INFORMATION TO THE PATIENT

AN ATTEMPT TO SATISFY THE PATIENT'S NEED FOR INFORMATION

Birgitta Engström
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FOR INFORMATION

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BIRGITTA ENGSTRÖM

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ABSTRACT

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Birgitta Engström

Department of Neurology, University of Umeå, Sweden

Dissatisfaction with medical information is a common problem among patients. There is also evidence that patients lack information that physicians believe they have given to the patient. The aims of this study were to 1) survey patients' subjective need for, and satisfaction with, the information that they received during their hospital stay 2) develop and evaluate systematic routines for giving information to the patients and also communication and collaboration between the medical and nursing staff concerning the satisfaction of the patients' need for information.

The study was an intervention project and the research perspective was organizational psychology.

Survey study. The patients experienced a considerable need for medical information, especially about the examination results and prognosis. The patients' need for information regarding prognosis was the least satisfied.

Intervention 1. A general improvement of the information to the patients occurred when the systematic routines were established. The patients' subjective need for information was unchanged throughout two years. Their satisfaction with information, after an initial improvement, did not increase throughout these two years. There was low correlation between the patients' and their physicians' estimations concerning the patients' need for information on diagnosis, prognosis and examination results. Likewise, concerning the adequacy of that information.

Intervention 2. Communication and collaboration between the medical and nursing staff included a system for assessment and solution of the patients' information problems. Problem-solving took place at a multidisciplinary team conference (MTC). Medical problems were better elucidated than the patients' psychological problems. After training of registered nurses (RN) as conference chairpersons, the patients need for information was better understood. The staff reported 42 information problems after training compared to two before. For half of the information problems decisions were discussed on steps to be taken in order to satisfy the patients' need for information. A year after the system for assessment and solution of information problems was established, the patients were more satisfied with information about examinations and their results and on information about medication (p< 0.05). Further, new norms for the patients' need for information were established and a change was initiated.

The results are discussed with regard to how and why patients' shall have information, by whom and to whom information shall be given, when and where information shall be given and which content it shall have.

Key words: Patient education, consumer satisfaction, patient compliance, patient care planning, communication.

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CONTENTS

LIST OF PAPERS.................................................................6
INTRODUCTION.................................................................7
SURVEY OF LITERATURE.....................................................8
    What do patients want to know?...................................8
    What to tell the patients?.......................................8
    Informed consent.....................................................9
    Patients' ability to make decisions............................10
    Information to relative(s)......................................11
    Effects of improved information..............................12
    Effects of giving potentially threatening information.....12
    Cognitive processes...............................................13
    Difficulties satisfying patients' need for information......14
    Shall some information be withheld?............................14
    What was lacking in the literature when the study started.16
AIMS OF THE STUDY..........................................................10

METHODS............................................................................19
    Subjects.........................................................................19
    Survey study (Paper I)..............................................19
    Intervention 1 (Paper II).........................................20
    Intervention 2 (Papers III and IV).............................20
    Statistics.......................................................................22

RESULTS.............................................................................23
    Survey study (Paper I)..............................................23
    Intervention 1 (Paper II).........................................23
    Intervention 2 (Papers III and IV).............................24

DISCUSSION.......................................................................26
    Methodological considerations..................................26
    Do the patients need information?..............................31
    Can information be dangerous to the patient?..............31
    Shall some information be withheld?............................32
    Information giving and communication between staff......33
    Information problems...............................................34
    The staff's reactions to changes in the care organization.34

CONCLUDING DISCUSSION...................................................36
    How information shall be given to the patient...............36
    How the patient processes information......................36
    Why the patient shall be given information..................38

CONCLUSIONS..................................................................42

REFERENCES....................................................................43

APPENDIX.........................................................................50

ACKNOWLEDGEMENTS.......................................................56

PAPER I  The patients' need for information.......................57
PAPER II  A study of changes in the information
          routines in a neurological ward..............................77
PAPER III Communication and decision-making in a study
          of a multidisciplinary team conference with the
          registered nurse as conference chairman...............95
PAPER IV Solving patients' information problems by the
          nursing process and collaboration between the staff.113
LIST OF PAPERS

This thesis is based on the following papers, which will be referred to in the text by their Roman numerals.


IV Engström, B. Solving patients' information problems by the nursing process and collaboration between the staff. Submitted to Int. J. Nurs. Stud.

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INTRODUCTION

From personal experience as a nurse I know that many patients complain about insufficient information during hospital stay. At the Department of Neurology, Umeå University Hospital, the organization of medical and nursing care was changed in 1976 from a task-oriented system to team care. The first three months with team care were evaluated by Strangert and Andersson (1977). They interviewed patients about their contact with the nursing staff and experience of received information during their stay. The interviews were made on a selected day. All patients admitted on that day were interviewed. They found that half of the patients were dissatisfied with the information about their disease and its treatment while most patients were satisfied with their contact with the nursing staff. The results suggested that team care per se was not sufficient to satisfy the patients' need for information during hospital stay.

From the patients' point of view, the general criticism of Swedish health care, above all, concerned the lack of information. It seemed that team care was a sound basis for development of a system for information giving.

The evaluation of Strangert and Andersson (1977) and the conclusions drawn therefrom provided the impetus to start this project.
Patients' satisfaction with information in connection with health care visits have been the subject of several reports (Cartwright 1964, Duff and Hollingshead 1968, Francis et al 1969). Patients felt that the information they received during their hospital stay was insufficient, contradictory and confusing (Skipper 1965, Allan and Armstrong 1984, Robinson 1985). Other studies have shown patients' dissatisfaction with information about their examinations, medications, diseases and treatments (Reynolds 1978, Hawkins 1979, Wilson-Barnett 1979, Stedeford 1981, Ley 1982a, Boman et al 1983). Dissatisfaction with information is commonly regarded as a problem by, and among, patients.

Physicians are reported to underestimate the patients' desire for information (Faden et al 1981, Waitzkin 1984, Waitzkin 1985). There is also evidence that patients often lack knowledge that professionals believe they have already given. Hulka et al (1975) found, in a group of diabetic patients, that only two-thirds of the information the physicians wanted to communicate was actually transmitted. A significant relationship between patient satisfaction and the amount of information given by the physician was found by Bertakis (1977). Consequently, information to the patient is a large problem that ought to be obvious to everyone working in health care, but it would appear to be not fully appreciated and adequately attended to.

What do patients want to know?

Spelman et al (1966) found in a study of general medical patients that patients complained of insufficient information about diagnosis, prognosis, progress, aftercare and the reasons for investigations. In a study of patients or parents of patients with seizures, Faden et al (1981) found that they wanted more extensive disclosures than the physicians offered, particularly regarding risks and alternative therapy. Patients also wanted more information about why they were to have investigations, answers on questions about their illness and treatment, etc (Cartwright 1964, Skipper 1965, McIntosh 1974, Allan and Armstrong 1984).

Ley (1982a) summarized a number of investigations of patients' dissatisfaction with information received. All patients were or had been hospital in-patients at surgical, medical and psychiatric departments. The studies showed that patients did not consider themselves to have received as much information as they desired and that what professionals thought had been communicated did, in many cases, not satisfy the patient's needs.

What to tell the patients?

It was often considered by physicians that patients did not really want to know that they were dying or that they had a serious illness, such as cancer, but in the studies reviewed by Ley and Spelman (1967) there was
a tendency for those who had cancer to be more in favour of physicians providing them with full information about their condition. With respect to disclosure to cancer patients, Goldberg (1984) argued that the strain created by lack of information unnecessarily isolated the patients and could create an atmosphere of mistrust and confusing communication. The perceptions of children and old people were generally underestimated, and these groups were at special risk for not receiving appropriate information. The physician's judgement of what the patient wanted to know and the estimation of the patient's likely reaction to being told could be mistaken. It was upon this basis that many decisions were made on what to tell patients (McIntosh 1974). The clinical approach valued action that was "in the patient's overall best interest", a position seen as "excessively paternalistic" by Goldberg (1984).

From a concept of autonomy, as the foundation for patients' rights, Ost (1984) argued that "there can be no such right to refuse relevant information, and that the claims for such a right were inconsistent with both deontological and utilitarian ethics".

McIntosh (1974) reviewed the literature on the processes of communication associated with malignant disease in the hospital setting. He referred to investigations on healthy individuals who had been asked if they would prefer to be informed if they had cancer and patients who had been informed that they had cancer. Both groups preferred to be told about their condition rather than being kept in ignorance. Lack of information might also hinder patients in coming to terms with their own existence and might also, paradoxically, increase stress through "the torment of fantasies arized to fill the void" (Goldberg 1984).

Informed consent

Davis (1985) argued that the informed consent principle is necessary and important because people have the right to make decisions on issues affecting their life. This right, supported by both ethical and legal systems, was philosophically based on three connected principles:

- that humans have a unique dignity and worth
- that a human being is never to be used merely as a means, but always as an end
- that individuals are endowed with an inalienable right to life, liberty, and the pursuit of happiness.

According to Cassileth (1980), most patients believed that consent forms were meant to "protect the physician's rights."

According to Boveman (1983), the concept of informed consent has been widely studied and debated. Some hold that acceptable exceptions exist to the duty of informed consent, e.g implied consent, emergencies, patient incompetence, and the "therapeutic privilege." The latter term applied when a decision was made "to withhold information which the physician judged might be harmful to the patient or which the patient might misinterpret" (Jonsen et al, 1982).
The relationship between the health care provider and patient was considered by Szasz and Hollenda (1972) to be divided into three basic types:

The first, in which the patient was considered as being inanimate and therefore unable to contribute actively, permitted the health care professional to behave as a parent with a helpless infant.

The second, were both provider and patient were active, but the patient was expected to look up to, respect, and obey the professional and never question, disagree, or argue.

The third, was one of mutual participation, in which the health professional had a view of, and relationship with, the patient that was quite different from those of the first two types.

O'Neill (1984) argued that a contrast often was drawn between standard adult capacities for autonomy, which allowed informed consent to be given or withheld, and patients' reduced capacities which demanded paternalistic treatment. But patients might not be totally different from the rest of us, in that all their human capacities for autonomous action are limited.

Boverman (1983) examined whether informed consent could be harmful or hazardous, or whether this moral and legal requirement was, in fact, also helpful to the patient's mental health. From the experience of more than 500 patients he concluded that he did not find a single example of a patient harmed by participation in a rigorous informed consent process.

Most patients reported feeling anxious, disturbed, or even shocked when the informed consent procedure produced unfavorable news about their disease. However, these patients and their families regarded the unpleasant feelings as appropriate to their situation, and they did not equate receiving bad news and feeling disturbed with being harmed. Concern about possible harm from telling the truth came mainly from physicians and was based on physicians' personal anxiety in a situation involving close emotional contact with another person - the patient. Davis (1985) concluded that "the ethics of informed consent insist that the patient be given all information necessary to make a decision".

Patients' ability to make decisions

As long as a patient does not make or say anything strange and acquiesces to treatment recommended by the medical professional, questions of competency do not arise. These questions usually arise when the patient refuses treatment or chooses a course of action which, in the opinion of the physician in charge, threatens his or her well-being (Drane 1985).

Abernethy (1984) argued that competence is presumed and does not have to be proved but incompetence must be proved. A high standard of proof is needed as a safeguard of the right to be let alone, because patient
autonomy is too easily thrust aside by such considerations as medical crisis and interpersonal conflicts. A patient may have hope, or may have quality-of-life priorities that outweigh life itself, and a competent patient should have the scope to express this.

Culver and Gert (1982) distinguished between two "levels of incompetence" in relation to valid consent. The first category of patients were referred to as "incompetent to give simple consent" and this group of patients would need others to make decisions for them. The second category of patients were those who were incompetent to give valid consent. Patients in this category could be mildly delirious, mildly retarded, or mildly demented with only a partial grasp of their situation. Neither a consent, nor a refusal of consent, could be considered valid since the patient lacks the ability to understand and appreciate the information being considered; thus a guardian should be appointed to decide on behalf of the patient.

According to Kilpack (1984), most efforts at defining competence have been directed toward consent to treatment. The health care providers are biased toward treatment. Therefore, it is imperative that the applied competency test is not selected on this basis.

Baumgarten (1980) discussed the term "rationality" as the term most commonly used when seeking to specify some minimal level of mental capacity that any patient must have in order to be judged capable of making or sharing medical decisions. To require that a patient chooses rationally in order to be judged competent is to impose a heavier burden of proof for medical competence than that which is imposed in other non-medical areas. Adults are not constrained from marrying unsuitable partners or wasting their money, however irrational these decisions may be. One can argue that medical decisions are more significant. But this is not always the case. A person's decision to abstain from seeking medical help for a serious illness may be both irrational and life-threatening, yet such a person should not be considered incompetent and a candidate for "paternalistic intervention".

Kilpack (1984) concluded that judgements of patient competence can be based on understood concepts and are not to be confused with bias held by the health care provider. Models of competency determination provide some conceptual understanding of how to act in a knowledgeable way.

Information to relative(s)

Barbarin and Chesler (1984), in a study of parents of children with cancer, found that parents' experience of support was best predicted by information transmission and the staff's acceptance of parental efficacy. When physicians, nurses, and other medical staff members failed to provide adequate information about treatment and prognosis, and when they did not involve parents in decision-making and care-taking tasks, parents were less likely to feel helped and supported.

Wilson-Barnett (1979) concluded that nurses and doctors should give information and up-to-date news of the patient's condition, even if they
were not directly asked. If the relatives are kept informed and are consulted about treatments and plans, they will usually be far more helpful and relaxed when the patient is in hospital.

Effects of improved information

In medical wards, patients' needs for information were found to be most acute prior to investigations (Wilson-Barnett and Fordham 1982). When Finesilver (1979) provided two interviews to patients before cardiac catheterization, at which the patients were encouraged to express their fears and given "orientation information" about the procedure, less distress during the procedure and higher satisfaction were reported. Johnson et al (1973) demonstrated that patients need to know how things will feel, what they will experience, how long this will last, and who will be there, to reduce anxiety and cope with stressful experiences.

A successful experimental attempt to increase satisfaction with information amongst general medical patients was reported by Ley et al (1976). A group of patients received extra interviews designed to increase their understanding of what they had been told about their illnesses. These showed significantly greater satisfaction than patients treated in the usual manner, and patients who received extra "placebo interviews" about their hospital stay.

Effects of giving potentially threatening information to patients

Little or no evidence of increased depression or anxiety was reported when patients were given additional information about test results (Greenwood 1973), even when they got access to their own case notes (Fischbach et al 1980). According to Myers and Calvert (1978), fuller information about drugs did not appear to decrease compliance, nor did it increase reported side-effects.

Ley (1982a) argued that the health professionals who did not believe that patients should be informed about such matters as a diagnosis of cancer, the risks of treatment, or the risks of investigations, predicted that the provision of such information would lead to:
- undesirable emotional reactions
- reduced compliance
- anxious over-concern
- more frequent reporting of side-effects of drugs.

No support for these propositions were, however, found in the empirical studies.

Nurses, in a study by Bond (1983), believed that open discussion with cancer patients of their feelings and the possible consequences of their illness would do more harm than good by precipitating even more stress than was already present. They believed that in the short-term patients would show excessive emotion by becoming "hysterical, crying or withdrawing from reality and by becoming morbid or even suicidal". In the longer term hysteria would turn to despair and result in loss of hope, which could reduce life expectancy.
Cognitive processes

People are thought to have certain cognitive structures, termed schemata, that function to pick up the information the environment offers. A schema is that portion of the entire perceptual cycle which is internal to the perceiver, modifiable by experience, and in some way specific to what is being perceived. The schema accepts information as it becomes available at sensory surfaces and is changed by that information (Neisser 1976).

When people are in a situation that is completely different from anything they have experienced before, they have little to rely on to help them interpret the experience and, as a result, their actions can be inhibited, hesitant or inappropriate. Being a patient is, for most people, such a situation. Therefore, providing patients with information about typical experiences they can anticipate during a given procedure will assist them to form a realistic schema (McHugh et al 1982).

Difficulties satisfying patients' need for information

According to Ley (1977), information transmission is often unsuccessful due to patients' failure to understand. Patients' failure to understand stems from three inter-related factors:

- material presented to patients is often too difficult for them to understand
- patients often lack elementary medical knowledge
- patients often have misconceptions which militate against proper understanding.

A basic psychological assumption is that an open communication situation must exist for the information to be transmitted (Watzlawik et al 1967). The communication situation, where the aim was to give information to a patient, has been the object of some studies. The communication process was, according to these studies, very complicated and especially when the receiver of the information was a patient who was influenced by illness, crisis, depersonalization, etc. (Daly and Hulka 1975, Lewenthal 1975, Comstock et al 1982, Hooper et al 1982, Falvo and Smith 1983).

Cohen and Lazarus (1979) stated that illness can be seen as a crisis or extremely stressful event. According to Gottesman and Lewis (1982), crisis is characterized by a set of psychological reactions including anxiety, depression, sense of helplessness and loss of self-esteem. In their study of patients with cancer and others undergoing surgery they found that the crisis of cancer appeared to produce a greater sense of helplessness than that of surgery. In their interpretation of their results they stated that any event that does not produce feelings of helplessness is not a crisis, even if depression and anxiety are present. From this interpretation they concluded that cancer patients experienced a "true crisis", while the surgery group experienced what might be termed a "short-term stress". Cohen and Lazarus (1979) argued that information has long been considered valuable as an aid to adjustment in stressful situations.
According to Lewenthal (1975), the experience of self-depersonalization during illness may lead the patients to believe that they cannot communicate with others. These barriers to communication may be either cognitive or motivational. They are cognitive when individuals are unable to categorize and describe their experiences. Motivational barriers may exist if patients believe that others are indifferent to their psychological experiences and if they anticipate criticism and negative self-appraisal for attempting to describe or for referring to their novel and confusing private experiences.

Communication is both verbal and non-verbal. Patients pick up information from the whole environment using both sight and hearing (Neisser 1976). According to Friedman (1979), the degree of consistency between verbal and non-verbal cues was of great importance, since sick people are quite vigilant in looking out for cues and seeking factual information about the nature and severity of their illness, and they often seek social comparison in discussions with other patients as to what they should be feeling in a time of emotional uncertainty.

Cartwright (1964) and Waitzkin (1984) found that patients from the professional classes were likely to ask questions, while those in the unskilled manual group more often waited to be told. Cartwright (1964) also found that younger people were more prepared to ask questions than older people. Women tended to receive more information than men, probably because of a greater tendency to ask direct questions (Waitzkin 1984). Few consistent findings emerged, however, when individual differences of recall were correlated with age, education, intelligence, level of anxiety, level of medical knowledge, race and sex (Ley 1982b).

Korsh (1984) argued that the physician must not only consider what the patient needs to know, but also what he or she wants to know. According to Goldberg (1984), disclosure of information is often not possible in a single or simple transmission event. It is a process that demands time and requires a clinician who can analyze and comprehend a variety of psychologic processes. One can certainly see a need for more collaboration between medical and nursing staff, both for the patient's sake and to discuss opinions on what patients should be told (Faulkner 1984). Without some ward strategy or plan for routine explanation to patients, information may, however, be given sporadically and incompletely (Wilson-Barnett 1979).

Shall some information be withheld?

Fenner (1985) stated that health care professionals have been schooled in a "paternalistic system", as evidenced by our views of clients and our attitudes toward colleagues. This paternalism sanctioned withholding information out of the belief that health care providers' power of judgement was superior to the client's.

McIntosh (1974) summarized some studies regarding why some physicians preferred to withhold the information to the patient that he had cancer. The most frequent reason for not telling the patient, when the usual
practice was to tell, was the danger of an unfavourable emotional reaction. Many physicians asserted that patients did not really want to know that they had cancer. Some writers felt that a patient should be given no more information than he asked for. Others believed that the patient should only be given enough information to enable him to co-operate in treatment. Skipper (1965) found that one of the most important reasons why staff made a practice of not telling patients about their illness and treatment, was that they believed it would confuse and worry them and might make the condition worse.

According to Bond (1982), the nurses believed in potentially harmful effects on patients of discussing their concerns. This fact was, together with the implications for nurses of managing their own emotional response if the communication should enter into difficult areas, sufficiently potent to dissuade nurses from becoming involved with the personal concerns of the patients.

Information process, ideology and organization of care

The relation between the information process, ideology and organization of the care provided is modelled in Fig.1. The usual situation for information is a communication between an informant (e.g., a physician or a registered nurse) to a receiver (e.g., a patient or a spouse/closet relative). A series of messages exchanged between persons is called interaction by Watzlawick et al. (1967). The information process is dependent of the medical and nursing staff's care ideology. The staff can have the attitude that information shall be helpful to the patients for making autonomous decisions or they can have the attitude of beneficence. This means that they believe that the medical and nursing staff are those who best know what is the overall best for the patient. They are acting in a paternalistic way. The organization of the delivery of medical and nursing care is of importance. Examples of organizational factors are: methods for assessment of patients need for information, routines for information giving, and routines for communication between medical and nursing staff concerning patients' need for information or satisfaction with information.

![Fig.1. Ideology of care, with regard to the information, showing its influence on the information process directly and also indirectly via the organizational changes that have been introduced due to the ideology.](image-url)
Most of the studies reviewed here were about the information and communication process. Many focused on the interaction between the patient and the physician (Comstock et al 1982, Hooper et al 1982, Ley 1982a, Falvo and Smith 1983, Waitzkin 1984). Patient and physician characteristics influencing satisfaction with information were also studied (Ley 1977, Comstock et al 1982, Hooper et al 1982) as were nurses’ communication with patients (Duff and Hollingshead 1964, Bond 1983, Faulkner 1984). Several studies involved patients psychological reactions to illness (Cohen and Lazarus 1979, Gottesman and Lewis 1982, Bond 1983). Other studies were attempts to give special information to groups of patients (Finesilver 1978, Davis 1981, Glanz et al 1981, Padilla et al 1981, Karlsson 1982, George et al 1983).

Information giving and the organization of care were very fragmentarily studied (Cartwright 1964, Duff and Hollingshead 1968).

Most studies of informed consent and patient competency had an ethical perspective and were consequently on the level of ideology (Boverman 1983, O'Neill 1984, Ost 1984, Hull 1985, Davis 1985).

What was lacking in the literature when the present study started?

From a theoretical point of view it is evident that most studies in the literature were descriptive and focused on the information process. The interaction between the physicians and their patients was subjected to several studies (Skipper 1965, Spelman et al 1966, Francis et al 1969, Hulka et al 1975, Ley 1977).

Roth (1963) studied information and the control of treatment in tuberculosis hospitals. He found that patients had great difficulty to obtain information about themselves and to use that information to make their own decisions on treatment. The manner in which hospital work was organized was a contributory cause.

Cartwright (1964) described the hospital service as it was seen by patients in England and Wales. She found that over half of the patients described some difficulty in getting information while they were in hospital and she concluded that hospital staff needed to recognize the patients' need. Cartwright argued that this task was even more difficult than the hospital staff often appreciated, and that too little attention was paid to it, both in the general organization of hospital routines and in medical curricula.

Duff and Hollingshead (1968) focused on the relationship between the care of medical and surgical patients and the social environment of a university and community hospital in the USA. Interviews were made with patients, their spouses, physicians and nurses. Observations were made in the hospital, as well as visits to the patients in their homes and studies of their medical records. The conclusion was that communication between patients and physicians was selective, so that the information sought by one and supplied by the other was usually incomplete and often misleading. They also found that there was "no communication between the physician and the nurse".

16
McIntosh (1974) reviewed the literature pertaining to the ways in which information was communicated to cancer patients and their relatives, or withheld from them. He argued that the ideological stance of doctors engaged in the treatment of cancer patients was likely to embody some judgement about the potential harm in informing patients about their condition. The judgement was based upon "typifications" of individual patients and conditions.

Several Swedish studies described patients' problems in obtaining information. Hellström and Leijd (1976) found that the information to the patients concerning their disease and the drugs prescribed did not always have the desired effect. Israel (1962) interviewed patients who were admitted to a Stockholm hospital for examination and found that half of them would like to know more about their illness. Strangert and Andersson (1977) interviewed 22 patients at the Neurological Department, Umeå University Hospital, and found that half of the patients claimed that they were dissatisfied with the medical information given throughout the treatment period.

None of the referred studies dealt with the question of the patients' subjective need for information throughout the hospitalization period. It was therefore considered of interest to elucidate possible associations between the patients' subjective need for information and satisfaction with information and the patients' background.

No study was found, in which an attempt was made to change the organization of medical and nursing care with the aim of increasing the patients' satisfaction with information during hospital stay.
The aims of the study were as follows:

- to survey and describe the patients' subjective need for information during the ward stay and their subjective experience of the adequacy of the information

- to elucidate possible associations between lack of information and the patients' background

- to elucidate some psychological and organizational factors of importance for the patients' satisfaction with the information received

- to design and evaluate changes in the method of organizing the transmission of general and medical information to the patients

- to design and evaluate a method for systematic communication between the medical and nursing staff concerning satisfaction of the patients' need for information

- to design and evaluate a system for assessment and solution of the patients' information problems

- to discuss the findings in terms of why information shall be given, and to whom and by whom, when information shall be given, which information shall be given, where and how information shall be given
METHODS

The total study was an intervention project with a research perspective of organizational psychology (Schein 1980). The project started in 1977 with a survey study and the data collection was completed in 1985 with evaluation of the effects of intervention (Fig. 2).

Fig. 2. A time plan of the different phases of the study.

Subjects

The University Hospital of Umeå is the regional hospital for a population of 650,000 and has approximately 1200 beds. The Department of Neurology (30 beds) is the only one in the region whilst there are about 12 surgical and 12 medical departments. Subjects in the first study (I) were inpatients from a surgical, a medical and a neurological ward. The studies II and IV included only patients cared for at the neurological ward. All patients received questionnaires when discharged to their homes. The staff’s communication and decision-making were studied at the multidisciplinary team conference (MTC) (III). The staff consisted of physicians, registered nurses, enrolled nurses, auxiliary nurses, occupational therapists and a counsellor.

Survey study (Paper I)

Interviews were carried out with 120 patients in order to obtain a general picture of the patients' need for, and satisfaction with, information during their hospital stay. The questions were about the general and medical information provided and psychological and
organizational aspects in the care of the patients. The patients were divided into two equal groups. One group was interviewed both during the ward stay and after discharge. The other group was only interviewed on the telephone after discharge.

**Intervention 1 (Paper II)**

The changes introduced in the care routines consisted of:
- systematic information routines for medical and general information
- systematic follow-up of information provided by a mentor system
- written communication between informants and mentors about the patients' satisfaction with information

A booklet on the medical examinations was compiled with the aim of increasing the nursing staff's skill to give and follow-up such information.

All patients admitted to the neurological ward during two years were included in the study. They received a questionnaire after discharge (see Appendix). The questions and the estimation scales were the same as in Paper I. The physicians estimated what they considered were the patients' requirements for information on diagnosis, prognosis and examination results. The physicians also estimated how adequate, from the patients' point of view, they thought their information in these questions had been. In addition, the physicians estimated how serious the patients' disease development was expected to be.

**Intervention 2 (Papers III, and IV)**

A training material was devised for the registered nurses as chairpersons of the MTC. The training was performed with aid of patient case reports and role play. The whole team was trained during an 8 hour period. Data was collected by tape recordings of the communication at ten MTCs before the training and ten MTCs after the training. A modified nursing process system for assessment and solution of the patients' information problems was developed (Fig.3). The forms for documentation and the nursing process system were introduced together with the training program for chairpersons. The system was evaluated with regard to its process and its effects on the patients' satisfaction with information. The same questionnaires to the patients and estimations by the physicians were used as in Paper II. The process was evaluated with regard to documented information problems and their solution.
Fig. 3. A model of the nursing process system used. The process starts with assessment and is considered completed when the patient is satisfied.
Statistics

A semipartial correlation method was employed for calculation of the association between variables (I) (Cohen and Cohen 1975). With this method, the effect of other factors on the association could be controlled. Student's t-test was used to test the differences between mean values (II, IV). Pearson's coefficient of correlation was used to test the correlation between factors (II). The Chi-square test for independence was used to describe differences between groups (II, III).
RESULTS

The data collection periods are shown in Fig. 2.

Survey study (Paper I)

The patients experienced a considerable need for medical information, especially concerning the examination results and the prognosis (Table 1). The patients' need for information regarding the prognosis were, however, the least satisfied (Table 1). The only background factor which correlated significantly with informational adequacy was the mode of admission (acutely or according to the waiting list) (p<.05).

Table 1. Median values of the patients' opinions concerning their need for information and the adequacy of the information received.

<table>
<thead>
<tr>
<th>Information</th>
<th>Need median</th>
<th>Adequacy median</th>
</tr>
</thead>
<tbody>
<tr>
<td>Results</td>
<td>5.9</td>
<td>5.1</td>
</tr>
<tr>
<td>Prognosis</td>
<td>5.8</td>
<td>3.2</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>5.7</td>
<td>3.9</td>
</tr>
<tr>
<td>Medications</td>
<td>5.6</td>
<td>4.5</td>
</tr>
<tr>
<td>Aftercare</td>
<td>5.6</td>
<td>5.6</td>
</tr>
<tr>
<td>Examination</td>
<td>5.5</td>
<td>4.7</td>
</tr>
<tr>
<td>Medical exam.</td>
<td>5.2</td>
<td>3.5</td>
</tr>
<tr>
<td>Routines</td>
<td>4.5</td>
<td>4.6</td>
</tr>
<tr>
<td>Facilities</td>
<td>4.5</td>
<td>5.5</td>
</tr>
</tbody>
</table>

Intervention 1 (Paper II)

The patients' subjective need for information was the same for both the years. Standardized alpha was 0.91. A general improvement of the information to the patients occurred when the routines were established. The patients' satisfaction with information was not increased over the two years (Table 2). There was low correlation (range 0.016-0.197) between the patients' and their physicians' estimations concerning the patients' need for information about diagnosis, prognosis and examination results. Likewise, with regard to the adequacy of that information, the written communication between the informants and the mentors was found to be insufficient.
### Table 2. Mean values of patients' estimations of the adequacy of the information they received for group 1 (N=255) and group 2 (N=246).

<table>
<thead>
<tr>
<th>Adequacy of Information</th>
<th>Group 1 mean</th>
<th>Group 2 mean</th>
<th>Statistical significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Results</td>
<td>4.457</td>
<td>4.525</td>
<td>ns</td>
</tr>
<tr>
<td>Prognosis</td>
<td>3.972</td>
<td>4.021</td>
<td>ns</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>4.510</td>
<td>4.558</td>
<td>ns</td>
</tr>
<tr>
<td>Medications</td>
<td>4.407</td>
<td>4.536</td>
<td>ns</td>
</tr>
<tr>
<td>Examinations</td>
<td>4.917</td>
<td>4.963</td>
<td>ns</td>
</tr>
<tr>
<td>Medical exam.</td>
<td>4.564</td>
<td>4.597</td>
<td>ns</td>
</tr>
<tr>
<td>Aftercare</td>
<td>4.832</td>
<td>4.955</td>
<td>ns</td>
</tr>
<tr>
<td>Facilities</td>
<td>5.416</td>
<td>5.354</td>
<td>ns</td>
</tr>
<tr>
<td>Routines</td>
<td>5.372</td>
<td>5.136</td>
<td>p &lt; 0.05</td>
</tr>
</tbody>
</table>

ns = not significant

### Intervention 2 (Papers III, and IV)

The system for assessing and solving the patients information problems included communication between the staff at the MTC. The registered nurse, the practical nurse (enrolled nurse and nurse's aide) and the occupational therapist had increased their verbal activity and the physician had decreased his verbal activity. The strictly medical communication was less illuminated, while the patients' psychological needs, especially concerning the patients' need for information, were better illuminated than before the training (Table 3). After the training, 42 information problems were reported (2 before). For half of them, decisions were made on steps to be taken in order to fulfil the patients' need. For the other half, the staff discussed how to handle the patients' need but missed the decision-making. The patients in group 2 were more satisfied (p < 0.05) with information concerning examinations and their results and regarding the medications a year after the study started (Table 4), although fewer information problems and follow-ups were documented on the forms. The registered nurses had difficulties formulating and documenting the problem-solving. New norms for the patients' need for information were established and a change was established.
Table 3. The content of four personnel categories' utterances per group of 15 patients at ten MTCs before and ten MTCs after training. Number of utterances; N = 118 before, N = 191 after.

<table>
<thead>
<tr>
<th>Content of utterance</th>
<th>Physician</th>
<th>R.N./Chairman</th>
<th>Prac. nurse</th>
<th>Specialist*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>bef. aft.</td>
<td>bef. aft.</td>
<td>bef. aft.</td>
<td>bef. aft.</td>
</tr>
<tr>
<td>Investigation</td>
<td>40</td>
<td>21</td>
<td>19</td>
<td>18</td>
</tr>
<tr>
<td>Treatment</td>
<td>11</td>
<td>6</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Prognosis</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Social aspects</td>
<td>5</td>
<td>3</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Cultural aspects</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Psychol. aspects</td>
<td>3</td>
<td>3</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Physical aspects</td>
<td>3</td>
<td>2</td>
<td>4</td>
<td>3</td>
</tr>
</tbody>
</table>

* Physiotherapist, occupational therapist, counsellor

Table 4. Mean values of the patients' estimations of the adequacy of the information received for group 1 (N = 129) and group 2 (N = 154).

<table>
<thead>
<tr>
<th>Adequacy of information</th>
<th>Group 1 mean</th>
<th>Group 2 mean</th>
<th>Statistical significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Results</td>
<td>4.08</td>
<td>4.42</td>
<td>p &lt; .05</td>
</tr>
<tr>
<td>Prognosis</td>
<td>3.61</td>
<td>3.82</td>
<td>ns</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>3.98</td>
<td>4.15</td>
<td>ns</td>
</tr>
<tr>
<td>Medical exam.</td>
<td>4.23</td>
<td>4.45</td>
<td>ns</td>
</tr>
<tr>
<td>Examinations</td>
<td>4.53</td>
<td>4.85</td>
<td>p &lt; .05</td>
</tr>
<tr>
<td>Medications</td>
<td>4.07</td>
<td>4.64</td>
<td>p &lt; .05</td>
</tr>
<tr>
<td>Aftercare</td>
<td>4.68</td>
<td>4.78</td>
<td>ns</td>
</tr>
<tr>
<td>Routines</td>
<td>5.05</td>
<td>5.22</td>
<td>ns</td>
</tr>
<tr>
<td>Facilities</td>
<td>5.28</td>
<td>5.19</td>
<td>ns</td>
</tr>
</tbody>
</table>

ns = not significant
Methodological considerations

The Swedish Health and Medical Services Act of January 1983 states that good health and medical services must particularly:

- Be of good quality and cater for the patient's need of security in care and treatment
- Be readily accessible
- Be founded on respect for the self-determination and privacy of the patient
- Promote good contacts between the patient and health and medical personnel.

Care and treatment must, as far as possible, be designed and conducted in consultation with the patient. The patient must be informed of his state of health and of the treatment methods available. If this information cannot be supplied to the patient, it shall be supplied to a close relative instead.

A broad classification of the content of the information to the patients before, during, and after hospital stay is shown in Fig. 4.

Information can be divided into general and medical information. General information covers the duration of the care period, the department, the care organization, the personnel, the ward routines, the facilities etc. Medical information covers the planned investigation, its results and the treatment. Medical information also involves information about disease, treatment, prognosis, aftercare, and consequences of the disease (Fig. 5).

![Fig. 4. A time schedule of when the information should be given.](image-url)
The present studies (I, II, III, IV) have only involved information to the patients during the hospital stay. This information shall, according to the Swedish law cited above, be given to all patients as a routine.

Planning of the project. Since the results of the survey study (I) showed patients' dissatisfaction with information during hospital stay and a lack of routines for information giving, it was decided that changes in the routines had to be introduced. The rest of the study was, therefore, planned as an intervention project.

The most usual method in attempts to increase the patients' satisfaction with information has been to select a group of patients to test an information package of some sort (Hayward 1975, Ley et al. 1979, Davis 1981, Glanz et al. 1981, Padilla et al. 1981, Karlsson 1982, George et al. 1983, Dodd 1984). This method, however, only provided better information to a restricted group of patients. In order to achieve a general increase in all patients' satisfaction with the information received during hospital stay, the organisation of the medical and nursing care and the information process (Fig. 6) was taken into consideration (II, III, IV).

Fig. 6. A model of the steps in the information process.
### BEFORE ADMISSION

#### MEDICAL INFORMATION

1 **REASON**
   - Medical investigation
     - Which
     - Why
   - Treatment
     - Which
     - Why

2 **SPECIAL PREPARATION**
   - Special diet
     - Which
     - Why
   - Fasting
     - Which
     - Why

#### GENERAL INFORMATION

3 **CARE PERIOD**
   - Duration

4 **TRAVEL BY**
   - Ambulance, taxi, own car, public transport, accompanied, health care employee

5 **HOSPITAL INFORMATION**
   - Date of admission
   - Special instructions for the stay
     - Clothing, flowers, visitors
   - Patient brochure
     - Visiting hours, hospital information, health insurance rules

#### AT ADMISSION

#### GENERAL INFORMATION

6 **ORGANIZATION OF CARE**
   - Team care,
   - primary nursing
   - Responsibility for information
     - Mentors, RNS, physicians

### 7 PERSONNEL
   - Head nurse, physician, mentors, other staff

### 8 FACILITIES
   - Ward, shower, toilet, store, dining room, TV-room, smoking room, nurses' office, treatment and examination room

### 9 EQUIPMENT
   - Department
     - Transportable telephone, books, hair-dryer, games, handicap aids
   - Ward
     - Radio, lighting, call alarm, bed functions

### 10 ROUTINES
   - Bed making, cleaning
     - Linen
     - Hospital clothes, sheet, towels
   - Times
     - Mealtimes, visiting times, round, pulse, temperature
     - Patients' own coffee-tea break
     - Routines, costs

### MEDICAL INFORMATION

11 **PLANNED MEDICAL INVESTIGATION**
   - (Why, how, when)
   - Medical investigation
   - Examinations
   - Consultations
   - Blod, urine samples

### THROUGHOUT HOSPITAL STAY

#### MEDICAL INFORMATION

12 **INVESTIGATION**
   - Examinations
     - Preparation, procedure, after-care
13 RESULT OF INVESTIGATION
Results of examinations
Diagnosis
Consequences
Treatment
Discharge
Transfer other department, other hospital

14 TREATMENT (Why, how, when)
Medication
Operation
Radiation therapy
Physical therapy
Occupational therapy, ADL-therapy
Counsellor talk, Aphasia training, Psychotherapy
Diet treatment
Other treatments

BEFORE DISCHARGE

HEALTH AND MEDICAL INFORMATION

15 DISEASE
16 CAUSED BY
17 DEVELOPMENT
18 CONSEQUENCES
  Function
  Activity
  Social
19 TREATMENT (Why, how, when)
  Medication
    Administration, quantity, distribution, side-effects, observations, changes, prescription, renew
  Operation
    Where, consequences
  Radioterapi
    Where, consequences
  Other treatments
    Where, consequences

20 SELF-CARE (Why, how, when)
21 REHABILITATION (Why, how, when)
  Possibilities
22 COMMUNITY ASSISTANCE
  Home care
  Financial help
  Handicap equipment
23 DISABLED PERSONS' ORGANIZATIONS
  (Why, how, when)
  Brochures
24 AFTER-CARE
  Placed on sick-list
  Next visit
  Contact person at hospital

GENERAL INFORMATION

25 NEXT VISIT
  Time
  Travel by

AFTER DISCHARGE

MEDICAL INFORMATION

26 NON-INSTITUTIONAL CARE
  Neurological
  Next visit
  (Why, when, by whom)
  Primary health care
  Next visit
  (Why, when, by whom)

GENERAL INFORMATION

27 ORGANIZATION
  Who can be contacted
    Physician, RN, district nurse, physiotherapist, occupational therapist, counsellor
    Telephone times

29
Satisfying the patients' need for information includes satisfying both a normative and a subjective need for information. Normative need means that someone other than the patient decides his need for information, e.g., about an examination. Subjective need means the need which is specified by questioning the patient or by the patients' questions, ponderings etc. regarding e.g., the examination. According to Leventhal (1975) the information has to connect to the patient's real world and form a dimension of how a procedure will affect his life.

A number of studies have illustrated the patient's normative need for information (Hulka 1975, Faden et al 1981, Ley 1982b, Boman et al 1983). Few studies took the patient's perspective and his subjective need for information into consideration (Cartwright 1964, Korsch 1984). Since it is the patient himself who has to consider if the received information is adequate for his need, the present study was designed to take the patient's subjective need for, and satisfaction with, information into consideration (I, II, III, IV).

According to Schein (1980), intervention should be based on a theoretical model of how the system works, and the model should, under ideal circumstances, predict the consequences of the intervention. Whether or not these consequences materialize as predicted then becomes a check on the initial theory. The model of theorizing, intervening, gathering data on the effects of the intervention, and then checking the theory prior to developing the next intervention is the sequence of activities which describes the action research model.

Careful design of the interventions implies well-thought-out theory, and studying the effects of the interventions implies the use of objective observation, interviews, measurements and whatever other techniques which are appropriate to the evaluation of the intervention in order to make it as nearly bias-free as possible (Schein 1980).

The results of the survey study (I) and thorough knowledge of the department studied was the basis for the planning of the first intervention (II). The second intervention was planned after the evaluation of the first intervention (III, IV).

Evaluation of interventions (II, III, IV). According to Schein (1980), a number of methods have to be used to evaluate the effects of the interventions. The method of sending questionnaires to discharged patients was one of the methods used to study the effects of the interventions. The questionnaires gave a general picture of the patients' subjective need for, and satisfaction with, the information. The response frequency was about 80 percent. Polit and Hungler (1983) estimated a response rate greater than 50 percent to be sufficient to generalize the results of a study to the target population. About eight hundred questionnaires were included in the intervention project, and were distributed in three periods between 1979 to 1985. The questions pertaining to information need were used as measures of the population stability and were tested for reliability. The results showed that the
The physicians estimated how serious the patient's disease development should be. The inter-rate reliability for this scale was 0.91 (I). In addition, the physicians estimated what they considered were their patients' requirements for information on diagnosis, prognosis and the examination results. The physicians also estimated how adequate they believed their information in these regards had been from the patients' point of view. The reason for this was to compare the patients' and their physicians' views on the information.

The communication between the staff and how the routines functioned were studied by evaluation of forms in the nursing record (II, IV) and by tape-recordings and observations of MTCs (III). Consequently, and in line with Schein (1980), different methods aimed at making the evaluation as valid as possible were used in the data collection.

Do the patients need information?

That the patients' subjective need for information was the same at the two studied periods provided knowledge about the importance the patients attached to the different information content that they received (I, II, IV). The patient's need for information on examination results and prognosis was the most important, which is in agreement with the findings of Spelman et al (1966). The information on prognosis was experienced as the most inadequate. The correlations found between the patients' background factors, informational need and informational adequacy did not explain the deficiencies in the information (I). These findings suggested that the patient's need for information was individual and dependent upon factors such as previous experience (McHugh et al 1982) and personality factors like autonomy of will (Gillon 1985) etc. Wilson-Barnett (1979) pointed out that a prerequisite for patients to feel that they had received sufficient and adequate information was that their individual needs had been satisfied. This means that satisfying only normative needs is not enough.

Consequently, the staff's lack of competence in assessing the patients' information problems and solving them is suggested to be due to the fact that the patients' need for information was not satisfied (III, IV). In line with this result was the report that physicians underestimated the patients' desire for information (Waitzkin 1985). Nurses, in a study by Faulkner (1984), appeared to have little insight into an oblique question from a patient who might be very anxious. More recently, there has been a growing recognition of the central role of communication in nursing practice and the need for interpersonal skills training in nursing education (Macleod Clark 1985).

Can information be dangerous to the patients?

Since the patients experienced a large subjective need for information (I, II, IV), their needs have to be satisfied. Previous reports have provided no evidence that information has any harmful effects on
patients or that it leads to reduced compliance and more frequent reporting of side-effects of drugs (Myers and Calvert 1980, Ley 1982a, Ley 1982c, Boverman 1983). Davis (1985) suggested that information could be dangerous because it allowed people to act autonomously and make decisions that health care professionals might find hard to accept. The right decision was, in this case, defined as the one that fitted into the health professionals' value system.

Patients' autonomy is emphasized in the Swedish Health and Medical Services Act and in the law of informed consent in the USA. According to Daly and Hulka (1975), and Ley (1982a), compliance with medical advice should increase if patients are given full information in an understandable form. Information helps the patient to cope with health care procedures (McHugh et al 1982, Karlsson 1982). Furthermore, it was reported (Maguire 1976, Weisman 1979, Henriques 1980) that, when a diagnosis of cancer was given, the immediate reactions to information were moderate and almost all patients adjusted well to the situation after an initial phase of anxiety of variable length.

According to Lewis et al (1979), an unexpected event can cause the patient severe psychological discomfort that cannot be resolved by ordinary coping strategies. An example of this was the information that the diagnosis was Multiple Sclerosis. New methods of coping are attempted, and if these also fail, the result is anxiety, depression, helplessness and a loss of self-esteem; in effect a crisis reaction. That so many patients were dissatisfied with information about diagnosis and prognosis could be caused by the patient developing an acute crisis reaction. Follow-up of the information is a valuable method of assessing how the patient has processed the information given. Many times, follow-up has to continue after discharge if the patient's need for information shall be satisfied.

Shall some information be withheld?

Patients' subjective need for, and degree of satisfaction with, information has already been discussed (I, II, IV). Ley (1982a) argued that the patients' dissatisfaction would provoke clashes with the views of professionals who frequently were less willing to share information with patients. According to Waitzkin (1985), uncertainty did not predispose to information withholding. That some physicians better satisfied their patients' need for information than others could be caused by their degree of certainty, which is in agreement with Waitzkin (1985), who found that, if anything, physicians tended to communicate more information when diagnosis or prognosis is uncertain.

Satisfying patients' information need is a complex and difficult task that demands systematic communication and collaboration between medical and nursing staff. This includes mentors' reports of patients' reactions and questions, problem-solving at the MTC, decisions on steps to be taken to satisfy patients need for information and evaluation of results. Results from other studies are in agreement with these suggestions. Pfefferbaum et al (1982), for example, found disparity between physician and patient perceptions of tests and treatments, with
physicians reporting significantly more patient fear, lack of understanding, discomfort, dissatisfaction with choice and preoccupation with illness than was reported by the patients themselves. Hull (1983) argued that many physicians felt morally bound to "protect" patients from the stress of a serious diagnosis or of knowledge of the risks involved with a therapy.

The staff's view of the patient was pointed out by Goldberg (1984) as an apparent conflict between the presumed obligations both to inform and to protect. Some care providers publicly upheld their paternalistic approach to disclosure. They maintained that it was their professional duty to provide only as much information as they considered would make sense to a particular patient at a particular time. Others maintained that it was the patients' right to know as much as possible. Jackson and Youngner (1979) argued that physicians must not use "professional responsibility" as a cloak for paternalism, but that they must be alert and not let the possibility of abuse keep them from the appropriate exercise of professional judgement. The statement of Boverman (1983) deserves to be repeated: There was, in his experience, not a single example of a patient harmed by participation in a rigorous informed consent process.

Information giving and communication between medical and nursing staff

The findings in Paper II that routinely given and followed-up information improved the patients' satisfaction with information was in agreement with Korsch (1984), who pointed out that the process of patient education should be viewed as a joint venture in which the patient helps to determine what information should be provided. She suggested that the physician should take the time required to find out what the patient, on a particular occasion, would specifically like to have explained, what some of the patient's actual questions are, e.g. in short, the patient's needs.

The time available to the physician on ward duty for each patient is restricted (I). It is an important and complicated task to satisfy the patients' need for information (Ley 1982a, Goldberg 1984) and more collaboration is required between medical and nursing staff, both for the patient's sake and to explore ideas on what patients should be told (Faulkner 1984). These facts support a system with mentors and follow-up of given information (II, IV), especially since the results of the survey study (I) showed that the patients had a great confidence in the nursing staff's capability to inform patients about examinations and diseases. Systematic collaboration between the staff is dependent upon a working communication.

One of the most difficult aspects of the design of organizations is "how to keep the right people communicating about the right tasks at the right time and with the right problem-solving and collaborative attitudes" (Schein 1980). Oral and written communication between informants and mentors was, in the present study, considered necessary in order to satisfy the patients' need for information. The written communication between the registered nurses and the mentors functioned
better than between the physicians and the mentors (II, IV). This communication probably contributed to the patients' experience of the information concerning the examinations as more adequate than information concerning examination results. The physicians seldom recorded on the forms that they had informed the patients, which meant that the mentors could not follow-up the information about examination results.

The mentors' follow-up conversations with their patients were important in assessing information problems (IV). The method was confirmed by McIntosh (1974), who argued that the important thing from the patient's point of view was not what he was told but what he thought he was told. An example of follow-up of information with assessment of information problems is a study by Bertakis (1977), in which the patients in an experimental group were asked by the residents to repeat in their own words the information which they had just been given. The physician was then able to repeat the information which the patient had forgotten or misunderstood. The patients were also asked if they had any questions. The retention of the information was 84 percent compared to 61 percent in a control group who did not get repeated information and the patients in the experimental group were more satisfied with the information received.

Information problems

If the patient has drawn some wrong conclusion, lacks important knowledge or is dissatisfied with the content of the information, then there is an information problem. The findings in Papers III and IV suggest that information problems have to be assessed. That is in agreement with Martin (1983), who stated that it is important to know which conceptions patients have about their illnesses. It is also in accordance with McIntosh (1974), who stated that it is important to know which conclusions the patients have drawn from the information received. If patients have drawn wrong conclusions, the staff has to be aware of it in order to provide them with a correct conception. The information problems, consequently, have to be solved if patients' satisfaction with information during hospital stay shall improve. The modified nursing process system, involving both medical and nursing staff, was found to be a successful system in that respect.

The staff's reactions to changes in the care organization

The fact that the physicians in the beginning tended to act like they always had done previously (II) suggest that they influenced the nursing staff to feel that the new system for giving information to the patients was not sanctioned by them. Later results (IV) suggested that the physicians had increased the quantity of information given. The physicians could, however, feel that the nurses demanded too much of them when they reported patients' information problems and called for collaboration in problem-solving and in formulating steps to be taken to answer patients' questions etc. Since "the physicians traditionally have a paternalistic view of the patients" (Goldberg 1984), they could
experience a conflict between their own aims and the nursing staff's and/or the patients'.

The medical and nursing staff's ideology of care is a factor which has importance for the information giving (Fig. 1). That is, if the members of the staff view the patients as autonomous individuals or as patients who do not know themselves what is the best for them. That is to say, an autonomy or a beneficent (paternalistic) view of the patient (Fenner 1985, Goldberg 1984). Further, the care organization and the information process were regarded as important factors (Wilson-Barnett 1979, Faulkner 1984, Goldberg 1984, Korsch 1984) (Fig. 1). Which routines are there for information giving and how is the information process designed? It was found to be of importance how the staff viewed the individual patient in the information process. For example, their view of the patient's competence in making their own decisions and of the patient's disease; that is to say, prognosis and "quality of life" (O'Neill 1984, Ley and Spelman 1967, Ley 1982c).

The Swedish Health and Medical Service Act emphasizes patient autonomy as the basis for the staff's information giving. The present studies (II, III, IV) deal with changes in the care organization and in the information process, and the results indicate that an effective change has been brought about. According to Chin and Benne (1976), a real change will not occur until people are brought to change their personal meanings, their perceptions of norms, and the values these norms have for them. Consequently, both medical and nursing staff when they are discussing how patients' information problems have to be solved must have a view of the patient as an individual, who is capable of making informed decisions (IV). Without that ideology they have difficulties to accept and follow new routines which are developed in order to give the patient knowledge for, among other things, autonomy.
CONCLUDING DISCUSSION

A study such as this provides a wealth of experience in addition to the factors that were studied quantitively. The contact with the patients, the discussions with the medical and nursing staff, and the observations made on the ward are items of knowledge and experience which have to be incorporated into the discussion of the results. This is achieved in terms of how and why patients shall have information, by whom and to whom information shall be given, when information shall be given, which content it shall have, and where the patient shall be informed.

How information shall be given to the patient

When the information to the patient is being planned, it is important to have in mind that information shall correct mistakes and add new knowledge to that which already exists about health and disease. Consequently, the informant must assess the patient's need, provide the patient with information and check if the patient's need is satisfied. Routines and methods must be developed for this.

The information and communication process used by the staff in order to satisfy the patient's need for information is described in detail in Papers II, III and IV. The information process and the care organization -- especially the routines for giving the information -- are influenced by the medical and nursing staff's care ideology (Fig. 1). According to the Swedish Health and Medical Services Act (1983), the patient shall be seen as a "person with autonomy". That means that the patient must receive sufficient information to make his or her own decisions and to act autonomously.

Follow-up of information with the mentor system is a feedback to the informant and a significant factor in the organization of the information process (II, IV). The steps of the information process are shown in Fig. 5. The mentor converses with the patient after the patient received information. If he has questions, ponderings, speculations etc., the mentor reports them to the informant who has to give the additional information which may be needed. A schematic model of the communication process in the neurological ward is shown in Fig. 1, Paper III.

If the patient has drawn some wrong conclusions from the information, lacks important knowledge or is dissatisfied with the received information, then there is an information problem. Assessing information problems and solving them is a task which has to be carried out by systematic collaboration and communication between the medical and nursing staff (IV). The MTC is a forum for that type of problem-solving (III). The method is a modified nursing process and a model is shown in Fig. 3.

How the patient processes received information

The informant's intention with the information is that the patient shall receive knowledge of his situation and his problems. Through a cognitive
The patient himself processes the received information. By follow-up of the given information, the informant gets feedback and a knowledge of the information that the patient still lacks. The cognitive adaptation shall, if it is not too disturbed by negative, organic cerebral and/or psychic factors, lead to a deepened knowledge – an insight into his own problems.

The cognitive process is influenced by organic cerebral factors such as intellectual capacity and memory function. These factors effect the cognitive process positively or negatively.

The cognitive process is also influenced, both negatively and positively, by psychic factors such as mood (the variable where the two extremes are deep depression and mania), emotions, personality and crisis reactions. In turn, these psychic factors can be influenced by the cognitive process and the patient may e.g become more depressed, the crisis may come under control etc. If, the patient, for example, is depressed, cognitive process may be hampered. Emotions like fear, anxiety, avoidance, worry, "nervousness" etc influence the cognitive process in a negative way. Pleasure, happiness, delight, satisfaction may influence cognition in a positive way. "Nervousness" on admission can be the cause of the patient failing to understand what the informant is saying. At the follow-up he then can say that he has not received any information at all.

Patients who suffer from physical symptoms with no apparent organic pathology, that is to say, patients with a diagnosis "hysteria" or "functional overlay", (Wilson-Barnett and Trimble 1984) often present complicated communication problems. The feedback in the process may be abnormal and the whole communication becomes "loaded with noise". This subject will not be further elaborated here.

Crisis is a series of mental reactions resulting in anxiety, depression, helplessness and a loss of self-esteem. A total crisis in the stage of psychical shock can imply that the cognitive process is completely blocked and, with that, the processing of knowledge into insight. The crisis may be influenced and relieved by information and to be effective it should be repeated to the patient upon several occasions.

If the cognitive process does not work properly, the patient cannot achieve the insight needed and someone else has to take over and perhaps make decisions for the patient. For example, the parents must be informed instead of the small child. When the child is growing up, the parents recede more and more into the background, to disappear entirely as information receivers when a spouse has taken their place. The situation can be the converse later on in life in that the son or the daughter has to be the one who is the receiver of information which the parent does not have the intellectual capacity to process, e.g. due to a dementia.

The spouse's (or the closest relative's) knowledge is of importance when the patient is processing his own knowledge. It is an advantage if the closest relative and the patient can receive information concurrently,
especially about the disease and its consequences. There are also many of other sources which influence the patient's information processing, some of which are listed in Fig.7.

Fig. 7. Sources of information to the patient.

<table>
<thead>
<tr>
<th>In the hospital: studied in this thesis</th>
<th>Additional sources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physicians</td>
<td>Spouse/closest relative</td>
</tr>
<tr>
<td>Registered nurses</td>
<td>Fellow patients</td>
</tr>
<tr>
<td>Enrolled nurses</td>
<td>Other relatives</td>
</tr>
<tr>
<td>Nurse's aides</td>
<td>Friends</td>
</tr>
<tr>
<td>Counsellors</td>
<td>Disabled persons organizations</td>
</tr>
<tr>
<td>Physiotherapists</td>
<td>and other interest organizations</td>
</tr>
<tr>
<td>Occupational therapists</td>
<td>Television</td>
</tr>
<tr>
<td>Psychologists</td>
<td>Radio</td>
</tr>
<tr>
<td>Students and others</td>
<td>Journals</td>
</tr>
<tr>
<td>Information brochures from the hospital</td>
<td>Books</td>
</tr>
<tr>
<td></td>
<td>Advertisements</td>
</tr>
<tr>
<td></td>
<td>Brochures</td>
</tr>
<tr>
<td></td>
<td>Pharmacy booklet</td>
</tr>
</tbody>
</table>

The content of the information the patient needs is shown in Fig. 4, together with the time during the hospital stay when various pieces of information ought to be given. A more complete description of the information content is shown in Fig. 5.

It is important that information concerning the disease and its consequences is planned and given some time before the day before discharge if the patient shall have any possibility to process the information and receive insight into his problems before he leaves the hospital (I). If this, for any reason, is not possible, planning for a return visit has to be made. The patient has to be told that more information shall be given at that appointment and perhaps he can use his discharge form (IV) to consider what further information is needed.

The system with medical ward rounds tempts to lead to disclosure of information at the bedside in the presence of other patients. For the protection of the patient's personal integrity, information, of course, shall be given privately.

Why the patient shall be given information

"Quality of life" is an expression which is widely used but difficult to define in precise terms. "Satisfaction with life", "subjective well-being", the "individual's possibilities to realize himself and influence his own situation" are other concepts used to elucidate "quality of life". For a healthy individual, many material and
immaterial factors influence his "quality of life". The fulfillment of
the United Nations Declaration of Human Rights is a basis for all
such discussions. Freedom to think and express your thoughts, freedom to
move where you want. The life in a family with appreciation and love,
and a life together with other people. Food, shelter, economic
freedom, possibilities for education and development and access to
social security or societal support when needed and thus, a sense of
confidence for yourself and your family. These are but a few factors
that could be mentioned in this context, just to enlighten the concept
of "quality of life".

Disease alters the conditions for life and it must be one of the aims of
medical and nursing care to restore the "quality of life". Knowledge/insight is the basis and the motivation for some processes and
factors which are aspects of "Quality of life".

"Struggle for life" in the Darwinian sense, is aimed at survival. For
the patient the expression can be used in the meaning of surviving as an
individual who feels that life has value and meaning, and who retains
dignity, self-respect and self-confidence.

Some consequences of disease can not be ameliorated -- the amputated leg
will never grow out again, the lost eyes will never be replaced, the
transsected spinal cord will not function any more. It is important for
the patient to realize such facts and to accept the inevitable,
otherwise it will not be possible for him to adapt to the situation and
to make use of all the possibilities that life, nevertheless, offers.

The hospital stay is a stressful period to most patients. Knowledge, not
only of his disease and its development but also of the hospital
procedures, examinations, what is expected etc, is a prerequisite for
the patient to develop and experience a sense of security, trust and
confidence. Thus, it may be possible to reduce the patient's fear and
anxiety. This is important, both for the hospital stay and after
discharge.

Each individual must be able to make his own decisions about his own
life which is the basis for an autonomy of living. A person, for whom
others made all decisions during a period of disease, may have
difficulties to recapture both his self-confidence and ability to make
his own decisions. An insight into his whole situation may help in the
rehabilitation process that aims at autonomy of living.

Sometimes, however, the patient does not have the competence to make his
own decisions. For the small child, the parents have to decide; for the
unconscious patient, a spouse or a guardian makes decisions etc.

According to the Swedish Health and Medical Services Act, information
shall provide a basis for autonomy on the patient's decisions pertaining
to living his own life.
Compliance with advice is closely connected to the patient's decisions about his own life. If the patient does not have knowledge of and insight into his condition, the risk is that he does not understand how important advice can be for his own existence and for his self-care. He can, for example, stop taking a medication that he needs or he can eat inappropriate food.

The discussion of why the patient needs information and how it is processed is summarized in Fig.8.
INFORMATION SHALL CORRECT MISTAKES AND ADD NEW KNOWLEDGE TO THAT WHICH THE PATIENT ALREADY HAS ABOUT HEALTH AND DISEASE

Fig. 8. How the patient receives and processes information and some reasons why information shall be given.
CONCLUSIONS

The main findings of the survey study and the interventions proposed for giving information to patients during hospital stay were as follows:

In the survey study (I):

- Patients reported their need for information as large, especially with regard to examination results and prognosis.
- Patients reported that their need for information on prognosis was the least adequately satisfied.
- The correlations found between the patients' background factors, informational need and informational adequacy did not explain the deficiencies in the information which the patient had retained.
- There was a lack of functioning routines for information giving on the three surveyed wards.

In the intervention studies (II, III, IV):

- The patients' subjective need for information was the same at the two periods.
- Systematic routines for information giving and follow-up of information by a mentor system brought about a general improvement of the patients' satisfaction with information.
- With the registered nurse as trained chairperson, the patients' need for social and psychological care was better elucidated during the MTC and the number of information problems reported were increased.
- The system for assessment and solution of the patients' information problems improved the patients' satisfaction with information.

The thesis further elucidated:

- The method of how information shall be given to the patients.
- The factors influencing the patient's processing of information.
- The content of the information.
- The question of where and when information should be given
- The question of why information should be given. Knowledge, and insight, is the basis and motivation for several processes and factors which are important aspects of "Quality of life".
REFERENCES


APPENDIX

HOW LARGE WAS YOUR NEED FOR INFORMATION DURING YOUR HOSPITAL STAY AT THE NEUROLOGICAL WARD?

1. How large was your need for information on the times for meals, rounds, pulse- and temperature measurements?  
   Very small: -3  -2  -1  +1  +2  +3

2. How large was your need for information on what your troubles may be due to and if you suffered from any disease?  
   Very small: -3  -2  -1  +1  +2  +3

3. How large was your need for information on whether symptoms would disappear or become worse in the future?  
   Very small: -3  -2  -1  +1  +2  +3

4. How large was your need for information on why the examinations needed to be carried out, on how one could have prepared oneself for them, and what the procedure was for the actual examination?  
   Very small: -3  -2  -1  +1  +2  +3

5. How large was your need for information on the findings of the examinations?  
   Very small: -3  -2  -1  +1  +2  +3

6. How large was your need for information at the medical examination on what the physician did and why he did it?  
   Very small: -3  -2  -1  +1  +2  +3

7. How large was your need for information on the ward facilities and the equipment? That is, the location of the smoking room, dining room, telephone cubicle, toilet, and how the bed, bedside table, radio, call bell and lighting functioned?  
   Very small: -3  -2  -1  +1  +2  +3
8. How large was your need for information on how you should take care of yourself after your discharge from the hospital? That is, if you shall be on sick-leave and if you need to come back for check-ups, then, if so, where and how often?

9. Did you get any new medication or was the old one changed during your stay at the neurological ward? If so, answer this question:

How large was your need for information on why the new medication was ordained or why the old one was changed, which side-effects the medication had and how you ought to take it?
HOW ADEQUATE WAS THE INFORMATION YOU GOT DURING YOUR STAY AT THE NEUROLOGICAL WARD?

<table>
<thead>
<tr>
<th>Question</th>
<th>Compl. inade.</th>
<th>Compl. adeq.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How adequate was the information on the times for meals, rounds, pulse- and temperature measurements?</td>
<td>-3 -2 -1 +1 +2 +3</td>
<td></td>
</tr>
<tr>
<td>2. How adequate was the information on what your troubles may be due to and if you suffered from any disease?</td>
<td>-3 -2 -1 +1 +2 +3</td>
<td></td>
</tr>
<tr>
<td>3. How adequate was the information on whether your symptoms would disappear or become worse in the future?</td>
<td>-3 -2 -1 +1 +2 +3</td>
<td></td>
</tr>
<tr>
<td>4. How adequate was the information on why the examinations needed to be carried out, on how one could have prepared oneself for them, and what the procedure was for the actual examination?</td>
<td>-3 -2 -1 +1 +2 +3</td>
<td></td>
</tr>
<tr>
<td>5. How adequate was the information of the findings on the examination?</td>
<td>-3 -2 -1 +1 +2 +3</td>
<td></td>
</tr>
<tr>
<td>6. How adequate was the information at the medical examination on what the physician did and why he did it?</td>
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8. How adequate was the information on how you should take care of yourself after your discharge from the hospital? That is, if you shall be on sick-leave and if you need to come back for check-ups and in that case, then, if so where and how often?

9. Did you get any new medication or was the old one changed during your stay at the neurological ward? If so, answer this question:

How adequate was the information on why the new medication was ordinated or why the old one was changed, which side-effects the medication had and how you ought to take it?
1. How important was it for you to speak with your fellow patients and to find out what they knew about illnesses, investigations and medicines?

- Very little importance
- Little importance
- Considerable importance
- Great importance

2. Who among the personnel did you find it easiest to discuss everyday matters with?

- Enrolled nurse
- Physician
- Nurse's aid
- Occupational therapist
- Registered nurse
- Physiotherapist
- Mentor

3. Do you think that the nurse's aid should give more information about investigations?

- No, no more
- Yes, some more
- Yes, much more

4. Do you think that the registered nurse should give more information on illnesses?

- No, no more
- Yes, some more
- Yes, some more

5. How often did you have to ask the personnel in order to get some information?

- Almost never
- Quite seldom
- Quite often
- Very often

6. How much importance were your mentors in enabling you to obtain the information you needed?

- Very little importance
- Little importance
- Considerable importance
- Great importance
Questions relating to the discharge form

The discharge form is the form on which the patient writes down the questions that they will put to the physician before they are discharged from the department of neurology.

7. Did you get answer to the questions that you had written on the discharge form?

☐ No, not at all
☐ Yes, partly
☐ Yes, completely

8. Of how much importance was the discharge form in aiding you to think about, and draw conclusions about, what information you needed?

☐ Very little importance
☐ Little importance
☐ Considerable importance
☐ Great importance
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