

INFORMED CONSENT
TO
MEDICAL TREATMENT

Processes, Practices and Beliefs

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INTRODUCTION

During the latter part of the 1980's the Law Reform Commission of Western Australia released Discussion Papers on some of the legal aspects and implications of medical treatment (Discussion Paper 77, *Medical Treatment for Minors*, 1988; Discussion Paper 84, *Medical Treatment for the Dying*, 1988; and Discussion Paper 65 Part II, *Confidentiality of Medical Records and Medical Research*, 1989). These Discussion Papers reviewed and considered the relevant legal provisions and law as these related to medical treatment for minors and the terminally ill, and examined the basis upon which the use of patients' medical records for the purposes of medical research is acceptable. One issue common to these papers is that of "consent". Subsequent to the commencement of this study, the Commission submitted Reports on *Medical Treatment for the Dying*, 1991 and *Confidentiality of Medical Records and Medical Research*, 1990.

As a result of the significance of consent to the matters being reviewed by the Law Reform Commission, in mid 1989 the Commission, in conjunction with the Western Australian Council for Social Service made an exploratory examination of the procedures and processes used to obtain consent from specific groups, for instance the terminally ill and minors. In conclusion the study recommended that further research on the processes by which consent to medical treatment is given be conducted. Accordingly the Commission made an application for a research grant from the Public Purposes Trust to investigate issues pertinent to informed consent to medical treatment.

During the past seven years, Australian courts have expressed, for the first time, opinions on cases dependent upon aspects of informed consent. To date, the High Court of Australia has not made a decision on informed consent, and consequently Australian analysis of the doctrine has been underscored by decisions made in the courts of Canada, the United States and the United Kingdom. The concept of informed consent emerged in Australia generally in the early 1980's, and since then, legal institutions such as the Victorian Law Reform Commission in conjunction with the Australian and New South Wales Law Reform Commissions have released Discussion Papers, which have explored aspects of informed consent and

recommended that the National Health and Medical Research Council outline guidelines for standards of disclosure.

Commentators on the doctrine of informed consent have noted that it springs from three main sources: moral, ethical, and legal. By 'moral' what is meant is the patient's right to determine his/her own destiny and what is done to his/her body. Notions of autonomy and self-determinism arise from such a perspective. By 'ethical' it is the fiduciary relationship between the patient and the medical practitioner that is under consideration. In this context, the doctor has a fiduciary duty or responsibility, as the person in a position of power, trust or confidence, to act in the interests of the other. By 'legal' the key issue is the contractual relationship between the patient and the medical practitioner. Not surprisingly, there is some tension between the three approaches as to what constitutes informed consent. Critiques on informed consent have explored both the tension inherent within each approach and the tension between the approaches. What remains at issue are the processes by which consent is acquired in a clinical situation and the factors that affect the interaction between the patient/parent and the physician. This has been the subject of considerable research completed by social scientists and health professionals. The emphasis in some of the empirical studies has been on determining the viability of the legal vision of informed consent.

This research study examines issues related to consent, such as the processes by which consent is obtained from the terminally ill, parents with infants born with an impairment or disability and parents with normal children. The Research Objectives are:

- 1) To critically appraise the findings of studies and surveys on procedures utilised to obtain informed consent to medical treatment. The analysis will focus on the decision making process by which consent is obtained from each target group.
- 2) To observe the processes by which patients/parents are given information about their complaint, treatment and treatment options. To determine if the decision is "informed". That is, does the patient/parent know and understand the details of the procedure, its potential side effects, risks and possible alternatives to the treatment recommended by the medical practitioner.

- 3) To identify who gives permission or consents to medical treatment in relation to each target group.
- 4) To appraise the attitudes of medical practitioners, health care workers and patients with regard to the provision of sufficient information upon the basis of which a patient can make a decision.

The study is divided into two parts. Part I commences with a brief summary of the components of informed consent, which are largely derived from court decisions. In describing the components, attention is paid to the relevance and applicability of the major components of informed consent to the terminally ill, minors and parents who render a treatment decision for their child. The second chapter critically reviews major studies and surveys conducted to ascertain how consent is obtained in a clinical situation. The findings of surveys are scrutinised in order to determine how informed consent operates in various clinical situations. Some of the issues which are pertinent to the processes by which consent is sought are explored. Studies which have been conducted in Australia, Canada, United States and United Kingdom are analysed.

The second part details the research findings of the empirical study conducted on consent to medical treatment in four hospitals in Western Australia. It begins with the methodology used to survey patients, physicians and nurses in terms of the details of the sample, procedure and research instruments. Analysis of the data is presented in subsequent chapters on a thematic basis. Chapter Four focuses on the procedures and processes by which consent to treatment is obtained. In Chapter Five the attitudes of physicians, nurses and patients to the disclosure of information pertinent to treatment is delineated. Chapters Six, Seven and Eight deal with issues relevant to the terminally ill, parents who seek to withhold or withdraw treatment for their seriously impaired children, and minors respectively. In Chapter Nine the ideologies or unspoken assumptions and beliefs that affect the dialogue between patients and physicians are briefly appraised. A critique and conclusions from the research study are given in Chapter 10.

The research study in effect gives "snapshot views" of various stages in consent processes as these occur in clinical situations. It offers a glimpse of the dynamic interaction between patients and physicians, and explores the critical elements of that exchange.

PART I
INFORMED CONSENT

THEORETICAL FRAMEWORKS
AND
EMPIRICAL STUDIES

CHAPTER I

COMPONENTS OF INFORMED CONSENT

INTRODUCTION

Historically, the modern doctrine of informed consent with its emphasis on patient participation in the decision-making process emerged in a social and political climate which attached considerable significance to notions of autonomy. Other factors, such as the complexity of procedures required for both diagnosis and treatment, contributed to the belief that patients should be involved in decisions that affect them. This Part provides a brief overview of the interrelated factors that underpin the doctrine of informed consent, before proceeding to examine how the concept of autonomy relates to consent to medical treatment.

Until about the time of World War II, patients had little need for extensive explanation of the risks and benefits of the proposed medical treatment. Judged by today's standards, medical therapies were relatively straightforward, and the risks were generally apparent to anyone (Mariner 1988:391). Submission to treatment justifiably implied an understanding of the procedure, and willingness to undergo it. Resort to the law was confined to the most egregious cases in which the physicians visibly harmed the patient by doing something that the patient clearly did not desire or foresee - for instance the amputation of the wrong leg.

The growing complexity of post-war medical technology meant that neither the risks of the proposed treatment nor alternatives to it were obvious to the laity. At the same time, rapid changes in medical technology dislocated the traditional medical world. When the practice of medicine was dominated by the general practitioner with firm roots in the community, the physician managed his patients with largely authoritarian control. The doctor's practice was based, however, on his direct knowledge of the patient as a person living within the context of family and neighbourhood. This knowledge can be seen to have tempered the physician's authoritarianism by giving him the opportunity to make personalised, though technical, decisions for, or with, his patients (Faden and Beauchamp 1986:60-90).

Further, the fact that medical procedures could harm as well as heal crumbled the foundations of traditional notions of "simple consent". In the United States, this combined with post-war revelations of shocking domestic medical experiments and medical genocide in Europe and the rebirth of organised reform movements in the early 1960's led to the emergence of the modern doctrine of informed consent. Hence, at its inception, the doctrine was premised on notions of autonomy and self-determination.

Since then the demystification of medical art, evident in television series, the popular press and the more sophisticated journals has enabled the general population, or at least a substantial portion of it, to become more aware of the various functions of the human body.

The doctrine of informed consent embodies the general principle that a person has a right to determine whether or not to undergo any medical procedure. The classic statement of the common law premise is that of Judge Cardozo in *Schloendorff v. Society of New York Hospital*:

"Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable for damages" [(1914) 105 NE 92, 93].

The right to informed consent means that every patient for whom any therapeutic or diagnostic procedure or procedures is proposed must be given all pertinent and material information about the medical situation, and that care and management cannot be started unless and until the patient has received such information and given consent to the procedures planned.

In a medical context, the doctrine of informed consent is generally perceived to be the guardian of individualism (Meisal 1979:414). Individualism comprises related issues and values, and refers to such interests as bodily integrity, psychic integrity, self-determination, dignity, autonomy and privacy. Meisal states that informed consent:

"Protects the patient's right to determine his/her destiny in medical matters; it guards against overreaching on the part of the physician; it protects his physical and psychic

integrity and thus his privacy; and it compensates him both for affronts to his dignity and for the untoward consequences of medical care" (Meisal 1979:414-415).

Informed choice may be seen as an aspect of free choice, since in the absence of material information a person cannot act responsibly or independently. The disclosure of material pertinent to the medical decision-making process is at the heart of informed consent. A patient whose consent is not sought may be denied the opportunity to participate in making decisions about the proposed treatment.

COMPONENTS OF INFORMED CONSENT

Generally it is held that the doctrine of informed consent is comprised of several components. The Law Reform Commission of Western Australia in its Discussion Papers on *Medical Treatment for the Dying* (1989) and *Medical Treatment for Minors* (1988) delineated briefly the major components of informed consent. The following summary is derived from these Discussion Papers, and those Papers published by the Law Reform Commission of Victoria (1987) on informed consent.

The components of informed consent are as follows:

Information or Disclosure

Certain information must be provided by the physician to the patient. Patients in general are presumed to know certain information; a particular patient, on the basis of personal experience, may be presumed to know additional information.

Competency

There is a legal presumption that patients have the capacity to comprehend the information that the doctor discloses. Exactly how competency is determined is somewhat unclear, but if a patient is not competent, then any decision made by him/her will not be considered legal.

Understanding

Judicial decisions implicitly assume that a person who is competent, when provided with information, will understand it. Since competency involves the capacity to understand, competency and understanding are closely related components of informed consent.

Voluntariness

The decision that a patient makes must be freely arrived at without pressure or coercion.

Decision

The patient must actually decide whether to accept or refuse treatment (LRCV:1987).

Hence, in theory at least, the doctrine of informed consent has transformed the medical decision making process from a "consensual" one in which the doctor proposes and the patient assents, to a "participatory" one in which the patient plays, or is permitted to play, a far more active role - considering information, weighing the alternatives, and balancing risks against benefits.

STANDARDS AND SCOPE OF DISCLOSURE

One of the critical issues still being debated about informed consent concerns the scope of disclosure required of physicians. If the medical profession were to face potential liability for deficiencies in this area, notions of fairness demand that their responsibilities be outlined with some clarity. On the one hand, procedures can be described in varying degrees of detail and complexity, and risks concomitant with treatment are numerous. In surgery, for instance, every procedure carries the risk of a number of complications, up to and including death. Most medications used today can cause dozens of side effects, although many of these are relatively uncommon. On the other hand, "complete disclosure", even if theoretically possible, would be extraordinarily time consuming, and may end up with patients being more confused than they were prior to disclosure.

The approach of the courts has been to establish standards of disclosure, which for the most part has emphasised the need for the patient to be given enough information to make an intelligent decision about the proposed medical treatment. This standard is underscored by the notion of self-determination, and is best articulated in *Canterbury v Spence*:

"The patient's right of self decision shapes the boundaries of the duty to reveal. The right can be effectively exercised only if the patient possesses enough information to make an intelligent choice. The scope of the physician's communication to the patient, then, must be measured by the patient's need and that need is the information material to the decision. The law must itself set the standard for adequate disclosure. The scope of the standard is not subjective to either the physician or the patient" [464 F 2d 772 (DC Cir 1972)].

The duty of disclosure has generally been described as the obligation to reveal to the patient the following:

- 1) The nature of the recommended therapy;
- 2) The expected benefits;
- 3) Any serious risks or side effects of that therapy;
- 4) Alternatives to that therapy. (including no, therapy at all), and their benefits and risks;
- 5) Any additional information that physicians would disclose in similar circumstances as a matter of good medical practice.

In stating the scope of the physician's duty to disclose information to a patient, Australian judges have applied a dual standard. In essence, the judicial stance has been to state that a doctor must provide information that a reasonable doctor would give a *reasonable* patient. The reasonable doctor standard can be expressed in several ways. The Victorian Law Reform Commission in its Discussion Paper on Informed Consent used the following definition:

"A doctor must explain what he intends to do, and its implications, in a way a careful and responsible doctor in similar circumstances would have done. If the doctor is a specialist, the standard is 'that to be expected of an ordinarily careful and competent practitioner of the class to which the practitioner belongs....A doctor is negligent if the doctor does not provide information and advice to a patient that accords with the 'practice existing in the medical profession' (LRCV:1987:8).

In determining what matter a reasonable doctor should consider in deciding what information to give the patient, standards can be derived from Australian cases which have dealt with the issue of informed consent.

"The personality and temperament of the patient and the patient's attitude" [*F v R*, (1983) 33 SASR 189, 206 (Bollen J)].

"...the patient's level of understanding. A doctor need not "cross-examine his patient exhaustively to ensure that she both understands and will remember his advice" but should give information that he thinks that the patient will understand after a fair appraisal of the patient's intelligence and temperament and apparent understanding, made in the light of the simplicity and complexity of the recommendation that he is making" [*Gover v South Australia and Perriam* (1985) 39 SASR 543, 558 (Cox J)].

The duty of disclosure, in effect, involves balancing clinical judgement and self determination.

EXCEPTIONS TO DISCLOSURE

As the doctrine of informed consent has evolved, the courts and commentators have recognised that some circumstances mitigate against a strict application of the doctrine. The duty of the physician to disclose information is mitigated by the patient's right of waiver, therapeutic privilege, incompetence and emergency. The first three of these exceptions are considered in some detail since each pertains to the development of a model of informed consent for minors, defective neonates and the terminally ill.

i) Emergency

In situations in which there is insufficient time to obtain the patient's consent, or the patient is physically incapacitated from giving consent, it is accepted that the physician will initiate appropriate medical treatment without consent.

ii) Therapeutic Privilege

It is well established in both case law and commentary that the physician may, in appropriate circumstances, be excused from compliance with the requirements of informed consent by "therapeutic privilege". This allows the physician to withhold information that he/she would otherwise be obliged to disclose if disclosure would be harmful. For instance, the doctor may

on the basis of his/her knowledge of the personality of a particular patient believe that the degree of information required by the doctrine of informed consent would severely upset the patient, and may even prompt the patient to unreasonably refuse needed surgical or medical treatment, which a reasonable person would not refuse after evaluating the risks. The physician is thus justified in withholding information.

Lord Scarman in *Sidaway* defined the scope of therapeutic privilege as follows:

"This exception enables a doctor to withhold from his patient information as to risk if it can be shown that a reasonable medical assessment of the patient would have indicated to the doctor that disclosure would have posed a serious threat ...of physiological detriment to the patient." (*Sidaway v Bethlem Royal Hospital Governors* [1984] 1 All ER 1018).

The judgement of King CJ in *F v R* indicates the extent to which doctors are, from the legal perspective, allowed to censor or withhold information:

"Even where all other considerations indicate full disclosure of risks, a doctor is justified in withholding information [when] the patient's health, physical or mental, might be seriously harmed by the information. Justification may also exist for not imparting information when the doctor reasonably judges that a patient's temperament or emotional state is such that he would be unable to make the information a basis for a rational decision" [*F v R* (1983) 33 SASR 189].

By and large, the scope of therapeutic privilege is not severely circumscribed, and its critics have argued that it threatens to swallow the general obligation of disclosure, thereby depriving the patient of all decisional autonomy (Faden and Beauchamp 1986).

iii) Right of Waiver

Waiver of the right of informed consent accepts that the patient can inform the physician that he or she desires treatment to proceed without the disclosure that would be normally required.

iv) Competency

Numerous critiques of informed consent have noted that the nearly exclusive focus on issues related to disclosure has deflected attention from other equally important aspects of informed

consent (Appelbaum 1985; Meisal 1979). The question of competency to provide consent is one of these aspects.

In practice, the physician attending the patient can decide that the patient would be adversely affected by a full disclosure of the proposed treatment, its risks and possible alternatives, and thereby not provide the information required by the doctrine of informed consent. In *Gover v State of South Australia and Perriam*, the physician Dr Perriam in defending his decision to not fully inform the patient stated that the patient was "very nervous and upset and not the sort of patient that would lightly take the description of all kinds of possible, but rare, complications".

Similarly, in *F v R*, it was held that the doctor was not negligent in not providing the patient with information about potential side effects and alternative procedures because the "mental and emotional condition as understood by the doctor...placed the doctor in the position of having to make the decision for her... First, if she had known of the risk, that might have caused 'hysterical blindness'". In effect the courts have affirmed that doctors can ascertain if their patients are capable of participating in the decision making process, without resort to any criteria designed to establish competency.

At the same time, from a legal perspective, several tests for competency have been proposed. Competency can be ascertained when the patient demonstrates one or more of the following:

- 1) "Evidence of choice
- 2) Reasonable outcome of choice
- 3) Choice based on "rational" reasons
- 4) Ability to understand
- 5) Actual Understanding" (Roth et al. 1977:279; Ott 1989:439-441).

Such a definition of competency has substantial implications in relation to medical treatment for minors, who may be sufficiently competent to make a decision, and for parents who are giving proxy consent for their child or seriously impaired infant.

With regard to minors it has been generally assumed that ill children are often distressed, dependent and immature, and their limited competence is further compromised by their illness.

Such vulnerable patients would therefore appear to lack the autonomy and competency characteristic of adult patients, and consequently are excluded from the consent process. Of late, however, various researchers who are particularly concerned with issues relating to the ability of children to give consent to medical treatment, have questioned the validity of such a narrow definition of competency.

Anderson argues that the ideal of reason or rationality discriminates against minors in several ways (1990:54-65). It encourages a black and white view, wherein a person is either capable or not capable of "reason". As Anderson notes, this view supports unrealistic attitudes that people suddenly become rational on their sixteenth or eighteenth birthday. Narrow interpretations of autonomy, while embodying ideals of respect for patients' safety and dignity, place too much emphasis on "reason", and tend to define harm and benefit through adult perceptions and values. This discriminates against children because it assumes that they cannot rise above emotions and contingencies to make a choice. It is further questionable if adults make rational calculations about medical treatment. According to Anderson, adults like children "make choices for one overwhelming reason - to gain freedom from chronic pain or disability, to be able to look 'normal', or to give up a seemingly hopeless struggle to survive" (1990:55). Nonetheless, the law allows adult patients, unlike minors, to make decisions which are respected.

In challenging the validity of competency as a criteria for making informed consent, Anderson cogently argues that a more relevant framework be used to allow minors to participate in the decision making process.

vi) Understanding

The understanding of disclosed material by patients and research subjects has probably been the subject of most investigation. All that the criterion of understanding requires is that the patient manifests sufficient ability to understand information about treatment, even if the patient weighs the information differently from the attending physician. Decision-making need not be rational in either process or outcome: unwise choices are permitted.

For the most part, court decisions have not focused on the issue of understanding. Attention has been principally focused on whether the patient was informed of the procedure and its attendant risks. Importantly, there is no onus on the physician to ascertain if the patient actually understands the material which has been disclosed.

vii) Voluntariness

In giving consent to treatment, patients must be free of coercion. Relatively little has been written about voluntariness because it is difficult to conceptualise and measure. While the matter is relatively simple for competent patients who voluntarily see a physician and make a decision about treatment themselves, it is slightly more complex when proxy consent is given by a parent or guardian for a minor child. Legal practitioners and researchers have on the whole focused on voluntariness as it relates to incompetent (mental) patients and prisoners. Again, voluntariness is an important aspect of consent with regard to minors.

DISCUSSION

These components of consent underscore the process by which consent is obtained for medical treatment. Components such as understanding and competency play a significant role in relation to the terminally ill, minors and defective neonates. The study utilises these aspects in its survey to determine the nature by which patients or parents/guardians give consent to medical treatment. Lastly, these components of informed consent have been observed and analysed in numerous empirical studies, which are reviewed in the next chapter.

This brief appraisal of the components characteristic of informed consent does not consider the ethical implications of informed consent. Rather, the summary is an elaboration of the legal aspects pertinent to informed consent.

CHAPTER II

REVIEW OF EMPIRICAL STUDIES

INTRODUCTION

Empirical studies of informed consent or some aspect of the decision-making process by which consent is obtained have proliferated over the past thirty years. While numerous surveys have been conducted in the United States, United Kingdom and Canada on aspects of the doctrine such as patient understanding of information disclosed to them, and the manner in which consent is obtained, as yet relatively few have been conducted in Australia. The most comprehensive survey completed in Australia is that by the Law Reform Commission of Victoria. This examined both doctors' and patients' general attitudes to the doctrine of informed consent.

The purpose of critically appraising the findings of major studies is twofold: firstly, to ascertain if it is possible to transpose the legal vision of informed consent to a clinical situation, and if so, what conditions and factors are critical to the operation of informed consent; and secondly, to scrutinise the methodological and conceptual approaches adopted in the surveys.

The various empirical studies can be viewed from broad perspectives, which are convenient for the purposes of general discussion. Many of the studies envisage the process of informed consent as mainly occurring between the patient (or in some cases the parent/guardian) and the physician. However, whereas some studies focus primarily on patient's roles and decisions, others pay greater attention to the attitudes and practices of physicians. A third category of studies emphasises the interaction between the various key participants. Typically, these latter studies incline towards an analysis of the barriers to informed consent, wherever these occur.

Derived from these observations of differing methodological emphasis is a classificatory typology, which will be used to consider the literature. Hence, the studies will be organised under the following headings:

- i) Patient or Parent/Guardian Oriented Studies
- ii) Physician Oriented Studies
- iii) Studies of Barriers to Informed Consent

Below is a brief elaboration of the typology used to critically appraise the empirical studies.

i) Patient or Parent/Guardian Oriented Studies

These empirical studies focus on the patient's capacity to render an informed decision about medical treatment. (For instance, Weithorn & Campbell, *The Competency of Children and Adolescents to make Informed Treatment Decisions* [1982] & McCarthy et al., *Mothers' clinical judgement: A randomized trial of the Acute Illness Observation Scales* [1990].) Included in this category are studies about patients' attitudes regarding medicine and medical treatment generally. (For instance, Steven & Douglas, *Dissatisfaction in general practice: what do patients really want?* [1988], and Hunt et al., *Views of what's wrong: Diagnosis and Patients' concepts of illness* [1989].)

ii) Physician Oriented Studies

A range of studies that focus on the attitudes and practices of physicians with respect to difficult ethical choices confronting them in medical practice has also been conducted. (For instance, Shaw et al., *Ethical Issues in Paediatric Surgery: A National Survey of Paediatricians and Paediatric Surgeons* [1977].) Others, such as the survey conducted by the Law Reform Commission of Victoria (LRCV) have sought to determine doctors' attitudes in relation to giving information to patients and patients' ability to comprehend and retain the information given (1987). With regard to doctors' attitudes and practices, Kuhse and Singer concentrated on doctors' attitudes with respect to requests for active help in dying from patients who were suffering from a terminal or incurable disease (1989:623).

iii) Studies of Barriers to Informed Consent

An increasing number of surveys have conceded that there are major impediments to the operation of informed consent in clinical situations. In this context, researchers and medical practitioners have assessed physicians interacting with the patient both in a hospital and in clinics (Harrigan et al. *It's how you say it: Physicians' Vocal Behaviour* [1989]), as well as

physicians' interpretations and response to patients' implicit and explicit messages (Robins & Wolf, *Confrontation and Politeness Strategies in Physician-Patient Interaction* [1988]).

These categories are used in this Paper primarily to discuss themes evident in the literature. It is noted that all the studies do not fall necessarily within one analytic classification only. Where they are complex, the studies will be considered under multiple headings. The findings of general surveys will be reviewed, and then studies that specifically relate to the terminally ill, minors and defective neonates will be examined.

PATIENT AND PARENT/GUARDIAN ORIENTED STUDIES

One of the most interesting findings evident in a range of studies is that patients want information about their ailments, proposed treatment and potential side-effects. In the patient survey conducted by the LRCV, patients indicated in their response to both the open-ended question (80%) and structured question that they want and expect to receive information (88%) (LRCV 1987:26). This study was based on a sample selection comprising 396 patients, of whom 28% were from Citizens Advice Bureaux, 50% from community organisations, and 22% from health groups, such as cancer support and patient self-help groups. The sample is skewed to older age cohorts, who are slightly more educated than the general Victorian population. In terms of methodology, a researcher met with each group, who were then asked to complete a questionnaire regarding their experiences with doctors. Upon completion of the questionnaires, approximately an hour of discussion ensued.

Despite biases intrinsic to the sampling and the method, the finding that patients want information is consistent with the conclusions of other studies. The *Report of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research* (1982) which examined the decision making process in a clinical situation, also shows that patients want full disclosure. The President's Commission concentrated specifically on critical components of the doctrine of informed consent including the question of how much information patients want, and conducted a survey of 805 physicians and 1,252 adults in order to determine their attitudes and experiences regarding the disclosure of information (1982 [Vol 2]:36-40).

The findings of the President's Commission show that 94% of respondents wanted their doctor to tell them everything about their condition, even if it was unfavourable (1982 [Vol 2]:136). Physicians recognised that patients are desirous of information. When asked "How many patients who come to you for treatment want you to give them a candid assessment of their diagnosis and prognosis, even if it is unfavourable?", 86% of physicians stated that all or most of their patients want to know the truth. At the same time, more detailed surveys of patients' attitudes towards their participation in decision making show that certain subgroups of patients may have a greater desire for participation than others. For instance, older patients and those who frequently visit the physician or who have had lengthy hospital stays, were found to have a lessened desire to participate, while those who had their family physician for less than one year scored above average in patient involvement in decision making (Meisal & Roth 1983: 126).

The significance of these findings has been modified by other studies which examine issues such as patients' perception of their own abilities to understand what information is provided by the physician, patients' recall of information and patients' behaviour in clinical situations. In relation to the general issue of understanding, when asked "When doctors give you information do you understand what is said?" 66.2% of respondents in the survey conducted by the LRCV said that they "usually" did. Yet, when asked "When doctors give you information do you find it difficult to recall what was said after you left?" only 24.7% said "never" and the greater proportion, 61.4%, said "sometimes" (LRCV 1987:72).

Robinson and Merav, in an effort to determine how much patients actually understand, made audio tape recordings of discussions they had with twenty patients, one to two days pre-operatively. Four to six months subsequently, the patients were re-interviewed, and the conversations recorded. The investigators found that "even with the influence of suggestion and a point-by-point review of every item covered in the original interview, patients could remember only 42 percent of the items that had been covered in the informed consent interview", and each of the 20 patients failed to recall major parts of the interview. The investigators concluded that the patients had "generally poor retention in all categories of informed consent information" (Meisal & Roth 1983:293).

Other studies have focussed on the patients' ability to understand one or more specific elements of informed consent, rather than just determining if the patient understood the information provided by the physician. However, findings on such issues are inconclusive. On the one hand, Morrow et al.'s study of patients in a radiation oncology clinic demonstrated that the patients had good understanding of procedures, purposes, discomforts and risks, but they scored low on knowledge of alternatives and diagnosis (Meisal and Roth 1983:328-45). On the other hand, Gray's study reported that 41% of research subjects interviewed knew "nothing" about risks of the procedures to which they had consented, and many more believed that no risks were present (Meisal and Roth 1983:332).

Similarly, Boreham and Gibson investigated the informative elements of doctor-patient interaction (1978:409-416). The research methods employed in this study provided for an examination of both patients' views and expectations about the provision of information concerning their illness, as well as their behaviour towards seeking such information during the actual consultation. In particular, the study was concerned with the extent to which information was provided in response to active requests from patients or whether it was largely determined by what the doctor chose to proffer.

The sample comprised eighty female patients who were interviewed at four different surgeries. An interview schedule was administered to each patient prior to consultation and a researcher observed the subsequent consultation between the patient and the doctor. Data was also collected by administering a brief questionnaire to the four participating doctors, and reports detailing the nature of the patient's illness were provided by the consulting doctor in each case (Boreham & Gibson 1978:411). The researchers' examination of the communication of information revealed considerable discrepancies between patient's expectations and their subsequent behaviour. The interview data indicated that, in general, both follow-up patients and primary consultation patients exhibited what the researchers considered to be a basic lack of information concerning their illness. This was despite the fact that the majority of patients themselves attached considerable importance to gaining this type of information.

The main thrust of the study's findings supports what might be viewed as a traditional model of doctor-patient interaction - one in which the dominant role of the doctor is complemented

by the passive role of the patient. The data collected shows that patient's behaviour in terms of lack of activity was not encouraged through the use of interpersonal tactics by the physician. While, the overall picture is one where the doctor is clearly the principal determiner of the information that the patient receives, this does not occur because the doctor refuses to answer requests for information, but rather because such requests are rarely made. The study shows that 23 questions were asked by the 34 patients presenting for a primary consultation, and 33 questions by the 46 follow-up patients. While these results may indicate that patients were somewhat more active in seeking information about their treatment than about diagnosis, it must be noted that 7 questions in the primary consultation and 22 questions in the "follow-up" all fell under the category of "name of drug" (Boreham & Gibson 1978:413). Thus, it appears that only a relatively small proportion of patients actually request further information about their condition and treatment.

The study supports conclusions reached by other studies which indicate that patients tended to think that questioning doctors implied a lack of confidence in doctors' judgements. The data reveals a high degree of overlap between doctors' and patients' views on what constituted "good" and "bad" patients, and that the ideal of both physicians and patients was the co-operative acquiescent patient who played an essentially deferential role.

Hence, empirical studies about patient attitudes and behaviour suggest that the likelihood of patients giving informed consent to medical treatment is minimal. Such barriers are likely to be compounded when the patient is suffering from a terminal illness, and especially when parents are required to make a treatment decision regarding their infant within tight time constraints. These issues are now reviewed in more detail.

Treatment Decisions for Infants

With regard to understanding information and making treatment decisions, Pinch and Spielman made a systematic examination of treatment decisions from the parents' perspective for the high risk neonate in the intensive care nursery. In relation to defective neonates, ethical dilemmas revolve around quality of life decisions. The advanced technologies available to sustain life in the neonate can dictate or determine the protocol of care. The decisions to use

these technologies are compounded by concern for the dependent nature of the infant, the cost of care, the time framework necessary to attempt a particular therapy, and the effect of care.

As Pinch and Spielman state, the actual role of parents in ethical decision making is under-represented in literature about health care and decision-making processes. Health professionals and others have tended to write about "parental participation in the ethical dimension of high-risk newborn care, rather than to report on dialogue with parents" (1990:713). Pinch and Spielman therefore sought to systematically describe the perception of ethical decision making by families with an infant in the neonatal care unit.

The sample comprised 32 families of newborns in a Level III neonatal intensive care unit (NICU), who were all interviewed prior to the infant's discharge. The sample included all mothers, two grandmothers (who had primary care giving responsibilities) and 21 fathers, who were interviewed over a period of twelve months. A semi-structured interview guide was used to probe the circumstances and decision-making of respondents, in order to explore sources of conflict, events that the parents experienced, and their thoughts and feelings about these issues relative to the moral dimension of their situation.

Overall, the study concluded that patients adopted a passive role in decision making responsibility, even in relation to the ethical dimension of new-born care. The researchers stress that "it is important to note that this was an acceptable situation for most of them" (1990:715). Parents and primary care givers cited the presence of stress, lack of comprehension of the technological details or a capitulation to the health professionals' expertise as a rationale for their diminished responsibility. Many of the mothers mentioned their physical and mental status as limiting their ability to concentrate or make rational choices. Clearly, the context in which permission for a procedure and discussion about treatment options is sought affects the participation of parents and patients in treatment decisions. What is particularly illuminating about this study is that parents, when specifically asked about their role in treatment decisions for the neonate, stated that "there was no decision-making required or that they were not involved in the process of decision-making in the majority of the situations" (1990:715).

Nonetheless, respondents were very aware of the need to sign informed consent forms in order for their child to receive treatment, but Pinch and Spielman state that parents discussed this "as a perfunctory permission-granting activity for them" (1990:715). For parents, this did not involve conflict nor did it pose a dilemma under most circumstances. They articulated the view that if the health professionals needed to implement a procedure, then "it should be done" (1990:715). In all there were few negative feelings shared relative to decision making and its ethical dimensions, but rather in the majority of families, acceptance and gratitude their perception of the situation.

Respondents, when asked to list concerns related to the infant for discussion, chose nutrition, cleanliness and sleep. The focus parents preferred appeared to be the domain of normal newborn care, not the technical aspects of high risk care that is generally provided in Phase III nurseries. Treatment decision-making encompassing such issues as the viability of extremely low birth weight infants, iatrogenic effects of antibiotics, oxygen and ventilators, the need for multiple invasive procedures and pain experienced by the neonate are only some of the ethical concerns apparent in the literature about care for defective neonates. Yet the content of decision-making for families of neonates in this study did not generally include these concerns. As the authors note "it certainly was not a priority item in any case and it clearly did not encompass moral conflict. It was striking by its absence yet the decision-making in these areas was critical in terms of the infant's status and prognosis" (1990:716).

Treatment Decisions for Minors

In relation to proxy consent, wherein parents give consent for their minor or incompetent child, little work in terms of empirical studies has been conducted. Throughout most of recent history, the rights of children have been either denied, ignored or subsumed by economic or filial duties. Under English common law, fathers exercised the utmost authority over their legitimate minor children. In the present century, awareness has increased that children have special needs, and must be extended certain rights if they are to be afforded an opportunity for development. While the community at large remains polarised over the issue, the use of courts to resolve conflicts between the rights of competent minor children and their parents attests to its growing controversy. Before proceeding, it is worth noting that much of the controversy about minors and their rights in relation to medical treatment revolves around sexuality: the

use of contraception, information on, and access to, abortion. Such controversy is in part explicable by the attitudes different groups express about the acquisition of rights by children.

The capacity of minors to give intelligent, if not informed, consent is being increasingly debated. For example, a study conducted by Suran and Lavinge compared the attitudes of parents and health care professionals towards a bill of rights for children in paediatric settings. The sample comprised 64 parents, 33 attending physicians, 27 nurses, 35 non-medical professionals and 18 administrators. Respondents were asked about their attitudes toward a locally developed ombudsman committee's bill of rights, and a bill of rights produced by the National Association of Children's Hospitals and Related Institutions [NACHRI] (Suran and Lavinge 1977:715-720).

In general the local bill of rights elicited significantly higher levels of agreement. This, however, is possibly because the local bill contained no references to abortion or contraceptive devices. Moreover, the NACHRI bill is uncompromising in asserting that these rights are to be extended to everyone, irrespective of age. The study also shows significant group differences. First, while their overall attitudes were favourable, physicians tended to have the least favourable attitudes towards the rights of children in paediatric settings. For instance, physicians registered more than 15% disagreement on the right of children to consent to their own care, regardless of age, if the individual was of sufficient intelligence (Suran & Lavinge 1977:719).

Further, the proposed rights with which physicians were least likely to agree varied widely in content. Items included the patient's and parents' right to timely access to competent health care; their right to the names and positions of everyone giving direct care; their right to be informed about significant alternatives to the treatment proposed; and their right to privacy and to request the removal of observers (Suran & Lavinge 1977:718). In addition, nurses were the least likely to agree that minor patients have a right to confidentiality in written communications. Not surprisingly, the pattern of responses indicates that the greatest opposition is related to any proposition that advocates free access to contraceptive devices and abortion.

While parents/ guardians and health care professionals, together with the general community, remain undecided about the rights of minors with regard to medical care, little attention has been paid to the capacity of minors to render informed decisions. In this context, Weithorn and Campbell conducted a study to ascertain developmental differences in competency to make informed decisions (1982:1589-1598). Ninety-six subjects (12 males and 12 females) at each of 4 age levels (9, 14, 18 and 21) were administered a test developed to assess competency according to 4 legal standards.

The test of competency to render informed treatment decisions consisted of: (a) a series of four hypothetical dilemmas; (b) an interview schedule detailing questions and probes for each dilemma; and (c) a scoring system designed to rate respondents' responses according to each of the four tests of competency. Further, alternative forms of dilemmas were developed for minor and adult respondents, and the terminology chosen was commensurate with age level. The researcher interviewed each subject, and interviews were audio-taped.

In general, the study shows that minors aged 14 demonstrated a level of competence equivalent to that of adults, according to "evidence of choice, reasonable outcome, rational reasons and understanding" with regard to the dilemmas of diabetes, epilepsy, depression and enuresis (1982:1595). Younger minors aged 9, however, appeared less competent according to standards of competency requiring understanding and a rational, reasonable process. Yet as Weithorn and Campbell note, "according to the standards of evidence of choice and reasonable outcome, these minors appeared competent" (1982:1956). Their focus upon sensible and important reasons suggests that they are capable of important involvement in personal health care decision-making, even if their developing competencies are not sufficiently matured to justify autonomous decision-making.

Overall the findings of this research do not lend support to policies which deny adolescents the right to self determination in treatment situations, on the presumption of incapacity to give informed consent. The ages of 16 or 18 as the benchmarks below which adolescents are seen to be incompetent to make decisions about their welfare do not reflect the psychological capacities of most adolescents. The study indicates that if age is used to determine competency, then it may be appropriate to use an age, such as 14, which more truly reflects a

standard of competency comparable to that of adults. Further, Weithorn and Campbell's study suggests that minors' understanding of treatment options, side effects etc. could vary depending on the way information is presented.

The last study of particular interest is that conducted by Goldman and Goldman, who sought to explore "children's sexual thinking"; "their sexual understanding at various ages, and to identify what processes of thought they use in trying to explain biological function" (1982:57-58). Goldman and Goldman interviewed 838 children in four countries - Britain, USA, Sweden and Australia. What is striking about their findings is that by and large Swedish children had far greater knowledge of contraception and abortion and were capable of making treatment choices about them. A comparison of their knowledge of contraception with Australian minors is illuminating. All Swedish children aged 9 or over had knowledge of contraception; no Australian child under 11 indicated that they were aware that contraceptive devices were available for men and women. 73% of Swedish boys and 40% of girls at 11 knew of contraceptive devices; whereas 5% of Australian minors had this knowledge. In Sweden at 13, 100% of males and 93% of girls knew; in Australia, at 13, 40% of males and 5% of females knew. At 15, 75% of males and 50% of Australian females knew of the availability of contraceptive devices (1982:274-280).

The results of the Australian and Swedish samples viewed together do not reflect the lack of cognitive capacity of minors under 16, but rather the effect of a basic lack of information. Sweden, after all, has an extensive sex education program in schools; and sex education and personal relationships are compulsory courses for 7 to 16 year olds. These findings substantiate the conclusions reached by comparable communication studies which indicate that minors are capable of understanding how their body functions and making a decision which affects bodily functions. The minor's ability to give consent is confirmed, but the onus remains on the health professional to ensure that the information is presented in a manner which facilitates or ensures understanding.

Treatment Decisions and the Terminally Ill

This section examines the process by which the terminally ill give consent to medical treatment. Numerous studies have focused on the attitudes of the general public and the

terminally ill patient to giving consent to the withdrawal of treatment. The study conducted by the United States President's Commission notes that over the past few decades there has been a shift in attitudes endorsing the right of terminally ill patients to have their life ended. The survey conducted by Harris in 1976 for the President's Commission found that 62% of the general public felt that terminally ill patients had the right to forego life-sustaining treatment. By 1981, a greater proportion of the general public (78%) shared such views (1982 [Vol. 2]:18-40).

In the survey conducted by the President's Commission, respondents were asked if they would like to make the final decision about withdrawal of treatment or whether they would prefer that their physician make the decision. Of respondents 43% felt that they, and not their physician, should be responsible for final choices about medical treatment. Further, when asked whether they would want a physician to inform them if they had cancer, virtually all respondents (96%) wanted to be told their diagnosis. Respondents (85%) also wanted to be given a realistic estimate of their remaining life-span (1982 [Vol. 2]:221-238). However, while the survey conducted by the President's Commission shows that respondents, if terminally ill, would like to be informed of their diagnosis and their prognosis, other surveys show that terminally ill patients' understanding of treatment is relatively poor.

Cassileth et al. administered written tests, one day prior to treatment, to 200 cancer patients who had signed consent forms for chemotherapy, radiotherapy or surgery. They found that "only 60% of all patients could correctly describe what their treatment would involve, 59% were able to list a major risk or complication, and only 27% could name one alternative treatment" (1980:896). Hence, it is questionable if a decision rendered by a terminally ill patient about medical treatment is actually informed.

Summary

The conclusions of the studies reviewed are now briefly summarised. First, it is evident that patients and parents would like to be informed of various aspects of their treatment and prognosis. However, studies which explore patient/physician interaction suggest that the patient is reluctant to actively participate in the decision-making process, and hesitant in soliciting information from the physician. Second, parents of infants in Level III Nurseries

consider their infant's welfare in terms of usual and routine care, such as nutrition, rather than actively participating in critical treatment decisions. Third, studies on minors' ability to give informed consent conclude unequivocally that most children over 14 are capable of making rational and reasonable decisions. Further, it was concluded that the minor's ability to make a reasonable decision is dependent upon the amount of information made available, and the manner in which information is given by the physician. Lastly, the studies suggest that situational barriers affect the ability of both patients and parents to make decisions. These issues are considered in detail in the last section.

PHYSICIAN ORIENTED STUDIES

In apparent contradiction to the empirical studies that indicate that patient comprehension of information on diagnosis, prognosis, risks and alternatives is generally low are studies which indicate that physicians believe that most patients are capable of understanding the information which is provided. In the President's Commission survey, physicians were asked "What percentage of your patients would you say are able to understand most aspects of their treatment and condition if reasonable time and effort are devoted to explanation?" Overall, 450/0 of physicians said that 90-100% of their patients could understand and an additional 34% said that 70-89% could understand (1982 [Vol. 2]:94). This does not mean, however, that physicians expended sufficient time to ensure that comprehension on the part of such a large proportion of patients ensued. Nonetheless, this finding suggests the workings of a strong set of beliefs or an accepted underlying ideology that prevents patients from actively seeking information or from retaining information provided.

Findings of other studies suggest that a critical factor which determines patient understanding is the manner in which doctors present diagnostic information. In general patients' responses to physicians' vocalisation is important because in communicative settings, people tend to be affected by various cues as they interpret the communicator's message. These cues may be subtle, brief or out of conscious awareness. Nevertheless research has repeatedly demonstrated the powerful impact of such cues on an individual's evaluation of the other's intent, attitude, competence, empathy and interest (Harrigan et al. 1989:88).

From this perspective, Harrigan et al. sought to evaluate physicians' vocal behaviour (1989:87-92). Accordingly, 30 doctor-patient interactions were analysed, and researchers found that greater weight was given to vocal cues when interpreting contradictory messages. Interestingly, the study shows that females are more accurate in decoding and transmitting nonverbal and vocal cues (1989:91). Finally, speech rate was associated with dominance: the faster the rate of speech the more dominant the physician was perceived. Such verbal cues possibly have a greater impact in situations such as continuing treatment for a severely handicapped child. Parents are placed in an unfamiliar environment, and in seeking information about their child may endeavour to ascertain their child's prognosis by decoding cues.

Treatment Decisions For Neonates

In this arena, difficult ethical problems in paediatrics proliferate together with professional knowledge, skill and technology. Advances in neonatology, genetics and paediatric surgery over the past few decades now present the medical profession and the public with unprecedented choices about the kinds and degree of effort to be made to save or preserve newborn or foetal life. Questions about the rights of physicians to deny or withdraw life-saving or life-sustaining treatment and to employ extraordinary measures are being widely discussed both within the general community and the medical profession. Increasingly, physician-parent decisions based on the "quality of life" of infants are being tested in courts, and there appears to be no consensus about who should make such decisions. Shaw, Judson and Manard examined the attitudes of professionals whose decisions form the basis of practice (1977:588-599). The researchers completed a nationwide survey of four hundred and fifty paediatric surgeons (SG) and paediatricians (PG). Although the survey was conducted in 1975, its findings retain some currency, principally because values attendant to the provision of health care have not altered substantially over the past two decades, although advances in technology have rendered decisions more complex.

Since the findings of this study are illuminating, the following analysis is detailed. Firstly, in response to the question: "Do you believe that the life of each and every newborn infant should be saved if it is within our ability to do so?" 83% of SG said "No" and 81% of PG said "No". The response indicates that physicians do not feel that they need to attempt to maintain

the life of a newborn simply because they have the skill and technology to do so, and that a set of values, including medical predictions concerning longevity and quality of life, underscore determinations about treatment (1977:589).

Further, responses to the following question give some indication of such values. Respondents were asked:

"If you agree that under certain circumstances it is permissible to allow certain severely damaged infants to die by withholding surgical treatment, list the criteria for making such a decision in order of priority: (a) infant's probable IQ; (b) potential quality of life (as child and adult); (c) cost to society (hospital care, institutionalisation); (d) possible adverse effects on the family (psychological, social, financial); (e) parents' willingness to raise the child at home" (1977:593).

A great majority of both groups marked the potential quality of life as the major criterion in making decisions about non-treatment. For both groups cost (c) and home rearing (e) were ranked far below other criteria, while SG placed slightly more importance on the possible adverse affects on the family than PG (1977:593). The questionnaire did not probe for the factors used to determine "quality of life", and it is likely that the infant's probable IQ is a such a factor. At the same time, it is worth noting that, by and large, determinations about the infant's probable quality of life are made not by one doctor alone, but by a team of paediatricians.

Respondents were also asked about who should make the decision about non-treatment. As the researchers note "physicians clearly have less trouble with the matter of 'who should decide' than with the questions involving criteria for these decisions" (1977:594). Subjects were asked:

"Again, if you agree that under certain circumstances it is permissible to allow certain severely damaged infants to die by withholding surgical treatment, number the following in order of who you feel should carry the major responsibility for such a decision: (a) the attending physician (or surgeon); (b) the child's parents or legal guardian; (c) a court of law; (d) clergy; (e) some kind of hospital-based multi-disciplinary committee" (1977:594):

Interestingly, half of each group (PG and SG) felt that parents should make the decision, while one-third of each group thought that physicians should carry this responsibility. A hospital committee was a strong third, while courts of law and clergy trailed behind. Nonetheless, although a significant proportion stated that parents should make the decision about non-treatment, respondents when asked "if you disagree with the parents' decision to withhold surgery, would you obtain a court order directing surgery?", 58.1% of SG and 70.0% of PG said "Yes" (1977:591). Hence, it would appear that physicians are willing to accept parents' decisions only when they concur with their determination, based as it may be on medical criteria. In general, the study indicates that physicians do not feel that the life of every newborn must be maintained, and more importantly have a set of values which underscore such decisions.

Subsequent to the research completed by Shaw et al. the US Supreme Court struck down federal regulations governing the treatment of severely handicapped infants - the so called "Baby Doe regulations" (Kopelman 1988:677). In order to determine paediatricians' views on the "Baby Doe regulations" and whether the regulations had affected their practice, Kopelman et al. sent questionnaires to the 1007 members of the Perinatal Paediatrics Section of the American Academy of Paediatrics. 494 members (49%) responded (1988:677-680).

Of the respondents, 76% believed that such regulations were not necessary to protect the rights of handicapped infants; 66% believed that the regulations interfered with parents' rights to determine what course of action was in the best interests of their children; and 60% stated that the regulations did not allow adequate consideration of infants' suffering (1982:678). Further, in responding to hypothetical cases of severely handicapped children, 32% said that maximal life-prolonging treatment was not in the best interests of the infants described, but that the Baby Doe regulations required such treatment (1988:677-683). The overwhelming majority of respondents (77% to 87% depending on the hypothetical case) wanted to consider the parents' wishes (1982:677-683).

Nonetheless, it is evident that physicians do refuse to accede to parents' decisions. Literature on physicians' refusal of patients' demands is sparse, and the literature that is available has reported on relatively uncontroversial issues in primary care, such as the denial of antibiotics

for viral infections. With regard to neonatology, Paris, Crone and Reardon document an instance where physicians treating an infant refused to re-institute mechanical ventilation on the basis that it would be inhumane (1990:1012-1014). At birth, the infant was resuscitated, stabilised, and eventually weaned from mechanical ventilation. Over a period of weeks, the infant's respiratory function improved, but the neurologic condition remained very depressed, with no responsiveness except to pain. Over the next 23 months, the infant underwent three operation, months of recurrent pneumonia and four cardiopulmonary arrests (Paris et al. 1990:1013).

While the mother continued to demand that everything possible be done to ensure the child's survival, physicians, nurses, hospital council and the ethics committee unanimously agreed that further medical intervention was not in the best interests of the child. In documenting the case, wherein the medical team's action "marks the first time that physicians - even in the face of judicial intervention...denied a request for potentially life-prolonging medical treatment for a patient in acute crisis", the researchers question the nature of the patient-physician relationship, and conclude that in refusing the request, the medical team and the hospital declined to violate their professional commitment to the patient (1990:1013-1014).

Decisions based on medical considerations, such as the belief that aggressive life-prolonging treatment is futile and inhumane, support the hypothesis that professionals prefer self-regulation and resent government intervention. This reinforces the conclusions reached by Shaw et al. In the earlier study respondents were asked if ethical issues should be "resolved in (a) the courts of law; (b) by legislation?" (Shaw et al. 1977:593). Although an impressive majority of respondents had initially indicated that discussion of such issues outside the medical profession was appropriate, only a small proportion (18.5%) thought that the actual decision-making should be put in the hands of judges and/or legislators (1977:593).

The findings of these empirical studies indicate that issues pertinent to neonatology and the treatment of defective infants require further research. Such research would identify those values which affect decisions reached by doctors, the process by which paediatric surgeons and paediatricians confer to make a decision about the "quality of life" that the infant may enjoy, the extent to which parents' views are taken into consideration, and indeed the degree to

which parents express self-determination and autonomy when rendering a non-treatment decision about their child.

Treatment Decisions and the Terminally Ill

Simultaneous with technological advances which have made treatment decisions in the arena of neonatology increasingly complex are those advances which have made it possible to maintain or prolong the life of the terminally ill. There is now widespread and continuing discussion about the relative merits of allowing a patient who is suffering from a terminal illness to request the withdrawal of forms of treatment which prolong life (Discussion Paper 84, *Medical Treatment for the Dying*). In accepting that the competent patient can exercise rights, the Victorian Government enacted the *Medical Treatment Act 1988*, which makes it an offence for a doctor to provide treatment which a patient does not want. Debate about the Act continues as indicated by the following summary.

Kuhse and Singer conducted a survey which was based on the general hypothesis that such legislation does little more than put into statute what is already medical practice (1988:623). The questionnaire was mailed to 2000 Victorian doctors, of whom 893 responded. The questionnaire asked a series of questions about their action in response to requests to hasten death. Only 40% of the respondents had been asked by patients to hasten their death. Further, most (75%) said that they discussed the patient's request with a relative or close friend of the patient, while 67% consulted another doctor. Almost all (93%) thought that the request was "rational" (1988:623).

With regard to taking active steps to bring on death, as distinct from the withdrawal of life prolonging or life sustaining treatment, only 29% of respondents replied that they had taken such measures. Importantly 65% said that illegality was a factor in their rejection of the request (1988:624:). It is also interesting to note that some of the doctors who had taken active steps to hasten death explained their actions in terms of relieving pain, rather than bringing about death. Comments made by respondents include the following:

"I believe that I was respecting the patients' wish to die peacefully in their own time and manner.'

'I was carrying out a decision which the patient had a right to make.'

'The patient was fully informed and rational. The prognosis was hopeless. Patient and family were subject to increasing distress. I would in the same patient's position have had the same attitude.'

'There is absolutely nothing I could give to patients to improve their condition or quality of life' " (1988:624).

Equally significant is that respondents, when asked if "the law should be changed to allow doctors to take active steps to bring about the patient's death in some circumstances", 60% answered "Yes" (1988:625). Again, comments made by the participants are illuminating. For example:

"I will not facilitate death by commission. I may refuse to prolong life by omission.

'Passive euthanasia is in widespread practice by not providing intensive or coronary care to very frail or demented elderly people. When quality of life is very poor and it is the patient's expressed wish, there is protracted suffering and withdrawal of current treatment would not provide rapid death free of suffering, active euthanasia is more compassionate.'

'There are mechanisms in place already for a doctor to provide heavy analgesia/sedation - which hastens the patient's death indirectly but effectively'." (1988:626).

In conclusion, the survey by Kuhse and Singer shows quite clearly that the majority of respondents support active euthanasia, and that there exists a quite striking dissimilarity between current law and widely accepted medical practice.

STUDIES OF BARRIERS TO INFORMED CONSENT

It has been cogently argued by researchers from a range of disparate disciplines, including health and the social sciences, that a range of structural and ideological barriers impinge upon patient/physician interaction, and these ultimately limit the ability of the patient to gain and retain information, and thereby be able to make an informed decision about medical care. Barriers include patient/doctor communication; perceptions of what's wrong; perceptions of the necessity of the medication; and unfamiliarity with the surroundings. These issues are examined in this section.

A substantial body of research describing communication between doctors and patients, both in the consulting room and in the hospital, has accumulated over the past decade. This

literature suggests that communication breakdown between doctors and patients is more the rule than the exception. Bouhris et al. in an effort to identify some of the reasons for such breakdowns surveyed 40 physicians, 40 student nurses and 40 hospital patients regarding their usage and evaluation of medical and everyday language in a hospital setting (1989:339).

In their study, medical language (ML) was defined as the "technical language used by medically trained people such as doctors and nurses. Medical language includes technical terms used in diagnosis, terms used to describe or explain surgical and other medical acts, as well as terms used to describe normal bodily functions" (1989:341). Everyday language (EL) was defined as "what must be said in the hospital setting using ordinary language that people with no medical training can readily understand" (1989:341). All respondents were asked to volunteer in the research by completing a written survey questionnaire. Printed instructions on the first page of the questionnaire included definitions of medical and everyday language. The researchers included nurses as part of their sample since nurses are integrally involved in providing or reiterating information given by the physician, and play a significant role in the interactive processes in a hospital setting.

The general hypothesis that doctors and nurses would converge to the everyday language of their patients received some support. More specifically, the findings of the study show that health professionals and patients differ substantially in their self reports of ML and EL use in the hospital setting. In all, the study shows that patients and nurses were in strong agreement when assessing patients' use of ML with other patients (10% and 13% respectively). Patients and nurses were also in agreement about the amount of ML patients used with nurses (15% and 16% respectively), and with doctors (19% and 23% respectively). However, doctors' perceptions of the amount of ML employed by patients differed from patients' and nurses' perceptions, since doctors perceived patients use ML only 5% of time with other patients, 6% of the time with nurses and 7% of the time with doctors. Analyses of variance showed that doctors consistently underestimated patients' use of ML relative to perceptions by both nurses and doctors (Bouhris et al. 1989:341-343).

At the same time, the three groups of respondents agreed that doctors use ML when speaking to other doctors and nurses. As regards perceptions of doctor-patient communications,

however, doctors' observations were at odds with those of patients and nurses. In line with doctors' own ratings of extensive EL use with patients (77% of the time), doctors did perceive other doctor as mostly converging to EL usage with patients (72%). In contrast, both nurses and patients reported that doctors used much ML when speaking to patients, (49% and 59% respectively). Hence, the study indicates that doctors underestimated patients' use of ML, while importantly, neither nurses nor patients perceived doctors converging to EL with patients as much as doctors asserted they did. Instead, patients and nurses perceived doctors to use much ML when conversing with patients.

Interestingly, the study shows that there was strong agreement between the three groups of respondents about nurses' use of EL. It was perceived to be 73% by patients, 69% by nurses, and 75 by doctors. Further, nurses' self reported convergence to ML with doctors (67%) was perceived to be 66% by doctors and 72% by patients. Thus, nurses were seen to converge linguistically to both patients in EL and doctors in ML (Bouhris et. al. 1989:342-343).

These findings indicate some of the communication barriers which may impede the effective operation of informed consent. Such language barriers are particularly significant in relation to parents/guardians who consent to treatment for their infants. As Spielman and Pinch noted, parents were frequently unable to state what was their child's diagnosis. Not surprisingly, there was a significant disparity between the parents' description of the near discharge status of their infant and the documentation in the charts of the infants who went home with substantial residual problems (Spielman & Pinch 1990:716).

Problems in patient-doctor communication have been attributed to differences in education, status, culture and other features which distinguish health professionals from their patients. Research by Broadbent et al. suggests that when a skill becomes highly practised, it becomes difficult to monitor application of the skill, and the knowledge surrounding it becomes implicit or automatic (1986:33-50). Implicit knowledge appears to be a factor in expert systems, where highly skilled people are unable to monitor or articulate their use of a particular skill. This may account, in part at least, for the discrepancy in reports of doctors' language usage. Since doctors use ML every day, it may become in some way an everyday language. Thus, terms commonly used within medical language may be perceived by doctors as everyday language.

In a similar vein, other researchers have examined communication problems between health professionals and experts from other fields. For instance, Stein listed communication problems between doctors and educators of sick children (1986:70); while Sheppard found inadequate and inaccurate communication between doctors and social service workers (1985:25). Finally, Barcia noted that communication difficulties also arise when specialists and general practitioners interact (Bouhris 1989:345). Such difficulties may arise when the general practitioner is unfamiliar "with the medical terms used by the specialist.

Compounding the difficulties that may arise because the patient and the doctor are in effect speaking "different languages" are the difficulties which can arise when the patient's perception of the illness itself differs from that of the doctor. In this context a group of women were interviewed over their construction of their illness experience before they saw a physician and subsequently over a period of several months following consultation. As Hunt, Jordan and Irwin note, "the act of seeking medical counsel for help in interpreting negative bodily sensations has been commonly treated as a crucial step in the process by which illness is understood and acted upon" (1989:945). The study was centrally concerned with two issues: one, the resources which individuals bring to bear when making sense of what they experience; and two, the process of explanation construction in which they are engaged. Twenty three women participated in the study, and they were interviewed five times over a six month period. The interviews consisted of both open-ended and fixed response questions. In addition, four participating physicians were also interviewed, and data was also obtained from patients' medical charts, patient observation in the clinics and during physician-patient consultations.

The study found that constructions of illness employed by respondents were specific to the context of their everyday life. They made sense of their illness through a process of reappraisal that produced modifiable explanations, logical to them in terms of their everyday thinking, and most importantly, useful in terms of their day to day needs. Further, the tentative notions that people held prior to diagnosis proved to be tenacious and long lasting. Hence, the physician's explanations were never accepted as replacements for prior concepts, but were often reworked in ways that reduced their inconsistency with previous ideas. The study suggests that this is in

part because pre-diagnosis ideas which individuals hold may present concepts which are linked with the overall pattern of their lives (1989:945- 955).

The social environment was shown to be salient in several ways: one, the experience of others provided sources of possible explanations; secondly, illness explanations were constructed in ways that verified or expressed current life circumstances such as financial limitations or changing employment; and finally and perhaps most importantly, explanations of illness are used to give meaning to various aspects of social existence. The researchers argue that such explanations "were used to give meaning to important life stages, to exonerate socially unacceptable behaviour, and as justification for certain social actions" (Hunt et al 1989:955).

The tentative conclusions reached in the study indicate that people or patients are actively engaged in a dynamic process of constructing understandings and interpretations of their experience and symptoms. It is essentially an interactive process: raw materials are taken from the social environment, and it appears that medical diagnosis often plays a comparatively minor part. While the study conducted by Hunt et al. does not deal with the terminally ill, it is likely that the social environment impinges, perhaps more acutely, upon the treatment decisions that such patients make. This observation was made earlier in the section analysing studies about patients, where the social environment and religious beliefs of respondents were noted in relation to their views about the legality of doctors administering pain killers to terminally ill patients.

Moreover, while the cost of providing life-prolonging treatment is not one that necessarily impinges upon the obtaining of informed consent, it is a factor that must be considered. Increasingly, the cost of ensuring the survival of extremely immature infants is being calculated. Doyle, Murton and Kitchen calculated the cost-effectiveness of neonatal intensive care up to the time of discharge over two separate eras of stable consumption of resources for assisted ventilation. They concluded that the overall cost-effectiveness for infants of 24-28 weeks' gestation during 1977-1983 compared to 1971-1974, when assisted ventilation was rare, was an additional \$62,268 per survivor (1989:558-568). Further, after 1983, the consumption of resources for assisted ventilation more than doubled. There were however, diminishing returns for gains in survival during 1984-1986, and the costs per additional

survivor averaged \$99,574 (1989:558-568). It would appear then that with decreasing maturity, these infants consume disproportionately more resources, and at the same time their outlook' for a survival that is free of neurological impairments and disabilities decreases.

In a study that dealt with similar issues Marshall et al. measured both the direct and indirect costs of providing care to infants in Phase II and Phase III nurseries (1989:568-574). The study indicates that various factors add to the cost of providing care, and that the cost is rising. This is not to suggest that physicians take into account the cost of providing care when recommending that treatment be withheld. It remains, however, one factor which may underscore the perceptions of an infant's condition, when scarce resources mean that not all infants in a Phase III nursery can have access to life-prolonging treatment. Accordingly, any detailed exploration of the values which underscore decisions made by neonatologists must necessarily take into account the cost of providing assisted ventilation or other treatment on a continuous basis.

In addition, structural and situational pressures also affect the ability of the patient/parent to render an informed decision about medical treatment. The fact that patients are ill or injured and often in pain is a dominant structural feature. As a result of the pain and discomfort of illness, whether physical or psychic, it is not surprising that in this type of situation, patients feel that only the doctor can alleviate the pain, or that they have to do something, which may make them more willing to do what the doctor suggests. Pain and discomfort can make the patient less assertive in seeking alternatives and asking questions. The feeling of helplessness is possibly compounded if the patient has been informed that a surgical procedure or test indicates a growth to be a malignant tumour. In this sort of situation, it is likely that the patient will actively seek reassurance from the physician and agree to the treatment recommended. Patients may make decisions to undergo treatment that the doctor recommended because they feel that they have no choice: they are in effect pressured by their illness.

Parents who are required to make a decision about their seriously impaired infant may similarly feel that the prognosis given by the physician is the only viable option. Of course, factors such as strong religious beliefs may make parents impervious to the option recommended by the physician. Nonetheless, it is clear that structural pressures have a

significant impact upon the treatment decision rendered. In this context, it is worth noting the comment made by mothers who sought admission for their improperly developing children to be subjects in a research protocol which offered no direct benefits to the children. When the lack of benefit was explained, only three of the 140 mothers refused to admit their children. The researchers contend that "a clue to the mothers' conscious motivation is contained in the recurrent statement, 'I have no choice'" (Meisal & Roth 1983:311).

Further, as many researchers have noted, another factor influencing decision-making is "inertia". Patients seem to get caught up in events that involve a range of physicians from different disciplines and receive so much technical information that they seem to feel powerless to play a volitional role in decision-making. Thus, when a recommendation is made by a physician, patients tend to go along with it, thereby transforming the "recommendation" into a "decision".

Finally, the conditions under which patients are requested to make decisions may also impose constraints on choice. For instance, parents are required to make a decision about their infant within a relatively short period of time. Such constraints no doubt affect how active the parent is in seeking information about alternative treatments or risks of the treatment recommended. Hence, the parent, like the patient who is in pain, makes a decision which is governed by the recommendations made by the physicians.

DISCUSSION

The picture that emerges from the literature review of empirical studies is that generally there are persistent barriers to effective communication between doctors and patients, and this also applies to matters of consent. A number of studies have indirectly examined the question of how much information patients want by studying the reasons for patient satisfaction or dissatisfaction with their doctors. Communication ranks high on the list of qualities patients view as important to their medical care. In a number of studies it has been shown that the quality of the interaction (measured in terms of the amount of time the physician spends with the patient, the vocal tones of the physician, the language and medical terminology used by the physician and the environment in which the interaction between the physician and the patient occurs) is the key to patient satisfaction with medical care. Hence, while many of the studies

conclude that patients want information, although they may not actively seek it, the studies are inconclusive about the nature of information desired by patients. In addition, although doctors may not volunteer information, when patients specifically request information, doctors tend to answer them.

With regard to understanding, almost all studies concur that patients remember little of what has been told. Structural and situational conditions inherent in being a patient make it more difficult to understand information relevant to decision making. Critiques of patient/physician exchanges are increasingly beginning to identify the interplay between various structural barriers, and how this affects the patient's ability to effectively communicate with the physician.

The complexities of patient/physician communication are exemplified by Pinch and Spielman's study of primary care givers in a Neonatal Unit. The primary care givers, mainly mothers, continued to care for their infant in terms of nutrition and hygiene. Despite the fact that their infant was in a serious condition, parent' interpretation of their child's illness was governed by their general perceptions of how to care for a healthy newborn. The use of mechanical ventilators and other technology, the time constraints and the fact that most mothers had just left the labour ward are all factors, both situational and cultural, which affect how active the mothers were in soliciting information from physicians and in participating in treatment decisions. Observational studies such as this provide the kind of subtle data that is impossible to capture in surveys or through examination of any one encounter.

Finally, comments on empirical studies from a methodological perspective. Empirical studies provide some insights into the nature of communication and the decision-making process in health care, but leave many questions unanswered. Often this is because most studies examine one component of informed consent in a well defined and limited context. For instance, patients were interviewed either before a primary consultation or subsequent to a follow-up consultation, or alternatively researchers have focused on examining an aspect of physician/patient interaction while the patient is in hospital. Little attention has been paid to the fact that doctors and patients, particularly within a hospital, interact over a period of time, and that frequently when a patient gives consent for a particular procedure to be undertaken,

alternate measures are undertaken more as a matter of course, if the original procedure was not effective. As Meisal and Roth observe, the studies fail to investigate the complex relationship among the components of informed consent, and focus more on the simple one-to-one relationship between pairs of components such as disclosure and understanding (1983:330).

Secondly, most discussions of informed consent assumed that disclosures made by physicians are used by patients to make treatment decisions, thus the emphasis is on ascertaining how much information was disclosed, and how much information patients retain. However, few studies have sought to determine just how patients make decisions and what the role of information is in that process. Little attention has been paid to the numerous sources from which patients can acquire information or the social ideologies which posit that the "doctor knows best", and that to question the doctor implies a lack of trust and confidence in their abilities. A few studies have examined the impact of social and cultural beliefs, and patients' interpretation of their illness. It is evident that many factors come into play. These include previous experience with particular treatments, and the patient's own assessment of what is best in terms of his/her values and life plans.

In conclusion, what remains striking about the conclusions reached by many of the studies is that, at one level or another, they are inconclusive. A partial explanation is offered by Meisal and Roth who in a comprehensive critique of empirical inquiries question the validity of many of the findings of these studies. According to Meisal and Roth:

"the empirical findings of informed consent are so riddled with conceptual, methodological and ideological flaws that the sum and substance of the corpus of their findings are of questionable worth. Because of the manner in which many studies are either designed, conducted or reported, we believe that it is impossible for the discerning reader of these studies to make independent determinations of their validity" (1983).

Leaving aside their general criticisms, Meisal and Roth's critique demonstrates that researchers have approached the operation of informed consent from a legal vision of the doctrine. Such studies have not been cognisant of the complexities inherent in the provision of medical care. The legal vision of consent with its well defined parameters identifies stages in a dialogue between the physician and patient. It does not, however, delineate the process itself.

Notwithstanding this, it is instructive to note that patients examine the process by which a decision was rendered, informed or otherwise, only when they are disillusioned with the physician, in one sense or another.

PART II
RESEARCH STUDY

**PROCESSES AND PROCEDURES RELATING TO
HOW CONSENT TO MEDICAL TREATMENT IS
OBTAINED**

CHAPTER III

METHODOLOGY OF STUDY

INTRODUCTION

The provision of information has assumed a more important role in the delivery of health care. The clinical importance of the provision of information about patients' ailments and their treatment has been illustrated in studies such as those by Robinson and Whitfield (1988), Rost et al. (1989), and Roth (1977). Further as Meisal and Roth (1983) and Bromberger (1988) have suggested, changing expectations of medicine and the health professional are beginning to impinge upon physician/patient relationships. Nonetheless, the communication of information between the physician and the patient continues to remain unresolved. This study focuses on the disclosure of information by physicians, and the attitudes and expectations of patients in relation to making treatment decisions, and is a reappraisal of the interaction between patients and physicians.

AIMS AND METHOD OF THE EMPIRICAL SURVEY

The main objective of the research was to investigate the attitudes of physicians to giving information about diagnosis, treatment and its attendant risks to the terminally ill, and to parents in relation to their children and infants. The Research Objectives of the survey are:

To observe the processes by which patients/parents are given information about their complaint, treatment and treatment options. To determine if the decision is "informed". That is, does the patient/parent know and understand details of the procedure, its potential side-effects, risks and possible alternatives to the treatment recommended by the medical practitioner.

To identify who gives permission or consents to medical treatment in relation to each target group.

To appraise the attitudes of medical practitioners, health care workers and patients with regard to the provision of sufficient information upon the basis of which a patient can make an informed decision.

DETAILS OF THE SAMPLE

The data presented in the following chapters was provided by a sample of three groups of respondents: 30 physicians, 30 clinical nurses and 30 patients. In order to gain access to

hospitals, details of the proposed research were sent to the Medical Directors of four hospitals in the Perth metropolitan area. The researcher met with the Medical Directors of the hospitals to obtain permission to interview patients, nurses and physicians.

For all but one hospital, permission was granted to interview respondents in each of the three categories. At this one hospital, permission to interview patients was denied. The Director of a second hospital requested an assurance that confidentiality would be maintained in any paper published by the Law Reform Commission. Such assurances were given by both the Commission and the researcher. It was further requested that the Australian Medical Association (WA Branch) be informed of the research being conducted. The researcher sought and obtained the Association's support for the research from Dr W Ruse, President (AMA - WA Branch).

Secondly, while, some physicians were willing to let the researcher accompany them on their ward rounds, most were unwilling. It was therefore decided to forgo direct observation of patient/physician interaction.

All respondents were assured that their responses and comments would remain confidential, and that the presentation of data would not allow for the identification of individuals. Characteristics of the three main groups of respondents are as follows:

Physicians

Physicians were selected by the Medical Directors of the four hospitals. Respondents specialised in a range of areas such as Respiratory Medicine, Medical Oncology, General Paediatrics, Anaesthetics and Surgery. The sample was not made at random, and consisted of 30 physicians. Of physicians, 28 were consultants and 2 registrars. The sample consisted of 6 females and 24 males; their average age was 44. The average length of experience each respondent had spent in his/her speciality was 14 years.

The researcher informed the Medical Director of the medical areas which were of interest, and the Medical Director selected respondents. In relation to the private hospital, the Medical Director provided the researcher with a list of the names of consultants. The researcher then

sought their participation in the study. Consultants were interviewed in their rooms. Only one consultant declined to participate in the study, on the basis that he was on holiday. At the public hospitals, the Medical Directors informed respondents of the research and the hospital's support for the research. The researcher then contacted respondents to make an appointment. However, on occasion, the consultant was either too busy or simply not available, and other respondents who worked in the same field were selected. As a consequence, two registrars are included in the physician sample.

The study was presented to the physicians as a survey on doctor/patient/nurse communication in the hospital setting, as this relates to the diagnosis and treatment of the terminally ill, defective neonates, and minors. Almost without exception, physicians asked if the Law Reform Commission was seeking to modify or change the law as it relates to the treatment of patients in the three categories. Respondents were informed that the Law Reform Commission was interested in ascertaining the processes by which consent to treatment was obtained.

Nurses

Clinical nurses or clinical nurse specialists were selected by the Director of Nursing or by the physician responsible for a particular area or ward. For instance, at one of the public hospitals, the researcher asked the physician whether it was possible to speak to nurses working in the ward. Alternatively, the Director of Nursing gave the researcher the names and duty roster of nurses working in areas, such as oncology and neonatology. Appointments with nurses were then made by the researcher. At the private hospital, the Medical Director arranged for the researcher to speak with nurses over two days. Again, the sample was not random.

Of nurses, 10 respondents work at a private hospital, and the remaining 20 work at public hospitals. Nurses selected worked in a range of areas similar to that of physicians such as neonatology, oncology, and surgery. The sample comprised entirely females; their mean age was 36. The average length of hospital experience as a qualified nurse was 10 years. Of the total sample, 11 nurses had worked with both the terminally ill and with minors.

The issue of consent was raised delicately with nurses. At the time of the study, the Health Department of Western Australia was seeking to determine the process by which consent

forms were signed in hospitals administered by the Department. Further, the Australian Nurses Federation in its Newsletter (Oct 1990) requested its members not to act as a witness to the signing of the consent form. The researcher stressed that the focus of the study was the interaction between nurses and patients as well as that between nurses and physicians.

Patients

At the two public hospitals where permission to speak with patients was granted, respondents were selected by the physicians treating them. The researcher requested that minors be in the age cohort 10-16, and that the terminally ill had been diagnosed with a malignant growth at least 6 months ago. Both in- and out-patients were interviewed at the public hospitals. As a result, patients interviewed were being treated by physicians who had also been interviewed by the researcher. The analysis of the data, however, does not attempt to correlate each group's responses. At the private hospital, the Medical Director selected patients. On occasion, the researcher sought permission from the consultant, if both he and the researcher were on the ward at the same time. Of the total sample of patients, 15 were minors and 15 had been diagnosed as terminally ill.

i) Minors

The mean age of minors was 13. All except one respondent were over 10 and under 17. Minors were receiving treatment for both minor and serious illness at both private and public hospitals. 4 had undergone a surgical procedure to have their wisdom teeth or tonsils removed. 5 were oncology patients who had been in and out of hospital for a period of years and continued to receive treatment, and the remaining 6 had various minor complications. All had undergone a surgical procedure, and 8 were out-patients. For all respondents, parents were accessible, although, except for the 7 year old, parents did not participate in the interview. The researcher sought approval from all parents before speaking to respondents.

ii) Terminally

The mean age of patients was 50. The distribution range was 45-70. 9 were in-patients, and 6 were out-patients. 13 had been diagnosed as having a malignant tumour at least 12 months previously, and two suffered from chronic respiratory failure. Of respondents, 11 were still undergoing curative or palliative measures, and 4 were being kept comfortable, since the

cancer had metastasised, and was in an advanced stage. All had undergone a surgical procedure, either to ascertain whether the tumour was malignant or as a curative measure. Of respondents, 11 had been treated with radiotherapy or chemotherapy.

DETAILS OF THE PROCEDURE

All respondents were asked to volunteer in the research study by participating in a structured interview. Questionnaires were sent to Mr C Ogilvie of the Law Reform Commission, Ms D Steele of the Health Department of Western Australia, Mr J Wilson (Research Consultant), and Dr A Hayes (Psychology Department, UWA) for critical comment.

In order to minimise one potential source of bias in the data - the possibility that respondents may relate dissimilarly to different interviewers - all interviews were conducted by the one researcher. Details of the questionnaire and procedure used for physicians, nurses and patients are now examined in turn.

Physicians

The questionnaire consisted of three sections. The first section dealt with the background and personal details of each respondent. In the second section, physicians were asked to evaluate their practices regarding the provision of information, and to assess the extent to which patients participated in making treatment decisions and actively sought information. The third section was divided into three parts, and dealt with hypothetical situations concerning the terminally ill, defective neonates and minors. Physicians were also questioned about their treatment practices when dealing with the terminally ill and with parents. 3 respondents stated that they lacked the expertise necessary to respond to questions dealing specifically with terminally ill, infants or minors.

The duration of each structured interview was approximately an hour. Interviews with 11 respondents lasted ninety minutes. Interviews were either conducted in the consultant's rooms or within the hospital. All respondents were informed at the outset that the researcher was happy for them to interrupt, and give examples or explain any aspect of their routine practices. 19 respondents volunteered explanations and commented on their interaction with patients. These comments were noted, and are included in the analysis of the data in the following

chapters. In one instance, physicians were probed for details. All physicians who treated the terminally ill were asked how a 'not for resuscitation order' was placed. This question was asked in the third section in the part dealing with the terminally ill, and is not included in the questionnaire. Some physicians initiated a discussion of how such orders are placed, and how he/she places a not for resuscitation order.

Nurses

The questionnaire consisted of two sections: the former dealt with background details, and the latter with self reports of how frequently patients and parents sought treatment and diagnostic information from nurses, the duration taken by physicians to explain the consent form, and nurses' attitudes to the provision of information to patients. The questionnaire administered to nurses was considerably shorter than that administered to physicians and patients.

The duration of the interview was 30-45 minutes. Nurses, like physicians, were informed that additional comments were welcome. However, most respondents (17) answered the question and did not volunteer any further information. 2 respondents repeatedly asked during the interview whether the researcher wanted to know what actually happened in the ward, or what the respondent believed should happen. On being informed that the question dealt with their experience of what happened on the ward, nurses asked if they could alter earlier responses. This was permitted. No other respondents indicated that they had any difficulty in comprehending what was meant by the question. Finally, 13 respondents mentioned either before or during the interview that "consent was not a nursing issue".

Patients

The questionnaire administered to patients consisted of five short sections. The first dealt with background details. In the second, respondents were asked to evaluate how much information they wanted physicians to give them, and report on whether physicians provided sufficient information. Patients were also asked if they relied on nurses for information about their treatment and its attendant side-effects. The third section concentrated on consent forms. All patients were asked who had explained the consent form to them, how long the explanation had taken, and when the explanation was given. Only the terminally ill responded to section four. Respondents were asked about various aspects of pain management.

Section five was only administered to minors, who were asked about their participation in treatment decisions.

In each of the 30 interviews, the initial approach to the patient was made by someone other than the researcher - either by the nursing sister or by the doctor. Once the patient had agreed to take part in the research study, the patient was introduced to the researcher, or the researcher introduced herself. Upon meeting the patient, the researcher stressed that permission to speak to them had been obtained from their physician, and that their responses would remain confidential.

The average duration of each structured interview with the terminally ill was approximately an hour. Respondents were interviewed either in hospital, or at an out-patient clinic. All respondents were asked to make comments during the interview. Of the total sample of 15, 8 volunteered details of their experience with physicians and nurses. Their remarks are included, where appropriate, in the following chapters.

Both minors and their parents were informed that permission had been obtained from their physician. The average duration of each structured interview was 45 - 60 minutes. While the researcher asked for their comments, most minors (11) did not make comments. Respondents were interviewed either in hospital, or at an out-patient clinic.

DATA COLLECTION

Two separate research instruments were employed in this study. Quantitative analysis is based on responses to the questionnaires, while the unsolicited comments proffered by respondents are the basis of the qualitative analysis. These remarks offer an insight to the interaction between patients, nurses and physicians.

The interviews consisted mainly of fixed-response questions, and a corresponding scoring system was developed. Any expressions of preference, including waiver and "don't know", were coded. Fixed responses are given as percentages for each of the three categories. All tabulations for physicians and nurses are based on a total sample of 30. However, for patients,

the analysis concentrating on the terminally ill and minors is based on a sample of 15. Again, data is presented as a percentage.

Spontaneous initiatives made by respondents were not coded, and are used to identify some of the factors which impinge on the respondents' expectations and behaviour within a medical context. Where physicians and nurses commented on the process by which a decision is reached, particularly with infants in Phase III nurseries, or the consent form is signed, their descriptions are given in detail.

DISCUSSION

One of the advantages of a sample, although small, that is chosen for particular characteristics is that it allows the research to focus on the nuances of their interaction. The parameters of this study are largely defined by the conclusions of other empirical studies, which were analysed in the previous chapter. The findings of these studies offer hypotheses which have been confirmed by direct observations and allow this study to concentrate on pertinent aspects of informed consent. The data analysed in the following chapters use the methodological framework delineated.

The intent of this research study is to describe processes and the interaction between patients, physicians and nurses in clinical situations. While the applicability of these findings may be somewhat tempered by the fact that the sample is small and not random, the study nonetheless offers "snapshots" of their relationships.

CHAPTER IV

THE CONSENT FORM

INTRODUCTION

The Consent Form is generally seen to confirm the contractual agreement between the physician and the patient. Increasingly, this assumption has been challenged. Legal and medical practitioners, as well as social researchers, have cogently argued that the complexity of language characteristic of consent forms, the moment when the explanation is given, and the relatively short amount of time spent on explaining those aspects necessary to obtaining consent all render the consent form somewhat meaningless. Eagleson's analysis of various consent forms used in Victoria shows that many use legalistic and difficult language. These difficulties are compounded in consent forms by the use of broad statements with no specific detail to guide the patient. Lastly, while such forms detail the procedure itself, attendant risks are frequently not mentioned (LRCV 1987:27-29).

Similarly, in the survey undertaken by the President's Commission, the researchers conclude that the ability of written consent forms to help ensure informed consent is minimal (1982 [Vol 3]:154-155). While the study noted various factors which make the consent form difficult to comprehend, it emphasised that educational attainment has a substantial impact on patients' ability to understand the consent form. Individuals without a usual source of care - either spouse or family - also have considerable difficulty in understanding the information given in a consent form.

This chapter is framed by the following research objectives which are:

To identify who gives permission or consents to medical treatment in relation to each target group.

To ascertain if the processes used to obtain consent in public hospitals differs from those used in private hospitals.

To examine the process utilised to obtain the patient's/parent's signature on consent forms. For instance, does the medical practitioner explain procedures to the patient/parent who then signs the form or is the task allocated to nurses?

To determine when consent is obtained. Immediately prior to the medical treatment or well in advance of treatment.

METHODOLOGY

This study concentrated on the process by which patients sign the consent form. Specific attention was not paid to whether patients actually understood the procedure to which they had consented. Both patients and nurses were asked a series of questions about the consent form. Physicians were not questioned about the consent form principally because other studies indicate that consultants tend not to administer consent forms in public hospitals.

All nurses (30) and patients (30) were asked questions relating to the above issues. It is noted that the analysis is based on self reports given by respondents. The study did not seek to ascertain the veracity of responses given to the questionnaire. The following analysis of the data is supplemented with the comments given by respondents during the structured interview. Where appropriate, responses are correlated to patients' and nurses' attitudes to the provision and adequacy of information.

ANALYSIS OF THE DATA

i) Who explained the Consent Form

Both patients (P) and nurses (N) were asked who generally explained the consent form to patient.

QPI: "Who explained the consent form to you?"

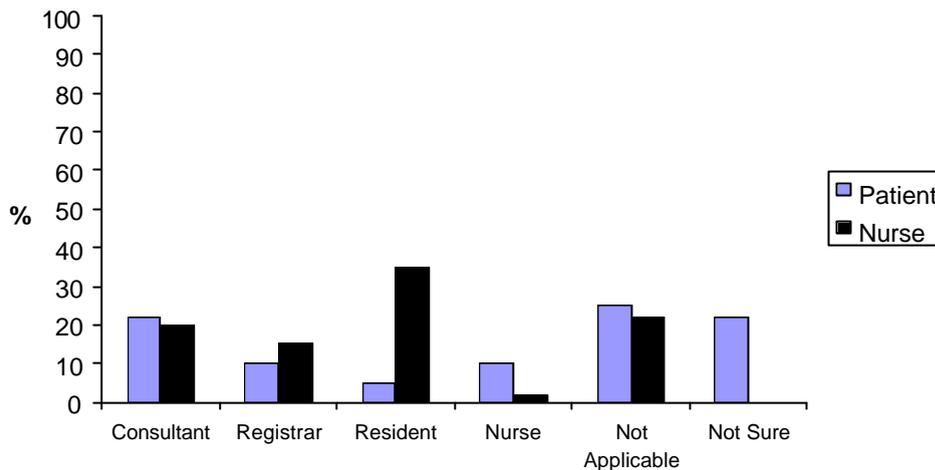
Similarly nurses were asked:

QNI: "In your experience, who explains the consent form to the patient?"

In response, almost a quarter of patients (23.4%) said that the explanation had been provided by the consultant. However, a similar proportion (23.3%) of patients were not sure who had given an explanation. Further 26.7% of respondents said that they had not signed a consent form for a surgical procedure because it was not necessary. From the total sample, then, almost a quarter were not sure who had provided them with an explanation, if indeed an explanation had been given. These respondents made the following explanatory remarks:

"I can't really remember who explained...I am not sure."
 "I don't know...it happened so quickly."
 "I don't think anyone explained. I was just asked to sign."
 "No one explained. I was just asked to sign...just before the pre-med."
 "I just don't know...was it important?"

Graph 1:1 Explanation of the Consent Form



Secondly, slightly more than a quarter of respondents (26.7%) stated that they had not signed a consent form because it was not necessary. One explanation is that consent forms are not mandatory in private hospitals. Patients receiving treatment at a private hospital made the following comments:

"Well, he knows what he's doing...I don't".
 "I mean...the doctor just said that the operation would make a difference."
 "What for?"

Patients' responses correspond with nurses' responses. Almost a quarter of nurses (23.4%) stated that consent forms were not necessary. These nurses made the following comments about the way in which consent forms are viewed and processed in the private hospital:

"Consent forms are usually signed in the consultant's room... if at all. We often don't have consent forms signed at all."
 "Some of the doctors here feel that its between them and the patient."

"The nursing staff don't enter... only enter as advocate for the patient. The consent form is a private contract between the patient and the doctor. "

"The paper means nothing."

"I think really...that verbal consent is enough for surgery."

"Patients come along, and they're no better or no worse informed than patients in other (public) hospitals."

"Oh, sometimes the patient signs the consent form at the Admission desk."

When probed about what happens with those patients who sign forms in consultants' rooms, responses by nurses indicate that the form is posted to the hospital or arrives with the patient. These forms are however frequently "incomplete" or "filled out wrongly", and are often not signed by the patient, the doctor or both. One nurse commented that:

"the secretary fills them out - because the doctor hasn't signed. It's witnessed by the secretary, but not signed by the doctor. "

Further, it appears that the consent form arrives after the patient has had surgery. The form is either posted to the hospital with the patient's file or the patient arrives with a signed consent form. Nonetheless, nurses commented that the form "gets lost in the system, and then you have to ring the secretary and ask her about it". Some respondents stated that the Consent Form is on the reverse side of the Clinical Information Sheet, which is usually completed since the information is medically necessary. Nurses concurred that they do not routinely check to see if consent forms are completed since "it's not a nursing issue".

Overall nurses and patients were in relative agreement about the incidence with which consultants and registrars explain consent forms to patients. However, there is little correlation between nurses' (36.7%) and patients' (6%) reporting of the frequency with which residents explain consent forms. One explanation is that patients may remember the consultant's explanation of treatment or procedure, because he/she is 'their' doctor. An explanation provided by a resident whom patients may have not met before is likely to be forgotten. This is possibly one reason why a relatively high proportion of respondents (23.4%) were not sure if they had received an explanation and if so who had provided it. Finally, while only a small proportion of patients (3.3%) stated that the nurse had explained the consent form, a relatively greater proportion of nurses (10%) said that they explained the consent form to the patient.

This incongruity is reasonable, since patients were referring to their experience within the hospital, while nurses were referring to their general work practices.

ii) Length of Explanation

Nurses and patients were then questioned about the length of time taken by the consultant/registrar/resident/nurse to explain the consent form. Nurses were asked:

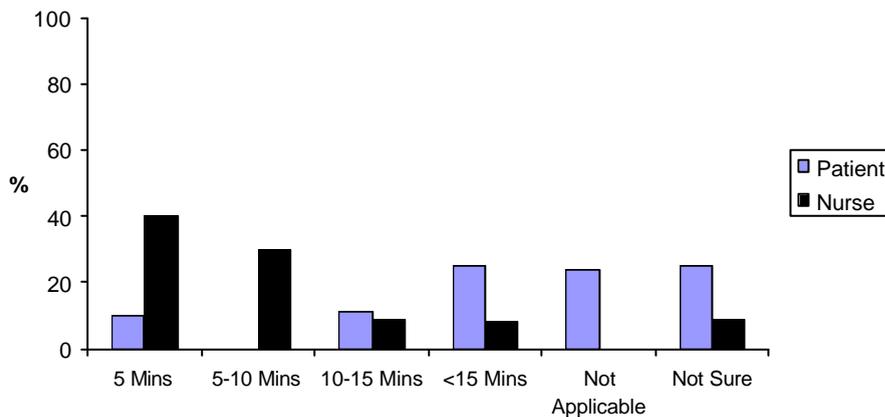
QN2: "In general, approximately how long does the explanation take?"

Similarly, patients were asked:

QP2: "Approximately how long did the explanation take?"

Over a third of nurses (43.3%) stated that less than 5 minutes was spent by health professionals to explain consent forms. In contrast to nurses, over a third of patients (40%) said that the explanation took between 10-15 minutes or longer. Of all patients, 13.3% said that the time spent was between 10 -15 minutes, and 26.7% said that the explanation took longer than 15 minutes.

Graph 1:2 Length of Explanation



Again, some respondents (23.4%) stated that the consent form was either not necessary, or they (26.7%) were not sure how long the explanation had taken because they simply could not remember.

iii) When Consent Form was signed

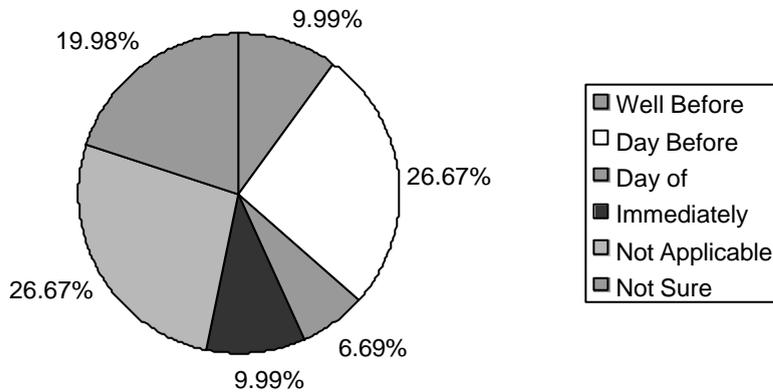
Patients were also questioned about when and where the explanation about the consent form had taken place. Respondents were asked

QP3: "When was the consent form explained and given to you for your signature?"

Over a third of respondents signed the consent form either on the day before (26.7%) or well before (10%). Patients who signed their consent forms well before being admitted to the private hospital commented that they had signed it in the consultant's rooms.

"Oh, I signed it in his rooms, months ago."
"My wife signed it, then...when we arranged to come here."

Graph 1:3 When the Consent Form was Signed



A smaller proportion signed the consent form either on the day of the operation (6.7%) or immediately before the procedure (10%). However, a substantial proportion (26.7%) were not sure when they had signed the consent form. A roughly similar proportion (20%) stated that the consent form was not necessary. Those patients who were not sure when they had signed the form made the following comments:

"God, I didn't know what was happening...I can't remember. "
"I was so worried...about the operation. I just don't know."

"Do most other people you talk to know about these things?"
 "It all happened so quickly."

iv) Where the Consent Form was signed

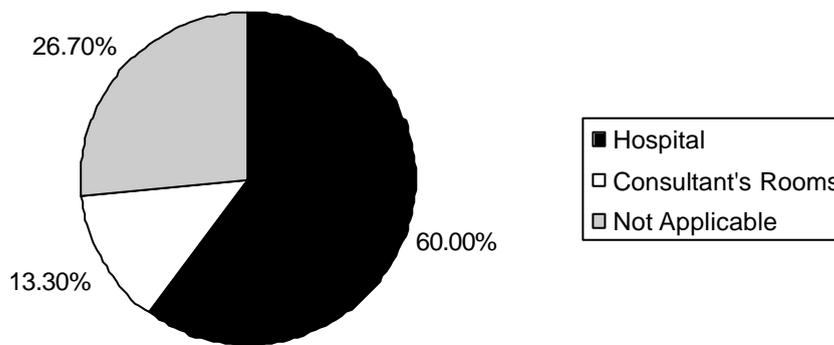
Patients were then asked the following question:

QP4: "Where did you sign the consent form?"

The majority of patients (60%) signed the consent form at hospitals. Some (13.3%) signed the form in the consultant's room, verifying nurses' comments that consent forms are often signed in rooms. Some respondents made these remarks:

"I know that I signed something at the hospital."
 "I remember signing something...I can't remember what though."
 "They asked Mum to sign something when we arrived...I think that it was about giving permission for me to have the operation."

Graph 1:4 Where the Consent Form was Signed

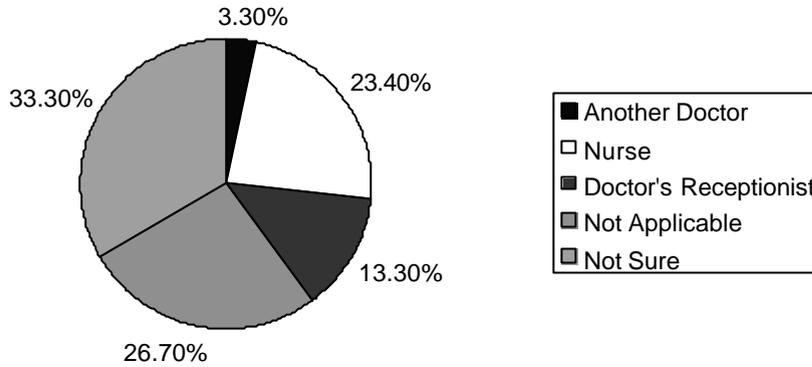


v) Witness to the Patient Consenting to Treatment

Respondents were also questioned about who had acted as a witness to their giving consent to a surgical procedure. Respondents were asked:

QP5: "Who witnessed your signing the consent form?"

Graph 1:5 Witness to the Consent Form



Only 3.3% of respondents said that another doctor had witnessed their signing the consent form. Of those who remembered, 23.4% said that a nurse had witnessed their signing the form, and 13.3% said that the doctor's receptionist or secretary had witnessed their signing the form at the consultants' rooms. 26.7% of respondents reiterated that the signing of consent forms was not relevant to them. The most common response by patients (33.3%) was that they simply could not remember who had acted as the witness. A higher proportion stated "Not Sure" in response to this question than to any of the previous questions. Respondents stated:

"I wouldn't have a clue."

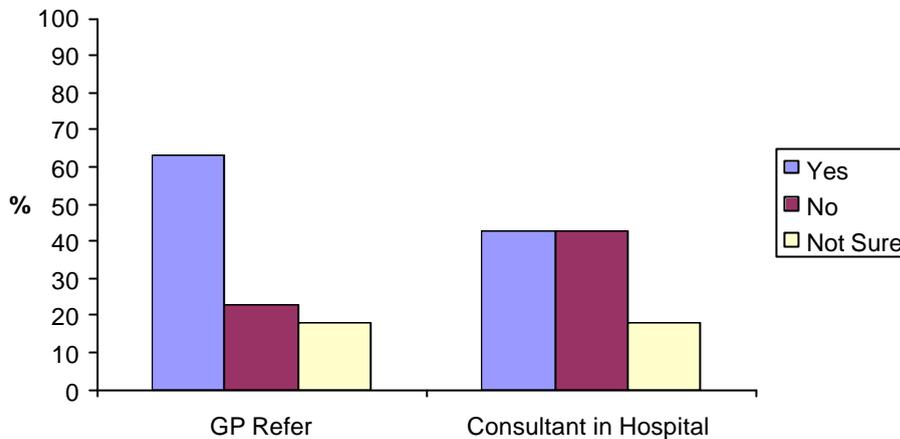
"If I can't remember who gave it to me to sign, I am not going to remember who was there watching me sign it."

vi) Patients' Knowledge of Health Professionals

Finally, patients were asked two questions not directly related to the process by which consent forms are signed, in order to determine if patients were able to differentiate between consultants, registrars and residents. Patients were asked:

QP6a: "Did your general practitioner refer you to the consultant?"

QP6b: "Did you first meet the consultant after you were admitted to the hospital?"

Graph 1:6 Patients' Knowledge of Health Professionals

Responses given by the patients indicated that they were aware that their general practitioner did not have the expertise of a consultant. Some respondents looked at the names given at the head of their bed. The chart gives by title the names of the consultant, the registrar and the resident. Over 60% of respondents stated that they were referred to the consultant by their general practitioner. Only a relatively small proportion were "not sure" as to who had referred them to the consultant and where they had met him/her. These patients repeatedly made the following comments:

"I met him when I came into hospital."

"I've seen so many of them, now."

"I've been in and out of hospital so many times now, that I really can't remember."

"You just get a specialist when you get here."

Nonetheless, respondents demonstrated that they were able to differentiate between the functions and care provided by various doctors.

DISCUSSION

The most consistent response given by all patients to all questions was "Not Sure". Almost a quarter of respondents were unsure about who explained the consent form; when the explanation had taken place; the length of the explanation; and who had acted as the witness.

This finding supports the conclusions reached in the empirical studies cited in the review of empirical literature. These studies reiterated how factors such as unfamiliarity with the hospital environment, the stress of being ill, and not yet knowing the details of their diagnosis and prognosis effectively act as barriers impeding both comprehension and retention of information provided by physicians. It is consistent with the findings of Robinson and Merav whose study shows that "all patients failed to recall major aspects of the interview". The researchers' conclusion that patients had "generally poor retention of all categories of informed consent information" is congruent with the findings of this empirical study (Meisal & Roth 1983:293).

However, the study also indicates that other factors contribute to patients' poor recollection of significant aspects of the consent and information processes. Nurses' responses and comments indicate that one explanation for patients' poor retention of information is the relatively short length of time spent by physicians when giving an explanation about the consent form. Of nurses 43.3% stated that the explanation took less than 5 minutes. On the one hand, it is apparent that physicians may in previous discussions with the patient have given a detailed explanation of the proposed procedure, its side effects and alternative methods of treatment. Thus, physicians may view reiteration of information as pointless, and as time consuming. On the other hand, by placing so little emphasis on the consent form, physicians encourage patients to view the consent form as merely a legal contract. Such a view reinforces the general perception held by patients that the "doctor knows best", and therefore patients do not have to actively participate in medical decisions.

Clearly, if patient participation is to be viable, then physicians have to view and treat the signing of consent forms as an important procedure. Similarly, patients have to be encouraged to view the consent form as much more than "signing a piece of paper so that the doctor can perform surgery".

The other finding of significance is that consent forms are not obligatory at the private hospital. At such institutions, the view adopted seems to be that in being admitted to the hospital, the patient has voluntarily made a contract with the physician. At the same time, it is apparent that private hospitals are seeking to make the signing of consent forms mandatory.

Specific research on this issue would identify the possible ramifications of not utilising consent forms.

Finally, it can be argued that the consent form is merely tangible evidence that the patient and the physician have discussed some aspects of the patient's treatment and condition. The consent form in itself does not demonstrate that communication that is satisfactory to the patient or meets the legal requirements of disclosure has occurred. However, in ensuring that the consent form is signed well before the procedure, and that the explanation is given by the patient's doctor or by the doctor with whom the patient has more than a passing familiarity, one of the outcomes will be that patients begin to appreciate that consent to treatment is in effect "informed" consent. If informed consent is to be more than an empty formality - and possibly a legal trap for unwary medical practitioners and researchers - the rules governing consent forms must take cognisance of the structural, situational and social factors that simultaneously impinge upon the dialogue between the physician and the patient.

CHAPTER V

ATTITUDES TO DISCLOSURE OF INFORMATION

INTRODUCTION

Physicians' attitudes about the provision of information to patients and their assessment of the patient's ability to comprehend information are factors which affect the amount of information which physicians give patients. Similarly, patients' expectations of their doctor, and their attitudes to their illness and the doctor, are also factors which impinge upon how actively patients seek details of their medical condition and treatment from the doctor. In the literature review, it was noted that while patients state that they want information about their treatment, the proposed procedure, its attendant risks and alternatives, patients are less active in soliciting information from their physicians.

The objectives of this chapter are:

To observe the processes by which patients/parents are given information about their complaint, treatment and treatment options. To determine if the decision is "informed". That is, does the patient/parent know and understand details of the procedure, its potential side-effects, risks and possible alternatives to the treatment recommended by the medical practitioner.

To appraise the attitudes of medical practitioner, health care workers and patients with regard to the provision of sufficient information upon the basis of which a patient can make an informed decision.

METHODOLOGY

Nurses, patients and physicians were asked a series of questions about their attitudes to sharing information within the hospital. The number in each category is 30, and all responses are given as a percentage.

ANALYSIS OF THE DATA

i) Patients' and Physicians' Attitudes to Information

Patients were asked the following questions about their treatment:

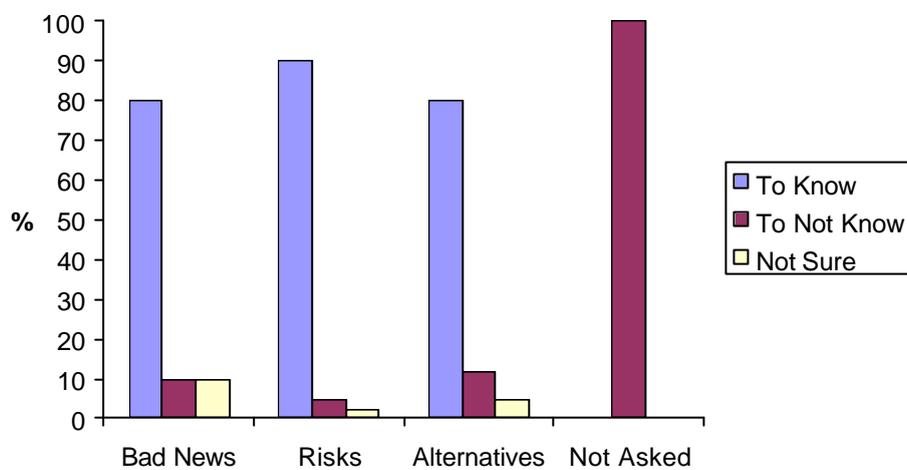
QP7a: "Do you want your doctor to tell you everything about your medical condition, even if the news is bad?"

QP7b: "Do you want your doctor to tell you about major risks in your treatment?"

QP7c: "And about different ways of treating your illness?"

QP7d: "Have you ever asked your doctor not to tell you the bad news?"

Graph 2:1 Patients' Attitudes to Information



The majority of patients wanted to know about all aspects of their medical treatment. None had ever asked the physician to not give them unfavourable news. Those respondents who preferred the doctor to withhold unfavourable news, and not tell them about risks and alternatives, were the terminally ill and some made the following remarks:

- "Long time ago, I said I don't want to know...so...now don't complain. "
- "I know...it's not good, so I don't need to know anything more."
- "I know nothing now...so what?"
- "If they think that it's necessary, I suppose they'd tell me then."

ii) Circumstances where Information is Withheld

Respondents were also asked whether the physician was justified in withholding information in particular situations. Patients were asked:

Do you think that a physician is justified in withholding information from a patient...

QPBa: "if the patient tells the doctor that he/she does not want to know bad news?"

QPBb: "if the information might make the patient anxious or upset?"

QPBc: "if the patient's family ask the doctor not to tell the patient?"

QPBd: "if telling the patient means that the patient might decide to not continue treatment?"

Respondents were fairly evenly divided in their responses to the first two questions. Of respondents 46.7% and 50% respectively stated that doctors were justified in withholding information if the patient had requested to not know "bad news", and if the physician thought that such information might make the patient "anxious or upset". These respondents also made the following comments:

"Some people just shut off. Doesn't make any difference. What they want should be respected."

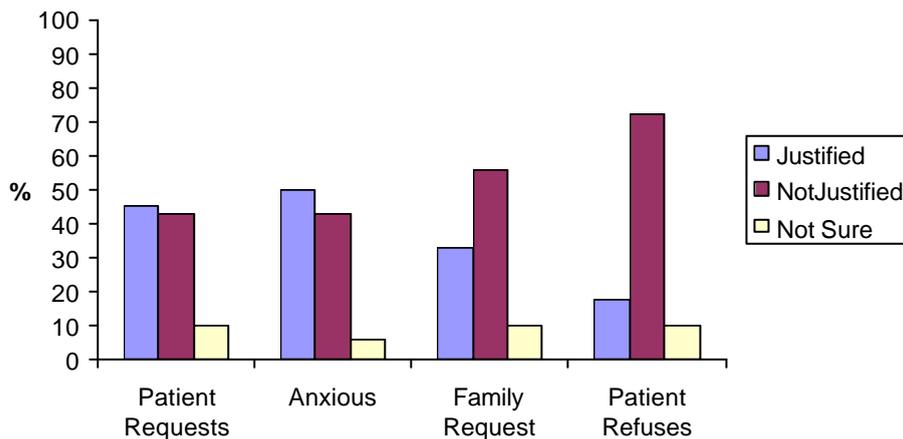
"It's up to the patient...you get sick of just being told things all the time..."

"That's a curly question".

"Would not do the patient any good. Really it would just make them upset."

"At the end of the day, he's been trained...he's the one with the knowledge."

Graph 2:2 Patients' Attitudes to Physicians' Decisions



Those respondents who felt that the doctor should not withhold information stated that:

"The doctor should ensure that the patient has support.
Doctors don't see their role as educators."

"Patient's got to find out why."
"Doctor playing god...got to stop."
"It's your life."

On the other hand, over half the respondents (56.7%) felt that doctors were not justified in withholding information simply because it was requested by the patient's family. Respondents stated that the patient had the right to know everything and that this was particularly important when the patient had a malignant growth. Respondents remarked that:

"Mum always told the doctor to tell me everything."
"I'd rather know than find out eventually."
"You know that something is wrong. If you've got cancer you look at yourself - your hand...and you can see yourself changing. You've got to know."
"I'm his patient. Not theirs."

One third felt that if their family felt that their being informed of their condition or prognosis would make them more upset, then the doctor should listen to their family. They stated that:

"If my husband told them not to tell me. Yes, I suppose."
"He knows me. He knows me better than the doctor."
"The family knows the patient better than the doctor."

Finally, the great majority (73.3%) stated that the doctor should not withhold information about the condition or treatment, simply because the doctor feels that telling the patient everything might mean that the patient would refuse further treatment, and made these remarks:

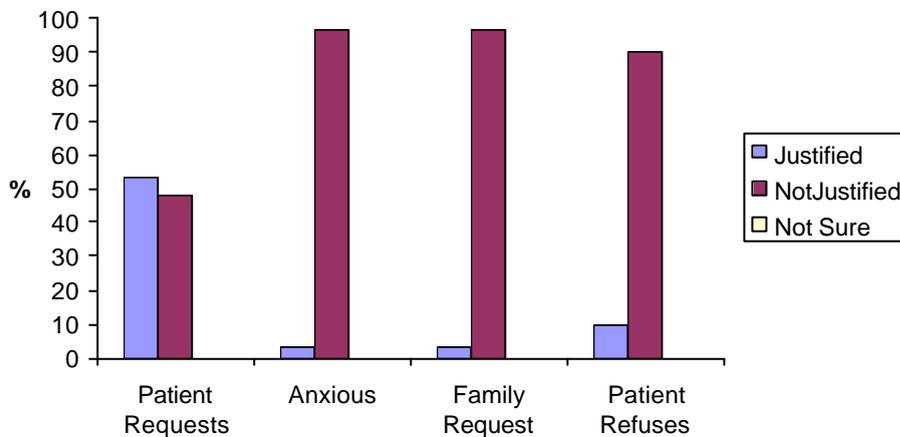
"Patients should have the choice."
"It's the patient's decision. All information must be told."
"It doesn't matter. Some people can't cope, and doctor may have to make that judgement. But, he has to tell them. It's not necessary to tell people unnecessarily unpleasant things. But...he has to tell me."
"If it's incurable, why should I come in here and put up with all this...the treatment really gets to you...it makes you sick. "

Responses to these questions contrast with responses to the earlier questions about risks and alternatives. Patients' responses indicate that they are willing to accept circumstances where their doctor or their families decide that it is more appropriate to withhold information.

Nurses were asked the same questions (QP B a, b, c & d = QN3 a, b, c & d) and their responses are given in the Graph 2:3. A slightly higher proportion of nurses (53.3%) than patients stated that the doctors were justified in withholding information from the patient, if the patient asked the physician to withhold information about their diagnosis or prognosis if it was unfavourable. Nurses made the following explanatory remarks:

- "Every case must be judged as an individual. I know many patients who were better off not having been told."
- "Shouldn't underestimate how well doctors know patients of long standing."
- "Depends. Basically on why patient does not want to know - it's acceptable if the patient is terminally ill."
- "It's his/her decision."

Graph 2:3 Nurses' Attitudes to Physicians' Decisions



Conversely, 46.7% of nurses felt equally strongly that physicians were not justified in withholding information, even at the request of the patient.

- "No patient's going to take it well. But, they have to know... and be told. So they can know what's happening."
- "Soap Box...it's a mistake...it can't be justified."

The overwhelming majority of nurses stated that physicians were not justified in withholding information on the basis that such information might upset the patient (96.7%); at the request

of the family (96.7%); or because the patient may be unwilling to continue treatment that is medically necessary (90%). Nurses' responses differ from those of patients. In comparison to patients, nurses are less willing to accept that the physician can justifiably withhold information from a patient, except at the request of the patient.

Nurses made the following comments in response to the questions. Their comments throw some light on some of the consequences that occur when the patient has not been told of his/her diagnosis.

"It happens... the doctor follows the wishes of the family. Nursing staff pick up that the patient is not to know. Nurses let slip purposely or not purposely. Patients talk to nursing staff about it...sometimes they talk to the doctor...but patient picks it inadvertently."

"They have to be told all the facts. It's no use trying to hide it from them...it makes it worse for them."

"It used to happen all the time...the family say don't tell mum or don't tell Gran. It's got better now."

"It makes it hard for the doctor."

"Why don't they want to know. When the chips are down - people manage."

Mostly patients know."

"It has a lot to do with how the doctor tells the patient in the first place. You don't just blurt it out."

"Most people are anxious and upset when they're told bad news - doesn't mean you don't tell them."

"The doctor has to judge...it has nothing to do with the family."

Comments made by nurses suggest that information about diagnosis is withheld from the patient occasionally, and this leads to problems such as the patient fearing the worst and being anxious without knowing exactly what is wrong. Their remarks show some disapproval of the manner in which information is given to the patient, while at the same time nurses acknowledge that most patients know when the news is unfavourable.

iii) Attitudes regarding Uncertainties about Medical Condition and Treatment

Patients were also questioned about their attitudes to physicians' uncertainties regarding medical condition and treatment. Respondents were told that often doctors can't be sure that they are right when they make decisions, and asked whether doctors should tell patients when they have:

QP9a: "Uncertainties or reservations about diagnosis?"

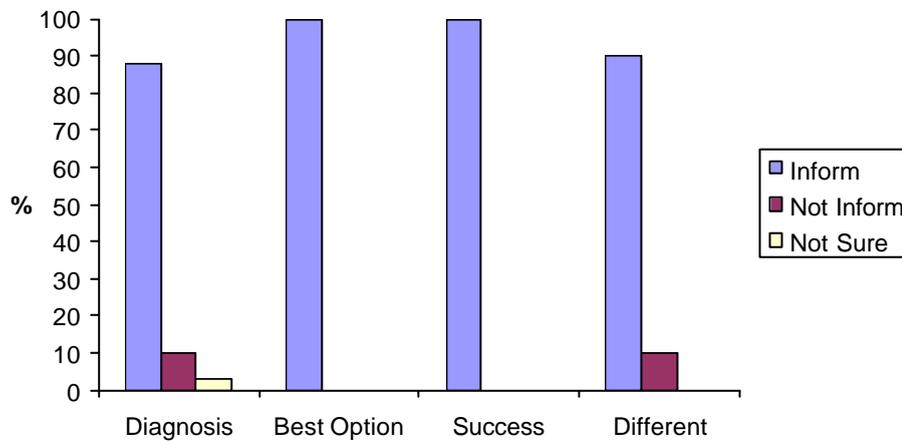
QP9b: "Uncertainties in their own mind about the best course of treatment?"

QP9c: "Uncertainties about whether the proposed treatment will be successful?"

QP9d: "[are there] different views within the profession as to the best approach?"

A substantial proportion of patients stated that doctors should tell them about their uncertainties. With respect to diagnosis 86.7%, and different types of treatment 93.3%, of patients wanted to be informed of physicians' uncertainties. All patients (100%) stated that doctors should mention to the patient when they are doubtful about the best treatment option and if the proposed treatment will be successful. Respondents stated that such information would enable them to seek a second opinion, and give them a better understanding of the options available to them, in terms of treatment or non-treatment.

Graph 2:4 Patients' Views on Physicians' Uncertainties



Only a small proportion of patients felt that the doctor should not inform them if the doctor had reservations about diagnosis (10%) and about different views within the profession as to the best approach (10%). These respondents made the following remarks:

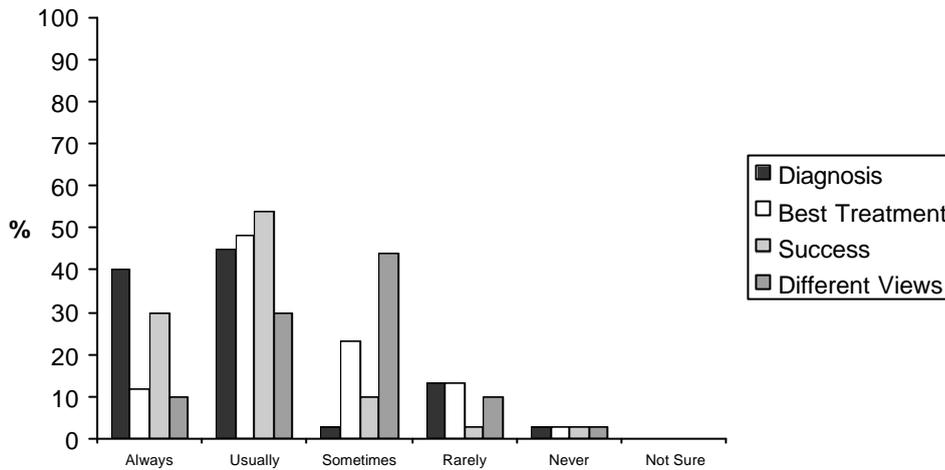
"It should be up to the doctor to discuss with other doctors, and make the decision."

"They tell us so much. Anyway."

"What's the point in telling me...I wouldn't know which to choose."

Physicians (D) were asked the same questions (QP9 a, b, c & d = QD1 a, b, c & d). Emphasis was placed on the frequency with which they gave such particulars to their patients.

Graph 2:5 Physicians' Discussion of Uncertainties



Overall, physicians reported that they "always" or "usually" informed patients about their reservations regarding diagnosis (83.3%); success of the treatment (83.3%). A relatively smaller proportion of physicians (60%) "always" or "usually" informed patients about doubts in their own mind about the best course of treatment, and a still smaller proportion (40%) regularly informed patients about different views within the profession about the best approach.

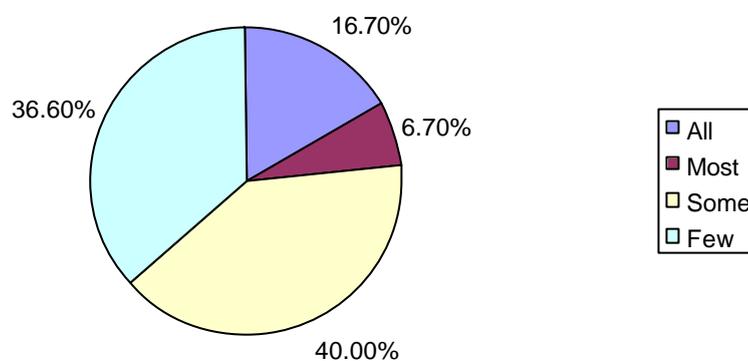
There is some correlation between patients and physicians, in terms of patients' preferences and physicians' disclosure of uncertainties regarding diagnosis and success of the proposed treatment. However, while patients wanted to be enlightened about physicians' personal misgivings relating to the best course of treatment and about different views within the profession as to the best course of treatment, physicians were less likely to volunteer such information.

iv) Assessment of Information given by Physicians

Patients were also asked to assess whether the information provided by the doctor covered issues which they regarded as important. Patients were asked:

QP10: "To what extent does your doctor tell you what your illness is about and how it is going to be treated?"

Graph 2:6 Patients' Assessment of Information given by Physicians

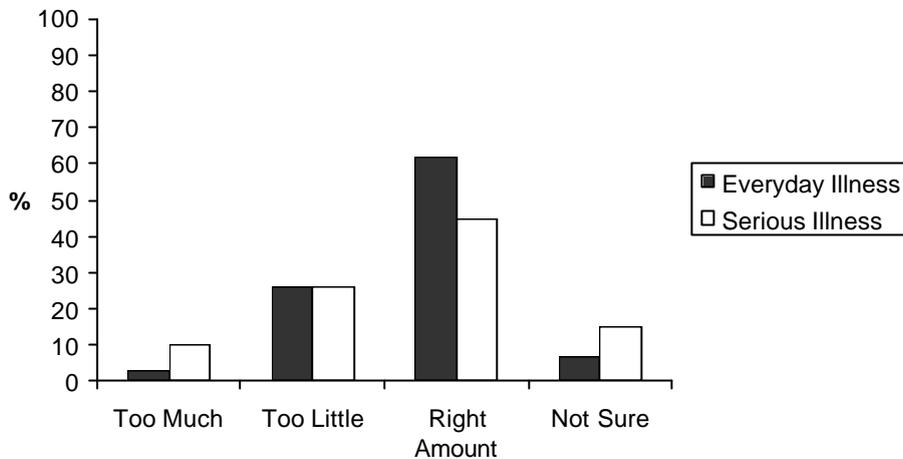


Over a third of respondents (36.6%) felt that only "some of the important issues" were explained by the doctor. A further 40% of patients stated that the doctor's explanation covered a few of those issues which they considered important.

However, patients' responses to the following two questions suggest that patients distinguish between physicians' explanation of the illness and physicians' explanation of issues which are significant to the patient. Patients were asked how much their physician told them:

QP11a: "For ordinary, everyday care?"

QP11 b: "For serious illnesses?"

Graph 2:7 Patients' Appraisal of Information - Types of Illness

Most respondents were satisfied with how much their doctors had told them about their illness. In matters of everyday, ordinary care 63.3% of respondents stated that their doctor told them the right amount. The proportion decreases to 46.7% for serious illness. Nonetheless, slightly less than a third (26.7%) stated that doctors told them too little for both everyday care and serious illness. Only 10% of patients felt that they had been given too much information in the case of serious illness. Patients made these general remarks:

"Some just tell you bluntly. Others very quiet."

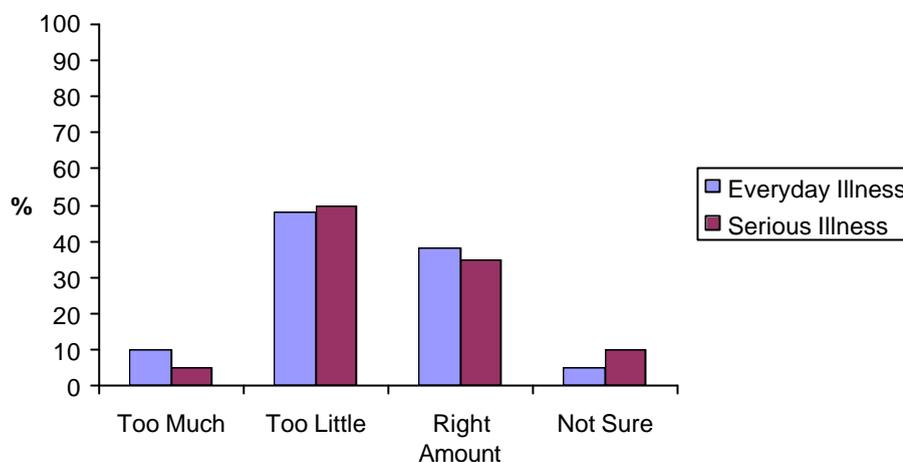
"It varies a lot...you know...some feel uncomfortable and avoid telling. Some are...satisfactory. Boils down to the individual doctor and how he feels about telling you that you've got cancer."

"Don't think that doctors tell you enough at all."

"Younger doctors and the more important the doctor, the more you're a piece of meat."

"They don't tell you, but...they talk in front of you...to other doctors...to the nurse."

Similarly, nurses were asked to assess the information given by physicians to patients (QN4 a & b = QP11 a & b). In contrast to patients, the majority of nurses stated physicians gave patients too little information both for everyday care (46.75) and for serious illnesses (50%). Further, a smaller proportion of nurses observed that physicians told patient the right amount in relation to everyday care (36.7%) and serious illnesses (33.3%).

Graph 2:8 Nurses' Assessment of Information by Physicians

Nurses made the following explanatory comments about the provision of information in relation to ordinary care and serious illnesses:

"It's difficult to guess what the patient wants to know"

"If it's related to the baby...then they don't go into a lot of detail...they hold back until they're certain."

"Problem not with them (patients and parents), but with time. Explanations should be given over time. Opportunity to come back and ask questions is not available...doesn't matter what you tell them...or how much. The first time."

"Patients don't listen...Doctors tell them...told but they don't retain."

"Nurses don't listen to the conversation."

"Oncology is different. Sometime patients don't want to hear."

"If the patient or the parent persist in...inquiries...doctor will be forthcoming...doctors don't ask what you want to know."

"Surgeons give booklets...but don't tell anything predominantly. Can never be too much...not when they've got cancer. "

"Hard to know what's said...said in rooms."

"Tell them, but patients don't hear. Patients don't register until information is repeated by nursing staff. Over and over."

"Doctors are reluctant to qualify extent of illness, unless absolutely positive, approach issue carefully. Not up front. "

"Most of it left up to nurses, but...believe that it's the nurses responsibility."

This discrepancy between nurses and patients is explicable, in part, when consideration is given to nurses' knowledge of the illness, treatment and side-effects. Nurses are also more likely to assess the information in terms of its medical content and relevance to the patient.

v) Physicians' Assessment and Attitudes to Patients

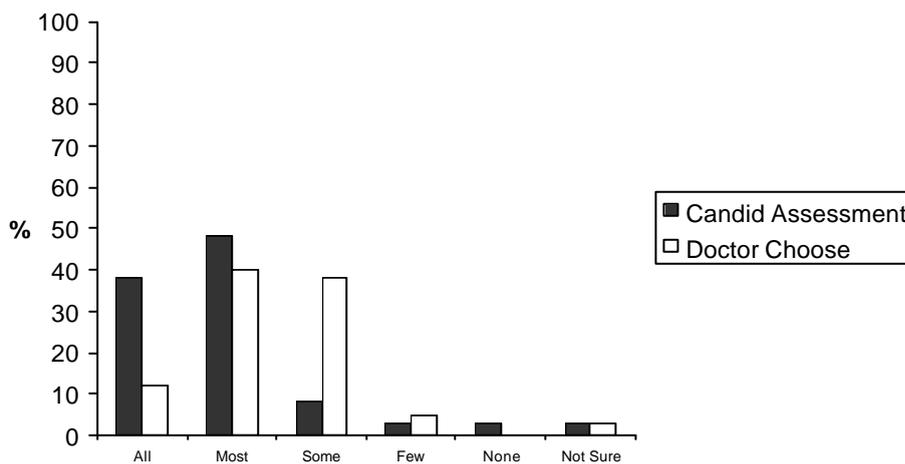
Physicians were asked a series of questions about how often patients wanted the doctor to make a decision concerning treatment and whether patients wanted a candid assessment of their diagnosis. Physicians were asked

QD2a: "How many patients who come to you for treatment want you to give a candid assessment of their diagnosis, even if it is unfavourable?"

QD2b: "In making a treatment decision what proportion of your patients want you to choose the best treatment option for them, rather than simply telling them about the alternatives from which to choose?"

More than three-quarters of the respondents (83.3%) said that "most" or "all" patients wanted a candid assessment of their diagnosis. With regard treatment decisions just over half the respondents (53.3%) acknowledged that patients prefer that the doctor make the decision. However, only a slightly smaller proportion (43.3%) stated that "few" or "none" of their patients wanted the doctor to choose the best treatment option.

Graph 2:9 Physicians' Assessment of Patients



Physicians made the following observations about their patients' and parents' expectations:

"Some just don't want to know or make up their mind."

"It depends whether the decision about treatment is curative or palliative. If it's curative - it's a medical decision. If it's palliative - then the parent or the patient or the child can decide."

It's not a field for people to make a decision - difficult for patients to evaluate."

"I wouldn't expect to make a choice. It would be inappropriate for me to make a choice. But the presentation of information can never be totally impartial."

"Take the view that all parents require a candid assessment."

"Patients and parents want to be told what is the best course. The approach is changing. Now, we explain the condition, mode of treatment, and then get the parents to agree."

"Look, they chose a doctor to make a decision. Patients say, 'it's in your hands, doctor'."

"Well, the parent's behaviour contributes to the child's illness, and they don't really want to know."

"We don't choose...we give guidelines."

Physicians' responses to the questions whether parents/patients want a candid assessment and want physicians to choose the best treatment option suggest that while patients want information, they don't necessarily want to make the decision. Their remarks suggest that physicians believe that parents/patients lack the expertise necessary to make an informed treatment decision.

Physicians were then asked if it was their practice to initiate discussion about diagnosis, the mode of treatment, its benefits and its side-effects with patients of whether they waited until the patient requested such information.

QD3a: "Diagnosis and prognosis of the patient's condition?"

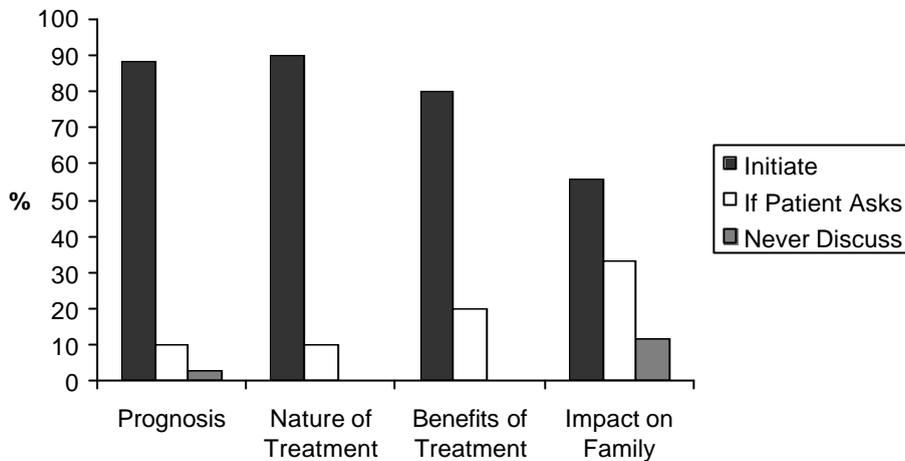
QD3b: "Nature and purpose of the treatment option proposed?"

QD3c: "The potential benefits of the treatment recommended compared to other alternative?"

QD3d: "The probable impact of the patient's condition on the patient's family?"

Overall, the great majority of physicians stated that they initiated the conversation about diagnosis (86.7%); mode of treatment (90%); and benefits of treatment (80%). Less than half the respondents (40%) initiated discussion about whether the patient's medical condition might affect his family. The impact of patients' condition on the family is relevant in relation to the terminally ill, minors and infants with serious complications.

Graph 2.10 Physicians' Discussion of Treatment Issues



Physicians made the following explanatory remarks:

"If the prognosis is poor, and the decision is whether to treat or not treat - then it's difficult."

"Will discuss how it impacts on the family, if it's relevant - chronic pain or cancer."

"Families are a demanding lot."

"The patient is the primary concern...it muddies the issue to talk about the family...unless they ask."

"It's a bit difficult to talk about the family...I try and allow parents to volunteer information...and then discuss."

"Dealing with the patient not the family...tend not to talk about the family or with the family, unless the patient requests. "

"Probably not as often as I should. The time is spent on medical/procedural aspects. I don't know the family or the spouse well."

The remarks indicate that physicians are willing to talk about issues that the patient raises, although they may feel somewhat uncomfortable about discussing such aspects either with the patient or the family. Secondly, it appears that physicians prefer to confine physician/patient discourse to medical and clinical matters. The findings describe a profession where the common pattern is physician initiation of discussion with the patient of medical issues that are related to diagnosis and mode of treatment. Only 10% of physicians do not routinely disclose diagnosis, prognosis and purpose of treatment.

Physicians were specifically asked how often they discussed the possible adverse consequences that may occur as a result of treatment.

"In your practice do you initiate discussion about:

QD4a: "Side-effects, including inconvenience and pain"

QD4b: Risk of disability - 1/1000

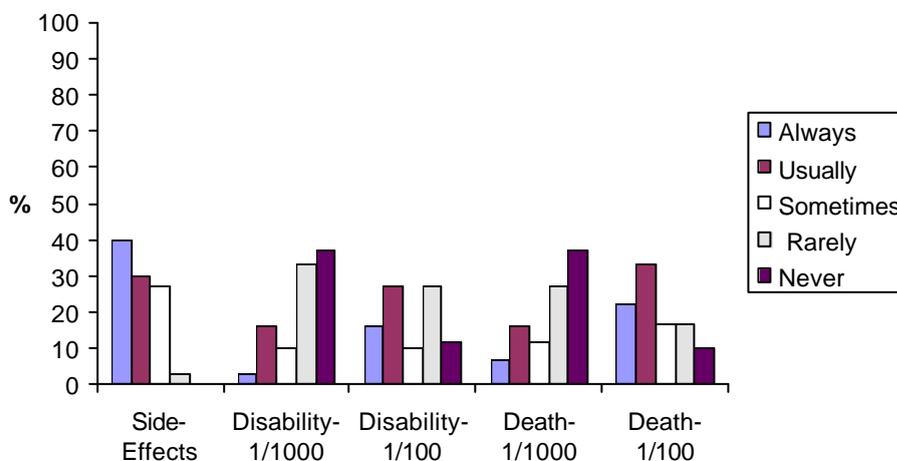
QD4c: Risk of disability - 1/100

QD4d: Risk of death - 1/1000

QD4e: Risk of death - 1/100

Over half the respondents stated that they "always" (40%) or usually (30%) informed patients about side effects. Physicians were less likely to disclose risk of disability or death that are about 1 in 1000. 70% of respondents "rarely" or "never" disclose a risk of disability that is about 1 in 1000; while 63% of physicians don't for a risk of death. Physicians were more likely to inform patients about a risk when the incidence was about 1 in 100. 26% of respondents informed patients about a risk of disability that was about 1 in 100, and 33.3% about a similar risk of death. A further 23.3% said that they routinely disclosed a risk of death that was about 1 in 100 to their patients.

Graph 2:11 Physicians' Discussion of Risks



Physicians made the following explanatory observations:

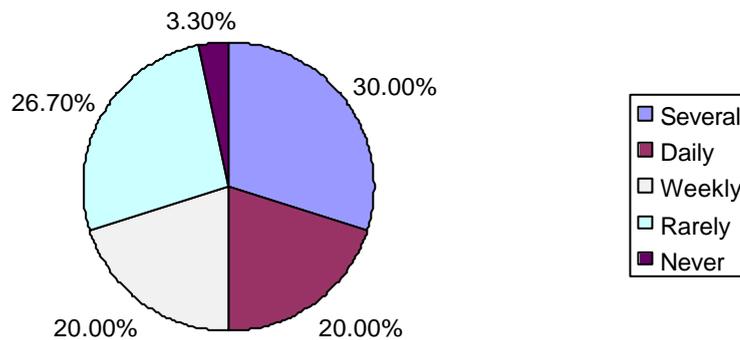
- "The risks are much higher for the treatment of infants in this nursery, about 1:20."
- "Use common sense...it creates anxiety...you have to be careful about what you tell a patient."
- "I'd tell the patient about most risks...unless it's going to make him feel worse."
- "If a patient asks me if the procedure ought to be done, then I would discuss the risks."
- "If the patient is relatively well otherwise, and we're using a drug that is dangerous...we'll inform."
- "They need to know. So we mention it briefly."
- "You weigh the costs...the treatment has risks, but is curative."

It is clear that physicians' disclosure of risks of treatment is related to the seriousness of the consequences and the likelihood of those consequences occurring. Physicians do not necessarily disclose all risks of death or disability from treatment.

Finally, physicians were asked how frequently they evaluate what to disclose to their patients.

QD5: "How often do you find yourself in a situation when you must make a conscious and deliberate evaluation of how much to tell a patient about his or her condition?"

Graph 2:12 Frequency with which Physicians evaluate how much



Physicians are fairly evenly divided on whether they disclose aspects of condition and treatment as a matter of course or whether they evaluate how much information the patients

wants, and how the patient will react to the disclosure. Half the respondents stated that they made an evaluation "several times a day" (30%) or "daily" (20%). 46.7% of physicians stated they that evaluated patients either "weekly" or "rarely".

When questioned about the primary factors that influenced how much physicians divulge to patients, respondents made the following explanatory comments:

"To be honest always...there is a need to inform clearly if it's a surgical procedure."

"How much I think that the patient is going to comprehend."

"My assessment of the patient's condition, of the patient's past life, education and vocation."

"I limit what I say...not how much."

"Depends who's with them."

"Uncertainty on medical part about what's going on. Sometimes we're only relatively sure...so express that there may be problems and hope it goes no further."

"The emotional status of the patient - how people receive bad news. "

"We tell them everything...don't tell them at one sitting, it undermines the relationship."

"Parents have a right to have all information about their child. "

"You pick up when they don't want to know."

It is noted that the frequency with which physicians make decisions about how much to tell patients about their condition does not address the frequency with which the physician decides to withhold information.

DISCUSSION

In response to a series of questions about the provision of information, the majority of patients were unanimous, and emphatically stated that they wanted information about the proposed procedure, its risks and alternatives. These findings are consistent with the conclusions reached by the Report of the President's Commission (1982), the study by the Victorian Law Reform Commission (1987) and various other empirical studies. Further, the physicians' response that over three-quarters of patients want a candid assessment of their diagnosis substantiates the patients' claim that they desire information.

Nonetheless, almost half the patients were willing to justify non-disclosure of information if the physician believed that such information may make the patient "upset or anxious". This

discrepancy indicates the extent to which patients believe and expect physicians to consider their possible reaction and act accordingly. It also suggests that patients believe that physicians should assume responsibility, not only for the physical, but also their mental well-being. That patients expect physicians to take responsibility is substantiated by the fact that over half the physicians stated that most or all patients wanted them to make a treatment decision.

There is little empirical evidence to whether and in what ways information can be harmful. On the one hand, there is clearly a need to define what is meant by "upset or anxious" and negative consequences resulting from the disclosure of information. On the other hand, there is also a need to distinguish between situational anxiety (caused by the illness itself and hospitalisation) and anxiety occurring as a consequence of information. Finally, the mere fact that some information might be upsetting in itself does not justify withholding information.

Conversely, over half the patients stated that physicians were not justified in withholding information at the request of their family. Patients were adamant that they were being treated by the doctor, and that they expected to make the decisions which affected them, unless of course they were too ill or incompetent.

With regard to physicians' uncertainties regarding treatment, there is some correlation between patients' preferences and physicians' disclosure of information regarding diagnosis and the success of the proposed treatment. However, physicians were less likely to divulge information when they had personal misgivings relating to the best course of the treatment and about different views within the profession.

Nonetheless, most patients participating in this study reported satisfaction with the amount of information provided by their physician, in relation to both everyday and serious illness. However, only slightly more than a third of respondents believed that the doctor explained what they considered to be the important issues. This may mean that there are discrepancies between what the physician believes that the patient wants to know and what the patient actually wants to know. As was observed in the Review of Empirical Studies, this frequently occurs because the patient is assimilating only those aspects of information provided by the doctor which relate to the patient's own perceptions of illness. Patients may view the illness in

terms of how it may affect their lives, rather than understanding the illness from a medical perspective.

Lastly in relation to patients, there is little correlation between patients' reporting that they would like all relevant information and their recollection of the consent process. With regard to consent forms, over a quarter were consistently "Not Sure" about various aspects dealing with the consent form. This disparity suggests a few possibilities. Firstly, patients do want to know, but stressed by their illness and unfamiliarity with the hospital environment, they therefore paid little attention to the signing of the consent form (which, after all, for most respondents took place on the day of the operation). Secondly, in conjunction with the above, the explanation given was simply inadequate, hence the patient's poor recollection of it. Finally, patients may view the consent form as a mere formality. The simultaneous operation of these factors possibly results in patients' poor recollection of the consent form. As was indicated by the literature review, various other factors also impinge upon patient behaviour.

All physicians were asked how frequently they initiate discussions with patients relating to various aspects of treatment, alternatives and risks. Physicians' pattern of disclosure is similar to those demonstrated in other studies. Broadly speaking, the majority of physicians usually initiate discussions with the patient about prognosis, nature of treatment, and side effects that are the result of treatment. Physicians were less likely to discuss the possible impact of treatment on the family and their disclosure of risks associated with treatment or a surgical procedure is related to the seriousness of consequences and the likelihood of such consequences occurring. Physicians do not necessarily disclose all risks of death or disability that may be a consequence of a procedure. Finally, physicians were questioned about their practices regarding the disclosure of information. Respondents were fairly evenly divided, with some physicians informing patients of various aspects of treatment as a matter of routine practice, while others evaluated how much and what information was pertinent.

The amount of information that is actually understood is more difficult to establish empirically. This study has analysed self reports made by patients, physicians and nurses with regard to the disclosure of information. It has not sought to establish the veracity of these self reports. It seems evident however, that for information to have been communicated

successfully, it needs not only to have been disclosed, but also "attended to, understood, accepted and put to use" (President's Commission [Vol 1] 1982:90-91). For patients to use information they must pay attention to the physician's communications, interpret and integrate new knowledge with beliefs that they already have, and recall and use that information.

Disparities observed in this study indicate that not only are there fixed limits as to what people can understand at any given moment, but patients, anxious and upset, in an unfamiliar environment, trying to remember new and possibly threatening information, are disadvantaged when trying to absorb the information given by the physician. Lastly, while the physicians participating in this study voluntarily presented information to patients, it is questionable if sufficient time was expended to ensure that patients felt at ease and did understand.

Attitudes to the provision of information and attitudes about acquiring information are important components of the interaction between patients and physicians. This study indicates that not only do patients want to know, but also that physicians are willing to disclose such information. Yet comments made by both patients and physicians indicate that some patients are dissatisfied with the way in which physicians interact with them, and some physicians feel that patients remain far too dependent on them, as well as being unable or incapable of retaining information given. As demonstrated in the literature review, patient/physician interaction is subject to numerous values and beliefs, and oscillates between patients' deference to the medical practitioner, availability of the physician, and the range of barriers from the use of medical terminology to the stress of being ill.

CHAPTER VI

THE TERMINALLY ILL

INTRODUCTION

Increasingly patients and the wider community are beginning to differentiate between life-sustaining and life saving treatment. If the treatment in question is likely to save the patient's life, then the patient can hardly be considered terminally, incurably or hopelessly ill. By contrast, when patients are terminally ill, any treatment that is administered can only be considered life-sustaining. Critical to such treatment is the management of pain. This chapter considers patients' attitudes towards aggressive and supportive measures, as well as the use of analgesics or narcotics to alleviate pain. Physicians were also questioned about their attitudes and decisions relating to the care of terminally ill patients.

This chapter is framed by the following objective:

To observe the processes by which patients/parents are given information about their complaint, treatment and treatment options.

METHODOLOGY

Patients and physicians were asked a variety of questions relative to palliative and curative care, and the use of "do not resuscitate orders." All physicians (30) were questioned about their treatment and care of the terminally ill. Those who specialised in the area commented at greater length. Of patients, only terminally ill patients (15) were asked the following questions. Both patients' and physicians' responses are presented as a percentage.

ANALYSIS OF THE DATA

i) Informing Patients of their Prognosis

Physicians were asked to imagine that they had a patient with a fully confirmed diagnosis of lung cancer in an advanced stage and asked which of the following they would be most likely to tell the patient:

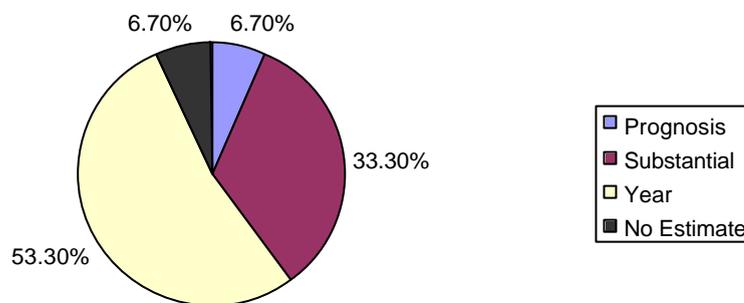
QD6a: "Give a straight statistical prognosis of the disease?"

QD6b: "Say that you don't know how long he might live but stress that it could be for a substantial period?"

QD6c: "Say that you can't say how long he might live, but stress that in most cases people don't live longer than a year?"

QD6d: "Refuse to estimate how long the patient may live, and give a straight statistical prognosis?"

Graph 3:1 Physicians' Practices - Prognosis



The most popular single response given by over half the physicians (53.3%) regarding what to tell a patient dying from rapidly progressing lung cancer was to say that "you can't say how long the patient may live, but stress that in most cases people don't live longer than a year." An additional 33.3% of physicians said that they would say that the patient may live for a "substantial period".

Physicians justified their approach by remarking that:

"You're always going to be wrong if you tell them how long they have."

"People have to make preparations, and they need to know that they don't have that long left."

"You can never give prognostic time - never say 'No hope'. It's unfair to leave them without hope."

"It's not a clinical situation - you can't give figures, but they have to start doing what they want to do...give them an end point to work towards. "

While physicians acknowledged that it was unproductive to give a strict time frame, most felt that the patient had to have some idea of their prognosis.

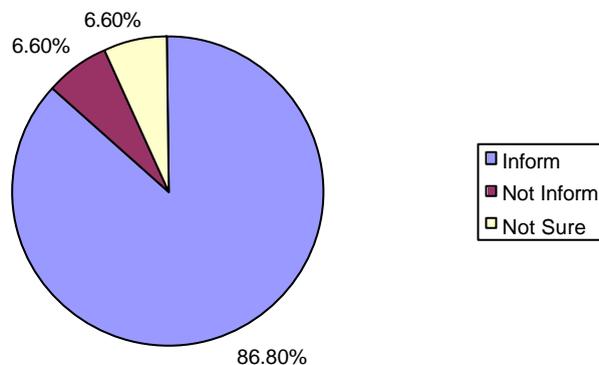
ii) Patients' Preferences regarding Prognosis

Patients were asked a similar question:

QP12: "Imagine a situation where you have cancer which usually leads to death in less than a year for most patients. Would you want your doctor to give you a realistic estimate or not tell you?"

In contrast to physicians' responses, the great majority of patients (86.8%) stated that they wanted to be given a realistic estimate of their remaining life span. This is congruent with an earlier finding of this study, where 90% of patients reported that they want their physician to tell them everything, even if the news was unfavourable.

Graph 3:2 Patients' Preferences - Prognosis



There is little correlation between patients' preferences and desire for accurate information and physicians' preferences to give only a rough indication of the time left to the patient. Only 53.3% of physicians were willing to stress that it was likely that the patient had not much more than a year, while 86.8% of patients wanted a realistic estimate. An additional 6.7% of physicians stated that they would refuse to "estimate how long the patient may live".

iii) Treatment Decisions - Patients and Physicians

Physicians and patients were then asked another set of matched items. Physicians were informed that the cancer had metastasised and was not responsive to the first cycle of chemotherapy, and asked:

QD7: "Do you consider the decision about whether to continue aggressive therapy to be primarily scientific or one which turns principally on the personal values of the patient?"

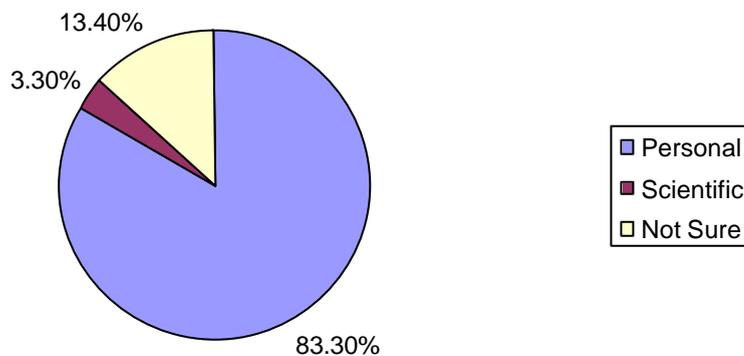
A substantial proportion of physicians (83.3%) stated that the decision was dependent upon the personal values of the patient, and made the following comments:

"There has to be some science to it. "

"Both the patient and the doctor can't make a decision when it's a terminal illness."

"It's not scientific - it's the balance between the treatment and benefits."

Graph 3:3 Physicians' Treatment Decisions - Values



When the question was put to patients, previous chemotherapy was not mentioned, and it was emphasised that the patient would die regardless of aggressive or supportive therapy. Patients were informed:

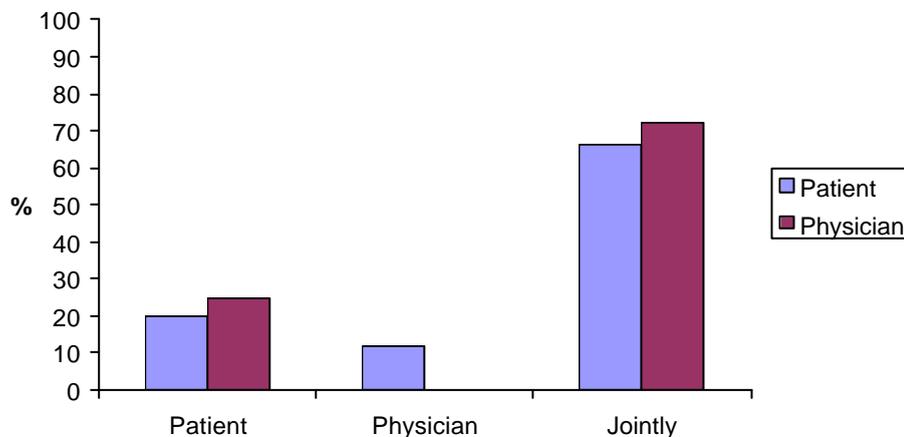
QP13: "There is a choice between aggressive therapy which will probably make you feel sick and will probably not help your condition and supportive therapy which also will not help your condition, but will allow you to be more comfortable. If you found yourself in a situation like this, who do you think should make the decision about treatment?"

Similarly, physicians were asked:

QD8: "In this kind of situation, who do you think should make the decision about treatment?"

The majority of patients (66.7%) and physicians (73.4%) stated that the decision about treatment should be made jointly. Physicians' responses to this question contrast with their responses to the previous question, where 83.3% of physicians concurred that the decision is dependent upon the personal values of patients. This incongruity suggests that while physicians consider the personal values of patients, physicians believe that the decision about treatment remains one which encompasses both medical criteria and the beliefs held by the patient. No physician stated that the decision should be made by the physician alone, while 13.3% of patients stated that the physician should take sole responsibility for the treatment decision.

Graph 3:4 Responsibility for Treatment Decisions



Patients made these explanatory comments about why they felt that treatment decisions were the sole responsibility of physicians:

"The patient can't make an informed decision. "

"It's the doctor's decision at all times. The patient doesn't know much."

Finally, a similar proportion of patients (20%) and physicians (26.7%) stated that the decision should be made solely by the patient. Physicians remarked that:

"The doctor can give the information, but ultimately the decision has to be the patient's. "

"In cancer there is a need for experimentation, and it is necessary to discuss this with the patient."

"I feel unhappy about forcing a patient to have treatment."

iv) Physicians' Practices regarding Resuscitation of Patients

A series of questions related to resuscitation was also asked of physicians in the context of case studies. Each of these questions is analysed in turn.

QD9a: "Now imagine that you have a hospitalised patient in great pain and in the last stages of a degenerative disease. You have been treating her for a long time, and know that she will never leave the hospital again. In the absence of any guidance from the patient, how likely would you be to order that she not be resuscitated in the event of cardiac arrest?"

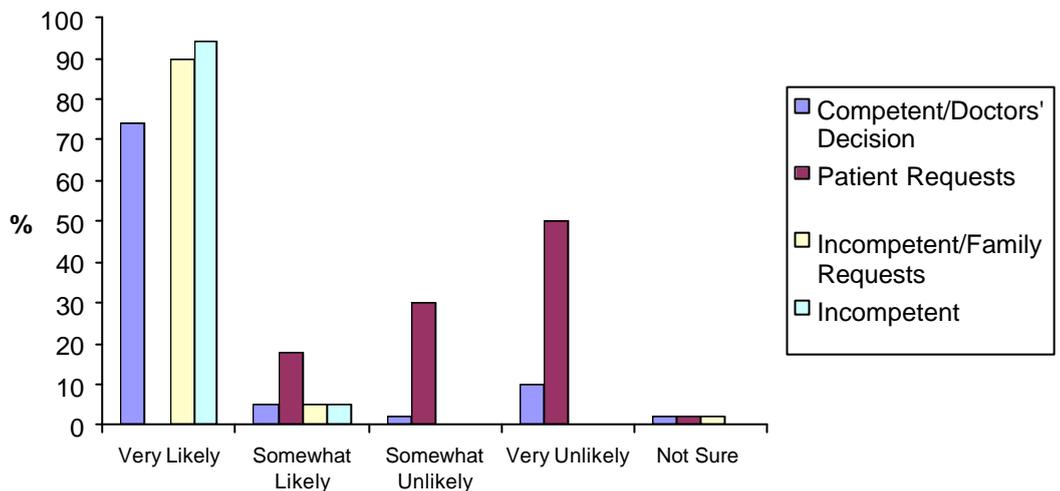
QD9b: "If this person asked you to do everything you could do to maintain her life, how likely would you be to order that she not be resuscitated?"

QD9c: "Now assume that the patient is terminally ill and incompetent. The immediate family request that a not for resuscitation order is placed. In the absence of any guidance from the patient, how likely would you be to place such an order?"

QD9d: "Assume that in the hypothetical situation just discussed, the terminally ill patient has no family and has left no instruction. How likely would you be to place such an order?"

Where the physician had been treating the patient for a long time, almost three-quarters of respondents (73.4%) were "very likely" to place a not for resuscitation order. However, if the patient requested that everything be done to maintain her life, only a substantially smaller proportion of physicians (16.7%) were "somewhat likely" to place such an order. The common response by physicians (50%) was "very unlikely". Two observations can be made from these responses. First, physicians' reports show that they are generally sensitive and responsive to patients' requests. Secondly, physicians are willing to make a decision about a patient who is terminally ill, on the basis of medical criteria, where there is no guidance from the patient.

Graph 3:5 Physicians' Practices - Resuscitation



These assumptions are generally supported by physicians' responses to the last two questions. Almost all physicians (93.3%) were "very likely" to place a not for resuscitation order, if the patient was incompetent, without family and had not personally indicated his preferences regarding treatment or non-treatment. Similarly, 90% of physicians were willing to accede to the family's wishes when dealing with an incompetent patient. Again, this indicates that physicians generally make decisions based on their assessment of the patient's health.

Physicians treating the terminally ill were probed about how not for resuscitation orders (DNR) are placed in the hospital. Doctors tended to vary in their practices. Most did not write

anything in the case notes, and informed everyone who was involved in the care of the patients of their decision not to take further extraordinary measures to sustain the patient's life. These physicians made the following comments:

"I'd talk to a colleague before making a decision. I'd talk to him a few times. I used to write in the notes, but...it's terrible if the patient gets better and reads the notes."

"It's generally given verbally."

"There is no formal process. It's a verbal communication to the resident, the registrar and the nurse."

"The process is verbal - it is difficult to write orders for no resuscitation - people over react. It may be written occasionally, when the junior medical staff are aggressive (regarding treatment)."

"If it has not been discussed with the patient, then it's only a verbal order. If it's discussed, it's written in the case notes."

"The issue is frequently raised by the resident or the nurse. Nurses tend to want to know exactly what to do...".

"The question is often asked by nursing staff...(nurses say) 'you're not going to resuscitate her, are you?' It's a policy decision ...it's ultimately the consultant's responsibility."

At one level, a DNR simply means that both nursing and junior medical staff know not to "press the yellow button" in the event of the patient having a respiratory or cardiac arrest. (The yellow button is next to the patient's bed, and if help is sought, the cardiac arrest team will arrive and immediately commence with a cardiac pulmonary massage and other extraordinary measures.)

However, comments made indicate that in placing a DNR order, physicians also stipulate what extraordinary measures are to be used in the event of a marked deterioration in the patient's condition, and often put a limit on drug dosage. Respondents were divided on what other care was provided, and stated that the extent of extraordinary measures used depended on the age and the overall health condition of the patient. Some respondents stated that the patient would be routinely treated for infection, and chest infections would be actively treated. Blood transfusions continue to be provided. Others stated that antibiotics would not be used to treat infections, and the patient would not be fed intravenously. Hence, it is apparent that a DNR order means more than "do not press the yellow button", and encompasses other measures. Finally, all respondents were unequivocal in claiming that the primary objective is to relieve

any pain suffered by the patient, and to ensure that the patient is kept as comfortable as possible.

When nurses were probed for details on DNR orders, they stated that the primary object was to keep the patient pain free. Nurses informed the researcher that physicians make the following comments when placing a DNR order, both to them and to junior medical staff.

"Don't do anything. "

"Don't do any heroics."

"There's not much more we can do for them."

"Not for bagging. "

"Don't do anything dramatic".

"It's a verbal thing...sometimes they say 'gentle resuscitation'...no idea what that means.'

Almost a quarter of nurses remarked that they initiate discussion about the continuing use of extraordinary measures with physicians.

"Doctors rarely think of it... I suppose because they're not there all the time. Usually it's the nurse who asks the doctor what to do...if the patient has respiratory problems."

"Often nurses will query...you know that the patient's not going to last...there's no point in gastric feeding or blood transfusions...so you ask them. "

With regard to writing an order in the case notes, nurses remarked that occasionally doctors will write that morphine is to be given as required or needed. This means that the dosage of morphine given is increased, and the patient will often die within three or four days. Alternatively, doctors may stipulate in the case notes the extent of extraordinary measures. Nurses stated that:

"Often with a lot of arm twisting, it's written in the case notes."

"We have to ask the doctor to write PRN.(Pain relief as required) in case notes."

"Occasionally, very occasionally, a doctor will write 'in the event of this patient having disruption to their cardiovascular status - no active measures should be taken!'"

This is consistent with comments made by physicians that nurses or junior medical staff frequently raise the issue of the nature and extent of care to be provided to the patient.

The issue of writing orders in case notes or giving a verbal order is complicated because while case notes are obligatory in public hospitals, they are not in the private hospital. The physician

who works at a private hospital tends to keep his notes on the patient, usually at his rooms. Charts completed by nurses tend to contain information on aspects of care such as the patient's medication, bowel movements and blood pressure. Nurses do not have easy access to the patient's previous medical history or to the consultant's notes on the patient. In contrast, at public hospitals, particularly teaching hospitals, medical charts on patients are generally detailed and offer a case summary of the patient's ailment and his/her progress.

Nonetheless, according to nurses working at the private hospital, some physicians leave their notes about the patient at the hospital, and stipulate the extent of extraordinary measures to be used. The point is that doctors may write a DNR order in nurses' notes, if the nurse insists, but the likelihood of such orders being written in case notes is less at a private hospital than at a public hospital.

Finally it is apparent that when patients request that the dosage of morphine is increased, the doctor accedes to their wishes. Nurses commented that:

"It's usually done if the patient asks for a morphine increase, and the doctor will write PRN. in the case notes."

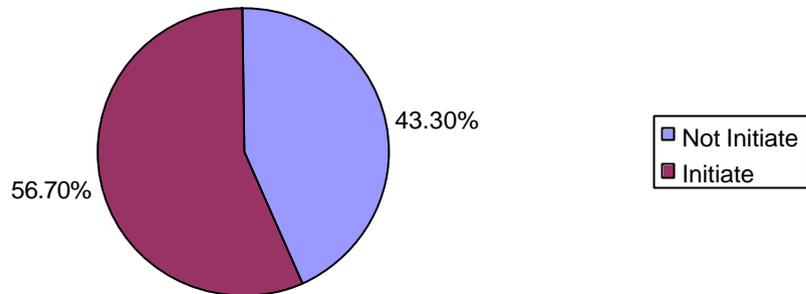
"We talk to the patients and usually the patient tells us, and then we talk to the doctor."

"Generally it is discussed with the patient's family...the patient is often beyond discussion by then."

"When the patient says enough...it's adhered to."

The issue of how DNR orders are placed is sensitive, and respondents stated that it occurs infrequently. Nonetheless, all physicians were asked whether in deciding to place a DNR order on a patient who was in the last stages of a terminal illness, they would raise the issue with patients.

QD10: "Would you initiate a discussion with this patient concerning resuscitation?"

Graph 3:6 Physicians' Initiation of Discussion - Resuscitation

Respondents were fairly evenly divided about initiating a discussion with the patient. Of physicians, 43.3% said that they would not initiate a discussion with the patient. At the same time, in response to an earlier question (QD9a) 73.4% of physicians stated that they would be "very likely" to place a DNR order if they had been treating the patient for a long time, and believed that it was unlikely that the patient would leave hospital. It is likely that physicians place a DNR if they believe that the patient is incurably ill and that the quality of life enjoyed by the patient is poor, without consulting the patient. The primary basis for such a decision is medical criteria.

v) Alleviation of Pain - Physicians and Patients

Lastly, both physicians and patients were questioned about their respective practices and attitudes concerning the use of narcotics for the alleviation of pain. Physicians and patients were asked a set of matched items relating to the doctor prescribing narcotics for a patient in severe pain, and the legality of such prescriptions.

QD11a: "Assume that another patient who is in severe pain and with no hope of recovery has asked you to help ease the pain, knowing that it might shorten his life. Under these circumstances, would you prescribe narcotics to reduce pain, even if the dose required might shorten his life?"

QD11b: "Do you think that the law should allow doctors to administer drugs that might shorten the life of patients in severe pain, if the patient has requested the drug and understands the consequences?"

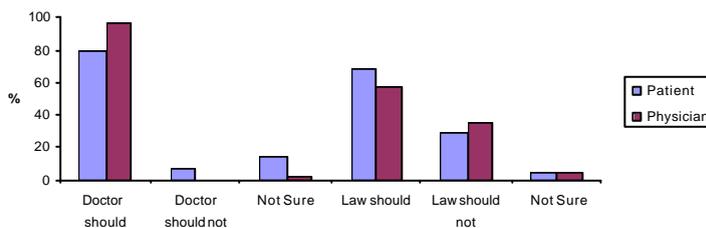
Similarly patients were asked:

QP14a: "Should a doctor be allowed to give drugs to reduce pain, if the patient has requested it, and knows that it might shorten his life?"

QP14b: "Do you think that the law should allow doctors to give drugs if the dying patient has requested the drug and understands the consequences?"

A slightly higher proportion of physicians (96.7%) than patients (80%) said that doctors should administer drugs for the alleviation of pain, even if it shortens life. However, while a similar proportion of patients (73.4) felt that the law should allow physicians to administer such drugs for the alleviation of pain if the patient requests it, a substantially smaller proportion of doctors (56.7%) agreed with the proposition. It is possible that physicians believe that the law had no role to play in the prescription of drugs for the alleviation of pain, and equally has no role in the relationship between doctors and their patients.

Graph 3:7 Attitudes to Pain Alleviation



In responding to the question, physicians who stated that the law should not allow doctors to prescribe drugs made the following remarks:

"The relief of pain is of paramount importance...should not administer the drug with the direct object of shortening life, but to alleviate pain."

"The motive is important - the alleviation of pain or the termination of life."

"There is no law against the use of opiates...doses that are medically justifiable, but...euthanasia - No."

"We don't have the right to do that...it's a dangerous right...and I can't see a method of supervision."

"I am philosophically opposed...I will not help them to kill them. I will help them to die with dignity."

"I really don't want the licence to kill."

"I am distinctly uneasy about administering medication that might terminate life. It is a social problem, and not just one for doctors to resolve. Law and society should look at it... maybe it's an issue of self-administration."

"Medicine can't cope with it...not sure that the community can. The law does not need to. It's not necessary - it won't give me more freedom or the patient."

Their comments indicate that physicians are uneasy about administering a drug with the intent to terminate life. Respondents' remarks suggest that some of them have considered the issue of administering drugs to terminate life, and have concluded that it is difficult to supervise. Some physicians believe that it is an issue for the community to tackle and resolve, and clearly feel uncomfortable about taking responsibility from a medical perspective alone. In addition, respondents raised the issue that the motive underpinning the use of drugs is important, and implicitly acknowledge that such drugs can shorten life. Lastly, it is evident from their comments that some physicians do not believe that the law has a role to play in the interaction between the patient and the physician.

Physicians who stated that the law should allow physicians to administer such drugs made the following explanatory remarks:

"It's only human to relieve suffering...the doctor's role is to relieve suffering - not just life saving...providing that the patient is competent."

"I don't think that one doctor should make the decision...there must be specific mechanisms for decisions. "

"It is ridiculous to imagine that doctors don't make such decisions now, without the involvement of the law."

"It's the motive...personal morality...side-effect might be death. "

"It's respect for the patient's wishes...the doctor should carry it out...perhaps the patient could sign a form."

"Not for the purpose of killing...pain should be relieved, and death as comfortable as possible."

From their comments it is clear that some physicians interpreted the question as one about euthanasia. This was despite the fact that the researcher stressed that the drug was for the alleviation of pain. Again, respondents stated that the motive was important, albeit one of the consequences is death.

DISCUSSION

One of the most obvious discrepancies is that a substantial proportion of patients and physicians want to be given a realistic estimate of their remaining life span, whereas most physicians feel that it is unproductive to give a strict time frame. Secondly, although physicians believe that treatment decisions are dependent on the personal values of the patient, they nonetheless also believe that medical criteria play a significant role in treatment decisions, which should be made jointly.

With regard to the placement of "Not for Resuscitation" orders, physicians' responses indicate some sensitivity to the patient's and the family's expressed wishes. However, if the patient is incompetent, then physicians are willing to make a decision determined primarily by medical criteria. This is consistent with the findings evident in other studies (Kuhse & Singer 1988; Cassoleth et al 1980).

Further, both patients and physicians concur that the use of narcotics for the alleviation of pain, even if the dose required might shorten life, is acceptable. Both groups of respondents stressed that the motive underlying the use of the drug is of paramount importance. With regard to the involvement of the law, a greater proportion of patients than physicians believed that the law should allow physicians to administer drugs for the alleviation of pain, if the patient has requested the drug. This may be because physicians believe that the law does not have a role in the patient/physician interaction.

During the structured interview physicians were questioned about the process by which "Not for Resuscitation" orders are placed. Their comments indicate that the practice of placing such orders, and the meaning of such orders in relation to the use of extraordinary measures, varies considerably. It has been cogently argued that such practices arise from the values and beliefs of the wider community. As yet, there has been little discussion about the issues relating to the

management of pain and euthanasia. It may, however, be appropriate to initiate a dialogue which addresses pertinent issues, in order to ensure that such orders are not placed by surreptitiously using euphemisms in an environment of secrecy.

Finally, an observation. Situational barriers have a greater impact on the terminally ill than on patients undergoing a single procedure on a once only basis. The process of diagnosis, alternative treatment, and then the focus on pain alleviation mean that the patient in the course of receiving either curative or palliative care acquires a series of different doctors, each of whom specialises in a particular area. For instance, a woman who finds a lump on her breast meets her surgeon either at his rooms or at the hospital. Subsequent to the biopsy, the patient is informed, usually by the surgeon, that the growth is malignant, and a lumpectomy is performed. The patient then meets an oncology physician, who treats her with radiotherapy. The patient's case notes have to be sent to the oncologist from the surgeon. In the event that secondaries are located, the patient may have a mastectomy, and chemotherapy. Without counting the registrars and the residents who examine the patient and provide medical attention, the patient in the course of 8 months can meet four different consultants.

Given the levels of stress experienced by oncology patients, it is not at all surprising that nurses working in the area stated that "you have to tell them over and over again, what to do and when to come." Not being able to maintain a relationship with one physician is also likely to contribute to the patient's stress.

If the objectives are to enhance communication between the patient and the physician, to minimise the stress experienced by the terminally ill patient, and to create an atmosphere where decisions about treatment or alternatively non-treatment can be made rationally and reasonably, then further research on the terminally ill is clearly necessary.

CHAPTER VII

TREATMENT DECISION IN LEVEL III NURSERIES

INTRODUCTION

The ethical decisions inherent in caring for infants and children in fatal conditions have not always been so problematic. When treatment options that have the potential to cure infants born at 23 weeks were not available, nurses simply provided comfort-care for the infant and the parents until death occurred. Now, because treatment options are available, questions such as "when should treatment be provided?", "what treatment should be provided?" and "Who decides?" are being raised with increasing urgency and frequency.

This research study delineates the process by which treatment decisions are made and identifies some of the attitudes of doctors in relation to the provision of treatment and care for infants in Level or Phase III nurseries. Level III nurseries provide high dependency care. This is often described as the care that is required by babies who have had pulmonary failure, severe recurrent seizures, and who were incubated and managed either with continuous positive airways pressure or with mechanical ventilation. Level III nurseries also provide low dependency care to infants who have impaired pulmonary function and a fractional oxygen requirement, and who require extremely close observation, including the majority of babies who weigh less than 1500gm. To the medically uneducated visitor, the nursery's dependence on technology is awe inspiring. It is often in this environment that parents in conjunction with neonatologists determine the treatment option appropriate for their child.

The research objective of this chapter is:

To observe the processes by which patients/parents are given information about their complaint, treatment and treatment options.

METHODOLOGY

All physicians (30) and nurses (30) were interviewed about their general work practices. Results of responses are given as a percentage. Some nurses worked in Phase III nurseries. All physicians were asked if they were willing to respond to questions dealing specifically with

neonatology. Three respondents declined to answer all of the questions in the section dealing with infants, and gave "don't know" as a response to some questions. These respondents stated that they lacked the expertise to give an informed response. Those respondents who specialise in neonatology detailed the process by which consent to treatment, and equally importantly, the process by which a decision to withdraw or withhold treatment is determined.

The sample does not include parents whose infants were being treated or had been treated. This was because of the time required both to obtain permission to access confidential medical records, and to seek participation from parents in the research study. Secondly, neonatologists generally did not believe that it was appropriate to interview parents who were visiting their infant in the ward.

ANALYSIS OF THE DATA

i) Attitudes to the Provision of Treatment to High Risk Babies

All physicians were asked what treatment options they would be most likely to give parents when their infant had Down's Syndrome with congenital heart complications. Down's syndrome with complications was deliberately chosen as a case history. In recent years, US and English Courts have handed down regulations which stipulate the extent of care to infants with trisomy 13 and 19 with congenital heart failure. Many of the respondents, particularly neonatologists, stated when answering this question "oh, you're referring to that case in the US or the UK". One of the major reasons for using Down's syndrome was to assess how much physicians knew of judicial decisions which affected their practice.

From their comments it was evident that most neonatologists and some physicians were familiar with *R v Arthur* (British Medical journal 1981:1340) This case involved the prosecution of a medical practitioner for the murder of a defective newborn infant. An infant born with Down's syndrome was rejected by its parents because of its handicap. After consulting the parents, Dr Arthur noted "Parents do not wish it to survive. Nursing care only." It was alleged that he also prescribed dihydrocodeine, a narcotic analgesic to be given orally, not more than once every four hours for the alleviation of pain. The dosage was 5 mg. When the baby subsequently developed pneumonia, antibiotics were withheld, and the baby died at 3 days.

Physicians were informed of the infant's condition, and then asked to choose from the following hypothetical responses:

QD12a: "Give a straight statistical prognosis of the problem?"

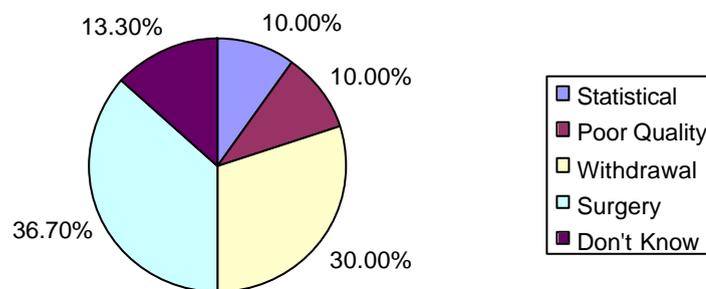
QD12b: "Say that you don't know how long the baby will survive, but stress that the quality of life that the child may enjoy will be poor?"

QD12c: "Suggest that withdrawal of surgery is an option?"

QD12d: "Recommend surgery to correct whatever is possible?"

A roughly similar proportion stated that they would recommend surgery (36.7%) or the withdrawal of treatment (30%). A smaller proportion of respondents chose to either give a statistical prognosis (10%) or stress that the quality of life that the child may enjoy will be poor (10%).

Graph 4:1 Physicians' Practices - Prognosis



Physicians who recommended surgery as the preferred treatment option made the following remarks:

"It's changed...since Baby A...now we talk to the patients and then decide what option to take. But I would initiate the discussion by recommending surgery, and then informing parents of other alternatives."

"There is a case in point...of course it has affected the way we deal with the issue."

"The baby has a potentially lethal condition... which can be fixed...and it has associated problems. Non-treatment is an option."

"Sound out parents...surgery is the easy and soft option."

"Prior to Baby A...well we gave the alternatives...now we recommend surgery."

Respondents' comments indicate that their recommendation of surgery is dependent in part at least on judicial decisions. In this context, the findings of Shaw et al. are relevant. In their survey of paediatricians in 1977, Shaw et al. found that 85% of paediatric surgeons and 65.3% of paediatricians were willing to acquiesce in the parents' decision to refuse consent for surgery in a newborn with Down's Syndrome plus congenital heart disease (1977:589-590). Hence, it is clear that judicial decisions have impinged upon neonatologists' medical practices.

Respondents were then asked what their likely responses would be to parents who were indecisive about consent to surgery when the infant had Down's Syndrome with duodenal atresia. The options available to physicians were:

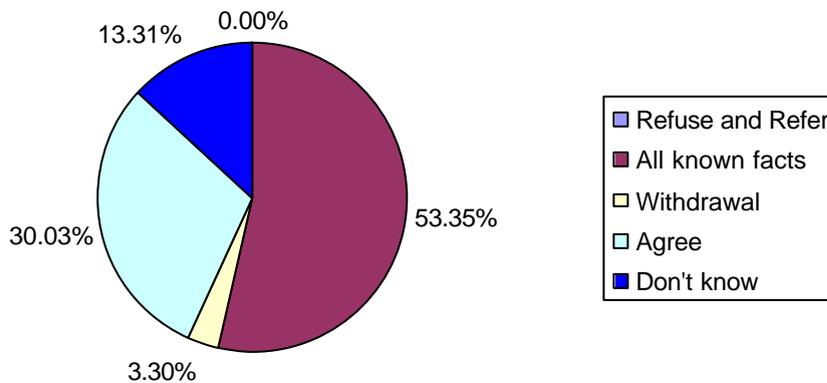
QD13a: "Refuse to operate even with full consent and refer to another surgeon?"

QD13b: "Try to provide them with all known facts about the infant's condition, and then tell them that you will respect whatever decision is made?"

QD13c: "Present the information in such a way that the parents are persuaded to withdraw treatment?"

QD13d: "Present the information in such a way that the parents are persuaded to agree to surgery?"

Graph 4:2 Physicians' Practices - Treatment



The majority of respondents (53.3%) stated that they would present parents with all relevant information and inform parents that they would respect any decision made by the parents. A slightly smaller proportion (30%) stated that they would present the information in such a way as to persuade parents to consent to surgery. Respondents made the following comments:

"Give the known facts and give opinion - tend not to leave parents totally floating."

"Well again, prior to Baby A, things were slightly different. The reality now is that mothers with Down's babies are aborting the babies...so often they don't have to make the decision...there is a screening test for Down's."

"I would tell the truth, nothing but the truth, and not always the whole truth."

"Down's Syndrome is one of these unfortunate conditions...an affliction for the human race."

"Duodenal atresia is treatable...it depends what else is wrong with the infant...not treating the problem means a slow and painful death...there are means of alleviating the pain...but it's a case of what the parents want, and what the choice means."

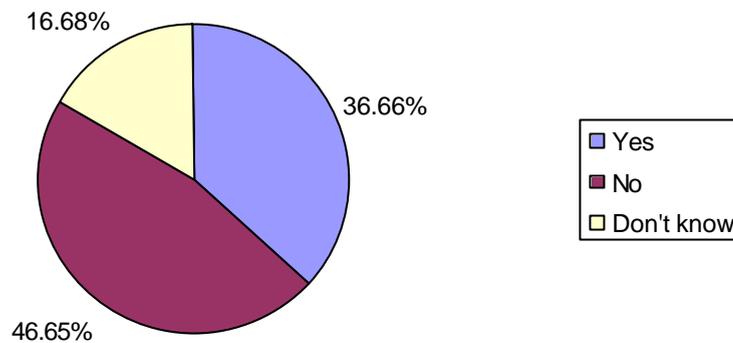
Again, respondents referred to judicial decisions. This finding is supported by those reached by Shaw et al. In the earlier study, physicians were allowed to choose more than one option, and were asked a similar question about a child with Down's and duodenal atresia. Both paediatricians (38.4%) and paediatric surgeons (51.7%) stated that they would present all relevant facts to the parent. (1977:591:592) The question has been the subject of a court case and the BBC's production of Hypotheticals. Literature on the issue indicates that physicians are divided on the issue: duodenal atresia can be effectively corrected by surgery; however, failing to correct it often means that the child will die. The likely cause of death would be the infant's condition, rather than a result of measures not taken by the physician. In view of the medical implications of a decision to provide surgery, physicians' preference for the provision of information (53.3%) suggests that criteria which are not necessarily medical are included in discussion between parents and physicians.

ii) **Physicians' Practices regarding Parents' Decisions**

Respondents were then asked if they would attempt to recommend surgery to parents who had decided against treatment.

QD14: "In the same situation as above, if the parents had decided to withhold treatment, would you recommend surgery?"

Graph 4:3 Physicians' Recommendation of Surgery



Almost half the respondents (46.5%) stated that they would not recommend surgery as a treatment option to parents who had made a decision. These physicians explained that:

"It's the parents' decision. Once they've made a decision, then within limits we have to accept the decision."

"I don't know...go with the parents."

"Well, it would be different if the parents rejected the child because it had a club foot...I have seen it happen...but, for this, well it's the parents' decision."

"You can't deny that parents' decisions are influenced by the physicians' presentation...objectivity...we try to be objective in the presentation."

A relatively smaller proportion of physicians (36.6%) stated that they would recommend surgery to correct whatever is possible, even if the parents had decided to withhold treatment. These respondents made the following remarks:

"I'd try and talk to the parents and suggest that surgery is the most effective option. "

"It's not possible to have a child these days and have no operation if that's an alternative. I think in this sort of situation, we'd try and talk the parents around."

"It can be a slow and lingering death, without the operation...I think that I'd tell the parents that."

Overall, physicians' responses suggest that some are willing to place greater weight on the feelings expressed and decisions made by parents, while others rely more heavily on medical

criteria to reach a treatment decision. Further, it is apparent that physicians differ in their analysis of when parents' decisions override medical criteria. Physicians for their part have generally tended not to view the correction of duodenal atresia in an otherwise normal newborn, or the correction in the newborn with Down's Syndrome with no other anomalies, as heroic (Shaw et al. 1977:594:595).

Shaw et al. asked their respondents to match their perceptions of "heroic" or "extraordinary" treatment with specific cases. Only 15% of respondents stated that the correction of duodenal atresia in a newborn with Down's and no other anomalies was a heroic measure. The majority of physicians (46.7%) stated that it was "the circumstances of the treatment, not the type of treatment" which determined whether it was heroic (1977:594). Shaw's finding supports the conclusion reached earlier that in circumstances such as these, where the physician is dealing with the parents and not the patient, and the parents are required to make a treatment decision that affects their child, then physicians are willing to place greater emphasis on factors other than medical criteria.

iii) Physicians' Practices when Parents insist upon Treatment

Physicians were then questioned about what they would be most likely to do if the parents were insistent upon treatment, when they felt that such treatment was to little avail. Physicians were informed that they:

QD15a: "have a patient for whom prognosis is poor and even with surgery it is statistically unlikely that the neonate will live longer than a year to eighteen months. The parents want everything medically possible done. In this situation, would you strongly recommend that treatment is withheld or withdrawn?"

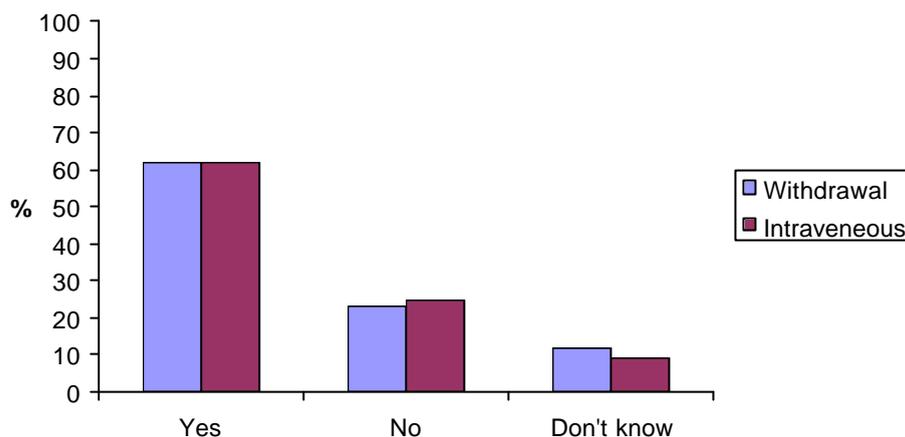
In a follow-up question, physicians were asked whether they:

QD15b: "would feed that baby intravenously, if the baby was not demanding food?"

The majority of physicians stated that although they would recommend to the infant's parents that treatment is withdrawn (63.3%), they would nonetheless feed the infant intravenously

(63.3%). A substantially smaller proportion (23.4%) stated that they would not make a recommendation to parents who had decided to continue active treatment. Slightly more than a quarter of the group (26.7%) stated that they would not intravenously feed the infant.

Graph 4:4 Physicians' Response to Parents' Decisions



Physicians made the following comments:

"You try and comply with the parents' wishes...it's a rare situation...but it does happen."

"You can't not treat the infant...if the parents want it...they'd know anyway."

"We would stress that we're only making a recommendation that treatment is withdrawn...and then we'd support them in their decision and follow through."

"You can only counsel them...can't make that sort of decision without the support of the parents."

"You cannot ride rough shod over parents. ..their feelings are a valid decision. "

" After a while, the parents, the mother who has been insisting on treatment knows that it's futile, and she'll say 'that's enough', and we don't mind waiting till then...because it has given the parents something."

Respondents comments indicate that although parents' wishes do not necessarily override the physician's concern for the child, the parents and their well being are considered by the doctor. This is generally consistent with the findings of other studies which show that neonatologists endeavour to acquiesce to parents' needs where their decision is reasonable.

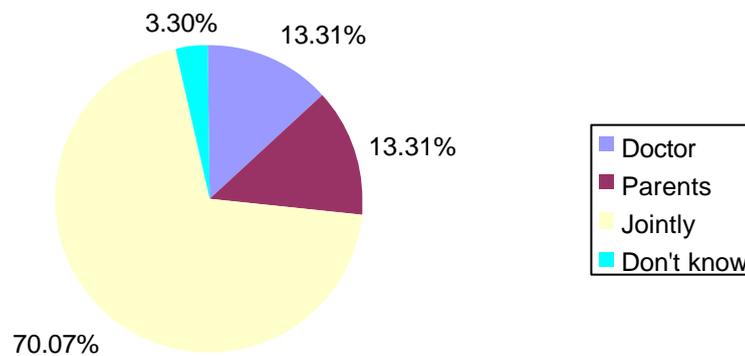
iv) Responsibility for Treatment Decisions

Finally all physicians were asked:

QD16: "Who should make the treatment decision when the prognosis is poor?"

Almost three-quarters of respondents (70%) stated that the decision about treatment, when prognosis is poor, should be made jointly by both parents and physicians.

Graph 4:5 Physicians' Perceptions - Responsibility for Treatment Decisions



Many respondents made the following explanatory comments:

"Parents should not have to make the decision alone...it can be burdensome later."

"It is a community decision. Parents don't have an inalienable right to decide."

"Parents can make the decision...but it's much more difficult without support, and the doctor's support."

"Parents can't make a decision without information and it has to be a reasonable decision."

Doctors' comments make it evident that while they believe that the decision to withhold treatment must be made with reference to medical observations and conclusions, parents' views influence any such decision. Further, physicians do not generally believe that decisions about treatment can be made or should be made on medical criteria alone. Only 13.3% of

respondents felt that the decision about treatment should be made primarily by the doctor. With reference to the earlier question, it is also apparent that physicians are willing to acquiesce in parents' demands for continuing treatment, even when the physician is conscious that treatment is futile.

v) Processes by which Treatment Decisions are Made

Lastly, respondents volunteered information about the process by which treatment decisions are rendered. Many respondents stated that the infant arrives at the Neonatal Unit from the hospital of birth. The parents are involved almost immediately. However, when treatment decisions appear fairly obvious and are based on medical criteria, parents are informed of the procedure and consent sought, but time is not set aside for discussions. Neonatologists acknowledged that when non-treatment or palliative care only is a reasonable option, then lengthy discussions between the physicians and parents or family members are initiated.

The procedure used at different hospitals, as well as the procedure adopted by different doctors, varies. At one hospital, it is a matter of routine practice for two physicians, either a neonatologist and a paediatric surgeon or two neonatologists, to be present during the initial discussion with parents. In effect, this means that there is a measure of peer assessment of decisions made by one neonatologist initially. A social worker is also invited to be present, if the parents so wish. The parents are invited to bring anyone they like to the discussion, which takes place in a secluded room. Respondents commented that some parents bring a priest, others bring their parents. It was also noted that on occasion the father of the child made decisions about treatment without consultation with the mother. Some nurses voiced their concern about this, and added that as far as possible steps were taken to ensure that all discussions took place between both parents and their physicians. This was done to ensure that medical staff were not placed between partners or spouses, and that both partners were given precisely the same information.

The initial discussion took approximately 45 minutes. Physicians and nurses remarked that it "was difficult for parents to comprehend much more at one sitting". Frequently, doctors met with parents at least twice more, for a discussion of similar length. Nurses are informed about the progress of the discussions, and warned if the parents have not been fully informed of their

child's prognosis. Physicians stated that nurses are encouraged to talk to parents, although much of their conversation is a reiteration of information already provided to parents by neonatologists.

Lastly, neonatologists and nurses working at this hospital stated that all decisions about withdrawing or withholding treatment are written down in the case notes. These notes also give details of who participated in such decisions (for instance, the names of the neonatologist, the surgeon, the parents and the social worker) and when the decision was made. Importantly, when the decision is to provide palliative care only, the neonatologist stipulates the nature and extent of care that will be provided to the infant. Physicians and nurses stated that this aspect of care was also discussed with parents.

Some units have adopted a policy with regard to decisions which constitute the withdrawal or withholding of treatment. An example of such a policy or philosophical statement is the following quotation. For the purposes of ensuring the anonymity of the hospitals participating in this research study, the source of the document is not given.

"When there is a question regarding the quality of life, and ethical and moral dilemmas regarding the institution or continuation of life support systems on babies who have profound handicaps or who are grossly immature, these issues shall be addressed by two consultant physicians and if there is doubt then a third opinion should be sought. The opinion arrived at would then be discussed with the parents and a consensus opinion of management arrived at. Generally the reasonable opinion of the parents would be taken as the most important guide for management proposals for that infant. These decisions need to be made in light of such factors as the views of the extended family, community and social supports, religious views, racial or cultural views and the changing pattern of curative medicine. The overriding guideline in the management in all such cases must be in the best interests of the child."

Not all neonatal units have developed such a philosophical statement or adopted the procedure outlined. Alternatively, physicians deal with the parents without another physician being present. In this event, the neonatologist stressed that a team of doctors would have discussed the infant's condition earlier, and that assessment was not made by one physician alone. Further, it is apparent that discussions between the parents and the physician take place in the Level III Nursery, amidst the technology, the mechanical ventilators, and of course the infant.

Upon making a decision to withdraw treatment, parents are encouraged to hold their child, either in a room available for such use, or alternatively take the child home or to a park. All respondents commented that parents occasionally take photographs of their child and have the infant baptised. Alternatively, the infant may be discharged for palliative care only. Parents are informed that they can return to the Neonatal Unit, but essentially, the parents take the infant home to nurse until death.

DISCUSSION

The findings of this research are generally consistent with the conclusions reached by other studies cited in the Review of Empirical Studies. Briefly, neonatologists and paediatric surgeons treat the issue of withholding care with some sensitivity, allowing infants to remain on life support systems, if this is so desired by the parents, although the physician is conscious that continuing treatment is futile. Neonatologists, in particular, appear willing to provide as accurate an appraisal of prognosis as possible to parents. In practice, it is clear that neonatologists continue palliative efforts to sustain the infant's life long enough to avoid undue haste and pressures on parents as they grapple with alternatives available to them.

Physicians' self reports of their practices regarding the disclosure of information and their responses to parents who insist upon treatment which may be futile in the long term suggest that neonatologists are likely to place greater emphasis on non-medical criteria and accommodate the wishes of the parents. The question that remains unanswered is the extent to which parents actually participate in the decision-making process concerning treatment.

Since parents were not included in the sample, reference is made to the studies analysed in the literature review. Studies that examined patient/physician interaction in neonatal units concluded that the major problem was the lack of adequate communication between the physician and the parents, which did not necessarily mean that the right words were not said, but rather that parents heard selectively or interpreted the information from a less than realistic perspective. Pinch and Spielman in their observations of primary child care givers noted that parents when asked about their role in treatment decisions stated:

"...that there was no decision-making required or that they were not involved in the process...and articulated the view that if the health professionals needed to implement a procedure, it should be done" (1990:715).

Parents expressed greater concern about the nutrition, cleanliness and sleep of their infant (Pinch & Spielman 1990:716). Parents appeared to prefer the domain of routine normal newborn care and not the technical aspects of high-risk care. In no other clinical situation are the roles of the patient/parent and the physician so clearly demarcated and delineated. Nonetheless, the question as to why the majority of parents do not actively participate in the decision-making process remains unanswered. In relation to this research, it is likely that informing parents of their child's treatment in a Level III Nursery amidst mechanical ventilators and other technological apparatus contributes to parents' feelings of helplessness and bewilderment.

In the years since Baby Doe was born in 1982, attempts to legislate decision-making on behalf of impaired or defective infants have not succeeded in easing the ethical debate over whose interests, the infant's or the parents', take precedence. Whatever moral, legal or ethical stance is adopted, it remains vital that parents, who remain the primary care givers of the child, participate in treatment decisions that affect the quality of life enjoyed by the infant. Despite the care taken by neonatologists to share information, it is also necessary to ensure that the impact of situational barriers (technological environment), and structural barriers (language used by the physicians and time constraints) are minimised so that parents have the opportunity to participate in discussions relating to their infant's treatment.

Generally speaking the findings of this study show that neonatologists make remarkable efforts to support parents while their infant is in a Level III Nursery. Such efforts are possibly necessary when consideration is given to the broader legal context in which treatment decisions are made. In Western Australia, a duty to provide "necessaries" is imposed by the *Criminal Code*. Section 262 of the *Criminal Code* states that:

"It is the duty of every person having charge of another who is unable by reason of age, sickness, unsoundness of mind, detention, or any other cause to withdraw himself from such charge, and who is unable to provide himself with the necessaries of life, whether the charge is undertaken under a contract, or is imposed by the law. .. to

provide for that other person the necessities of life; and he is held to have caused any consequences which result to the life or health of the other person by reason of any omission to perform that duty."

There is no doubt that "necessaries of life" includes medical aid and medical treatment. Both physicians and parents are aware that the withholding or withdrawing of treatment can be interpreted by the courts as a criminal act. At the same time, it is uncertain whether the doctor's duty to treat terminates if parents refuse to consent to treatment. It is arguable that since the parents have terminated their contract with the doctor, he/she is under no duty to provide treatment for the infant. One of the conclusions that can be derived from this study is that the current legal uncertainty concerning the criminal liability of withdrawing/withholding treatment encourages neonatologists and paediatric surgeons to give detailed explanations of the infant's condition and treatment. It is noted that neonatologists are conscious of judicial decisions which impinge upon their practices.

Hence, physicians confronted with parents who deny that they made or shared in the decision to withdraw treatment have access to case notes which detail when and who made decisions, as well as the extent of information which was given to parents. Physicians' practices are also designed to ensure that their behaviour can be defended in court. Discussions with other physicians and peer assessments of decisions made by one neonatologist all act as safeguard measures. It also means that parents are given information about diagnosis or prognosis which has been the subject of considerable discussion between a number of physicians.

It may not be desirable that legal uncertainty acts as an impetus for physicians to disclose information to parents. Nonetheless, any alternatives, either in terms of legal measures or ethical committees, must consider the possible impact of such measures on neonatologists. This study clearly shows that presently neonatologists inform parents of various aspects of their child's medical condition and treatment, and that such discussions take place over 45 minutes. These physicians routinely consult with their peers about decisions for which they are individually responsible. This study indicates that neonatologists are both supportive of parents and sensitive to their wishes, and with regard to the doctrine of informed consent, such practices are the objective.

CHAPTER VII

MINORS AND CONSENT

INTRODUCTION

The law has long presumed children and adolescents to be incapable of making important life decisions, including decisions about their own health care. The general rule in common law countries is that when minors need medical treatment, consent may be provided by the parent or the legal guardian. (Parents do not have a blanket ability to provide consent. They may only consent to procedures that are medically or therapeutically necessary.) This approach has been increasingly questioned. It has been argued by various groups, health professionals and lawyers, that the consent of a minor of sufficient capacity - one who has an understanding of the nature and purpose of an act - is valid. In Chapter II, studies which show that minors are capable of understanding important aspects of treatment were identified (Weithorn & Campbell 1982; Goldman & Goldman 1982).

The purpose of this chapter is not to ascertain whether minors are capable of giving informed consent, but rather to determine what currently occurs in clinical situations. Hence the research objectives of this chapter are:

To identify who gives permission or consents to medical treatment in relation to each target group.

To appraise the attitudes of medical practitioners, health care workers and patients with regard to the provision of sufficient information upon the basis of which a patient can make a decision.

METHODOLOGY

All physicians (30) were questioned about their treatment and care of minors, although only some specialised in the area. Physicians who had little or no experience in the treatment of minors gave "Not Sure" as a response. This accounts in part for the high proportion of respondents who stated "Not Sure" to some questions. Of patients, only minors (15) were asked the following questions. As was noted in the chapter on methodology, minors generally

did not make comments. Both patients' and physicians' responses are presented as a percentage.

ANALYSIS OF THE DATA

i) Disclosure of Information to Minors

All physicians were asked about their routine practices when disclosing information about minors to parents.

QD17: "When treating minors between 12 to 16, in a non-emergency situation, do you give information about the medical condition and treatment together or separately?"

Two-thirds of respondents (66.7%) stated that their routine practice was to give information to the minor patient and his/her parents together. Many of these physicians qualified their response by saying "Mostly". A substantially smaller proportion of physicians (13.3%) stated that they generally gave information separately. Those respondents who stated "Not Sure" explained that they had negligible experience in treating minors and in interacting with minors and parents.

Respondents who stated that it was their practice to inform both parents and child together made the following explanatory comments:

"It's difficult when the child is seriously ill...with leukaemia for instance. While I would probably inform the parents of the initial prognosis, from there on we all discuss treatment. The child is quite aware that...he/she is very ill. "

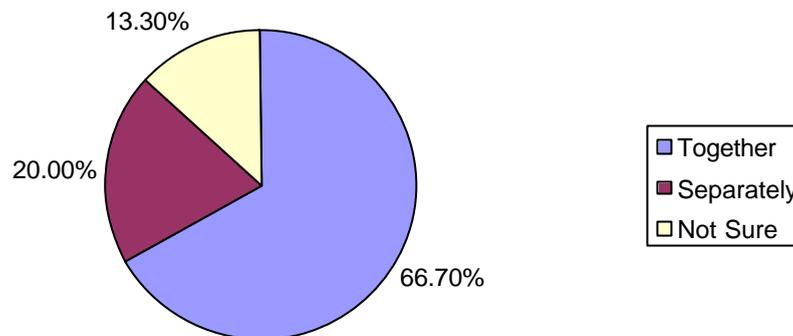
"It depends on the age of the child...I think. Overall, it's better to talk to both...I think that the issue of the minor's right to confidentiality is valid and that his rights have to be respected."

"When it's drug treatment - it's inappropriate for the child to be made anxious, so I tell the parents about the drug and it's possible side-effects... but don't really see the point of going into the details with the child. "

"It is enormously difficult with homeless youth or kids who've just left home and don't want you to contact their parents. We generally just contact the social worker and take it from there."

"I usually try and see that the minor is in agreement with having the parents in on the discussion. "

"It depends if the parents come with the minor. If the patient is 15, then he/she can give consent. I would inform the parents in the course of time."

Graph 5:1 Physicians' Practices of Disclosure

Respondents who stated that it was their practice to inform separately made these comments:

"Well...it depends...if it's personal then I feel that I should talk to the child first."

"If it has to do with contraception...then I would raise the matter with the child alone...unless mother and daughter raised the subject with me...together. Sometimes they're just a little embarrassed."

"It's a major problem seeing kids with sexual problems. I ask the parents, usually the mother to leave the room, and respect the confidentiality of the child. I don't think that it's the way to go. But, 99% of the time the parents will leave the room. I don't communicate with the parents."

"Look, the parents know when they bring their 15 year old son or daughter to me that his/her problem relates to sexual activity...and they don't want to be in the room and embarrass the child."

Overall, comments made by physicians indicate that they are conscious that issues such as confidentiality and respect for minors' rights impinge upon their medical treatment of minors. Where the physician dealt with medical problems arising from sexual activity, then the physician is more likely to respect the minor's right to confidentiality. However, where the medical condition of the child is serious and the proposed treatment is complex and carries risks then physicians are more likely to inform the parents first.

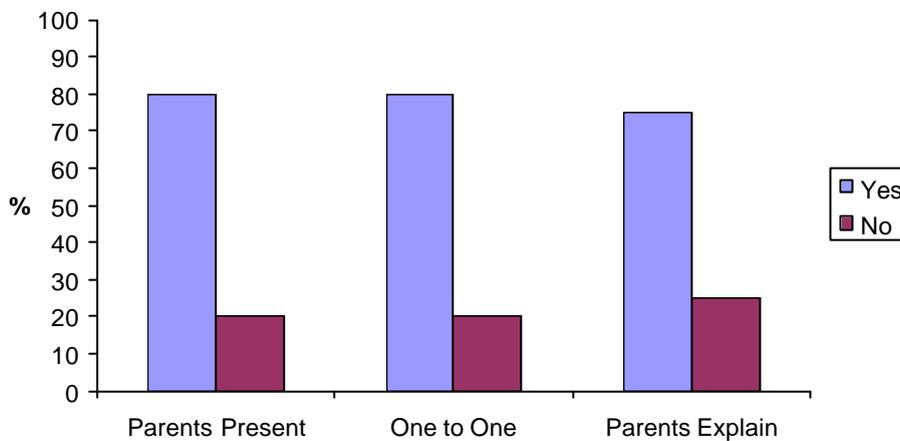
All minors were asked a series of question about who informed them of their condition and treatment.

QP15a: "On each occasion that you have seen your doctor, have your parents been present?"

QP15b: "Did your doctor explain the proposed I treatment to you on a one to one basis, even when your parents were present?"

QP15c: "Did your doctor explain things to your parents who then explained it to you?"

Graph 5:2 Minors' Reports of Disclosure



Almost three-quarters of minors stated "Yes" in response to all three questions. According to minors (80%), their parents were present during a consultation and although their parents were present, doctors explained the treatment to minors (80%) on a one to one basis. At the same time, 73.4% of minors stated that doctors explained aspects of their treatment to their parents who then explained it to them.

From these responses, it is possible to conclude that when a minor is being treated and parents are present or involved, both parents and physicians take care to ensure that the child is not unduly anxious. The nature of the information discussed between parents, the minor and the physician was not questioned in this section. Minors' responses to general questions about risks and alternatives are not significantly different from responses given by adult patients. (See Chapter V - Attitudes to Disclosure of Information).

ii) Consent Forms

All minors were asked the following two questions.

QP16: "Who signed the consent form?"

QP17: "Were you at any stage given a test to determine maturity or competency?"

All minors (100%) stated that their parents signed the consent form and that they were not given any test to determine maturity.

These comments suggest that minors, when accompanied by their parents, are quite happy for their parents to take care of them, or more perhaps accurately to continue to take care of them. For these minors, their parents' involvement was not an issue, indeed they expected their parents to be involved and with them.

Minors made the following comments in response to QP16:

"Well. Mum does all those things...I don't know...but if there was something to sign then Mum signed it."

"I think that Mum signed it when we went to see the doctor. "

In response to QP17, minors made these remarks:

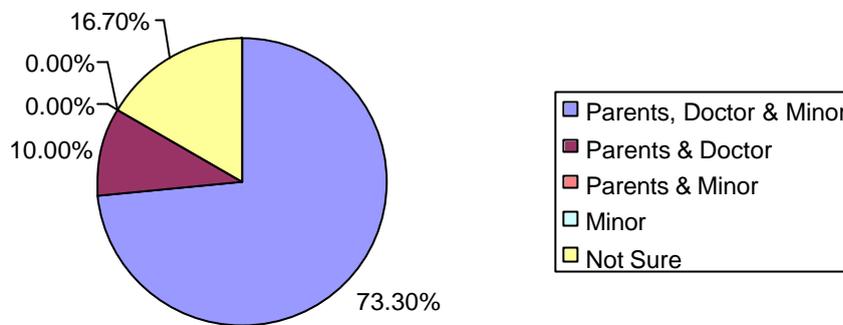
"Well, they didn't need to because my Mum was with me."

"My parents are here too - when Mum goes home, Dad stays with me...so they talk to the doctor."

iii) Treatment Decisions for Minors

Physicians were asked about their practices in relation to treatment decisions.

QD18: "Do you think that decisions about medical procedures which are complex and invasive should be made by parents alone, parents, the physician and the child, or the physician and the child, or the parents and their child?"

Graph 5:3 Treatment Decisions for Minors

The majority of physicians (73.3%) stated that treatment decisions should be made by the parents, the minor and the physician. A substantially smaller proportion (10%) stated that such decisions should be made by the parents and the doctor only. This corresponds with earlier comments made by physicians that it is inappropriate to make a child unduly anxious by providing them with the details of a medical procedure. None of the physicians stated that decisions should be made by doctors alone or parents alone.

Physicians were also asked a series of questions relating to hypothetical situations.

QD19a: "Imagine a hypothetical situation where you are treating a minor, who you think is sufficiently competent to participate in the decision-making process. He has a chronic degenerative disease, and his parents ask you not to inform him of his condition. How likely would you be to acquiesce with their request?"

QD19b: "Assume that another minor's preferred option regarding treatment does not coincide with his parents' decision. How likely would you be to persuade the parents to accept the child's decision?"

QD19c: "Now assume that you are treating a 15 year old patient who has just had a severe asthma attack. In trying to determine what triggered the attack, your patient voluntarily informs you that she is on the pill. How likely would you be to divulge this information to her parents?"

In relation to QD19a, over half the respondents were either "Very Likely" (26.7%) or "Somewhat Likely" (26.7%) to concur with the wishes of the parents. Slightly over a third of respondents were either "Somewhat Unlikely" (16.7%) or "Very Unlikely" (10%) to acquiesce in the parents' request that the physician not inform the minor of his condition. A fifth of respondents stated "Not Sure".

Physicians who stated that they were likely to concur with the parents wishes made these remarks:

"I would try and talk to the parents...talk them out of it. Kids guess...and the kid gets very lonely without talking."

"I'd discuss it with the parents, and discuss it and encourage them that it is best if the child is informed...yes, it happens."

"It's a lead up to a pretty big argument. I'd try and change the parent's mind. I have told in the past - if the kid asks me a direct question, then I would not lie."

"The child needs to know the truth...I'd try and persuade the parents. Parents are over-protective."

"I'd accede to the parent's wishes. There's plenty of time - I'd tell if the child asks."

"Accede reluctantly...it hinges on whether the child asks a specific question. "

Those who were unlikely to acquiesce with the parent's request made these comments:

"It depends...I suppose on how strongly the parents feel that the child is not informed...but you have to tell eventually."

"As a doctor, I would lose the confidence of the parents if I informed the kid. I would strongly recommend to the parents that the kid is told. I'd tell if the kid directly asked me. There was a child here who was not informed...both medical and nursing staff were asked to not tell the child. The child was very upset that the parents had not told...never been trusted with the truth. It was a drama, and everything eventually came out...but the stress for us and for the child, who had imagined the worst - that the disease was incurable."

"I would try and persuade the parents that it was wrong - I can't really go against them...I would not be on speaking terms with them if I did. So I'd work on them."

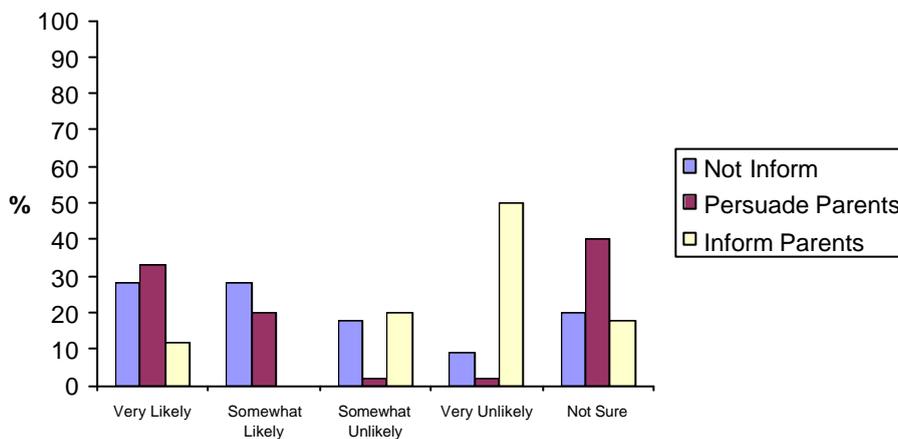
"I don't think that the parents' wishes are reasonable."

Overall, the comments made by both categories of respondents indicate that physicians generally believe that it is more appropriate to inform the child of his/her condition. Physicians who stated that they were likely to accede to the parent's wishes remarked that they would try and persuade the parents to change their mind, and that they would and have in the past informed a child, when the child asked them a specific question. Physicians who stated

that they would be unlikely to concur with such a request referred to the anxiety not informing can cause a child. In effect, physicians' explanatory comments indicate that they are aware that while they are treating the minor and responsible for the patient's well-being, albeit a minor, they are in fact responsible to the parents. Hence, physicians seek to persuade parents to change their mind and inform the child.

Physicians' comments also indicate that where they believe parents' requests to be inappropriate, they will attempt to alter the decision made by parents.

Graph 5:4 Physicians' Practices - Disclosures to Minors



In relation to QD19b, over half the respondents were either "Very Likely" (33.3%) or "Somewhat Likely" (20%) to try and persuade the parents to change their mind. A substantially smaller proportion were either "Very Unlikely" (3.3%) to attempt to persuade parents to accept their child's preferred option. A high proportion of physicians (40%) stated "Not Sure". Almost all respondents asked the interviewer whether one option was in fact better than the other, and were informed that each treatment option had relative merits. All respondents who stated that they were likely to persuade the parents to accept their child's wishes stated that they would only do so if the option preferred by the child was also their preferred option or if there was little difference between the two options.

Some of the physicians who stated "Not Sure" commented that they could not think of a situation where two treatment options were roughly similar, and were therefore uncertain about how they would react in such a situation.

Finally, in response to QD19c, almost three-quarters of respondents stated that they were "Somewhat Unlikely" (20%) or "Very Unlikely" (50%) to divulge information obtained during a consultation about contraception to the parents of the child. Less than a fifth of respondents were "Very Likely" (13.3%) to inform parents that their child was on the pill. In response to this question, the proportion who answered "Not Sure" (QD19c: 16.7%; QD19a: 20% & QD19b: 40%) was relatively smaller. This suggests that generally physicians have definite views about minors and contraception.

Physicians who stated that they were unlikely to divulge such information to parents made these explanatory comments:

"I'd tell her that she should tell her parents."

"I'd ask her if her parents knew, and say to her 'Don't you think that they should know?'".

"Parents really ought to know...try and convince her to tell her parents".

"Encourage patient to tell her parents. There's too much responsibility placed on the doctor for family problems. Not up to us to sort out...I don't think that it's fair - the whys, wherefores and legalities. It's the doctor who makes the faux-pax - when either party is not fully informed. "

"She would not have got it from me."

"You've gotta say that you wouldn't."

"As a specialist, I'd buy out. I'd let the local doctor know, and leave it with him...find out if he put her on the pill. If he didn't, I'd tell him and let him decide what to do about it."

"Well, I didn't put her on it...I just found out and I didn't ask."

Physicians who stated that they were likely to inform the parents of the child made the following remarks:

"The parents should know...I'd try and tell her to tell them if they did not already know... and I'd tell her that I'd tell them."

"Oh...encourage her to tell...tell her I'd have to tell."

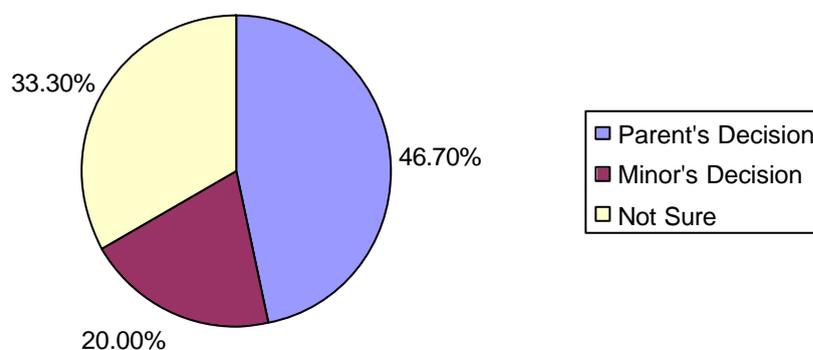
Physicians' comments indicate that they prefer to respect the minor's right to confidentiality with regard to the use of contraception. A number of respondents stated that they would try and persuade the minor to inform her parents, and voiced their relief that they had not provided the prescription.

Finally, minors were asked about their expectations of the physician.

QP18: "Imagine a situation where your decision about treatment is different from your parent's decision. The doctor thinks that both treatments are more or less the same. Would you expect the doctor to listen to you or to your parent?"

Almost half the respondents (46.7%) expected their physicians to accept their parents' decision, while a third (33.3%) stated "Not Sure". A slightly smaller proportion stated that they would expect the doctor to accept their decision.

Graph 5:5 Minors' Expectations of Physicians



DISCUSSION

Minors' responses illuminate little, other than confirming that none of the hospitals who participated in the study seek to ascertain if the patient is capable of making decisions in relation to his/her health, and participating in the decision-making process. From a theoretical perspective, it is evident that minors with parents (with whom they live and are not estranged from) do not expect to participate in the decision-making process in a meaningful sense, since

it is presumed that their parents will play that role. Such a presumption is made not only by minors, but by the community at large.

Physicians' responses indicate that they are conscious of the complex issues that can arise when treating a minor. When asked about their likely response to parents who requested non-disclosure of information to their child, although over half the respondents stated that they were "Very Likely" or "Somewhat Likely" to acquiesce in the wishes of the parents, these respondents also stated that they would endeavour to persuade the parents to inform their child. Physicians' concern that the minor patient be informed stems from two major sources: medical and confidentiality. Firstly, by medical, what is meant is that the physician is anxious that failure to disclose will have a negative impact on the child's health. Hence, physicians commented that while they may inform parents first and separately of a serious prognosis, they would then discuss various aspects of treatment with both parents and the child present. Secondly, physicians perceive a need to maintain confidentiality, particularly with regard to sexual matters. A substantial proportion of physicians (70%) stated that they would be unlikely to inform the parents of a child who voluntarily informed them that she was on the pill.

Physicians' comments indicate that they are conscious that parents are legally responsible for the child, and that the needs and wishes of parents cannot be ignored while their child is being treated. Hence the attempt to persuade parents to accept a decision which the physician believes to be to the benefit of the child. In this sense, physicians' general pattern of behaviour in relation to the treatment of minors is not dissimilar to their treatment of the terminally ill or seriously ill infants: physicians tend to persuade parents or patients to accept their decision if they believe it to be medically valid.

In all, this study indicates that there is a general presumption that parents will play an active role in relation to the medical care provided to their child. Accordingly, while the wishes of the minor may be considered and met, there is little expectation on the part of physicians, at least, that the minor will participate in the decision-making process, as attested by a physician's comment: "If the patient asks a direct question - then I will answer".

Empirical studies reviewed in Chapter II conclusively show that minors, particularly those 14 or over, are capable of being actively involved in treatment decisions, and comprehend aspects of treatment and care (Weithorn & Campbell 1982; Goldman and Goldman 1982). The findings of research do not lend support to policies which deny adolescents the right to self determination in treatment situations, on the presumption of incapacity to give consent. However, minors can participate only however when they are given the opportunity to do so. This study indicates that the provision of health care to minors does not consider their capacity to participate in decisions which affect them, while their needs and wishes are considered by physicians. The onus remains on health professionals to present information in such a way as to facilitate or ensure understanding by the minor, and on society to appreciate that minors are capable of participating in treatment decisions.

CHAPTER IX

IDEOLOGY AND MEDICINE

INTRODUCTION

Anthropological and sociological approaches to the provision of health care have examined informed consent as occurring between two parties, each situated in an ideological setting that may differ from the others to varying degrees (Drummond and Mason 1990; Calnan 1990; Cunningham - Burley 1990). Ruthven defines ideology as:

"that never fully articulated system of assumptions by which a society operates and which permeates everything that it produces... Ideology is manifest in the ways we represent ourselves...and determines, for example what is deemed to be socially acceptable behaviour for men and women." (1989:22)

Many commentators have critically appraised the values, beliefs and rules which underscore patient/physician interaction from such a perspective. For example, in relation to patient participation, recent critiques on a range of disparate areas, including the health of families (Backett 1990:57), women's reproductive health care (Porter 1990:182), and the components of medical ideology (Meisal and Roth:1982) all acknowledge the influence of the patient's beliefs on the patient's behaviour.

Any analysis of the processes by which consent is obtained reflects the values of what participants believe to be appropriate modes of conduct and behaviour within the medical arena. The President's Commission for the *Study of Ethical Problems in Medicine and Biomedical and Behavioural Research* (1982) took the approach that the "issue is the definition of the patient-professional relationship, as well as the appropriate role of formal and informal modes of social regulation in shaping it". (1982 [Vol 1]:31). Clearly, the resolution of these issues requires an appreciation of not only the processes by which consent to medical treatment is acquired, but also an understanding of the values that circumscribe patient/physician interaction.

In this chapter some of the major values that underpin physicians' attitudes about the disclosure of information and patients' attitudes about information are briefly appraised. The

emphasis is on how such unspoken assumptions and beliefs affect the dialogue between the patient and the physician. For instance, some patients may differ both from other patients and physicians because they believe that they have no business interfering in the exercise of medical judgment. Such patients do not think that they are transferring their "right to decide" to the physician, because they do not believe that they have any right to decide about medical treatment.

The objective of this chapter is:

to appraise the attitudes of medical practitioners, health care workers and patients with regard to the provision of sufficient information upon the basis of which a patient can make an informed decision.

METHODOLOGY

Nurses, patients and physicians were asked about their attitudes to sharing information within the hospital. The number in each category is 30, and all responses are given as a percentage.

ANALYSIS OF THE DATA

i) Patient Participation

Physicians and patients were asked a set of matched questions about patient participation in the decision-making process. Physicians were asked the following question:

QD20: "Do you believe that increasing the patient's role in medical decision-making is likely to improve the quality of medical care or reduce the quality or have no effect?"

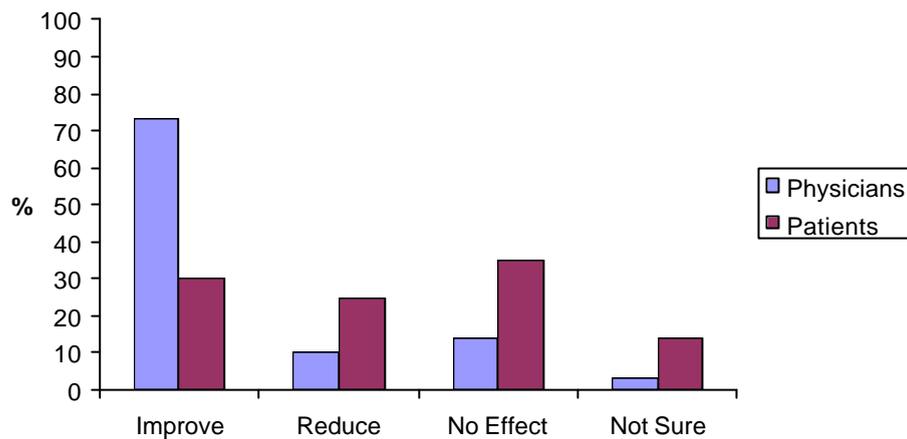
Similarly, patients were asked:

QP19: "Do you think that if the patient had more say in what was to happen in medical treatment and care, it would improve the quality of medical care, reduce the quality or have no effect?"

Although almost three-quarters of physicians (73.4%) stated that increasing patient participation would have a positive impact upon medical care, less than a third of patients

(30%) believed that their contribution would be positive. A third of patients (33.3%) believed that their participation would have no effect, and a slightly smaller proportion (23.4%) stated that their participation would be detrimental. In contrast, only 10% of physicians stated that they believed that increased patient participation would have negative impact.

Graph 6:1 Perceived Impact of Patient Participation on Treatment



Physicians who viewed greater patient involvement positively made these remarks:

"Generally. It depends. Some issues are too complex. It's difficult for them to understand."

"Can't prove one way or another. People's ability to make decisions in complex areas is limited by their lack of expertise, and are incapable of making a reasonable decision."

"Marginally - the improvements are only marginal. Decisions made in the mainstream of care are correct."

"No doubt about it...if the parents believe that they are participating then it makes it much easier."

"It's a two edged sword as a general rule...it depends how you judge quality ...some patients are able to communicate better."

Physicians who felt that patient participation would have no effect or would reduce the quality of care provided made the following observations:

"It's a case of more rights with insufficient knowledge. It's quite involved - it's too sophisticated."

"There's no doubt that people making decisions about things that they don't know about leads to the reduction in the quality of care provided. Uninformed persons making medical decisions - then it can have negative consequences."

"It's too complicated - complex issues. It involves much more time - takes about three times as long to talk about the treatment. Patient involvement confuses the issue. For instance, with regard to mastectomy, women have their own and often don't have a balanced view - most of them - about what you're talking about. They find out from those women's magazines. Breast cancer drives me batty."

"It's only really appropriate when it's about palliative care... not for other measures."

Overall physicians' comments indicate that they have misgivings about patient participation in the decision-making process. Even physicians who acknowledged that increased patient participation would have a positive impact upon the quality of medical care provided expressed particular concerns. These physicians had reservations about the ability of patients to understand the complexities of condition and treatment and make reasonable decisions. In effect, physicians were concerned about patients'/parents' lack of medical expertise. Physicians, who stated that greater patient involvement in decision-making was likely to reduce the quality of medical care, raised similar concerns about the harmful results that were likely to occur if patients with insufficient medical knowledge made treatment decisions.

ii) Perceptions of Responsibility

Patients, physicians and nurses were questioned about their views on the extent of physicians' responsibility to inform patients of treatment, attendant side-effects and risks, as well as alternatives.

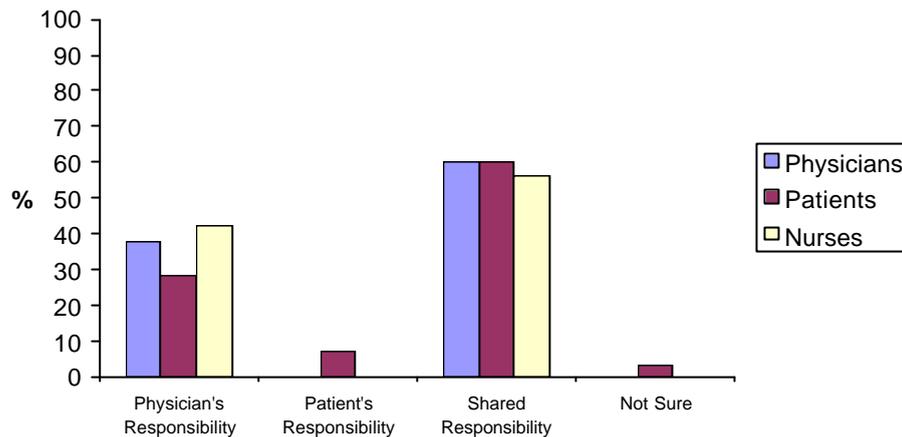
QD21;QN5: "Do you think that it is primarily the doctor's responsibility to make sure that the patient is fully informed about his condition and treatment or is it the patient's responsibility to ask the doctor or is it a shared responsibility?"

QP20: Do you think that it is mainly the doctor's responsibility to tell the patient all about the illness and how it will be treated or should the patient be the one to ask the doctor to explain about these aspects or is it a shared responsibility?"

Almost two-thirds of physicians and patients (63.3%) believed that it was a shared responsibility. This means that both groups believe that it is the responsibility of the physician to discuss the patient's condition and that the patient also has a responsibility to ask the doctor about relevant issues. While a slightly smaller proportion of nurses (56.7%) believed that it

was a shared responsibility, a roughly similar proportion (43.3%) stated that it was primarily the responsibility of the physician to inform the patient of condition and treatment.

Graph 6:2 Perceptions of Responsibility



Physicians who believed the provision of information was a matter of shared responsibility made these observations:

"Doctors have a responsibility to tell...patients have a responsibility to let the doctor know that they don't understand, raise issues which are important to them and discuss with the doctor."

"Some patients and some parents are more prepared to stand up for their rights and take responsibility."

"I try to explain everything that I can always...things that you miss out on...and it's good when patients and when parents ask. It's makes it so much easier."

"In an ideal world, patients would take more responsibility."

"The doctor can only tell so much...the patient has to ask."

"It should be shared. Patients have got to take responsibility for their own health...we can't deny them that...but do they?"

"The doctor can think of some things, but there are other things that the patient or the parent worries about that the doctor does not know about...it helps when they tell you what's worrying them."

"We are trained to know what is the matter or what's wrong - usually the parent is too emotionally involved. The doctor anticipates what's worrying them - if you don't do that you end up making more work for yourself."

"Maybe that it's more the doctor's responsibility...the doctor knows more about the illness."

Of physicians a substantially smaller proportion (36.7%) stated that it was primarily the responsibility of the physician to initiate discussion about the patient's diagnosis and treatment. These physicians made the following comments:

"One does not operate on a legalistic level, operate on an ethical basis - personal more than professional...I would be prepared to break the law if I thought that it was appropriate. It remains my responsibility...how could the patient know what to ask...the patient can really only raise his concerns and his fears. "

"It's a really hard question...in reasonable circumstances...it's the doctor's responsibility to provide the patient with information."

"And in informing a discourse is started...it has to be the doctor's responsibility in initiating."

Overall, physicians' comments suggest that they are conscious and willing to accept the responsibility arising from their expertise. Physicians acknowledged that while they can and do impart information acquired through their qualifications and experience, it is also vital that the patient engage in a dialogue with physicians about their condition and proposed treatment. Physicians believe that patients have a responsibility in actively seeking information from the doctor and in informing the doctor of their concerns. This is consistent with the earlier finding which shows that 73.4% of physicians believe that increasing the patient's role in decision-making is likely to have a positive impact.

Similarly, nurses acknowledged that physicians *vis a vis* their expertise had an obligation to initiate discussion regarding treatment and condition. Nurses made the following comments:

"Patients come in with a pre-disposed condition and are not in a position to know about surgery - to know what's he's doing, to know what's wrong."

"Patients don't know what questions to ask. They are not informed. They do not have the insight - particularly the elderly who have been brought up to do as they are told and not ask. The onus is on the doctor to ensure that the patient knows - the patient can't be expected to ask questions about what's what."

"There's a knowledge deficit in the patient. They are unsure about what questions to ask...they are in an unfamiliar environment. "

"Look, patients don't know what questions to ask."

"Patients don't know how to ask, where to ask or how to begin."

Clearly, health professionals, as indicated by both nurses' and physicians' comments, are aware that patients do not necessarily have the expertise to comprehend complex details about their

diagnosis and its treatment, and that therefore it is primarily the responsibility of the physician to ensure that the patient is informed. Accordingly, neither group stated that it was primarily the responsibility of the patient to seek information from the physician. In contrast, while 36.7% of physicians and 43.3% of nurses stated that it was the primary responsibility of the physician to inform the patient, only 26.7% of patients believed that physicians were responsible. A further 6.7% of patients stated that it was the primary responsibility of patients to seek information about treatment and condition from physicians. No nurses or physicians stated that such matters were the primary responsibility of patients.

Patients who believed that the primary responsibility for disclosure of information lay with physicians made the following remarks:

"The doctor is a busy man...I'm a bit overawed by doctors...but, I feel that...you know...he should tell me."

"I think he should tell me everything...I don't really know what to ask...and they're all so busy and they stand around fidgeting. "

"You're often too worried to know about all these things. I think that they should tell you."

"The patient is in shock...and you don't think of important things to ask...you're emotionally upset."

"The doctor knows the facts...the patient doesn't...really all I can ask the doctor is 'will I be OK after the operation?'...not much really is it."

For these patients, their lack of knowledge affected their ability to ask pertinent questions of the doctor. In this respect, patients' comments are similar to the comments made by physicians and nurses who felt that the primary responsibility for disclosing information lay with the physician. Secondly, their comments indicate that they are inhibited by being in an unfamiliar environment and don't ask questions both because they don't know what to ask and because the doctor appears to be busy. Some patients acknowledged the impact of being ill on their interaction with physicians: the patient is simply too "emotionally upset" and "in shock" to ask relevant questions.

Those who felt that it was a shared responsibility made these remarks:

"Well, they tell you what's wrong...but, then you've got to ask them what you want to know."

"It should sort of...go backwards and forwards from you to the doctor."

"I'd like it to be a shared responsibility...but as it is I've got to prompt them for all that I've been told."

"Patients need to ask more questions. I'm the kind who needs to know everything. I guess you could say that I'm the kind that wastes the doctor's time...asking my questions. "

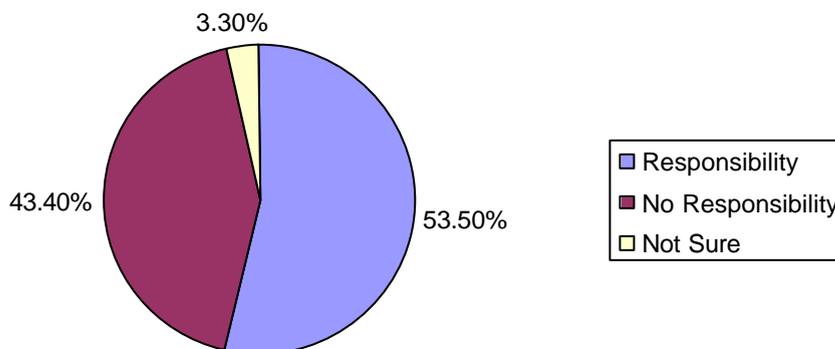
"It depends on the patient...I'm a trained nurse...so I know what to ask...but, the average patient out there would not know."

For these respondents, the patient had a clear responsibility to establish a dialogue with the doctor. Only one patient, who worked as a nurse, commented on the general ignorance of the patient regarding treatment, and how this affects the ability of the patient to seek further information from the physician. In all, patients seemed unaware of how their general unfamiliarity with the environment, their illness and their lack of expertise in medical matters could and would affect their ability to ask pertinent questions of the doctor. Conversely, both nurses and physicians were aware of the effect of some or all of the factors mentioned.

With regard to perceptions of responsibility, only physicians were asked the following question.

QD22: "When a patient disagrees with your recommendation for a particular procedure or treatment that you think is necessary medically, do you feel that it your responsibility to persuade the patient to agree to treatment?"

Graph 6:3 Physicians' Perceptions of Responsibility



Physicians were more or less evenly divided in their response. While 53.3% believed that they had a responsibility to persuade the patient to have treatment which was in their view medically necessary, 43.3% stated that it was not their responsibility. Only 3.3% of respondents were "Not Sure".

Physicians who believed that they had a responsibility to persuade the patient made the following explanatory remarks:

"You tell them that they can't...can't not have treatment. We're awfully good persuaders...but it almost never happens...it happens though."

"I've tried twice. Imagine that I'm a farmer with a sick lamb. Do you hit it on its head with a hammer or just let it die. I think I'd try and persuade the patient again."

"If it's in the interests of a child I would persuade - if it's a life threatening condition which can be treated. I would bypass the parents and refer to the law. It does happen. For instance, a blood transfusion is medically necessary for a child, and the parents who are Jehovah's Witnesses refuse. Well, then you simply go to the law. The parents are enormously relieved - to have the decision taken over."

"It depends on the risks and the benefits - if the risks were small and the benefits substantial. Yes. "

"Of course. It's child abuse if the parents refuse treatment...it's neglect. As the doctor I have a clear responsibility to persuade and failing that to refer to the law."

"There are all shades of necessity...try and encourage them to the best course of action - unobtrusively. Perhaps encourage rather than coerce."

"Some patients have funny ideas...as the doctor you have to try and persuade them to accept the best option. A patient here, about 28, had his testicles removed, and then refused post-operative radiotherapy which has a 95% curative chance. Well...a year later the cancer metastasised - in the lymph glands, curability of maybe 70%...stupid idiot."

"As a general rule, as a profession - we're very persuasive...we talk them around."

"I'd persuade, but, not coerce...never coerce."

Respondents' comments indicate that physicians believe that they have an obligation to persuade the patient to accept the treatment when it is medically necessary and when the likelihood of success is substantial. Further, physicians feel that the patient may make the wrong decision for personal reasons without realising the possible harmful results, and that therefore the physician should persuade the patient to accept the treatment, which is medically necessary. This suggests the extent to which physicians are willing to override the patient's personal misgivings when the doctor believes that the treatment is necessary.

Physicians were unequivocal in stating that when they were treating a minor and parents refused treatment for their child, then they would seek redress from the law. For physicians the primary concern was the well being of the minor. Lastly, physicians acknowledged that the way they present information to patients and parents can affect the decisions made by the two groups with regard to treatment. Physicians took pains to emphasise that while they were willing to "persuade" parents/patients, they would not coerce parents/patients to accept treatment.

Physicians who stated that they felt no responsibility to persuade patients to accept treatment made these observations:

"If the patient is fully informed of the consequences - then it's their decision."

"It's my duty to inform the patient of the best form of treatment...in surgery treatment can't be undertaken without the patient's consent. But it's up to the patient after I have informed the patient of the procedure."

"I'd go over things...let them make their decision...and let them know that the door is still open. "

"I have a responsibility to give information...I have no responsibility to either persuade or coerce."

"Responsibility to let them know what their options are."

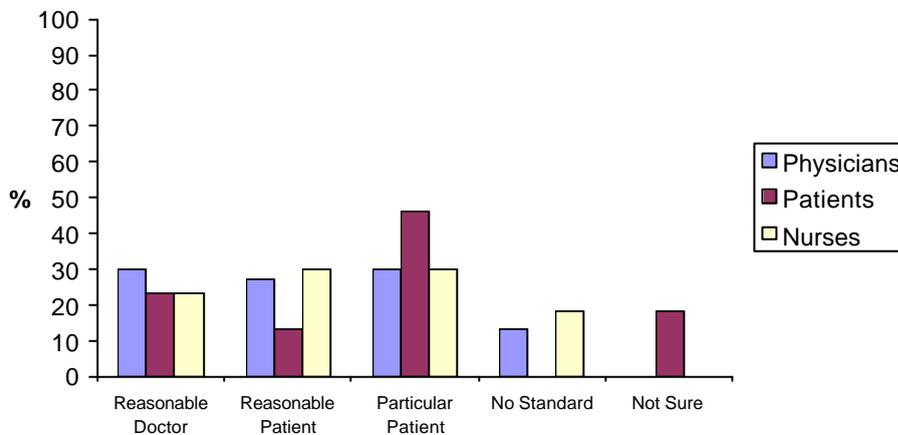
For these respondents, their responsibility was limited to informing the patient/parent of the best treatment option and the likely consequences of refusing treatment. These physicians believed that it was the patient's responsibility to consider the options and make a decision. While physicians emphasised that they had a responsibility to disclose information to the patient, physicians did not state that they had a responsibility to ensure that the patient understood the information given.

Lastly, patients, physicians and nurses were asked their views about minimum standards of disclosure.

QD23;QN6: "Physicians and nurses were informed that various standards can be used to define a physician's legal obligation to disclose information about the proposed treatment, potential risks and alternatives, and asked which of the following standards they preferred. " (Standards listed below)

- QP21: "Patients were informed that it is generally felt that doctors should be legally required to tell people about what treatment they are to have, how risky it is, and about different ways of treating their problem, and asked which standard they felt was the most appropriate."
- a) "The physician should disclose the information that the average reasonable doctor would in similar circumstances.
 - b) The physician should disclose the information that the average reasonable patient would consider relevant to his/her decision about medical treatment.
 - c) The physician should disclose the information that the particular patient would consider relevant to his/her decision about medical treatment.
 - d) No general standard. "

Graph 6:4 Standards for the Disclosure of Information



Physicians and nurses were fairly similarly and evenly divided in their preferences. Almost a third of each group preferred one of the three standards outlined. A smaller proportion of nurses and physicians stated that no general standard was desirable. The majority of patients (46.7%) stated that the most desirable standard was the one which focused on the particular needs of the patient. While this standard means that the physician considers the specific needs of the individual patient, it also means that the physician determines what the needs of the patients are. In the other two standards, a more objective standard is established.

DISCUSSION

In many respects there is little convergence between the views of patients, physicians and nurses. Overall, there is greater agreement between nurses and physicians. While over two thirds of physicians felt that greater patient participation in medical decision-making would have a positive effect, less than a third of patients took the same view. In fact, of patients a third believed that it would have no effect and a slightly smaller proportion believed that increasing the patient's role would have deleterious effects on the quality of medical care. Although health professionals expressed reservations about the ability of patients to participate in a decision-making process that required an understanding of complex issues, it appears likely that physicians believe that increasing patient participation would lead to increased patient compliance with medical treatment, thereby increasing the quality of medical care. Doctors may view this exchange as a means of getting patients to take responsibility for themselves, adhere to mutually decided regimens and thereby achieve a better medical result. Patients however tended to view their role in the exchange between the patient and the physician from a different perspective. While over two-thirds of physicians (73.4%) believed that greater patient participation would have a positive impact upon the quality of medical care, less than 30% of patients took the same view. Patients' comments suggest that patients feel that their lack of medical knowledge precludes them from contributing or actively participating in treatment decisions. Considerable evidence indicates that patterns of passivity characterise behaviour in relationships, such as the doctor-patient relationship, particularly in the case of hospitalised patients. For example, Meisal and Roth in a participant observation study of consent and medical decision-making conclude that:

"The doctor's ordinary role, in practice was to decide what was to be done and to inform the patient of that decision. Ordinarily, this information came in the form of a recommendation...The patient's ordinary role, in practice was to acquiesce in the doctor's recommendation. Patients played a more active role when the doctor presented alternatives without placing any preference on them...on balance, the typical patient role was one of passive acquiescence." (1982:391-392)

At the same time, patients expressed their willingness to take responsibility for themselves by actively seeking information from physicians. In contrast, both nurses and physicians stated that patients may not know what questions to ask.

In conclusion patients, physicians and nurses were conscious that patients lacked the expertise necessary to participate more fully in medical decisions concerning their health. It indicates the extent to which both patients and physicians believe that information simply cannot be shared because it is too complex and detailed. Commentators have noted that it is the function of medical ideology to safeguard its knowledge basis (Mariner 1989; Katz 1984). Paul Starr has argued that "the rise of the medical profession depended on the growth of its authority" (1982:20). Katz argues that:

"modern conceptions of disclosure and consent were entirely foreign to the definition of modern medicine throughout its professional evolution. Patient obedience is a residue...in the conscience of physicians...still forms part of the professional self-image." (1984:26-29)

Such perceptions are changing, particularly with the rise of concepts such as patient participation and consumer rights. That the process of change is slow is demonstrated by patients' reiteration of their lack of expertise. Patients like physicians generally tend to view "health" or "well being" from a medical perspective. If informed consent is the objective, the primary pre-requisite is a re-definition or re-evaluation of health and the respective roles of physicians and patients.

PART III

CONCLUSIONS

CHAPTER X

CRITIQUE AND CONCLUSIONS

At the heart of many of the issues and problems in medical decision-making discussed in the literature review and indicated by the empirical study lies the question of the patient's right to determine what treatment he/she receives and how to reconcile that right with the doctor's duty to give the patient the most appropriate treatment available. This question is posed in various forms: for example, does the patient have sufficient information, which is understood, that will enable him/her to agree to the treatment recommended by the doctor, and when and how far may parents consent or refuse treatment for their child? These issues are not answered in this study, which explored aspects of the interchange between physicians and patients, and in so doing raises further questions.

The findings of this study are now briefly summarised. In relation to disclosure, the picture that emerges of the process is one that shows that generally patients are desirous of information about the proposed treatment and its attendant risks, and that physicians initiate discussion about the prognosis and the nature of the treatment. However, patients' desire for information about their medical condition and its treatment does not correlate with their recollections of the consent process. With regard to consent forms, over a quarter of patients were consistently "Not Sure" about various aspects relevant to the signing of the consent form. As was discussed at the conclusion of Chapter V which deals with attitudes to the disclosure of information, this indicates that it is likely that patients are stressed by various factors, such as their illness and their general unfamiliarity with the hospital environment, and therefore paid little attention to the consent form.

This suggests that patients may view the signing of the consent form as a mere formality, and that the explanation given may have been inadequate. The simultaneous operation of these factors accounts for patients' poor recollection of the process by which the consent form is signed. Thus, although patients voiced a desire for information, a range of other factors, such as language and situational barriers, impinge upon patients' appreciation of information disclosed to them. At this juncture, it is stressed that this study did not seek to ascertain what

aspects of treatment information were disclosed to patients by physicians, and is based on the self-reports of patients, physicians and nurses.

Other factors operating in conjunction with situational barriers include the nature of information desired by the patient and the patient's perceptions of appropriate behaviour. Firstly, while most patients reported satisfaction with the information given by doctors in relation to both everyday illness and serious illness, only slightly more than half the respondents believed that doctors explained what they considered to be important issues. This highlights the discrepancy between what physicians believe that patients want to know, and the nature of the information desired by the individual patient. As Meisal and Roth note:

"this is not surprising if 'information' is viewed monolithically. Patients probably do want information about aspects of treatment and not about others." (1982:334)

This discrepancy suggests that decisions about medical treatment are made in a manner different from that contemplated by the doctrine of informed consent, and is supported by the conclusions of various studies (Hunt et al. 1989; Meisal & Roth 1982; Pinch & Spielman 1990). Informed consent is premised on disclosure, and the findings of this study indicate, like other research demonstrates, that the question of what information is desired by patients in order for them to make a decision concerning medical treatment has yet to be adequately answered. Certainly, the impact of the health beliefs and values of the patient on the patient's approach to his/her illness is now being increasingly explored. One of the misleading assumptions of empirical studies of informed consent is that consent, albeit informed consent, is actually obtained in the manner and to the extent required by the law. This in itself is a matter for further investigations.

Secondly, as was observed in Chapters V and X, patients, nurses and physicians tend to view patient/physician interaction from a range of somewhat dissimilar perspectives. These underlying values add yet another dimension to the exchange and dialogue between physicians and patients/parents.

The complexities inherent in clinical situations are manifest in patient/parent and physician interaction, particularly in relation to the treatment of the terminally ill as well as minors and infants. With regard to the terminally ill, it was observed that these patients meet a number of physicians during the course of their treatment and undergo various procedures. The point at which consent is given for a particular treatment is then seen as consent for further treatment, and the option of non-treatment is not considered. In relation to non-treatment as an option, physicians demonstrated some sensitivity to the wishes of the patient and the parents of a seriously ill infant. Nonetheless, overall physicians' comments and responses show that physicians are prepared and indeed prefer to make a decision that is based on medical criteria. Further, physicians are willing to persuade patients/parents to change their minds and accept a decision based on such criteria.

Thus the linear model of informed consent, in which it is assumed that a doctor provides a competent patient with information about treatment options, and the patient understands that information and voluntarily renders a decision about treatment, neither reflects nor predicts what occurs in clinical situations. Obtaining informed consent, as opposed to obtaining a signature on a consent form, is rarely a discrete event, but often takes place over a period wherein a number of factors impinge upon the interaction between physicians and parents/patients. A variety of situational and structural barriers affect the exchange between patients/parents and physicians, and this association is further underscored by assumptions about appropriate patterns of behaviour. Empirical studies answer some questions, but leave many unanswered. This study, in conjunction with the review of other literature, gives some indication of the complexity of the processes, and offers "snapshots" of aspects of patient/physician interaction.

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