use of the term and/or make a decision with regards to disclosure.

### Euphemisms

Clinicians use different terms for schizophrenia. Approximately half of both professional groups use other terms for schizophrenia although more social workers use terms which are actually descriptions of symptoms that the patients are experiencing, such as: "mood swings" and "difficulty with your thoughts"; psychiatrists tend to use terms which are clinical psychiatric labels such as "recurrent psychotic disorder", and "acute psychotic episode". A few members of both of the groups do, however, use the colloquial term of "bad nerves".

Among those psychiatrists and social workers who use other terms for schizophrenia, 42.% (of the total population) of psychiatrists as compared to 32% of social workers claim patients prefer these terms . From Dinham's study (1972), one might assume that some patients would prefer the term 'bad nerves' or 'nerves ' because "it is more desirable to be identified as having 'nerves'... those with 'nerves' are less dangerous, have a better chance of recovery, can be treated within the community more successfully, and are less likely to be physically and socially isolated-- than to be identified as mentally ill." (Dinham, 1972, p.54). Dinham's arguments may strengthen the opinions of the clinicians who believe that some patients may prefer to hear euphemisms for schizophrenia. In fact, some social workers report that patients prefer euphemisms to schizophrenia because there is less of a stigma and they are less fearful of the euphemisms. Some psychiatrists also believe patients are more comfortable and familiar with euphemisms.

Jones put forward an interesting argument that disclosure would make the illness more acceptable, thus taking away its mystique ("Confronting Myths",1986, p.2). He believes that it is important to disclose to patients when they ask for the information, claiming that using the word schizophrenia is the "first step towards destigmatizing the illness". Jones explains that when he replaces the word schizophrenia with words such as chronic psychosis he feels he is stigmatizing his patients, the very thing he had criticized the public for doing ("Confronting Myths",1986).

One psychiatrist claims that using the word schizophrenia with a patient does not always mean that the patient would get useful information from various organizations set up to help schizophrenics and their families.

There is very little payoff in telling [patients] they have schizophrenia. Now there is a big payoff in telling a person "You are a diabetic". You can say: "You have diabetes, here's some good literature on it, it describes your condition, there are a lot of people out there like you who have to take insulin injections every day..." You can delegate that to diabetic education here. There's not a big payoff in telling [patients] that they're schizophrenic...

The debate continues as to whether or not the term schizophrenia or euphemisms should be used.

#### Alterations in the Approach when Patients are Unaware of Their Diagnoses

The majority of social workers (73%) claim that special skills are

required in dealing with patients who are uninformed about their diagnostic label, whereas one fifth of psychiatrists maintain that different techniques are required when they treat and educate patients who lack specific knowledge about their diagnoses.<sup>13</sup> Psychiatrists who claim that different techniques are not required seem to imply that all that is different for patients is knowing the actual label of schizophrenia. Different techniques are required because of patients' differing abilities for insight, differences in levels of intellect, and differences in their being actively psychotic.

One psychiatrist, who does not believe in disclosing the word schizophrenia to patients, uses a different approach to educate different patients because the illness could take different forms. This psychiatrist states:

I am relying on me as the educator instead of handing them a book or pamphlet. Since the disorder varies so widely from person to person, I am trying to educate them on an individual, one-to-one basis on what their disorder is and what is good for them. So I have to [formulate] an individual [education] package for every relative and for every patient as opposed to being able to say, "Go to diabetic education and here is the standard package for you". "I have to totally individualize every patients" [education].

It appears that some psychiatrists are using varied approaches with different patients and over time with the same patient.

On the other hand, some social workers report that special skills and alterations to their interventions are necessary when patients do not know their diagnoses. It is obviously problematic for the social worker who feels that (s)he would not be able to intervene if patients do not

know their diagnoses. These special skills include scheming on the workers' part in order to enlist psychiatrists' cooperation in revealing diagnoses to patients when social workers are required to impart information without revealing the diagnoses. These situations can create ethical problems for those individuals involved.

With some patients it may be more of "What is the point in telling them when it is just a word" and they have gone on so long without knowing, as a few psychiatrists and social workers have stated. However, what leads up to and follows the disclosure of the word may be important for some, if not all, patients. How comfortable the psychiatrists and social workers are in revealing the diagnoses is an important factor. Some psychiatrists seem comfortable in revealing diagnoses including schizophrenia, while other psychiatrists appear not to be. Some would not disclose because they claim the patient would not be able to understand the diagnosis, while other psychiatrists mention they believe they could gear the explanation to the patient's level.

#### Psychiatrists' and Social Workers' Roles

A comparison of the psychiatrists' and social workers' roles with schizophrenic patients and their families reveals some differences in their approaches and also some significant overlap in relation to the area of disclosure of the diagnoses. Overlap is apparent in the following areas: assessing of patients and their family situations, disclosing the

actual diagnosis, educating and correcting misconceptions about the illness, providing supportive psychotherapy, providing interventions aimed at reducing stress for the family and the patient, supplying resource information, and being involved in rehabilitation. Variation does exist within and between both professions in these roles.

Psychiatrists' and social workers' assessments of patients and their families influence their disclosure practices. Assessment is an important role for both professions. The educational bases of the two professional groups is different and yield differing types of assessments. Psychiatrists' and social workers' assessments are based on indicators which may not always be objective, such as: what is the extent of the information patients have about their illnesses, whether patients know their diagnoses, whether patients wish to know their diagnoses, whether patients can understand their diagnoses, and how patients and family members are coping with what they know and the actual illness behaviour. These subjective aspects of the assessment leave room for error. For example, it appears that some psychiatrists use the educational achievements of patients as indicators of ability to comprehend, along with other patient characteristics. Educational achievements of individuals are not necessarily good measures of intelligence or the ability to comprehend abstract concepts. The educational achievements of patients also relate to other factors such as the functional level of the patient. Thus, these clinicians draw on their training, experience, and clinical skills to make their assessments.

Undoubtedly, there are times when these professionals would be wrong in some aspect of their assessments, but one would hope that in an ongoing therapeutic relationship with patients, they would be able to correct error(s) and change the treatment plan(s) accordingly.

### The Role of Educating Patients

An important role for psychiatrists and social workers is the education of patients and their families about schizophrenia. The purpose of social work is to assist patients and their families to expand their coping abilities and education is one means to this ends (Caputi, 1982). Education is a significant part of social workers' activities. Their elaborations of the various roles that they perform with schizophrenic patients show that their involvement in this capacity can be extensive. Half of the social workers specifically mention that they provide education to patients. The social workers in this study highlight that they can become involved with patients at various stages of their illnesses: from the time individuals are first identified as being ill to the stage of chronicity. At each stage of the illness importance could be placed on educative functions. Schizophrenia affects the cognitive functioning of the patient and clouds and complicates the whole picture of patient education. Also, the stress these patients experience in their environments creates additional anxiety and further impairs their cognitive abilities (Hatfield, Spanoil & Zipple, 1987).

In general, psychiatrists' roles appear to center on their patients

although some do indicate that they periodically work with families. Psychiatrists were not asked to comment on the importance of their educational role with patients and families except with reference to social workers providing this service.

According to some of the social workers, one important ramification of patient's not knowing their diagnoses is that it limits the types of educational and therapeutic opportunities. Thus, uninformed patients may be less able to avail themselves of complete services and not know why or completely understand interventions which are made on their behalf. Also, patients may not be completely informed of the importance of their ongoing compliance to their treatment and of the risks involved with the various psychiatric medications.

Some social workers claim that knowledge improves rehabilitation and patients' overall ability to cope, that the effectiveness of treatment is enhanced with patients having more knowledge of their illness and that knowledge allows patients to take more of an active part in their treatment. Stone (1979, cited in Dinicola & Dimatteo, 1982) discovers that not allowing patients to have a more active role in their treatment could lead to resistance to treatment. Svardstad in 1976 (cited in Dinicola & Dimatteo) finds that, if the physician "refused to share" information with the patient, then the patient responded with resistance, thus obviously reducing the effectiveness of the treatment. Some psychiatrists in Green & Gantt's study (1987) find that the more information patients have about their illness, the greater the compliance

with treatment. "Greater cooperation in turn makes it possible to reduce medications after the acute symptoms have subsided in an attempt to prevent the development of tardive dyskinesia" (Green & Gantt, 1987, p. 667). Bebbington & Kuipers (1982) maintain that revealing not only assists patients to be compliant with treatments but simplifies counselling.

Anderson, Reiss, & Hogarty (1986) find that if schizophrenic patients know their diagnoses, they then can talk to others and know they are not alone. In their psychoeducational model Anderson, Reiss & Hogarty (1986) maintain that patients within a group for schizophrenics derive benefit because they are with people with similar problems enabling them to receive support. Also "the recognition of not being alone in having unusual thoughts and experiences often decreases feelings of embarrassment and loneliness" (Anderson, Reiss, & Hogarty, 1986, p. 213). If these sources are correct, then talking to others appears to improve the treatment. Some psychiatrists in Green & Gantt's study (1987) who disclose to the patients their diagnosis are optimistic that families who know the diagnoses would become members of support groups.

#### The Role with Families and Evidence for Disclosing

Some psychiatrists and social workers perceive that the social worker role includes having more involvement than psychiatrists with families. Of the social workers, 68% mention providing patients' families

with education about schizophrenia as a part of their roles. One worker states that working with families "is a key role for social work for it differentiates us from other disciplines in that we tend to be the profession within the health care system that has the most to do with families". Lister (1980) claims that social workers are frequently identified as the professionals on the health care team that deals with families.

On the other hand, a few workers mention that they would prefer that psychiatrists take more of a role in educating families about schizophrenia. Some psychiatrists also mention the importance of social workers and psychiatrists educating patients and families.

Clinicians' roles with families are important and, with the proper interventions, patients could either be spared relapses or experience increased time between relapses. Clinicians, in educating patients and families, relieve the families' guilt, reduce stress for patients and families, and deal with the specific problems of living with a chronic illness. This requires much patience, skill, understanding, and up-to-date information about current etiologic research and treatment approaches (Taylor, 1987), information about the needs of patients and families who have to contend with the illness, and knowledge of available community resources. Furthermore, understanding relevant material is in itself insufficient. What is required is understanding it in such a manner as to be able to present the material to families and patients in a coherent and helpful fashion. It requires effort to understand the material but a greater

effort to understand the material well enough to present the material. Skill and energy are required in order to engage in this process which ranges from deciding when to reveal to patients and families the appropriate information, to presenting the information in a positive light. The process also involves being able to deal with the ongoing setbacks and difficult behaviours that are presented by the illness, and the various forms that the illness may take.

Not disclosing appears to complicate social workers' tasks in these areas. A few workers mention that families seem to cope better by having knowledge of patients' diagnoses. According to one worker, families do not understand what is happening with their family member and they can construe that some of the behavior is deliberate. Another worker illustrates how families cannot make sense of the patients' behaviors:

"...families of schizophrenics have a lot of problems. They simply cannot understand how anybody that they live with can become so confused, changed from normal to weird, often to have such inexplicable behavior; it is like a horror show "you are not sure what the person is going to do next"

For these individuals, obtaining more information on schizophrenia would appear important. Other families, according to workers, suffer from worry, guilt, and the belief that they have done something wrong. If one believes that schizophrenia is primarily an organic illness then adequate knowledge for these families is essential. The emotions of worrying, blaming themselves for causing the illness, and feeling guilty are

reported in the literature by authors like Dr. E. Fuller Torrey (1983) and Anderson, Reiss, and Hogarty (1986). Anderson, Reiss and Hogarty (1986) state that "most families claim that not knowing about the illness is worse than any information they have received no matter how grim the data about the course and prognosis may be" (Anderson, Reiss & Hogarty, 1986, p.73). Gantt & Green believe that to equip families with the necessary knowledge and skill and to give them the best opportunities to adapt to the patients' illnesses and associated stressors requires a "thorough discussion of the diagnosis" (Gantt & Green, 1986, p. 101). One can best deal with the families' guilt in relation to believing they caused the illness by explaining schizophrenia as a biological illness and one no longer viewed as an illness caused by the families or by schizophrenogenic mothers. Clinicians who believe that families would be better off if they knew the diagnosis would probably be more likely to arrange for families to know or would reveal to them themselves.

#### Whose Role to Disclose?

All of the psychiatrists and most of social workers (82%) agree that disclosure of diagnoses to patients rests with the psychiatrists. However, some psychiatrists (55%) maintain social workers can reveal the diagnoses to patients and their families in situations where this is practical. In Gantt and Green's study (1985/1986) 59% of the psychiatrists have no objection to patients being informed by other

professionals. Some psychiatrists are comfortable with social workers revealing the diagnoses of schizophrenia in specified situations while other psychiatrists are not. A few social workers assert that they do not have sufficient knowledge to disclose the diagnosis; it also might be possible that they do not have sufficient knowledge to educate patients and their families about the illness.

It appears that social workers in general rely on the acceptance and support of physicians and psychiatrists in performing their roles. The input social workers request from psychiatrists regarding disclosure may ensure that patients and their families receive the opportunity for increased autonomy in their decision making. Social workers may also be fulfilling their role of assisting patients and families to access the services of physicians. The quality of life model as put forth by Caputi (1982) has the social worker enhancing the care offered by the health care team and has the social worker conveying medical and psychosocial information and identifying problem areas in communication.

Another reason social workers involve psychiatrists with regards to disclosure might be that social workers are concerned about the reactions they might receive from psychiatrists; only a small number of social workers comment that they would receive a negative reaction from the psychiatrists they work with if they did disclose diagnoses to patients without consulting the psychiatrists. However, if a direct question is asked of social workers about whether they have concerns about

psychiatrists' reactions if they reveal diagnoses to patients and families it is conceivable that more social workers might report having these concerns.

Less than half of the psychiatrists (42%) spontaneously report that they would be angry if they discover a social worker disclosing the diagnosis of schizophrenia to a patient without involving them. One psychiatrist feels that if (s)he encounters a social worker who has told an acutely deluded patient his/her diagnosis, then (s)he would assume that the social worker knows very little about schizophrenia, and would tell the patient to get a new social worker. This reaction is understandable given that the psychiatrist has a responsibility to the patient and is liable for the treatment which the patient receives. Each profession is also accountable to patients and families for their actions. Given the psychiatrists' responsibility, it is not unrealistic for them to expect to be informed of the treatment being offered by other professions and for them to want to retain control over how disclosure is to be carried out. The position paper written for Canadian psychiatrists states that other mental health disciplines need to keep psychiatrists informed of the patient's treatment and progress. Psychiatrists also require that a consistent approach is taken with the patient (el Guebaly, 1984) and a discussion of the approach allows for consistency.

What has become apparent from this study is that who tells should depend on how the functions of the team are divided and coordinated since there are role overlaps on mental health teams. A few psychiatrists

mention that policies could be put in place as to how the team should function with regards to disclosure. One hopes that how those functions would be divided would be based on the team members' respective professional and personal capabilities, as a couple of psychiatrists and social workers suggest. The one important criterion for suitability to the task of disclosure involves the establishment of a trusting relationship with the patient and also with the family when disclosure is being considered. Another important criterion is how the patient and family perceive the person revealing the diagnosis. For example, is it better for these individuals to hear the diagnosis from someone whom they see as an "expert" or is it preferable that they hear it from someone whom they see as being less threatening, like a social worker or nurse. Other important factors accrue to whoever does do the revealing: the individual should have the required knowledge to disclose, sufficient empathy and skill to reveal, enough time to follow up disclosure or arrange for follow-up to take place, and the necessary ability to deal with any repercussions resulting from disclosure. Roberts (1985) states that the use of teams should not just ensure "the appropriate place in the sun for various professionals" (Roberts, 1985, p. 149). For some patients the issues of disclosure may not seem as relevant or complex, for example, if a patient does not have persecutory delusions. Again, the majority of social workers and psychiatrists in this study claim that it is the psychiatrist's role to disclose the word schizophrenia to the patient, but this does not exclude other trusted people at certain times from being appropriate to

reveal or being present when the psychiatrist discloses. The initial revealer for a patient could be a family member, a social worker, psychiatrist, psychologist, nurse, or any qualified professional or combination thereof, which can be defined by the team. Sometimes patients ask for their diagnoses when the psychiatrists are not available to them; and it is conceivable that more than one person on the team or in the family could be designated to disclose.

#### Consensus

Consensus does exist within the Newfoundland professions of psychiatry and social work in a few specific areas in relation to disclosure. Psychiatrists in general view the revealing of the diagnoses of schizophrenia as their role. Psychiatrists perceive social workers as having a role to play in educating schizophrenic patients and their families about the illness of schizophrenia. Psychiatrists agree in their etiologic conception of the illness of schizophrenia as being organically based. Also, consensus exists in that psychiatrists are not influenced by the patients' genders in revealing the diagnosis of schizophrenia.

There is consensus among social workers that some patients should be informed of their diagnoses of schizophrenia.

It is interesting to note that consensus exists among social workers that some patients should know the diagnoses of schizophrenia whereas this same consensus does not exist among psychiatrists. Hence, one suspects that more social workers would be dissatisfied with the state of

affairs that not all patients are informed of their diagnoses of schizophrenia.

Psychiatrists and social workers continually need to look at the process of "disclosing" which includes disclosure of the word schizophrenia. Their disclosing practices need to be evaluated continually in the light of the total picture of the patients and their families, the resources available, the manpower available to help educate the people affected, the approach utilized--whether it is a multidisciplinary or interdisciplinary team approach or individual effort and their roles within the team, their own psychiatric work experience, their evolving values, their life experiences, the breakthroughs in research on the illness and theories about the illness, et cetera. The process of fine tuning how and when patients are told is not something that individuals decide upon once and for all because, as they gain more experience as clinicians they might develop a heightened sensitivity to the issues of disclosure and how to reveal. This heightened sensitivity could result in a reexamination of the whole area. One's approach to doing therapy does change with one's knowledge, one's experience and one's theoretical perspective. Hence, this researcher is in agreement with Kondziela (1983) who is against any rigid rules with regards to disclosure since each case has to be examined individually as to when and how and if disclosure will occur. It is also this researcher's belief that almost all patients should know, and possibly more patients should know than the psychiatrists and social workers are telling. For some patients it

is definitely a matter of when is the most appropriate time to disclose to them.

### Recommendations

The major recommendations of this study are summarized as follows:

1. "Disclosing" should be kept constantly in mind as a goal of therapy and one should remember that an important piece of "disclosing" is disclosure.
2. Based on the current knowledge about schizophrenia, the psychoeducational approach is a viable method for psychiatrists and social workers as well as other mental health professionals to use with patients and their families.

The Newfoundland social workers and psychiatrists in this study are attempting to teach patients and families about the illness of schizophrenia and a psychoeducational approach could be easily adapted to their present approach if it is not already used. The generating of information, including the disclosure of diagnosis of schizophrenia, is essential in the psychoeducational approach (Anderson, Reiss & Hogarty, 1986). The clinicians' view of the illness also needs to be similar to the one espoused by this approach.

The psychoeducational approach is developed out of studies of expressed emotions. Vaughn & Left and others demonstrate that "high levels of emotional tension" cause patients to relapse at a greater rate

than those patients who are discharged into homes where fewer emotional tensions exist (Grantt & Green, 1985/1986). Thus, the goal of the psychoeducational approach is to lower the high levels of expressed emotions in the family (Hatfield, Spanoil & Zipple, 1987). Anderson, Reiss and Hogarty (1986) outline some of the necessary requirements for education and therapy with schizophrenic patients and their families. Some psychiatrists in Green & Gantt's study (1987) maintain that "psychoeducation should arm the patient and the family with as much knowledge and understanding as possible, since it is demonstrated that information about mental illness enables families to gain a feeling of mastery that lessens feelings of anger, helplessness, isolation and stigmatization (Green & Gantt, 1987, p.637). Adams & Paris (1979) find that revealing the actual diagnosis lessens the family's sense of guilt.

Some of the clinicians in this study are using components of the psychoeducational approach, including helping families provide a nurturing and supportive environment and assisting families in improving patients' functioning. Some psychiatrists make specific reference to minimizing the high emotionality in the family. A comment from one worker is that (s)he perceives that families specifically have an easier time than patients in dealing with the knowledge of the diagnoses. Dealing with the families always has implications for patients as well since stress in patients' living situations is related to a poor prognosis and one of the important stressors is emotional tension within the family.

The education that social workers and psychiatrists are giving to patients and their families can possibly be more extensive if more patients are informed about their diagnoses, and more professionals are educated about the psychoeducational approach and the effects of schizophrenia on patients and their families. The goal of the psychoeducational approach is to reduce the relapse rate for patients. One can conceptualize the potential benefits of having more than one professional educating patients and their families in a coordinated fashion.

3. The issues of disclosure and disclosing must be examined in relation to personnel since what may be appropriate in one setting in terms of who should reveal, how they should reveal, and when they should reveal, may not work in another setting.

4. If social workers wish to play more active roles in disclosure of the diagnosis to patients or their families, or if psychiatrists wish them to do this, then the social workers need to have sufficient knowledge of the illness. For example, they should have knowledge of symptoms, signs, treatment, and current theories of etiology. Since social workers' roles, as well as other team members' roles, are reciprocally influenced by the other team members, it is important that social workers desiring a more active role in disclosing and disclosure demonstrate competence and willingness .

5. With numerous people involved, assumptions should not be made as to what information various professionals give out. It is useful

when approaching patient and family education that it be structured so that false assumptions are not made regarding information which has been given. A detailed discussion about the process and the information should occur. Schizophrenia education should be well structured.

6. It would be useful as part of the team rounds that a brief discussion occur and be documented as to what the patient presently knows about his/her illness, whether (s)he knows the name given to his/her illness, and his/her degree of insight.

7. Disclosure of the word schizophrenia and "disclosing" are long and involved tasks and it is important that more than one individual be involved and that continuity is ensured. Individuals could be either present when disclosure occurs, or be available, before and after the disclosure, to the patients and the family for support and further information and reinforcement.

8. Further study on this area would be valuable.

These recommendations, in the context of the exigencies of mental health practice, may seem somewhat overwhelming or overzealous, but a coordinated effort can provide more effective services to patients and their families in the area of disclosure and disclosing. With more effective education and subsequent increased patient autonomy, relapses may be less frequent, and patients and families may feel less distressed by what can sometimes be a disabling disorder.

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## Footnotes

1. These statistics should not be assumed to reflect accurate prevalence rates because some patients would have had more than one admission in the same year and others would not have been hospitalized every year.
2. The total number of schizophrenic patients (1466) that the 31 psychiatrists perceived treating in a one year period was derived from their combined estimations. This figure was almost three times the documented number (580) of schizophrenic patients discharged from hospitals in Newfoundland and Labrador in the period between April 1, 1983 to March 31, 1984. Some of the difference between these figures could be accounted for because the psychiatrists within this study may have included in their estimates patients from their clinics and from their office practices as well as their hospitalized patients. Some of the numbers within this estimated total could represent duplications since some psychiatric patients move from doctor to doctor, hospital to hospital; on the other hand, not all patients would be hospitalized in a given year. Psychiatrists' figures were much smaller than those obtained by extrapolation from Statistics Canada; if in June 1986 there were 568,349 people in Newfoundland and if one percent of the population have schizophrenia (Torrey, 1983) then 5683.5 people should have schizophrenia in Newfoundland at that time; of course not all patients

would have contact with psychiatrists for numerous reasons.

3. This was not an accurate figure since it was derived from social workers' estimates of their caseloads but it suggests that only a minority of those patients who knew their diagnoses, understood their diagnoses.
4. Inquiries were made about the diagnosis "Obsessive Compulsive", but because of the lack of clarification in the interviews as to whether this referred to the Obsessive Compulsive disorder or Obsessive Compulsive personality, these data are omitted.
5. Those who did not qualify may have felt that it was not necessary to state the obvious or there may be a few psychiatrists who do not feel that they need the consent of the patients to reveal the diagnoses to the family.
6. Not all psychiatrists elaborated on their reasons for not revealing the diagnosis of borderline personality disorder.
7. One psychiatrist was inadvertently not asked what criteria/classification system (s) he utilized.
8. A few mentioned 'psychotherapy' but it is inferred that they meant supportive psychotherapy; insight-oriented psychotherapy has been

generally felt to be ineffective or detrimental with schizophrenic patients by the vast majority of psychiatrists.

9. Beyond the more global references to rehabilitation such as correcting the social climate and social rehabilitation, the specific components that were mentioned included: supportive housing, work therapy, supportive groups, psychiatric day care programs, psychiatric drop-in centers, and special clubs promoting friendship.

10. Specific family interventions mentioned were: family therapy, educating families about the illness, minimization of the high emotionality in the family.

11. What the researcher assumed the workers meant by insight was whether or not patients realized they were ill and that the symptoms they were experiencing were related to their illnesses.

12. These examples did not imply that all the programs within each category listed above require the symptoms and diagnoses.

13. The difference in terms (special skills and different techniques) or the alterations in psychiatrists and social workers approaches can be accounted for by the use of terms in the interviewing instrument.

## Appendix A

### Background Information to the theory of Expressed Emotions

Curiosity reigned in the 1950's at the Medical Research Council Social Psychiatric Unit in London, England, to find out why some schizophrenic patients who, when discharged from hospital to reside with their families (spouses, parents, et cetera), did worse than those patients who lived on their own. Researchers set out to answer this question (Brown, Carstairs, and Topping 1958; Brown, 1985; cited in Mintz, Liberman, Miklowitz and Mintz,1987). The earlier works by Brown echoed the skepticism about the view of schizophrenia as being predominantly caused by a pathological family system. This research revealed that the degree of expressed emotion in families is associated with an ensuing relapse in the patient's condition in the following year (Kanter, Lamb, and Loeper,1987). The degree of expressed emotion was qualified as being high or low. This association is a statistically significant relationship and does not suggest that the level of expressed emotion (EE) in the family caused the relapse (Hatfield, Spanoil & Zipple,1987; Anderson, Reiss & Hogarty,1986). Although there has been a propensity in mental health workers to assume from these findings that the family caused the patient's relapse, the expressed emotion in the family and the patient's relapse is possibly a consequence of other factors (Hatfield, Spaniol,& Zipple, 1987).

The theory on EE operates from the view that the schizophrenic

patients have biological and cognitive deficits which result in their being sensitive to socioenvironmental stresses (Mintz, Liberman, Miklowitz, and Mintz, 1987). The stress these patients feel from the environment creates anxiety which further gets in the way of their cognitive functioning (Hatfield, Spanoil, & Zipple, 1987). These deficits interfere with the manner in which these patients process stimuli. They have some difficulties screening large amounts of environmental input. These deficits make them susceptible to psychosis when overwhelmed by not being able to process all the incoming stimuli. This view is in line with the "Diathesis-stress model" (Drake & Oscher, 1987) which is a biopsychosocial model of schizophrenia (Kanter, Lamb, & Loeper, 1987).

The Camberwell Family Interview was developed as a method for reliably determining the family's outward attitudes towards the patient (Kanter, Lamb, & Loeper 1987). The concept EE was operationally defined, using five scales which measure the family's behaviour concerning criticisms, hostility, emotional overinvolvement, warmth, and positive remarks that the family had towards the patient. This interview was administered after the patient was admitted into hospital. High levels of EE on 3 (criticism, hostility, and overinvolvement) of the 5 scales has been shown to prognosticate relapse in the 9 months following hospital discharge. (Mintz, Liberman, Minklowitz & Mintz, 1987).

EE is one of many factors that could be associated with the patients' relapse and it is the one most researched factor (Drake & Oscher, 1987).

A number of research studies now report consistent findings of relationship between EE levels and patients' relapse (Brown, Birley, & Wing 1972; Vaughn & Leff 1976, 1981; Anderson, Hogarty, & Reiss 1980; Liberman et al., 1980; Falloon et al., 1984, Vaughn et al., 1982; Falloon, Boyd, & McGill, 1984). In these studies, relapse ranged between 48 and 62 percent in high EE families and between 9 and 12 percent in low EE families. Unfortunately, most of these studies had no control groups, were based on patients from a mixture of diagnostic groups, and varied in subjects' age, gender, and stages of schizophrenic illness. The time period for follow-up of the patient varied from 9 months to 2 years (Platman, 1983, cited in Hatfield, Spaniol, & Zippie, 1987, p. 223).

Thus, what can be seen is that high EE families have patients with a much higher rate of relapse.

To better understand the EE results it is important to examine various studies focusing on drug and social treatment. Hogarty, in 1984, (cited in Anderson, Reiss, & Hogarty, 1986) provided a review of studies of chronic schizophrenic patients with numerous exacerbations in their illnesses and found that 80 to 100% would relapse when taken off their drugs; an even higher percentage deteriorated on the medications as the number of their previous episodes of illness increased (Anderson, Reiss & Hogarty, 1986). Approximately 40% of patients suffering from schizophrenia have a psychotic relapse within the first year after their discharge. The relapse rate at 9 months after discharge for groups just receiving psychotropic medications was 50% in Leff's (1982) study and 44% in a study by Falloon et al. (1982) (cited in Hogarty & Anderson, 1986).

Various researchers have examined the role of social therapy on

the rate of relapse of patients with schizophrenia. Hogarty, Goldberg, Schooler, & Ulrich 1974 (cited in Anderson, Reiss, & Hogarty, 1986) studied a group of schizophrenics, randomly placing them with either social therapy or no social therapy at the time of hospital admission. After two months these same subjects were randomly given either a placebo or antipsychotic drugs. The findings revealed that, of those given medications only, 48% would experience another episode within two years. Eighty per cent of those placed on a placebo with social therapy deteriorated as did 80% of those who had just received a placebo. Those who had the drugs and social therapy relapsed to the tune of only 37%. As can be seen, social therapy on its own was not useful in preventing deterioration in the schizophrenic illnesses but, combined with medications, helped reduce relapses even when compared with medications alone (Anderson, Reiss & Hogarty, 1986). However, the time frames are not identical between these studies since the studies examining social therapy review the relapse rates at two years while the EE studies examination of relapse rates vary from 9 months to 2 years. These results point to the importance of providing social therapy to schizophrenics, especially with the goal in mind of reducing the high EE levels in the family. There is accumulating evidence that psychosocial interventions augment the patient's drug treatment (Hogarty and Anderson, 1986).

The family environment can provide care or produce stress contingent upon the ability of the family, their fund of information on

schizophrenia, and the professional service and resources available to them (El-Islam,1979; cited in Mintz, Liberman, Miklowitz & Mintz,1987). The studies on EE do not lead to any specific protocols for intervention with families, but what have developed are a variety of psychoeducational approaches which have as their goal the lowering of high levels of expressed emotion in families to prevent patients from relapsing (Hatfield, Spanoil, & Zipple, 1987).

There have been numerous criticisms levied at the expressed emotion studies. Kanter, Lamb, & Loeper (1987) claim their criticisms limit the significance of the findings and pose a valuable question as to whether the EE findings can be explained as a result of the family's effect on the patient or the patient's effect on the family. A grave concern expressed is that the studies on EE view those families with high EE as the culprits, as "bad", "inadequate", and as exhibiting "undesirable behaviour", which only adds to the families' sense of guilt (Kanter, Lamb, & Loeper,1986; Mintz, Liberman, Miklowitz, & Mintz,1987). Other criticisms are directed towards the construct of EE which is composed of parts which have little relatedness to each other; thus, clinical applicability is felt to be reduced (Kanter, Lamb, & Loeper, 1987). The research presupposes that the family's EE level is consistent over time but this has not been verified through study (Hatfield, Spanoil, & Zipple, 1987). The EE construct places families in one of two categories where, for instance, one additional criticism during the Camberwell Family Interview changes the family's level (Hatfield, Spanoil, & Zipple, 1987).

Even with the criticisms levied and the controversy concerning the studies on expressed emotions in families and patients' relapse rates, these studies have shown the importance of combining social therapy with drug treatment and have assisted in developing a new method of intervention: the psychoeducational approach to dealing with patients and families which is harmonious with the biopsychological view of schizophrenia (Kanter, Lamb, & Loeper, 1987). An important component of the psychoeducational approach is the education of patients and their families about the illness of schizophrenia, which includes disclosure of the diagnosis of schizophrenia (Anderson, Reiss & Hogarty, 1986). Previously, psychotherapy was being provided with very little information since earlier training by psychiatrists and psychotherapists argued against "a candid exchange of information as a method of changing family patterns" even though families often asked for information (Anderson, Hogarty, & Reiss, 1980, p. 499).

The relatively recent biological research and results (such as the dopamine studies) have swayed psychiatrists' and social workers' beliefs away from the view of schizophrenia as a problem in the patient's psychosexual development or as an outcome of the family system. Rather than providing a patient with "psychotherapeutic treatments for the victims" (Taylor, 1987, p.118) and therapy for the family, mental health workers should be providing rehabilitation for schizophrenic. Rehabilitation is now necessary since one cannot talk another out of a physical infirmity; one can only support the other with information (Taylor,

1987). Given the present factual and theoretical information one could assume that more information would be shared with patients and their families, including patients' diagnoses.

## Appendix B

QuestionnairesInterview for Social Workers

Male Female

# of interview \_\_\_\_\_

- 1) Have you ever treated clients who suffer from schizophrenic illnesses?
- 2) In the last year how many schizophrenic clients have you seen?  
(Casework relationship)
- 3) What do you see as your role in working with a schizophrenic client?
- 4) What do you see as your role in working with families who have a schizophrenic member?
- 5) In the last year how many of your schizophrenic clients knew their diagnosis?
  - 5 a) How did those who knew their diagnosis find it out?
  - 5 b) How many of these who knew their diagnoses understood what their diagnoses meant?
  - 5 c) How do you define understood?

6) In the last year how many did not know their diagnoses?

7) Have you felt that patients could be adequately informed about their illness without knowing their diagnoses?

8) How have you handled the situation of a client who did not know he or she had a diagnosis of schizophrenia?

8 a) Did you inform the client of his/her diagnosis of schizophrenia?

8 b) Did he/she not knowing pose any special problems?

8 c) Did he/she not knowing require any special skills?

8 d) How did he/she not knowing affect your intervention?

9) Have clients ever asked you for their diagnoses?

If yes

9 a) What did you do?

10) Have you thought that those clients who are unaware of their diagnoses would want to know their diagnoses?

11) Have clients indicated verbally or otherwise that they did not want to know their diagnoses?

Yes No

11 a) How?

- 12) Are there terms that you use instead of schizophrenia?
- 12 a) What are they ?
  - 12 b) Do you feel patients prefer them? Why?
- 13) Have family members ever asked you about a client's diagnosis?
- 13 a) If they have asked you, how have you handled these situations?
  - 13 b) If the families did not ask, do you think they wanted to know the diagnosis?  
Why? What do you mean?
- 14) Have the patient's family ever requested that you not reveal the diagnosis to the patient?
- 15) Do you have an opinion as to whether schizophrenic patients should be told their diagnosis?
- 16) Have you ever discussed the issue of disclosure versus non-disclosure of the diagnosis with a psychiatrist or physician with regard to a specific client's treatment? If yes-
- 16 a) How have the psychiatrists or physicians explained their position?

17) Do you inform clients of these diagnoses? show card

manic depression,	yes	no
unipolar depression,	yes	no
borderline personality disorder,	yes	no
schizophrenia	yes	no
organic brain syndrome,	yes	no
obsessive-compulsive	yes	no

18) Do you inform the families of these diagnoses?

manic depression,	yes	no
unipolar depression,	yes	no
borderline personality disorder,	yes	no
schizophrenia	yes	no
organic brain syndrome,	yes	no
obsessive-compulsive	yes	no

19) Would you prefer that the psychiatrist revealed these diagnoses to patients and their families rather than revealing the diagnoses yourself?

manic depression	yes	no
unipolar depression	yes	no
borderline personality disorder	yes	no
schizophrenia	yes	no
organic brain syndrome	yes	no
obsessive- compulsive	yes	no

20) Do any agencies to which you refer clients require the applicant's symptoms and diagnosis for acceptance into their programs?

yes          no

21) Do physician's discharge summaries accompany your client's application to any community agency?

yes          no

If yes-

21 a) Who sends the discharge summaries?

22) How many years have you been working as a psychiatric social worker with schizophrenic clients?

Interview For Psychiatrists

Male Female

# of interview \_\_\_\_\_

- 1) Do you treat schizophrenics?
- 2) What do you see as the main etiology of schizophrenia?
- 3) Have you felt that you have diagnosed schizophrenia more, less or the same amount, as your colleagues?
- 4) What diagnostic classifications or criteria do you use in diagnosing your schizophrenic patients?  
If more than one-
  - 4 a) Why?
- 5) What is the best treatment that you feel you can offer your schizophrenic patients in Newfoundland?
- 6) How many schizophrenic patients have you treated in the past year?
- 7) How many of these patients knew their diagnoses?

8) How many of these patients who knew their diagnoses understood what the diagnoses meant?

8 a) How do you define understood?

9) In general do you believe that schizophrenic patients should be informed of their diagnosis?

9 a) Why?

10) Have you thought that those patients and their families who were unaware of the diagnosis of schizophrenia would want to know the diagnosis?

11) What problems have you had disclosing the diagnosis of schizophrenia to patients and/or their families?

12) Have any schizophrenic patients indicated verbally or otherwise that they did not want to know details about their illness and their diagnosis?

yes no

If yes

12 a) How?

13) Have families requested that you not release the diagnosis of schizophrenia to the patient?

If yes

13 a) How have you handled this situation?

14) Have you felt that patients could be adequately informed about their schizophrenic illness without knowing their diagnosis?

15) If you were not sure of the diagnosis of schizophrenia would you let the patient know that you were considering the diagnosis?

16) Are there terms that you use instead of schizophrenia?

If yes

16 b) What are they?

16 a) Do you feel patients prefer them?

17) Does not telling a patient his/her diagnosis of schizophrenia call for your using different techniques with regards to treating and educating the patient about his/her illness?

18) Have you ever written on the medical chart why you would not like to reveal the diagnosis of schizophrenia?

19) Has a social worker ever questioned you about your disclosing or not disclosing the diagnosis of schizophrenia?

If yes

19 a) How have you handled this?

20) Have you consulted other disciplines as to whether or not the patient should be told his/her diagnosis of schizophrenia?

If Yes

20 a) Whom have you consulted and for what reason?

21) If a social worker informed a patient of his/her diagnosis of schizophrenia without it previously having been discussed, what would you do?

22) How do you think social workers should conduct themselves when patients and patients families come to them with questions about their diagnosis?

22 a) What would you suggest they do?

23) Do you feel that social work has a role to play in educating families of schizophrenic patients about their illness?

24) Do you feel that social work has a role to play in educating schizophrenic patients about their illness?

25) When deciding whether or not to reveal the diagnosis of schizophrenia have you felt you might be influenced by;

the patient's gender?	yes	no
the patient's age?	yes	no
the patient's level of education?	yes	no
the patient's level of functioning?	yes	no
the patient's personality factors?	yes	no
the history of family mental illness?	yes	no
the patient's psychotic symptoms?	yes	no
a good prognosis versus a poor prognosis?	yes	no
first hospital admission versus several admissions?	yes	no
the patient's popular misconceptions about the illness?	yes	no
that it might be countertherapeutic?	yes	no
ethical dilemmas?	yes	no
the patient's ability to give informed consent?	yes	no

26) Are there any other factors which influence whether you reveal the diagnosis of schizophrenia?

If yes

26 a) What are they ?

27) In general, do you inform patients of the following diagnoses?

manic depression,	yes	no
unipolar depression,	yes	no
borderline personality disorder,	yes	no
schizophrenia,	yes	no
organic brain syndrome,	yes	no
obsessive-compulsive	yes	no

28) In general, do you inform patients' families of the following diagnoses?

manic depression,	yes	no
unipolar depression,	yes	no
borderline personality disorder,	yes	no
schizophrenia,	yes	no
organic brain syndrome,	yes	no
obsessive -compulsive	yes	no

29) In general would you prefer that social workers reveal these diagnoses to the patient and their families?

manic depression,	yes	no
unipolar depression,	yes	no
borderline personality disorder,	yes	no
schizophrenia,	yes	no
organic brain syndrome,	yes	no
obsessive- compulsive	yes	no

## Appendix C

Letters to Social Workers

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Date \_\_\_\_\_

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Dear \_\_\_\_\_

I am a candidate for the Masters of Social Work Degree at Memorial University of Newfoundland. In order to fulfill the thesis requirements for this program I am proposing to undertake a study to attempt to determine why psychiatrists and psychiatric social workers choose to disclose or not disclose the diagnosis of schizophrenia to patients and/or their families.

The importance of this issue is evident in the current lack of consensus within these professions regarding the risks and benefits of disclosure and non-disclosure. Whether or not psychiatrists disclose the diagnosis of schizophrenia has implications for social work intervention

and ultimately the patient.

It is intended that this study will: a) facilitate a better understanding of psychiatrists' and psychiatric social workers' perspectives regarding disclosure of the diagnosis of schizophrenia to patients and /or their families, b) enhance working relationships between these two professions, and c) ultimately contribute to the provisions of services to schizophrenic patients and their families.

In order to do a study of this nature, cooperation will be needed from both professional groups. I will be interviewing all Newfoundland psychiatric social workers who are employed by a hospital and who have either a B.S.W. and/or a M.S.W. I have prepared a questionnaire which would require an interview of approximately one hour's duration.

All the information that will be gathered will be kept in the strictest confidence. The information will be reported in summarized form so that no individual can be identified.

I will be contacting you by telephone to find out if you are willing to participate in this study and, if so to set up a time which will be convenient for you.

I am looking forward to further discussing this interesting topic with you.

Yours sincerely,

Mary A. Smyth

## Appendix D

Letters to Psychiatrists

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\_\_\_\_\_  
\_\_\_\_\_

Date \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Dear \_\_\_\_\_

I am a graduate student in the Masters of Social Work Program at Memorial University of Newfoundland. I am doing a study of the decisions of psychiatrists and psychiatric social workers to disclose or not to disclose the diagnosis of schizophrenia to patients and/or their families.

The importance of disclosure and non-disclosure of diagnosis as an issue is apparent in the lack of consensus within the profession regarding the consequences and advisability of disclosure. It is expected that this study will: a) enhance our understanding of this subject, b) promote better working relationships between the professions, and c)

ultimately serve to improve services to schizophrenic patients and their families.

The success of this study is dependent on the cooperation of both psychiatrists and psychiatric social workers. All psychiatrists in Newfoundland and all those physicians who have completed the four-year residency program in psychiatry are included in this study as are all psychiatric social workers. A one-half hour interview with each respondent is necessary for the study and to facilitate a brief interview it would be desirable to have it taped.

All the information that will be gathered will be kept in the strictest confidence. The information will be reported in summarized form and no individuals will be identifiable.

I will be contacting you by telephone shortly to invite your participation in this study and if possible to arrange a convenient time to meet.

I am looking forward to further discussing this interesting topic with you.

Yours sincerely,

Mary A. Smyth

Appendix E  
Letter of Introduction



MEMORIAL UNIVERSITY OF NEWFOUNDLAND  
St. John's, Newfoundland, Canada A1B 3X8

School of Social Work

Telex: 016-4101  
Tel.: (709) 737-8165

1986 12 02

Dear Professional Colleague:

I am pleased to introduce Mary Smyth who is a Graduate Student in our Master of Social Work Degree Program. Mary is currently involved in a study of psychiatrist's and psychiatric social worker's disclosure practices with regard to the diagnosis of schizophrenia.

In order to carry out this research, she will need the cooperation and participation of respondents from both these two professional groups.

Mary is already conducting interviews with psychiatrists and social workers in St. John's. She has completed interviews with professionals in areas outside St. John's. I am hopeful that you will be able to meet with her within the next month. She will be contacting you for an appointment. The study is an important one and merits the support and encouragement of the Health Professions. The study findings will be made available to you upon completion.

If you have questions on any aspect of this study, Mary or I will be happy to provide additional information. I may be contacted at Memorial University of Newfoundland at 737-8044, and Mary may be contacted at 364-4171. We thank you for your cooperation.

Yours sincerely,

Dr. Frank R. Hawkins  
Director

FRH/cmb

## Appendix F

Consent Statement

This research project will fulfill the thesis requirement for a Masters Degree in Social work from Memorial University of Newfoundland. The study will explore the disclosure practices of psychiatrists and psychiatric social workers pertaining to the diagnosis of schizophrenia. This information might facilitate a better understanding of each profession's perspective on this issue and ultimately enhance their working relationships. This information will be obtained through face-to-face semi-structured interviews with both groups.

All the information that will be gathered will be kept in the strictest confidence. The information will be reported in summarized form so that no individual can be identified.

You are free to not answer any questions, or to not participate at all. If you consent you are still free to withdraw from the study at any time.

Any questions I have about participation have been answered and I give my consent to participate.

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(SIGNATURE)

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(DATE)





