PATIENT & NURSE COLLABORATION
IN DECISION-MAKING CONCERNING
LONG-TERM MANAGEMENT
OF
A NEWLY FORMED COLOSTOMY

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The greatest amount of care has been taken while scanning this thesis,

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ABSTRACT

This study included three Projects which investigated aspects of decision-making in a nursing context. The specific decision studied concerned selection of a long term management strategy for use by a patient with a newly fashioned colostomy.

Literature reviewed reveals debate about the extent to which patients should participate in decisions about their health care, but ongoing work using the Autonomy Preference Index provides an argument for partnerships in decision-making between patients and health care professionals.

Project 1 of this study involved the development of a formal research-based decision analysis instrument, designed specifically for use by patients still in hospital following colostomy surgery. The instrument included the following methods of long term colostomy management: containment ("just wearing a bag"); attempts to control the colostomy using diet and/or regular medications; attempts to "train" the bowel; intraluminal plugs; colostomy irrigations; any combinations of these methods.

Project 2 used Kim's framework for collaborative decision making in nursing as its theoretical underpinning and investigated the difference in outcomes (satisfaction and goal attainment) between three groups of patients using three different decision making methods. Sixty patients with a newly fashioned colostomy at large metropolitan teaching hospital were assessed to determine their preferences and expectations about decision-making, then randomly allocated to one of the treatment groups. The "Instrument" group used the decision instrument developed in Project 1; the "Discussion" group used discussion with collaborative decision-making; and the "Advised" group received advice from a stomal therapy nurse. Patients were interviewed after 6 weeks and again after 18 weeks to assess their satisfaction with the decision making method and whether they had attained the goal decided upon during the decision process.
Those in the “Discussion” group were more satisfied with the decision process than those in the other two groups. Those in the “Instrument” and “Advised” groups did not differ with regard to their satisfaction at 6 weeks and this was unchanged at 18 weeks. At 6 and 18 weeks those in the “Discussion” and “Advised” groups attained their goals to a greater extent than those in the “Instrument” group.

Project 3 was undertaken to explore the patients’ perspectives on goal attainment and satisfaction using the three decision-making methods. Some patients reported problems with the level and style of collaboration associated with the use of the decision instrument, which they found to be somewhat impersonal and non-interactive. If they disagreed with the instrument’s choice they exercised a right of veto, reclaimed decision making autonomy and sought a goal of their own choice. Patients were more likely to follow advice from the nurse than from the instrument, and this was reported to be due to the quality of the relationship with the nurse, confidence in the nurse as a credible authority and the benefits of knowing reasons for the advice given. Generally speaking, those in the “Advised” group interpreted the situation as delegation of decision making rather than as parentalism. Overall the “Discussion” group’s method was the most effective. Patients in the “Discussion” group could explore the extensiveness, attainability and affective meanings of choices before selecting their goal. Several overarching themes emerged, including ideas about rationality and the quality of decisions, the role of emotions and feelings in decision-making, and a focus on how decisions are usually made.

This study contributed to the knowledge base in stomal therapy nursing, decision theory, collaborative practice in nursing, assessment of patient satisfaction and health communication theory. The clinical implications and applications of the findings are far reaching because of the pervasiveness of patient decision-making in nursing practice.
CHAPTER ONE

which provides an introduction to the problem, its significance to patients and nurses, and an overview of this study which includes three separate projects.

Decision-making is the process of choosing between alternative courses of action – including inaction. When people are ill or undergo surgery they must often make decisions about lifestyle changes to accommodate permanent alterations to their anatomy, physiology and body image. At the time of making these decisions they may not know relevant “facts” and may be more or less reliant on health care professionals for information and assistance in making decisions. How should such decisions be made? Are there ways to make decisions more effective or more satisfying?

While these questions apply to many nursing situations, the impetus for this study arose when, as a stomal therapy nurse¹, I was repeatedly assisting people with a new colostomy - a surgically created abdominal opening into the colon to allow the exit of faeces and flatus (Broadwell & Jackson, 1982) - to make decisions about long term colostomy management. These decisions are not straightforward for patients because there are several possible outcomes (colostomy management methods). Each outcome may be unfamiliar to the patient and each is associated with a degree of uncertainty. Additionally, individuals have different values and ideas about lifestyle, and therefore different utilities - preferences for particular outcomes (Schwartz & Griffin, 1986). Finally, patients are making these decisions at a stressful time when clear thinking may be difficult and they are anxious to make a decision which minimizes embarrassing “accidents”. Together these circumstances lead to a situation known as “decisional conflict” which has been recognized by the North American Nursing Diagnosis Association and has been the subject of studies in a range of disciplines including nursing, medicine, economics and psychology (McFarland & McFarlane, 1989).

¹ A stomal therapy nurse is a registered nurse who specialises in the care of persons who have a colostomy or other similar artificial orifices.
1.1. The significance of the problem to the patient

The significance of the problem to the patients is illustrated by the story of Jo, a 48 year old car salesman, who underwent surgery for rectal cancer one week ago. He now has a permanent colostomy. He had never before heard the word “colostomy”, but he had heard of people who “wear a bag” and now he is wearing one. He is emotionally affected by his diagnosis and surgery. To make matters worse, when the colostomy acts he has no control as it fills the bag and makes loud noises. He feels embarrassed and humiliated. He has asked his family and friends not to visit. He is becoming withdrawn and depressed about his situation and is dreading going home.

Jo has been told that the surgery was successful and he should be able to lead a normal life. But he wonders how life could be normal with this colostomy? Will his wife want to be with him? Will people think he is offensive? How will he explain the noises? How can he possibly go to work like this? Will he lose his job? How will the family cope if he cannot return to work? He is constantly worrying about these questions.

A stomal therapy nurse has taught him to change the bags. She has been trying to help him to see his situation in a more positive way. She is worried because he is due for discharge in two days and if he fails to cope at home he risks physical, psychological and social problems. She has advised him that there are other possible colostomy management methods, which he may wish to use in the long term, involving some alterations to diet, regular medications, regular enemas, the use of plugs inserted into the colostomy, or various combinations of these. She has explained each method, together with their advantages and disadvantages, and has explained that the decision is not straightforward, there is some uncertainty involved because each method may produce different outcomes for different individuals.

Each of the management methods she has explained sounds as though it will
involve changes to his lifestyle. He believes that he will not be able to cope with things as they are now - just wearing the bags - and he wants to try something different soon. But he does not like the idea of doing any of the things she has described. Some of them are quite repulsive to him. He is facing decisional conflict and asks the nurse for advice and guidance.

1.2. Significance of the problem to nursing

Nurses need to understand their role and be comfortable with advising and guiding patients who face decisional conflict. Documents defining the domain of nursing practice indicate that nursing includes assisting those with "deficiencies in decision making and the ability to make personal choices" (American Nurses Association, 1980). Furthermore, it has been proposed that it is a specific role of the nurse to help patients make decisions for themselves wherever possible.

Nursing should concern itself with the validity of the information the individual has, the processes whereby the individual uses the information to reach self-care decisions, and methods whereby the decision-making ability of the individual is enhanced... It is not the role of the nurse to provide the utilities or values the individual holds. The nurse may, however, help the individual to clarify his or her goals (Spangler & Spangler, 1983, p.102).

In this statement the nurse is seen as an agent, facilitating the patients' decision-making, and the study reported here explored ways in which this may be achieved. This thesis argues for a collaborative decision model. A major assumption was that there is a need to construct decision making situations so that patients have the information and the ability to make informed, optimal decisions based on their own values, not those of their health care professionals (Boyd, Sutherland, Heasman, Trithchler & Cummings, 1990). For this to happen, patients and health care professionals need to work together, but this is not always allowed by the nature of the relationships between them.

Chapter 2 outlines some ideas about patienthood, evolving relationships between patients and health care professionals, and ethical considerations pertaining to patient care decisions. This information provides a rationale for the collaborative
decision model used in this study and its potential for bringing a new focus to colostomy management decisions.

Studies concerning decision-making in relation to nursing practice usually focus on the nurse making clinical nursing decisions (Thomas, Wearing & Bennett, 1991) rather than the nurse assisting the patient to make decisions. There have been studies concerning patient decision-making about issues such as cancer therapy (Degner & Aquino, 1988; Degner & Beaton, 1987; O'Connor, 1989) and the withdrawal of life-sustaining treatments from neonates (Rostain, 1986), but few reported studies about patient decision-making relate to more usual decisions which are primarily the responsibility of the nurse.

However, one writer who has studied this broader picture of nurse decision-making is Kim (1983b), who proposed a theoretical framework for collaborative decision making in nursing practice. Kim’s work concerned those decisions which directly affect the patient and for which the decision responsibilities rest primarily on professional nurses. Kim’s work was based on the assumptions that there are many different types of nursing decisions which influence health, and “clients have resources to be active participants in making such decisions and their participation may have effects on the outcomes of nursing care” (Kim, 1983b, p. 271). In Kim’s framework the outcomes are the level of collaboration, the nature of the decision being made, goal attainment, satisfaction with the decision process and autonomy. Kim’s framework is described and discussed in Chapter 3 and was used as a theoretical underpinning of this study.

Some studies using Kim’s framework had found little evidence for collaborative decision-making in usual nursing practice and a suggestion was made that this might be because there were no institutionalised means to include patients in decisions, or because nurses did not know how to include patients in decisions (Kim, 1987). Nurses were found to be generally competent at supplying

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2. See section 2.2.1. for a discussion of the politics of names for the lay person.
information, but access to information, by itself, does not ensure good judgment or
decision-making. To facilitate decisions made by patients, nurses need to
understand how people generally make decisions and some of the suggested
methods to improve decision-making. Such matters are discussed in Chapter 4.

1.3. The main aim and research questions for this study

Although there are well developed ethical arguments for collaborative decision-
making (Brody, 1980), other writers (Steele, Blackwell, Gutmann & Jackson,
1987) argue that there is insufficient evidence that collaborative decision-making
affects outcomes. This study sought to find such evidence.

The main aim of this research was to investigate aspects of decision-making in
stomal therapy nursing practice. The data gathered from the participants help
answer the following specific questions. Is it practical and effective for health
professionals to develop formal decision instruments for use when making
decisions involving patients which are repeated frequently in the course of their
practice? Do patients prefer autonomy, mutuality or delegation when making
decisions about their own care? Does the level or style of collaboration in decision
making affect patient outcomes such as satisfaction and goal attainment? What
happens when a patient expects or prefers one level or type of collaboration but is
placed in a situation where that level or type is not permitted?

1.4. The overall plan of the study

The answers to these questions were sought using three interconnected Projects.
The first Project involved the development of a formal research-based decision
instrument which was subsequently used as one of three decision-making methods
in the second Project. It was after using the three decision-making methods in the
second Project that patients were assessed at 6 weeks and at 18 weeks to determine
whether there were differences in the outcomes, satisfaction and goal attainment.
The third Project involved a qualitative exploration of the patients’ perspectives
concerning the three decision-making methods used in the second Project. These three Projects will now be described.

1.4.1. Project 1: Development of a formal decision instrument

The repetitive nature of some nursing care decisions may favour development of formal decision instruments which systematically incorporate the information which both patient and nurse consider to be relevant to the decision. Chapter 4 traces the background, rationale and development of such an instrument.

The aim of Project 1 was to develop a formal research-based decision instrument to assist patients with a new colostomy decide upon a long term management strategy.

Colostomy management is an appropriate context for the development of a decision instrument, since it has the following features which facilitate routinization of decision-making and application of decision analysis methods:

1. The decision is a common one, recurring frequently;
2. Input from the patient is relevant because the decision effects their lifestyle and it is ultimately the patient or their carer who uses the colostomy management method selected;
3. The decision is important because “accidents” with the colostomy can be devastating for the patient and may lead to psychosocial problems such as depression and social isolation;
4. There are a finite number of options to choose from.

These aspects of a colostomy management decision-making instrument are discussed in Chapter 4 together with details about the various relevant attributes of the management methods considered for selection by those using the decision instrument.

This Project’s unique contributions to the field of stomal therapy nursing arise from the fact that it systematically and critically considered “taken for granted”
aspects of lifestyle after creation of a colostomy, such as the role of diet, medications and enemas, and developed a better knowledge base for the decision than had previously been readily available. Project 1 then used that information to apply decision theory in a new arena, stomal therapy nursing. Furthermore, the literature review to develop the instrument pointed to deficits in knowledge about colostomy management which need to be addressed, thus directing attention to areas for future stomal therapy nursing research.

Project 1 contributed to knowledge about decision theory by developing a relatively simple, practical means of eliciting utilities from people who would probably be too ill to use more complex decision analysis methods which have traditionally been employed. The administration of the formal decision instrument used a simple card sorting technique to elicit patients' utilities in a direct manner. This is the first reported instance of a card sorting technique being used for this purpose.

1.4.2. Project 2: An investigation of three decision methods

The aim of Project 2 was to determine whether there were differences in satisfaction and goal attainment between three groups of patients using three different methods to make decisions about long term colostomy management.

Chapter 5 outlines the methodology for Project 2. Sixty patients were assessed for preferences and expectations about decision-making and then randomly assigned to one of three treatment groups employing varying strategies to decide about long term colostomy management. One group used the decision instrument developed in Project 1. Another group used a collaborative discussion and decision-making process and the third group received advice from a stomal therapy nurse. After six weeks and again after eighteen weeks patients were assessed to determine their level of satisfaction with the decision-making process, and whether they had attained the goal set during the decision-making process.

Chapter 6 reports quantitative analyses of data derived in Project 2 to determine
whether there were differences in the outcome measures - satisfaction levels and goal attainment - between the three decision-making treatment groups, and whether there were other factors, apart from the three differing treatments, which may have influenced outcomes. Also explored in Chapter 6 were the effects on satisfaction and goal attainment of patients who expected or preferred one level of involvement in decision-making but were allocated to a treatment group in which those expectations or preferences were not allowed.

Project 2 validated and extended Kim’s (1983b) framework for collaborative decision-making in nursing by using it in a study with a prospective experimental design. Some previous studies using Kim’s framework had concentrated on the factors contributing to collaboration such as the attitudes and beliefs of the participants, so the level of collaboration was the dependent variable. In Project 2 the controlled levels of collaboration, as the independent variable, allowed attention to be focussed on the effects of the differing levels of collaboration on outcomes such as goal attainment and satisfaction. There was also opportunity to explore the relationships between patient expectations and preferences, actual levels of collaboration, and the levels of satisfaction and goal attainment. Results indicated that the components of Kim’s framework logically explained the phenomena being observed and that it was a useful way of conceptualising decision-making in nursing practice. Project 2 also further developed Kim’s framework by including mutuality in decision-making as an alternative. Although Kim’s framework concerns collaborative decision-making in nursing practice, in previous studies using the framework a dichotomy of autonomy or delegation, with no option for mutuality, limited the interpretation of the findings. The current study overcame these limitations.

Project 2 also tested and developed further some ideas about mutuality in decision-making proposed in health communications literature (Bennett, Irwin & Bieri, 1995; Smith & Garko, 1991) by testing whether the idea of “talking things over” was integral to the notion of mutuality in collaborative decision-making, and found that it was.
1.4.3. Project 3: In the patient's voice

Project 3 is reported in Chapter 8 and presented the patients' reasons for their differing levels of satisfaction and goal attainment when using the three decision-making methods. This Project also reported the patients' ideas about the nature of the decisions they had made in terms of their extensiveness, attainability and affective meaning - terms taken directly from Kim's framework. Rather than using a formal qualitative method (such as grounded theory or phenomenology), Project 3 created a freer, modified form of content analysis for elements of meaning derived from the patients' own words.

This Project contributed to knowledge about collaborative decisions because it indicated that the process was as important as the decision, and the best process was the collaborative discussion method because it was two directional and interactive. Patients placed importance on the nurse who was giving advice being a credible authority on the subject and giving reasons for the advice. It was important for patients to have the opportunity to express their feelings about options outlined by the nurse. It was possible to determine a range of patient perspectives about extensiveness and attainability of the decisions, and to trace an evolution over time from negative to more positive affective meaning of the decisions. These aspects are described and discussed in Chapter 8.

Project 3 contributed to stomal therapy knowledge about why people select or reject some colostomy management strategies which might otherwise have appeared reasonable choices to the stomal therapy nurse.

1.5. Conclusion

A review, general conclusions and discussion about the issues arising from the three Projects are detailed in Chapter 9. Stated simply, the results of this study suggest that outcomes such as satisfaction and a sense of mutuality or partnership may be as important to the patient as attainment of outcomes related to physical
wellbeing. Furthermore, a collaborative discussion was the best way to achieve mutuality in decision-making. Major themes arising from this study concerned the nature of decision-making in practice, how people normally make decisions and the roles of emotions, feelings and information when nursing care decisions are being made. In Chapter 9 consideration is given to the application of these findings to future research and nursing practice.

While this thesis concerned a study of the application of theory about decision-making to a specific practical situation which is very common in stomal therapy nursing practice, the findings are readily transferable to many other nursing situations, such as decisions about how to feed a newborn baby, or how to manage a chronic leg ulcer. The common thread is that nurses have input into these decisions, but it is the patient or their carer who must implement the method selected. Although nurses have in theory argued for patient participation in such decisions, this participation is usually not evident in practice. The result is frequently non-compliance with the method preferred by the nurse who has usually based that preference on theoretical knowledge and rational thinking. From the nurses’ perspective the outcomes of non-compliance are poor, but little is known about the patients’ views about decision processes and outcomes. In this thesis particular attention was paid to the often neglected patient perspective. It is hoped that this thesis will enable nurses to ensure decision-making is an interactive process with a two-way flow of relevant information, and provide them with the impetus to expand their practice beyond information giving and receiving into the realm of interpretation of what a nursing decision really means to the patient concerned.
CHAPTER TWO

which discusses human relationships in general and then considers changes in working relationships between patients and health professionals. Attention is then directed to ideas about patient participation, models incorporating mutuality and partnerships and the Autonomy Preference Index.

This chapter commences by outlining a frequently cited model of relationships between lay people and health professionals by Szasz and Hollender (1956), and describes how it has been applied, initially to doctor-patient relationships, and later extended to influence the philosophies of other health professionals, including nurses. A review of this work is important because in any relationship the philosophical preconceptions of the interacting parties influences the process of decision-making. Consideration is given to ideas concerning the nature of patiencethood and changes in relationships between lay persons and health professionals. Models incorporating mutuality and partnerships are introduced, together with a discussion of contradictions arising in studies concerning increased patient participation in medical decision-making. Particular attention is paid to the development of an Autonomy Preference Index which seeks to gain insight into patients’ preferences for involvement in decisions. This Index is used in Project 2.

2.1. Human relationships: a general model

Forty one years ago Szasz & Hollender (1956) proposed three general models of human relationships using as their prototype relationships between parents and their offspring when they were infants, older children and adults. They then applied the three models to doctor-patient relationships. The prototype for the activity-passivity model was the relationship between parent and infant and was applied to the situation where the doctor does something to a patient. The guidance-cooperation model was based on the relationship between parent and older child. This was likened to the situation where a doctor advises a patient to do something, such as taking a course of medicines, and the patient co-operates. The
mutual participation model was based on a relationship between parent and adult offspring and is likened to the situation where a doctor helps a patient to help him/herself, for example with a chronic illness. The two are said to work in partnership, with the patient actively seeking the expert help from the doctor. Although the initial application of the prototype was to medicine, its general nature is such that it is applicable to relationships between patients and other health professionals, including nurses.

The prototype of the relationship between parent and offspring also illustrates the idea that, because a relationship is an abstraction, it can vary as either of the interacting parties varies. As a child grows and develops self-help abilities a wise parent will diminish their control. Furthermore, no one type of relationship in these three models is intrinsically better than another, they are suitable for different contexts. For example, a parent who has both an infant and an adolescent must have a repertoire of interaction styles and know which is appropriate when dealing with each child. These comments can equally be applied to patient - health professional relationships. Of course, patients are not children, and health professionals are not their parents, and inappropriate use of the activity-passivity and guidance co-operation models has led to accusations of “parentalism” in health care (Byrne, 1989).

2.2. Perspectives on patiencethood

2.2.1. Names for the lay person

Before investigating relationships between lay persons and health professionals, it is worthwhile considering how we refer to the lay person within these relationships. The traditional name has been “the patient”, from the Latin, “patiens” implying suffering. The Australian Pocket Oxford Dictionary (Moore, 1993) defines “patient” as “a person receiving or seeking medical or surgical treatment”, and this implies dealings with a doctor. However with the rise of allied health services the patient may now deal with a range of health professionals, and as early
as 1929 the Australian Public Hospitals Act defined a patient as "any person receiving relief or assistance from or by any hospital" irrespective of which health professional was administering that assistance. There are of course a number of ways in which the lay person is conceived differently. In economic models there is the "consumer" or the "customer" (NSW Health Department, 1994), and in some nursing models (Meleis, 1985) there is the "client", a term preferred because it simply means "a person using the services of a professional person" (Moore, 1993) and is not specifically linked with medicine.

These changes in names for the lay person are regarded by some as linguistic manipulation or "shifting metaphors" (Steele et al., 1987) and treated lightly by others such as Alford (1994, p. 20) who said "... a call girl has a client and a shop has a customer ... a client is someone who you need as part of your business, a patient needs your help".

However, given that a metaphor is the figurative use of a term in a context in which it is not literally applicable, these terms - customer and client - are not metaphors. These terms are often literally applicable in the current social and economic environment where health care institutions are being forced into a more competitive mode and marketplace orientation and where legal issues, such as informed consent, are real. However, despite acknowledging these issues, in this thesis to avoid confusion, the lay person will generally be referred to as the "patient" unless discussing a model in which they are specifically conceived differently, in which case the term used in that model will be adopted.

2.2.2. Changes in patient - health professional relationships

Naming the lay person is but one instance of the view that relationships are interacting systems. Systems theory indicates that if one component of any system changes there will be changes elsewhere in that system, either in the output or the process (Bernhard & Walsh, 1990). The amount of active involvement expected of the patient has therefore varied over time and is related to changes in broader
societal interests in personal responsibility, self-direction and autonomy, as well as from changes in the nature of health care problems and in aspects of health care delivery (Steele et al., 1987). The notion of the "activated patient" has swung between the extremes of active self-help to passive acquiescence to medical dominance, then back again to autonomy. The current trend is for an intermediate position of "partnerships" between patients and health professionals. Each of these ideas will be discussed in turn.

2.2.3. The "activated" patient

"Activated" patients are those who reject the passivity of sick role behaviour and assume responsibility for their own care (Parsons, 1951). The origins of the activated patient can be traced from mid eighteenth century England, when Wesley accused the medical profession of mystifying its work in order to distance itself from the public (Starr, 1982). Self-help health care regained popularity until technological medical developments moved health care outside the realm of the "ordinary" person and reasserted the unquestioned authority of the medical profession. Patient acquiescence was assumed. Relationships in which the patient played a passive "sick" role and the professional was dominant became the norm (Parsons, 1951; Suchman, 1965) and there was generally little place for participative decision-making with medical professionals. The doctor gave the orders and the patient complied, and sometimes a nurse was involved to ensure that the doctor's orders were carried out.

The period around World War II was a turning point resulting in further major changes in western society including complex general technological development and a better educated, informed and articulate public. Movements such as individual and civil rights, consumerism and feminism became popular. The "me" generation had been born (Smith & Garko, 1991, p.3) and these changes in values and relationships in general also had an impact on working relationships between lay people and health professionals.
2.2.4. "Informed participants" or "reluctant collaborators"?

Debate continues between health professionals, ethicists and social scientists concerning the nature of the ideal professional-patient relationship in this altered environment. In the economic model, increased information places consumers in the role of evaluators of services who must be acknowledged as intelligent, capable of setting priorities, and eager to communicate with each other and with health care providers. A NSW Health Department booklet entitled Health Outcomes (1994, p.14) advises that "Consumers want to be involved in personal health decisions, and there is a growing demand for information on health outcomes". However, Lancaster (1982) claimed that it is a mistake to assume that all consumers of health care are well informed, and Waterworth and Luker (1989) argued that, even if they are well informed, it is a mistake to assume that all patients want to be involved in decisions about their nursing care. Waterworth and Luker's study identified an attitude which they named "toeing the line" where patients were more concerned about pleasing the nurse than about collaborating in decisions about their care - patients tended to accept a collaborative role, even though it was not what they wanted. Other studies identified a "competence gap" (Danziger, 1978; Haugh & Lavin, 1981) in decision-making abilities of patients compared with the professionals. Some patients do not even try to cross that gap, or to evaluate what their situation, let alone try to collaborate in making decisions. Such people consider themselves as lay persons with regard to health care decisions, even when those decisions increasingly concern activities of daily living such as diet or exercise (Tuckett, Boulton, Olsen & Williams, 1987).

2.2.5. The need for more active patienthood

Despite the reluctance of some patients to collaborate, it has been argued (Cox, 1992) that the need for more active patienthood is tied in with changes in the nature of illnesses, and an increasing emphasis on management of chronic illness. These changes often result in alterations in lifestyle and self-care on an ongoing basis. It seems logical that the patient or their carer needs more involvement in decisions,
because it is they who will need to carry out the treatments in the long term. Furthermore, the increasing complexity of medical treatments for both acute and chronic illness has led to growth in allied health professions with whom patients frequently have more ongoing contact than with their doctor. Some of the momentum to decrease medical dominance over patients came from these developing groups of allied health professionals struggling against medical hegemony (Steele et al., 1987).

Major health problems are often a result of the individual’s lifestyle and behaviour, creating a need for emphasis on preventing rather than curing illness and a requirement that individuals take responsibility to choose their lifestyles and actions with health in mind. Arnston (1989) called this “citizen health competence” and it requires the exercise of a certain amount of autonomy. But how can people be expected to be autonomous if they are not encouraged to participate in health related decisions? In this context, fostering dependence in health care relationships undermines the general goals of the World Health Organisation (WHO, 1984) which described active patient involvement as a duty and a social, economic and technical necessity. There are simply not enough health resources for everyone, so people must accept responsibility for their own lifestyle and actions.

If health care consumers have responsibilities, they also have rights. Some authors propose the right of the patient to be involved in their care, however, this argument is countered by those who claim that people also have a right not to be involved if they so choose (Alfidi, 1975; Childress, 1982). The issue of patient rights leads to consideration of the ethical principles involved. Indeed, it has been the ethicists who have best elaborated the concept of patient autonomy.
2.3. Ethics and patient - professional working relationships

In the ethics literature, models with passive patient and dominant professional have been labelled "paternalistic" (Byrne, 1989) since they presuppose that the health professional is benevolent and beneficent, and makes all or some of the decisions that would ordinarily be the patient's to make. The term "paternalism" is now superseded by the term "parentalism" which is currently considered more politically correct. Taking away the male connotation of "paternalism" helps convey the message that parentalism is not only practised by doctors (traditionally a male dominated group) but also by nurses (traditionally a female dominated group) and others. The following arguments presented by ethicists and social scientists apply equally to relationships between nurses and patients as they do to relationships between doctors and patients.

Moral dilemmas surrounding parentalism arise from the claim that beneficence should sometimes take precedence over autonomy (Omery, 1989). In the realm of decision-making, patients have diminished autonomy if health professionals intentionally withhold certain information, even if it is because they believe it to be in the patient's best interest (Thompson, 1990). However, opponents of parentalism propose that motives are not always altruistic and may indicate fear of confrontation or the urge to maintain power or control over the situation (Bok, 1979). Ethicists such as Emanuel and Emanuel (1992) proposed patient autonomy through such practices as informed consent and patient empowerment. But their critics claimed that these practices are often limited by the reality of the situation, and that some patients are unable to give consent because they do not, or cannot, understand the technology or complexity of their condition and treatments, either because they have never had the ability, or because of the impact of their illness or their psychological reaction to it (Thomasma, 1983).

According to Smith and Garko (1991), advocates of passive patienthood models argue that patient participation takes up too much time, undermines the "healing force" of the experts' authority, and burdens sick people at a time when they are
most vulnerable. Such advocates propose that sick people often want the decisions made for them because they recognise the professional’s greater expertise and because they desire to be dependent, so they delegate the responsibility to the professional. Cross and Churchill (1982) refer to this as “paternalism with permission”. This allows the option for delegation, if that is what the patient desires. Forcing a person into decision-making autonomy when it is not their wish is as much an act of paternalism as making the decision for them when they wish to make it themselves. There needs to be some intermediate course of action between delegation and autonomy - the development of partnerships.

2.4. Models incorporating mutuality and partnerships

The pendulum has swung from passive patienthood to empowered, autonomous patienthood, but, as outlined above, there are problems with both of these extremes. To overcome these problems, models have been developed which incorporate the idea of partnerships, negotiation and mutual decision-making (Christensen, 1990; Emmanuel & Emmanuel, 1992; Thomasma, 1983) in which the health professional provides the knowledge and decision-making skills that the patient lacks. Brody (1980) justified such mutuality on six ethical grounds: reduction of power imbalance; consistency with a growing awareness of the limitations of clinical knowledge; benefits to patient self-esteem at a time when they are feeling out of control; reduction of any tendency to view patients as objects to be manipulated; providing patients with more realistic expectations; and possibly improving the outcomes of treatment. Others proposed that too much of the momentum has come from ethicists’ views of what ought to be done, and there is not enough scientific evidence to provide convincing arguments that patient participation is of benefit to the patient (Steele et al., 1987). This study aims to contribute to such evidence.
2.4.1. Studies of increased patient participation

Numerous studies have been undertaken to identify and investigate hypothesised benefits from increasing patient participation. These studies have included assertions that dialogue in the relationship will expand (Brody, 1980) giving greater symmetry in the interaction as patients ask questions, offer opinions, state their personal treatment goals and otherwise participate (Greenfield, Kaplan & Ware, 1985). Increased dialogue should result in greater sharing of information. Patients would become more aware of the “grey” areas in medical knowledge and therefore develop more realistic treatment goals and expectations (Brody, 1980), and professionals would be more able to negotiate individualised, patient-centred treatment plans. If mutual decisions were being made there would be higher levels of agreement between clinician and patient (Speedling & Rose, 1985; Starfield, Wray, Hess, Gross, Birk & D'Lugoff, 1981). Furthermore, because the patient has participated in the decisions they would develop a greater sense of commitment to and confidence in the treatment plan (Schulman, 1979). Ultimately, the patient would be more satisfied (Putman, Stiles, Jacob & James 1985); more compliant with the treatment plan (Schulman, 1979) and more likely to enjoy the physical, psychological and functional benefits the treatment can provide (Greenfield, Kaplan & Ware, 1985).

When Steele et al. (1987) critically reviewed some of the above studies they found the results to be mixed, but came to three broad conclusions. Firstly, patients in general wished to be informed about their illnesses and the treatment options available to them. This may enable them to anticipate and prepare so they can cope with distress or discomfort which may result from the illness or treatments. However, whether information is beneficial depends on patient preferences and personality traits. Secondly, not everyone desires or benefits from an active role in decision-making, and there is little evidence that this is sought by most patients in most situations. Unfortunately, clinicians were often found to be poor judges of patients’ information needs and participation preferences. Thirdly, the biggest problem Steele et al. found with the research was that “the links between patient
autonomy and clinical outcomes tend to be weak, ambiguous or mediated by unexamined variables" (p. 19). They proposed that this was because much of the research was atheoretical. They could identify no coherent theory of patient autonomy to provide a framework for the studies. There was no agreement about operational definitions so it was difficult to compare findings from various studies. They believed that some of the research was “an uncritical adjunct to the advocacy of a particular ideological stance” (p. 21) rather than a systematic search for answers.

On the basis of their critique, Steele et al. (1987) recommended that clinicians should try to understand individual patient’s perspectives and tailor their approach to accommodate the individual’s preferences, rather than adopting relationship styles which assume either passive or active patiencthood for everyone. Unfortunately the literature which they reviewed did not specifically address the notions of partnerships and mutuality in decision-making.

2.4.2. Contradictions in the findings on patient preferences

While attempts have been made to gain insights into patients’ preferences for involvement, Smith & Garko (1991) found that results in the social science literature about patient preferences for decision-making were contradictory. They identified two streams of research. The first asked who should make decisions about patient care and the second asked how should the decisions be made; that is, how should the professional-patient relationship be enacted. Studies looking at who should make decisions found a preference for delegation by the patient of that responsibility to the health professionals (Krantz, Baum & Wideman, 1980; Pendleton & House, 1984). Studies looking at how decisions should be made found that patients wanted to participate in decisions (Haugh & Lavin, 1981; Mark & Spiro, 1990). It was suggested that the apparent contradiction arose from the difference in questions asked, and that if an option for mutuality was included this might help by combining who and how in the same question.
2.5. Attempt to solve the contradiction: Autonomy Preference Index

Ende, Kazis, Ash and Moskowitz (1988) also identified the apparent contradictions in the findings on patient preferences but proposed that they arose because argument for patient participation was based on ethical reasoning, not on patient preferences.

Some authors have found little interest in decision-making among patients, while others claim the opposite. Not surprisingly, arguments for or against patient autonomy or physician paternalism, limited or otherwise, have been based principally on normative ethical reasoning without appropriate consideration of patient preferences (p. 23).

They also proposed that the apparent contradictions were further contributed to by weaknesses in the studies and therefore developed an instrument which tapped into preferences from the patient’s perspective. This instrument operationalized information seeking and decision-making, two dimensions identified as discriminating active patients from those seeking a more passive role. Their scale was called the Autonomy Preference Index (API). To identify key measurable dimensions of patients’ preferences for autonomy, they used a Delphi technique which involved a panel of 13 clinicians, medical sociologists and ethicists with special interest in patient autonomy, but included no patients. However, their items were field tested with patients to check content validity and items were discarded, modified or retained according to their feedback and the ability of the item to discriminate between patients. Bennett, Irwin and Bieri (1995, p.3) claim Ende et al. (1988) have repeated a similar error to the one they wanted to remedy, that is, not looking from the patients’ perspective. Given that clinicians have been found to be poor at perceiving patient preferences for involvement (Steele et al., 1987), it seems illogical not to use patients as the primary source when developing a scale to measure a dimension from the patients’ perspective.

Ende et al. (1988) developed and tested their API which included a 15 item “Decision-making Preference Scale” and an 8 item “Information-seeking Preference Scale”. They found that overall there was a desire for information, but a
preference to delegate decision-making to doctors. No relationship was found between scores for information levels and scores for patient preferences. Even when doctors were in the role of patients they did not want greater decision-making than their health care providers (Ende, Kazis & Moskowitz, 1990). The subjects in the studies described above were not explicitly asked whether they wanted to participate in mutual or collaborative decision-making.

2.5.1. Modification of the API

Smith and Garko (1991) claimed that Ende et al. (1988) failed to resolve the contradiction because their scale did not offer mutuality as an option. Accordingly, Smith and Garko modified the API. Because there seems to be general agreement that patients want information (Dennis, 1990), Smith and Garko’s work used only the “Decision-making Preference Scale”, and did not include the “Information Seeking Preference Scale”. Smith and Garko’s “Decision-making Preference Scale” was divided into two sections - three vignettes, each vignette containing three items, and six general items. The vignettes described hypothetical health situations of increasing severity and were included to allow assessment of whether preferences changed with changing severity of illness. The six general items in the original API set out a context and asked subjects to respond on a 5 point scale about who they think should make decisions in that context. In order to include mutuality in decision-making as an explicit option, two statements were added to each of the original items. Each statement was then presented in three forms: “you should decide”; “the doctor should decide”; “you and your doctor should talk it over and decide together”. When Smith, Garko, Bennett, Irwin and Schofield (1994) administered the modified API in the United Kingdom, the United States and Australia they found mutuality to be the preferred method for decision-making.
2.5.2. Evolution of the API Items

Examples of the original API, and modifications by Smith and Garko (1991) are included in Appendix I, but as an illustration of the differences between them, one item is shown below in its two forms. In the original API fifteen item “decision-making Preference Scale” patients responded to each item on a five point Likert scale (Ende et al., 1988, p.29). Responses ranged from 1 = strongly disagree to 5 = strongly agree. For every second item the direction of the phrasing and of the scoring was reversed, to prevent response bias.

You should decide how frequently you need a check-up.

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In Smith and Garko’s (1991, p.22) revised version the single item became three separate items so that the options for autonomy, delegation and mutuality were made explicit. All items were scored 1 = strongly disagree to 5 = strongly agree. The method of scoring allowed a summing of the preference types across sets so three scores were obtained: a patient preference score, a doctor preference score and a mutuality preference score.

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Your doctor should decide how frequently you need a check-up.

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You and your doctor should talk it over and decide together how frequently you need a check-up.

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2.5.3. Conclusions from Smith & Garko's modified API

Using this modified API, Smith and Garko (1991) found that, if the possibility for joint decision-making was not offered, participants chose delegation over autonomy, but when mutuality was offered, it was usually selected as the preferred method. This finding is reflected in the cross-national data as well as in respondents from cultures where individualism is assumed to be less important than collectivism, such as Hong Kong and the Peoples Republic of China (Bennett, Smith & Vanderford, 1995; Smith & Bennett, 1995).

Reflecting on their work, Smith and Garko identified five important conceptual issues which have been drawn upon in the use of the modified API in this thesis.

1. Preferences for decision-making are not necessarily bipolar, so preference for mutuality should be acknowledged and ways should be found to create relationships which foster mutuality.
2. Context matters. The preference for delegation was greatest when illness was more severe, but this relationship may not be linear. Subjects want a stronger role when their information and preferences seem relevant. In this study the severity of the illness and the relevance of information and preferences will be held fairly constant.
3. Power and control did not seem to be as important an issue as is often proposed, since a patient may regain control at any time by not carrying out a treatment which has been ordered.
4. The process of deciding may matter more than who decides and it is difficult to distinguish between the decision and the process of talk in which it is embedded.
5. Single decisions are not isolated acts, but rather they build on each other.

These ideas reinforce the notion that the relationship between patient and health professional is important since it is the context in which decisions are made. How that relationship is enacted, will depend upon the philosophical preconceptions of the interacting parties (Haugh & Lavin, 1981). Much has been written about factors
which influence patient preferences for decision-making (Brody, 1980; Cross & Churchill, 1982; Smith & Garko, 1991), but in practice, clinicians deal with individuals, so the most important clinical consideration is how skilfully the clinician and patient can manage their interdependence (Irwin, 1991).

2.6. Summary

Relationships in health care settings are changing due to broader changes in society, and changes in the nature of illness and how it is managed. There is still considerable debate about how much patients should participate in decisions about their health care. From an ethical perspective autonomy is preferred, notwithstanding there is no convincing evidence that it is necessarily linked to improved clinical outcomes. Studies on patient preferences have yielded conflicting results, but ongoing work on the Autonomy Preference Index provides an argument for mutuality in relationships between patients and health care professionals. This information provides a background for Chapter 3 which considers the specific context of relationships between patients and nurses and work on collaborative decision-making in nursing.
CHAPTER THREE

which concerns the nature of working relationships between patients and nurses and how they may view decision-making. Kim’s framework for collaborative decision-making in nursing is introduced.

Whilst the previous chapter examined general changes in working relationships between patients and health professionals, this chapter narrows the focus to specifically examine patient-nurse relationships and the nature of decision-making within those relationships. Mention is made of a range of nursing theories and some different ways theorists view decision-making in nursing, including a view of nursing as a partnership. Finally, a theoretical framework for collaborative decision-making in nursing is described in some detail since it is used in the theoretical underpinning for Projects 2 and 3 of this study.

3.1. The nature of patient-nurse working relationships

In one sense, Szasz and Hollender’s (1956) parenting prototype for human relationships, outlined in the previous chapter, seems to fit well when considering patient-nurse relationships. It is no linguistic accident that the verb “to nurse” also means “to suckle an infant”, “to care for the young”, “to care for the sick and infirm” and “to promote the development of” someone (Moore, 1993). Professional nursing had its origins in maternal duties and the themes of compassion, care and promotion of development have been retained. Nursing has a traditional image as “ministering mothers” (Bonawit, 1989, p.166) but today it also has an avowed interest in promoting its members as “patient advocates” (Hamric & Spross, 1989, p.12) and this includes advocacy in relation to medical “paternalism”. This is a contradiction. Nursing has long been practised in what ought technically to be termed a parental fashion, with actions being taken by the nurse, in the best interests of the patient, with or without their consent. Frommer (1981) postulates that nurses learn this behaviour, either formally during their education, or informally through socialisation in a health care system which encourages and reinforces such behaviours. How then can nursing claim to act as patient advocate in relation to medical “paternalism”? 26
It is possible that the contradiction arises because nurses now hold a greater range of views about the nature of nurse-patient relationships. In Australia, nurse education was hospital-based until the 1980s, and included intensive socialisation in the workplace, but the transfer of nurse education into the tertiary sector has resulted in nurses now being exposed to various nursing theories, each of which is shaped by the temporal, sociopolitical, cultural and experiential context and perspective of the theorist. It may be hypothesised that an individual nurse's approach to nurse-patient relationships will be influenced by the theory of nursing he or she embraces. This in turn will bias their view of decision-making within the patient-nurse relationship - the subject of this study.

3.2. Some nursing theories and how they view decision-making

Meleis (1985) assigns various nursing theories into broad categories such as "Needs" theorists who view patients as requiring nursing to meet certain needs, and where decision-making is primarily a parental function of the nurse. "Interaction" theorists present nursing as a deliberate interpersonal process where decision-making is primarily by the nurse, but is validated by the patient. "Outcome" theorists conceptualise the goal/outcome of nursing care as bringing balance and harmony between the individual and their environment. The role of the nurse is as an external regulatory mechanism with an orientation towards illness and disease, and decision-making has some collaborative aspects. When one considers even this range of views about the nature of nursing, it is easy to understand how nurses hold differing views about nursing in general and, in particular, about decision-making within the patient-nurse relationship.

3.3. Decision-making and the method of delivery of nursing care

A nurse's approach to decision-making will also be influenced by the method of delivery of nursing care in the workplace. For example, "The Nursing Process" - a method used extensively in Australian hospitals from the late 1960s - implies patient participation in decision-making.
In 1961 Orlando had proposed a process involving the interaction of patients’ behaviour with the nurses’ reaction to it, leading to a nursing action designed for that patient’s benefit. This idea was elaborated by subsequent theorists to become a variation of the scientific method, involving steps such as data gathering, diagnosing, planning, implementing and evaluating so that care was individualised for each patient. It is this which has come to be known as “The Nursing Process”, in which it is “... inherent in the philosophy of individualised care ... that each individual, when able, should be given the opportunity to be fully involved in making decisions about treatment and health care” (James & Biley, 1989, p.32).

In theory “The Nursing Process” involves patients in decision-making in an explicit way, even though it denies them control of the process. Care plans are frequently moved to the bedside, with the aim of encouraging nurses to discuss care and write up the plans in conjunction with the patient. But in practice the nursing process often does not match up to the theory. Although a greater involvement of patients in decisions about care and treatment was thought to have many positive effects (such as reduction of anxiety, increased knowledge and satisfaction, and increased compliance with health care objectives and treatment regimen), Biley (1989) found little research based evidence of this occurring.

3.4. Christensen’s Partnership Theory of Nursing Practice

Christensen (1990) was also interested in the use and benefits of “The Nursing Process” and used a grounded theory approach to examine what was occurring between patients and nurses in a surgical ward. She proposes nursing practice as a partnership in which the patient and nurse are both depicted as experts working together, each providing different expertise relevant to the task. They must communicate since neither can function without the other’s information.

Using the anthropological concept of “passage” - a social process involving significant change in a person’s circumstances - Christensen portrays the experience of undergoing surgery and its related nursing as a type of passage for
the patient. She describes specific work for both the patient and the nurse as the patient passes through four phases of the passage - The Beginning (pre-admission), Settling In, Negotiating the Nursing Partnership and Going Home. Decision-making between patient and nurse is part of that work. Christensen's work had been influenced by the writings of Kim (1983b) who examines a specific aspect of the partnership, that is, collaborative decision-making. This study also uses an adapted form of Kim's framework which is described and discussed in the next section.

3.5. Kim's Framework for Collaborative Decision-making in Nursing

Kim's (1983b) theoretical framework for collaborative decisions in nursing is based on certain assumptions. Firstly, that in nursing care situations many different types of nursing decisions are made for clients, and these influence clients' health in a variety of ways. Secondly, that "clients have resources to be active participants in making such decisions and their participation may have effects on the outcomes of nursing care" (p. 271). Kim focusses on those decisions which directly affect the client and for which the decision responsibilities rest primarily on professional nurses. She defines collaborative decision-making as an interactive process, "an act of selecting a choice among two or more possible alternatives for a prospective action by a group of individuals (two or more parties) mutually influencing the decision" (Kim, 1983b, p.276). Collaboration is a two sided interactive process which is more likely to occur if both parties favour collaboration or if the party with the most control in the interaction favours collaboration (Kim, 1988).

Kim's framework is shown diagrammatically in Figure 3.1. and incorporates contexts, interaction and outcomes. Each of these will now be dealt with in turn.
Figure 3.1. A Theoretical Framework for Collaborative Decision Making in Nursing (Kim, 1983b).

**Context of Participant**

- **CLIENT RELATED FACTORS**
  1. Role Attitudes
  2. Knowledge
  3. Personal Traits
  4. Definition of Situation

- **NURSE RELATED FACTORS**
  1. Role Attitudes
  2. Knowledge
  3. Personal Traits
  4. Definition of Situation

**Context of Situation**

- **ORGANISATION OF DECISION MAKING**
  1. Organisational Structure and Process
  2. Delivery System
  3. Routinization of Decisions

- **NURSING CARE DECISION TYPE**
  1. Program Decision
  2. Operational Control Decision
  3. Agenda Decision

**Primary Outcomes**

- **LEVEL OF COLLABORATION**
- **NATURE OF DECISION**

**Secondary Outcomes**

- **CLIENT OUTCOMES**
  1. Goal Attainment
  2. Autonomy
  3. Satisfaction
3.5.1. The context of participation

Kim postulates that there are two contexts which influence the degree to which clients participate in collaborative decisions about nursing care. These are firstly, the context of the participants - the client and the nurse - and secondly, the context of the situation in which the decision takes place - the organisation and the decision type. These four components are independent but interdependent and operate to hinder or promote collaborative decision-making (Kim, 1983b, p. 277). Each will now be described and discussed.

3.5.1.1. The context of the participants: clients and nurses

Clients and nurses have certain characteristics and resources which determine their willingness and ability to participate in collaborative decisions. Within this context of the participants Kim proposes four influential factors - role expectations, knowledge, personal traits and definition of the situation.

Clients' participation may be influenced by their expectations and attitudes about the sick role which have arisen through socialisation and through experiences in similar situations. A person will be influenced by cultural and social norms. Furthermore, someone who has experienced nursing care could be expected to have stronger expectations than someone who has not. Another part of the context is a real or perceived knowledge gap between client and nurse which may also affect the client's inclination to collaborate in decisions, perhaps causing them to adopt a dependent position, even when their input may be important to the decision. Conversely, a person who believes they have relevant knowledge may be more inclined to participate in decisions.

Psychological theories about personal traits - such as those relating to locus of control, personality and social learning theory - suggest that some clients are more prone to seek or not seek participation in decisions regardless of other modifying factors. Finally, a person's definition of the situation may influence their behaviour
with regard to participation. For example, if a person perceives they have no control over outcomes they may not bother to participate in decisions. As another example, if a person perceives that the nurse has beneficent motives and good control over what is happening, that person may decide the best course of action is to delegate decision-making to the nurse.

Generally speaking, nurses have more “power to control” (Kim, 1983b, p.278) the process of decision-making in relation to nursing care, and the factors which influence them parallel those already described for the client. Nurses’ role expectations and attitudes are built up through socialisation during their education, professional associations and workplace experiences. These expectations and attitudes then influence nurses’ behaviours, including the way they interact with clients, perform nursing actions and control nursing care situations, such as through collaboration in decision-making. Nurses’ knowledge affects any collaboration. For example, those possessing a high level of nursing knowledge may be more confident in having control over nursing care decision situations, and would perceive a greater gap between their own knowledge and that of the client. These factors could in turn be mediated by the nurses’ personal traits such as locus of control, self-concept or dominance which may also influence behaviours allowing clients to participate in decision-making. The nurses’ definition of the situation will also vary with regard to their perception of inherent power and attribution of responsibilities and this is another major factor influencing decision-making.

3.5.1.2. The context of the situation

The context of the situation includes the organisation of decision-making and the type of nursing care decision which needs to be made.

The organisation of decision-making includes the organisational structure of the institution in which the nurse works, some having a more hierarchical structure and varied distribution of power, which may affect decision-making. Organisation
also includes the philosophy of health and nursing care. For example, one would expect a difference in philosophy of nursing care between a hospice and an oncology ward in an acute care hospital. The nursing care delivery system, such as job assignment, team nursing, primary care, or the use of methods such as the nursing process (see Section 3.3) will also influence the nature of decision-making since they indicate who is responsible for decisions made. Another factor is the routinization of decisions, using standing orders, protocols or critical pathways. All these factors may promote or hinder the amount of collaborative decision-making which may occur between client and nurse.

Three types of nursing care decisions are identified, and they differ in their meanings in nursing process and the time involved in making them during the delivery of nursing care.

1. *Program decisions* involve decisions about program content and goal priorities. They take into account the alternatives to be considered when dealing with health care problems and planning of nursing care. Usually there is a knowledge gap between the nurse and client with regard to these matters since the health problem often elicits different meanings for client and nurse in terms of requirements and consequences. Furthermore, clients have the specific knowledge about themselves, their symptoms and peculiarities and the nurse has the professional knowledge about which nursing care needs to be done and how it can be implemented. Such decisions usually do not have to be made in haste. A decision about how to manage a colostomy in the long term fits well into this category since it involves considering the patient's peculiarities and preferences when selecting a management method (goal) and then determining what the patient has to learn from the nurse to attain that goal.

2. *Operational decisions* involve selecting the way in which actions will be performed to achieve certain outcomes. Therefore the person making the decision needs to know how to perform the actions and which outcomes are likely to be achieved, for example how to apply a particular dressing to promote healing. Such
decisions usually require immediate choices.

3. Agenda decisions involve prioritising actions or sequencing activities, for example setting up a schedule so that certain nursing care will all be achieved in a set period of time. These decisions may need to be made quickly at times.

3.5.1.3. The outcomes

In Kim’s framework, the context of the participants and the context of the situation interact to produce primary and secondary outcomes.

The first primary outcome is the level of collaboration. It is conceptualised as a continuum on which the lowest level of collaboration is characterised by complete domination of the decision-making by one party, usually the nurse. The highest level of collaboration involves both parties equally influencing the decision-making. The second primary outcome is the nature of the decision which is conceptualised in terms of the extensiveness, attainability and affective meaning of the decision, rather than the absolute meanings of choices made.

The secondary outcomes are client outcomes which arise out of the primary outcomes. In the framework, the major client outcomes are goal attainment (which includes the notion of compliance), satisfaction and autonomy. Goal attainment is usually assessed by the professional’s criteria, whereas satisfaction and feelings of autonomy are usually assessed using the client’s criteria.

3.6. Ideas related to Kim’s work incorporated into this thesis

3.6.1. Decision types

An exploratory field study using a structured observation method in an acute care setting found that the types of nursing care decisions proposed in the framework are operationally feasible and useful for further studies (Kim, 1983a), however this
this study uses only one type of decision - a program decision, about long term colostomy management.

3.6.2. Level of collaboration in nursing practice

Studies investigating the level of collaboration in usual practice reported that, although nurses stated that they believe in collaborative decision-making, it was not evident in practice. Kim proposed that “either there is a lack of institutionalised process by which nurses can include clients in decision-making in acute care settings, or the situational factors are such that it is not possible for nurses to include clients in collaborative decision-making” (Kim 1983a, pp.4-5). These propositions led this writer to the idea of designing a formal decision instrument which could be used to institutionalise collaboration in a specific decision. The development of the decision instrument is described in Chapter 4.

3.6.3. The contexts of the participants

Kim found that, while collaborative decision-making was an ideal generally accepted by most nurses in an acute care setting, there was little evidence of collaborative decision-making actually taking place. Kim proposed that clients’ beliefs were not as influential in determining the level of collaboration as what was allowed by nurses in the practice setting (Kim, 1991, 1985).

Results from another mailed survey (Kim, 1983a) also suggested that, although nurses generally believe in collaboration, they do not believe clients have the right to have complete control over nursing care decisions, but that there should be shared responsibility. The most preferred practices for collaborating included providing opportunities for collaboration and allowing input before decisions are made, although about 11% only informed clients of decisions requiring their cooperation. Over 90% of nurses believed clients should seek or ask for information, although very few believed patients should demand complete control. Usual practice was believed to have low levels of collaboration. The conclusion
was that either nurses were not expressing their true beliefs or, if they were, they were not acting on them.

Kim proposed that nurses' expressions of these beliefs may not be their personal belief structures but rather normative expectations of the profession and that actual behaviours are more an expression of their personal beliefs. Alternatively, nurses may genuinely believe clients should collaborate but may not know how to include them in collaborative decisions. With these findings in mind, the decision literature was consulted to find ways in which nurses could include patients in decisions. This is also explored in Chapter 4 and incorporated into the current study.

3.6.4. Outcomes

Kim's (1987) report comprised a program of studies seeking to explain the nature of the client-nurse interaction and to propose its use as a medium for improving patient outcomes. It included a study by Bringsjord, Burchard & Murray (1987) concerning the effects of collaborative decision-making during negotiation for pain management which was based on the assumption that clients with a greater degree of control and a higher level of collaboration in nursing care decision-making would be more likely to produce positive outcomes of care. That is, to be satisfied with care and to attain the goals of nursing care. The results showed that there was no significant difference in pain levels nor in anxiety, but the clients who had high level of collaboration were more satisfied with their care. It may be that, from the client's perspective, satisfaction may be as important an outcome as attaining physical goals. For this reason, in the current study goal attainment and satisfaction will both be considered equally important outcomes. In 1988, Kim stated a literature-based assumption that perceived levels of satisfaction with client-nurse interaction are likely to be influenced by the alignment between what is expected and/or desired and what is perceived to have occurred with respect to contribution to decision-making. This assumption is tested in Project 2 of this thesis (Chapters 6 & 7).
3.7. Discussion

Collaborative decision-making is a major issue which pervades nursing practice. Kim’s framework offers one way of examining this issue. Its great strengths are that it is clear and logical and could be easily applied in the practical situation. However, three difficulties arise which make it difficult to meaningfully interpret results from some studies using the framework. Fortunately these difficulties do not arise from the framework itself, but rather from the measurement of some of its components.

Firstly, in at least one study using the framework, there is an implied acceptance of a power paradigm in explaining the relationships between the client and nurse, and this is despite discussions about changes in society and the emergence of consumerism (Kim et al., 1993). Now it may be argued that for many nurses and clients their relationships are based on a power play, but it is also possible that for many they are not. Kim’s framework is neutral on this subject since it acknowledges that a variety of client and nurse related factors may occur. However, the application of the framework has not made allowance for this latter group who do not interpret their nurse-patient relationship in terms of power. For example, in a study using Kim’s framework (Kim et al., 1993), the instruments used to measure patients’ attitudes included “the general consumerist attitude scale” and “the consumerist attitude in health care scale” (Haugh & Lavin, 1979 & 1981).

Haugh and Lavin’s work had been undertaken from a perspective which sees decision-making as a control issue, so that either the patient or the professional is “in charge”. If one has more control or influence, then the other has less. This premise is challenged by the idea that there is not a fixed amount of power or control in a relationship (Smith & Garko, 1991). Furthermore, a health professional does not have true control unless the patient actually complies with the treatment ordered. Deciding is not controlling. Although Haugh and Lavin correctly asserted that non-compliance is not always an act of “sabotage” or even of self-assertion, sometimes it may be. The patient does potentially have that
power. *Decision-making* needs to be followed by *decision-taking* if the patient is considered to have true control.

In the current study, the purpose of investigating the client-related factors in Kim’s framework was to identify attitudes which influence collaborative decision-making. From the above comments, it seems that there are contradictions between what Haugh and Lavin’s scale measures and what Kim’s framework is seeking to explain. This needs further explanation.

Haugh and Lavin clearly recognised that: “From the bargaining perspective, each party to the interaction brings different resources to the encounter, and is prepared to negotiate an acceptable set of terms for the relationship which may include agreements on both diagnosis and treatment” (1981, p. 213). But their instrument looked at *who* makes the decision and it only offered a dichotomy: the patient or the professional, with no option for selecting mutuality, or “negotiating an acceptable set of terms for the relationship”. For example, scale item 1 allowed the person to opt for:

“Obedience and respect for what doctors tell you is most important”, or

“Relying on your own judgment and making your own decisions about what doctors tell you are most important”.

This is incongruent with the basic concept of Kim’s framework which is collaboration. Kim’s framework is about *how* decisions may be made. Haugh and Lavin’s consumerist attitude and behaviour scale is not tapping the relevant construct. For these reasons, it was decided not to use Haugh and Lavin’s scale for the current study. This is discussed further in the methodology section in Chapter 6.

As shown in Chapter 2 of this thesis, work on patient participation in decisions about health care has progressed beyond ideas which only offer a dichotomy and newer models now incorporate ideas about mutuality and partnerships. Since Kim’s framework is about collaborative decision-making, it seems more logical to use an instrument which taps into subjects’ attitudes towards collaboration.
A second problem with interpretation of results from studies using Kim’s framework comes with the attempts to assess the effects of collaboration on the outcomes of nursing practice. Most of the studies cited have indicated that high level collaboration is not a common phenomenon. Even when it is said to have occurred, there has been no control over the degree or nature of that collaboration. An instance of this is seen in the work by Bringsjord, Burchard and Murray (1987) where, although there are scripts outlining intended levels of collaboration, there is no indication of how this was ensured (for example by using an independent observer). So, it is not surprising to find that client participation in decision-making has not had a major effect on nursing outcomes. Is participation the same as collaboration? How is the participation defined? Does it mean the nurse gives information and the client listens and follows advice? Kim (1983a) stated that perhaps nurses do not know how to include clients in collaborative decisions, even when they mistakenly believe they do. With this in mind, the current study controlled the level of collaboration using specific criteria and independent assessors, and measured the outcomes of the decisions so that meaningful conclusions could be drawn.

The third problem with interpretation of results from studies using Kim’s framework lies in the measurement of satisfaction, which is a complex multidimensional outcome. Which aspect of satisfaction is being assessed? Is it satisfaction with the level of collaboration in the decision? Is it satisfaction with the nurse-client relationship? Is it satisfaction with the nursing care received? Or is it satisfaction with the physical outcome of nursing care? These questions need to be explicitly answered. It is possible that a person may be satisfied with the level of collaboration in decision-making, but this is overridden by dissatisfaction with adverse physical complications. Or the person may be dissatisfied with level of collaboration but this is overshadowed by the nurse’s pleasant manner as she gives orders. This observation will lead to the use of a very specific satisfaction measure in Project 2 (see Section 6.10.2.).
3.8. Summary

This chapter examined some aspects of patient-nurse relationships and the nature of decision-making within those relationships. The dynamics of the relationships and the decision-making between specific nurses and those in their care will depend in part upon the individual nurse’s theory of nursing and the method of organising nursing care in their work context. To indicate the range of views that exist, attention was directed to some general categories of nursing theories and how they conceptualise decision-making within nursing practice. Specific attention was then paid to Christensen’s (1990) Partnership Theory of Nursing Practice because it fits logically with the concept of collaboration and, based on the clinical experience of the researcher, it has ecological validity. Mention was also made about the method of organising nursing care called “The Nursing Process” since it has been widely used in Australian hospitals for many years.

Finally, Kim’s framework for collaborative decision-making in nursing was examined in some detail because it deals with the specific content which forms the basis of this thesis. Ideas from other studies using Kim’s framework were described and discussed since they are incorporated into the adapted form of the framework which is used as part of the theoretical underpinning for Projects 2 and 3 of this thesis. The next chapter describes Project 1, the development of a formal, research-based decision instrument which was used in Project 2 to set up an experimental situation which encouraged collaborative decision-making between patients and nurses.
CHAPTER FOUR

which discusses general ideas about decision-making and techniques to improve decisions, including the Simple Multiattribute Rating Technique which will be applied to a nursing decision in Project 1

Kim's (1983a) work suggested that although nurses generally recognise that patients have much to contribute to decisions about their care, there is little evidence of collaborative decision-making in nursing practice. The reasons for this phenomenon are uncertain, but it has been suggested that it might be due to organisational constraints or situational factors; or it could be that nurses may not know how to include patients in decision-making. Although nurses are often willing and able to supply information to patients, they may not know how to help patients to use that information to make decisions.

It has been suggested that "the best mechanism for giving patients a greater role in the decision-making process is to increase the use of decision analysis" (Schwartz & Griffin 1986, p. 227). This involves what Fischhoff (1982) called "a division of labour", within which the nurse's work requires clinical and scientific expertise which are used to define and structure the problem, identify the alternative actions and outcomes and provide the relevant probabilities of each outcome occurring. The patient's work involves providing information about what is meaningful to them. The decision analysis then combines all the information to allow a relevant decision to be made. This method is clearly congruent with a partnership model of nursing.

In the following sections, ideas from general decision theory are described, together with a brief overview of the limitations and problems generally encountered when people make decisions. Some techniques which help to improve decision-making are introduced. Attention is specifically focussed on the Simple Multiattribute Rating Technique of Edwards (1971) which is applied to a nursing decision in Project 1 of this study as a means of assisting patients to organise and appraise information as they make a decision about long term management of their
newly fashioned colostomy.

4.1. General ideas about decision-making

After realising that a decision is to be made, a decision maker usually explores information and classifies the situation, generating alternative outcomes (Carroll & Johnson, 1990). If a decision is complex, decision makers do not usually consider all the possible outcomes, rather they structure the situation in order to have a manageable number of items for investigation. Next they identify the attributes of each of those possible outcomes, that is the characteristics which might cause them to accept or reject deciding upon that outcome. Then they evaluate each attribute, employing rules of varying formality and complexity which they have gained through experience. Once the attributes have been considered a decision will be made. After acting upon that decision, feedback may contribute to learning and be incorporated into the next decision process. This general plan is summarised below in Figure 4.1.

Figure 4.1
General Plan for Making Decisions

Explore situation & classify information

Generate alternatives

Evaluate attributes using rules

Make a decision

Feedback
4.2. Common problems encountered when making decisions

Two major groups of problems arise when making decisions. One group relates to the fact that decisions may be complex and people have limitations when dealing with complex information. Other problems for decision makers arise from the uncertainty of the outcomes. Because the best choice is not always obvious, the result of a particular decision is a matter of probability. Probability is measured on a scale that goes from 0 to 1, where certainties are assigned probabilities of 1 and impossibilities are assigned probabilities of 0 and everything else is assigned a probability somewhere in between these extremes (Schwartz & Griffin, 1986). These two groups of problems will now be discussed briefly.

Research in cognitive psychology has revealed limitations in attention, memory and calculation, and the effects of these limitations on decision-making are important. Because we cannot deal with large amounts of information at one time we tend to simplify situations, to formulate decisions through limited viewpoints which highlight some aspect of the situation, but ignore others. We have developed a variety of sometimes successful shortcuts (heuristics) for making decisions within the constraints of our limitations (Kahneman, Slovic & Tversky, 1982; Wright, 1984).

Simon (1978, p.10) formed a view that some people behave rationally within their limitations by using a strategy called “satisficing”, which means that they opt for the first available course of action which seems good enough to meet their minimum requirements. For other decision makers, the perceived “salience” of one option overshadows all other options such that the other options are not even considered (Pierce, 1993, p. 23). Some decision makers randomly consider whichever subset of attributes happens to come to mind and seems to be particularly relevant at the time that the decision is being made (Kahneman et al., 1982).
While the studies mentioned above describe the process of decision-making and identify limitations in that process, they do not assist decision makers to improve the quality of their decisions. These studies beg the difficult question: "What is a good decision in a probabilistic environment?" Quality is determined by the process, not by the outcomes of decisions. This must be the case since the same outcome may be chosen through careful consideration or randomly (through flipping a coin), and good decisions may lead to poor outcomes and vice versa. The studies cited above indicate that the processes used in real life are sometimes far from optimal even when the decision maker is functioning under desirable conditions. But when the decision maker is a patient who is ill, stressed and facing decisions in which the stakes are high or the options are uncertain and hard to comprehend, then there is a justification for more careful analysis and assistance from others, if available.

The technique known as decision analysis is about such assistance. The goal is to structure and simplify the task of making the decision as well and as easily as the nature of the decision will allow. There is an opportunity for nurses and patients to work together in such a task. The nurse may provide information about the possible outcomes and assist the patient to organise and appraise those outcomes meaningfully in terms of their own values. The challenge is to develop a decision analysis method which is "user friendly" for people who are recovering from illness and surgery.

4.3. Techniques to improve decisions - decision analysis

Decision analysis techniques are usually used to prescribe how decision makers ought to proceed in certain situations. Based on classical economic theory (von Neumann & Morgenstern, 1944), these techniques use formulae which guarantee the best long-term chance for successful outcomes. Critics make much of the fact that real life decisions consistently diverge from these models (Bazerman, 1986; Dawes, 1988; Hogarth, 1987; Kahneman et al. 1982) but surely that is the point of the exercise. The decisions made using decision analysis should be different,
they should be better, because the process used is more thorough. Rather than using heuristics they allow the decision maker to take into account a range of variables which they may not be able to handle under other circumstances. Decision analysis allows decision makers to determine their own preferences rather than rely on the values of some other party. This is the purpose of Project 1, to develop a “user friendly” decision instrument to assist a person with a newly formed colostomy to make a decision about its long term management based on their values rather than those of the stomal therapy nurse.

4.3.1. Defining some terms used in decision analysis

Common terms used in decision analysis need to be defined before the techniques can be described. A utility is an individual preference for a particular outcome. Nursing decisions involve patient’s utilities for outcomes which may involve tangibles like money or intangibles like pain, embarrassment or quality of life. Being able to conceal a colostomy under tightly fitting clothing may be more important to a professional dancer than it is to an elderly resident of a nursing home, so concealment is said to have a higher utility for the dancer.

A subjective expected utility involves a person’s belief that something is likely to occur. Subjective Expected Utility theory is a way of making decisions when outcomes are uncertain, such as not knowing how frequently an individual’s bowel is going to act after colonic surgery. According to Schwartz and Griffin (1986), there are general steps by which Subjective Expected Utility theory is applied. The decision maker forms an internal cognitive representation of the decision task and assesses the probability (likelihood) of attaining the various outcomes. These probabilities may be estimated from the relevant literature, but when the required data are unavailable or equivocal, subjective probabilities (educated guesses) must suffice. The consequences of the various outcomes are assigned a utility value by the decision maker, then the probabilities are combined with the utility values for all relevant outcomes. Finally the decision maker usually selects the option with the highest (utility x probability) score and this is called
maximising utilities. For example, if 3 foods are listed on the menu but the patient with a new colostomy fears they may have loose stools after eating, and this will cause inconvenience, an estimate is made of the probability of loose stools not occurring with each of the foods and that with the highest probability is selected.

A further refinement of this technique is Multiattribute Utility Theory which is used when each outcome can be decomposed into its constituent attributes and then these can be valued separately. Each potential outcome is assigned a level of importance on each attribute and the outcomes are recalculated, usually by addition, to determine their multiattribute utility. That is, each attribute's combined utility is simply the sum of the utilities of the attributes by their assigned level of importance (Edwards, 1977; Hogarth, 1987; von Winterfeldt & Edwards, 1986).

Taking the previous example of the three foods listed on the menu. Suppose the individual disliked one of the foods available, and suppose all three had the potential to cause loose stools and wind pains. These are now three attributes for consideration: likes and dislikes, loose stools and wind pains. A utility is assigned for the importance of eating food which is liked, a utility is assigned for avoiding loose stools, another utility is assigned for avoiding wind pains. These utilities are then multiplied by the probability of each occurring with each of the foods. The (utility x probability) scores are summed for each food and the food with the highest total score is selected.

There is a problem if the utility for one attribute is stronger than the utility for another. In the example of the food, it may be that the utility assigned to eating something one likes far outweighs other aspects. There needs to be a valid but practical way to compare the utilities. Raiffa (1969) and Edwards (1971) both worked on aspects of Multiattribute Utility Theory but approached it from different perspectives. Keeney and Raiffa's (1976) system of eliciting utilities requires decision makers to make difficult judgments between pairs of hypothetical options, but Edwards believed that more direct assessments of utilities would be easier and less subject to errors, so he developed a technique called the Simple Multiattribute Rating Technique (SMART) which helps decision makers organise their utilities.
4.3.2. Simple Multiattribute Rating Technique (SMART)

The thing that is unique about SMART is that once the relevant attributes of the outcomes are identified, they are ranked in order of importance, thus also ordering the utilities. Next attributes are rated by making ratio estimates of the importance of each attribute relative to the one ranked lowest in importance. The importance weights are then summed and each divided by the sum. The relative value of each attribute is ranked on a scale of 0 to 100. This is done for each attribute of each outcome. The overall values for each outcome are calculated using an additive model, and the outcome with the highest overall value is chosen.

Edwards and Barron (1994) justified this strategy as “heroic approximation”, stating that unlike the other more sophisticated methods, they do not use complicated methods to elicit utilities, rather they identify “the simplest possible judgments that have any hope of meeting the underlying requirements of multiattribute utility measurement, and try to determine whether they will lead to substantially sub optimal choices in the problem at hand”; if not, they use them (p. 310). SMART is straightforward in the way it elicits utilities and relies on simple additive models and numerical estimates, yet its robustness has been demonstrated (Edwards & Barron, 1994). For these reasons it was selected for use in Projects 1 and 2.

Although these decision analysis techniques have been available for over twenty years, one reason that they have not been used widely arises from the fact that measurement of utilities is not easy. Difficulties arise because one assumption underlying the concept of utility is that values can somehow be expressed using a common scale. Because of this problem, SMART has undergone various metamorphoses and the most recent versions (SMARTS and SMARTER) try to compensate for differences in spread of utility measurements and in doing so have become almost as complicated as the procedures they sought to replace (Edwards & Barron, 1994). This is why the later versions are not used in this study. Schwartz and Griffin (1986) commented that a “practical method for measuring
utilities is particularly important if decision analysis is ever to become accepted as a routine part of clinical practice" (p. 233).

This study documents an attempt to develop and test a decision instrument which is sufficiently user friendly to be utilised by post-operative patients who are facing a decision about changes in lifestyle. The method employed for eliciting the utilities is modelled on an evaluation ranking scale developed by Pascoe and Atkisson (1983) to assess patient satisfaction levels, and involves a card sorting technique. The application of this method contributes to the development of decision analysis and is described in section 5.9.1.

4.4. Application of SMART to a nursing decision

4.4.1. The decision to be studied

The decision investigated in this study concerns the selection of a long term management strategy by people who are still hospitalised following surgery to create a permanent colostomy. Immediately post-operatively all patients wear a bag to collect their bowel actions, but for long term management several options are possible. A person may wear a collecting bag on their abdomen or insert a tampon style of plug into the lumen of the colostomy. They may alter their diet, take medications or give themselves periodic enemas into the colostomy. Some people use a combination of these methods.

4.4.2. Reasons for selecting this decision

During my work as a stomal therapy nurse, I have often wondered why most people seem to choose to wear a bag when the other colostomy management methods are also available and seem to be reasonable alternatives. I thought perhaps that nurses may influence the decisions by failing to tell people about all of the management methods available or by presenting the choices in a biased manner. Studying this decision should satisfy personal curiosity about this subject.
However, the decision about long term colostomy management was also selected because it has several features which facilitate routinization and which fit in well with the framework of the SMART decision analysis method.

Firstly, the decision about how a patient with a colostomy will manage it in the long term is important and warrants careful consideration. “Trial and error” approaches are unsuitable because “accidents” in public may be devastating and failure to manage the colostomy can have serious psychological effects, including depression and social isolation.

Secondly, the decision is a common one. Each year in the state of New South Wales (NSW) several hundred people undergo surgery resulting in the formation of a colostomy and they are often attended to by specialist stomal therapy nurses whose role it is to educate, counsel, support and otherwise assist with rehabilitation. Stomal therapy nurses are therefore involved in such decisions frequently, and could use an instrument to structure their decision-making processes with patients.

Thirdly, the decision is one in which the input from the patients is relevant since the outcome affects their lifestyle and it is the patient, or their carer, who ultimately uses the method selected. Stomal therapy nurses may have developed expert and informed opinion about the various methods in general, and indeed may favour some methods because of their own values or preferences. But nurses cannot know the patients’ preferences unless they ask them. A decision analysis instrument provides an explicit structure for obtaining this information in a simple manner.

Finally, the decision is appropriate for an application of multiattribute utility theory such as SMART, since there are several possible outcomes (ways to manage the colostomy) and there are several main reasons which might cause a patient to select or reject these outcomes. There is uncertainty about the outcomes. How frequently will the colostomy act? How will diet affect bowel actions? Will medications be
needed? Will the appliance be visible under clothing? Will plugs or irrigations be more effective than wearing bags? The patient has no way of knowing the answers to these questions, yet they need to make a decision. What they do know is their utilities for various attributes of these possible outcomes.

4.4.3. The contribution of this study to nursing practice

The decision about long term colostomy management is also an interesting one from a clinical nursing perspective. Studies comparing methods of colostomy management have often indicated that the irrigation (self-administered enema) method has several advantages compared with other methods, yet irrigation is not widely used in NSW. All irrigation sets and other appliances are issued through the Colostomy Association of NSW. In May 1997 the officers of that Association acknowledged that they had 3934 members, but had only issued 278 irrigation sets during the preceding 12 months. This means that at most only 7% of members were irrigating. Reasons for this low usage of the irrigation method are not clear, but Stuart (1972, p.1294) proposed that many patients are not informed about the method: “The tendency has been to reserve the use of colostomy irrigation for those patients who request it. Yet the patient is often not informed of its availability and so remains ignorant of its advantages”.

By explicitly including the irrigation method as a decision choice, along with the other currently and locally available methods, the results from this study help to explain the reasons people select or reject various colostomy management methods. As will be explained in section 6.4 of this thesis, each patient was informed about each colostomy management method in a manner which did not bias one method over the others. This is particularly important because it is known that the manner in which information is presented may have a powerful effect on choices (Fischhoff, 1982). The use of research-based information in the decision instrument helped to ensure that the information supplied to the patient was not limited to the personal experience or values of the individual stomal therapist.
4.5. Summary

This chapter described some aspects of decision-making in general and some decision analysis methods. This information is important as the background to the development of a decision instrument in Project 1 which was used in Project 2 as one method of patient-nurse collaborative decision-making. The following Chapter concerns Project 1 which involved a review of literature about colostomy management methods and its use in the development of a decision instrument.
CHAPTER FIVE

Project 1: which concerns the development of a decision instrument to facilitate collaborative decision-making between patient and stomal therapy nurse deciding upon long term colostomy management.

In preceding chapters it was proposed that, although nurses generally recognise that patients have much to contribute to decisions about their care, collaborative decision-making is not often evident in practice. This may be because there are not situational features or institutionalised ways to promote this inclusion of patients in collaborative decision-making, or perhaps nurses do not know how to facilitate decision-making.

Some experts in decision theory advise that the best way to increase patients' role in decisions is to use techniques within the framework of decision analysis (Schwartz & Griffin, 1986). These techniques require the nurse to define and structure the problem, identifying possible outcomes and the attributes of each outcome which might be relevant to the patient when making their decision. Using professional knowledge and experience the nurse advises the patient of the general probabilities for success with each of the outcomes. The patient then contributes relevant information about their utilities for the various attributes. All this information is then combined using a decision instrument to reach the decision. To date, there has been no practical method to elicit utilities from patients in the early post-operative phase, but Project 1, the focus of this Chapter, combines all of these ideas and develops a decision analysis instrument which is practical and simple to use and which makes explicit the information the patients need to contribute, and the reasons various decisions are made.
5.1. Overview of the method of development of the instrument

This decision instrument was developed in four stages which are listed below.
1. A literature review was undertaken to identify:
   * the outcomes - the currently and locally available methods of long term management for a colostomy about which the patient is making a decision.
   * the attributes - characteristics of the management methods which might cause a decision maker to select or reject a management method.
2. A Delphi technique was used to verify the outcomes and attributes and to refine the attributes.
3. Literature analysis was used to calculate or deduce probabilities - estimates of the likelihood for the individual to be able to perform or experience each of the attributes when using the colostomy management methods successfully, and an expert panel is used to verify the probabilities.
4. A pilot study was undertaken to evaluate and revise the instrument.
These processes are outlined (see Figure 5.1) and fully described in the following sections.

5.1.1. Literature review to identify outcomes and attributes

A meta-analytic review of the relevant literature on long term colostomy management was undertaken in order to determine the outcomes, attributes and probabilities for the decision instrument. Meta-analysis is the statistical analysis of a large collection of results from individual studies for the purpose of integrating the findings. It is more rigorous than casual, narrative discussions of research studies which typify most attempts to organise research literature (Glass, 1976).

To perform this meta-analysis, a computerised literature search was conducted using three of the most relevant data bases - Medline, Combined Index of Nursing and Allied Health Literature (CINAHL) and Dissertation Abstracts. Additional papers were then identified from the references reported in those studies. Initially the search was for studies comparing various colostomy management methods.
Figure 5.1
Flowchart Showing Method of Development of the Decision Instrument

LITERATURE REVIEW TO IDENTIFY

OUTCOMES
is CURRENTLY AND
LOCALLY AVAILABLE
METHODS OF
LONGTERM
COLOSTOMY
MANAGEMENT

ATTRIBUTES
is CHARACTERISTICS
WHICH MIGHT
CAUSE A DECISION
MAKER TO SELECT
OR REJECT ANY
OUTCOME

VERIFIED BY EXPERT
PANEL OF SPECIALIST
NURSES AND FORMER
PATIENTS USING 4
ROUNDS OF DELPHI
TECHNIQUE
(ITERATIVE FEEDBACK)

PROBABILITIES
FOR EACH ATTRIBUTE
FOR EACH OUTCOME

VERIFIED BY PANEL OF
EXPERT NURSES

OUTCOMES, ATTRIBUTES AND PROBABILITIES COMBINED TO
FORM SMART INSTRUMENT

PILOT STUDY

REVISION USE IN PROJECT 2
However, there were so few of these that the domain of interest was widened to include papers concerning any of the long term colostomy management methods. Other relevant information was obtained from books, patient education materials and specialist stomal therapy nursing journals, most of which are not refereed. Papers were limited to those published after 1900 and in the English language.

Using these processes, two hundred and seven papers were obtained which met the criteria. These were then sorted according to country of origin (England, North America, Australia and other), because it had become apparent that predominant ideas about colostomy management differ, particularly between England and North America. Indeed one paper is titled: “Colostomy irrigation - a transatlantic controversy” (MacLeod, 1972). Next, the papers were sorted into chronological order. In recognition of the fact that there have been major developments in the features of colostomy appliances and irrigation equipment in the past 30 years, papers published before 1970 were not used for information relating to colostomy appliances or irrigation since they reflect a different set of circumstances, not comparable to later times. Some earlier papers were used in the section about diet and colostomy management since there was no evidence of dramatic changes in ideas in these areas.

Many of the papers were not scientific studies, but were anecdotal reports or discussion papers and did not contain information which could be used in a meta-analysis. Papers were therefore sorted according to whether they were discussion papers, anecdotal reports or scientific studies. Rather than eliminate large numbers of papers and lose potentially valuable information, general information from discussion papers and anecdotal reports was deemed to be potentially useful for determining the outcomes and attributes for the instrument, but only “scientific” papers were acceptable for calculating the probabilities. These empirical papers were further scrutinised for evidence of scientific rigour such as random selection of subjects, use of controls, adequate definition of variables and tests of validity and reliability of any instruments used.

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Only thirteen "scientific" studies were identified and scrutinised (these studies are included in Appendix Two and marked with an asterisk in the reference list). On review, it became clear that there were methodological problems with most of these studies, including non-random selection of subjects, and frequent reliance on retrospective mail and telephone surveys. There was only one prospective controlled trial which compared irrigation with the "spontaneous action" method. Only one paper used inferential statistics, the others described percentages of persons falling into various categories. Another major drawback was the frequently inadequate definition of variables such as the management method people were using when they did not irrigate their colostomy. Sometimes it was impossible to determine whether any comparison was justified between findings of different researchers.

The disappointing conclusion was that, in order to get a better understanding of how people cope with the various methods of long-term colostomy management, what is needed are better designed studies with more appropriate analyses than those currently reported in the literature. The apparent lack of scientific rigour and sophistication in these studies was upsetting and precluded the use of the meta-analysis technique. In order to avoid what Eysenck (1978, p. 517) referred to as, "garbage in ... garbage out", it was decided to use a modified form of meta-analysis, using those few descriptive statistics which were clearly defined and obviously comparable with each other to determine some of the probabilities.

The outcomes (possible methods of long term colostomy management) and attributes (features of those methods which might cause a patient to select or reject each method) were determined from the broad range of literature and then verified by a panel of experts including patients and stomal therapy nurses using a Delphi technique. This is a technique for data collection which uses questionnaires which are mailed to a panel of experts in "successive waves, with feedback from previous questionnaires included with successive questionnaires" (Seaman, 1987, p. 285). Later the probabilities for the various attributes occurring in each of the outcomes were derived from the more "scientific" studies and also subjective probabilities.
were provided by a panel of expert stomal therapy nurses. These processes are described in detail in Sections 5.5. and 5.6.

5.2. The outcomes for inclusion in the decision instrument

This section deals with the identification of the outcomes to be used in the decision instrument. The long term colostomy management methods considered in this study are: simply wearing a bag, use of diet, medication, intraluminal plugs, irrigation and any combination of these. Although mentioned in the literature, neither surgery to slow intestinal flow (Habr-Gama, Santos, Souse & Delatorre, 1990; Ortiz, Marti & Saenez, 1989; Schmidt, 1982), nor biofeedback (Reboa, Frascio, Zanolla, Pitto & Berti Riboli, 1985) will be considered further in the context of this study since neither is routinely practised for colostomy management in NSW and they were not options available in the institution where this study took place.

Before considering the outcomes, some aspects need to be discussed. Some terms in the literature about colostomy management are confusing. Today when one calls a method “natural” or “spontaneous” one assumes that it occurs in response to instinct or innate rhythms, and without external cause. However, in the past “natural evacuation” (MacLeod, 1972) or “spontaneous action” (Williams & Johnston, 1980) often involved “judicious dietary restrictions, controlled fluid intake, and the use of medications” (Devlin, Plant & Griffin, 1971, p. 414), and was the method commonly recommended for those who had slow or normal intestinal function prior to their operation. By today’s definitions this sounds far from natural or spontaneous. Writers often do not specify exactly which methods their subjects were using so this has made it difficult to draw meaningful conclusions from much of the literature.

There is an option for being ‘natural’ or ‘spontaneous’ in the literal sense. This is the option for ‘just wearing a bag’, collecting and disposing of the output, with no attempt to control the colostomy using diet or drugs. This option has always been
available and some writers have called it: “Natural Evacuation ... that is, to let it come naturally, as it will” (Lenneberg & Mendelssohn 1969, p. 211). In the context of this study this outcome will be referred to as “containment” in order to distinguish it from the confusing misnomers “natural evacuation” and “spontaneous action” which occur elsewhere.

Although there is an abundance of anecdotal and prescriptive information about diet and medications for people with a colostomy there are few studies, mainly simple descriptions from mailed surveys. Unfortunately, they often lack clear operational definitions, are ambiguous about the actual diet and medications being used by subjects, and rarely report the degree of success of the methods chosen. These facts make it difficult to explore diet and medication as two separate management methods. This is not to say that there are not people who use only diet or only medication for colostomy control, just that it is difficult to extract data about their specific experiences from the literature.

These problems are compounded by the fact that there are various ways of using diet and medications for colostomy management, and it is not always clear which method was being used. Some authors promote diet and timing to “train” the colostomy to act at regular times. Others advocate following a rigid “constipating diet”, and if necessary using regular laxatives. There is also the idea of regularly or intermittently using medications such as bulk forming agents or stool softeners to regulate the consistency of the motions. Lastly there is a “trial and error” approach, eliminating whatever causes the colostomy to act too frequently or causes motions to be of inconvenient consistency.

Not only are there different ideas about how special diet and medications should be used, there are also beliefs that they should not be used at all. Jeter and Bertsch (1973) concluded that diet with or without medications does little to regulate bowel actions. MacLeod (1972) agreed, and proposed that bowel activity was more likely to be related to premorbid bowel regularity. Terranova, Sandei, Rebuffat, Mannotti and Bortolozzi (1979, p.33) concluded that “diet is an individual matter based on
eating habits, bowel movements and gas formation, but every patient should be
warned about some foods as potential problem causes”.

These difficulties need to be remembered when considering the methods of long
term management for a colostomy which will be used as the outcomes in the
decision instrument. Each will now be described and discussed, giving attributes
for consideration in relation to each outcome.

5.2.1. Outcome 1: Containment - “just wearing a bag”

Clinical experience over nineteen years leads this author to the opinion that people
generally dislike dietary restrictions and irrespective of whether they use dietary
restrictions and/or drugs, the majority of people still have more than one
evacuation daily, and at irregular times. It may be for these reasons that many
select containment - that is, they wear a bag, collect the output and dispose of it,
with no attempt to control the colostomy.

Currently in NSW there are many factors which encourage people to use this
method. Although early ostomy bags were cumbersome and not odour proof,
newer equipment permits fairly efficient collection of effluent and is usually odour
proof for 48-72 hours so long as it is sealed properly. Filters allow flatus to pass
without causing odour, although its noisy passage is still a problem for some
(Airey, Down, Dyer, Hulme & Taylor, 1988). The development of products such
as karaya and synthetic polymers help seal bags to the skin without jeopardising
skin integrity (Black, 1985) and there are now many ostomy appliances which
include a separate wafer and a bag to facilitate speedy, frequent changes.
Furthermore in NSW bags are now usually single use, readily disposable and
supplied free through a Government funded scheme.

There are no controlled studies which evaluate containment or compare it with
other methods, however in various articles there is indirect reference to this
method. For example Grier, Postel, Jyarse and Localio (1964, p. 1241) concluded
that: "dietary restrictions seem to have had little effect in regulating the frequency of natural evacuation". Some people in their study found it too much of a hardship to try to control their colostomy so they ate whatever they liked and "put up with the consequences" (p.1238). In 1964 when appliances were less reliable, the consequences may have been dire, but today the consequences may be quite acceptable - merely more frequent changes of odour proof bags.

There are however still people who have some degree of psychological difficulty adjusting to the idea of "wearing a bag" and in particular to the notion of "carrying the intestinal discharge outside of the body" (Terranova et al., 1979, p. 32). For some it is not wearing the bag, but what is in it, that causes their distress.

In summary, the first outcome is containment - "just wearing a bag", changing it as required and making no attempt to control the colostomy actions. The main attributes for consideration by the patient include not wanting to use diet or medications to control the bowel, not having an aversion to wearing a bag on their abdomen nor to changing it intermittently as required nor being unduly disturbed by the noise of passing flatus.

5.2.2. Outcome 2: "training" the bowel

Some believe that regulation of the timing of meals and fluids will regulate the timing of colostomy actions. In 1960, Todd (p.233) advocated "training and conditioning the bowel to act by natural evacuations once or twice a day", and in 1961 Goligher advocated "natural evacuation" stating that "the aim of colostomy management is to regulate colon peristalsis so that colostomy actions take place only once or twice daily and at set times when it is convenient to deal with them. In the majority of cases this state of affairs is easily achieved" (p. 600).

This idea is also noted in a report from Denmark of 75 people using "spontaneous colostomy function" (as opposed to stimulating the bowel with enemas), with about one half having a well regulated rhythm of defaecation. "Many of them knew
more or less the times at which defaecation would occur. The first was usually shortly after breakfast, but some reported that they could vary the time of defaecation by altering their meal times” (Amrdrup & Christensen, 1967, p. 747). Unfortunately there is no indication in this report of what people ate, whether they took any medications, nor any mention of their premorbid bowel habit.

The ability to regulate the timing of colostomy actions has been explained as a form of “training” by means of stimulation of the gastrocolic nervous reflexes, by which the colon and rectum are stimulated to empty when anything enters the stomach. This was said to require perseverance, “... a sigmoid colostomy can be trained to act once a day; and later it may even be trained to work at the same time each day. However, this may take up to a few months” (Hughes & Wilson, 1967, p.15).

Writing about the same phenomenon, Lenneberg and Mendelssohn said “a reflex establishes itself quite naturally in some people: in most instances mild stimulation, such as juice, coffee, a meal, a mild laxative or an enema is needed” (1969, p. 207).

While these notions about training the bowel may be true, there is, however, no published controlled study providing evidence to support these claims, and other similarly experienced clinicians have publicly doubted them. Rowbotham (1968) stated that people wrongly speak of colostomy control in the same way as they speak of toilet training in an infant, where an “accident” implies inability to learn or develop a function closely associated with living habits. He strongly proposes that, “colostomy control in the absence of a competent colostomy sphincter is not possible” (p.90). The point being that even if the bowel is trainable (Doughty, 1996) the colostomy is not.

In summary, despite controversy and the lack of scientific evidence, there seems to be, in the “folklore of medicine”, international recognition of the notion of bowel “training” through the use of strict regulation of timing and volume of food and fluids, so it is included as one of the outcomes for the decision instrument. The attributes for consideration by the decision maker would centre on whether they are
prepared to follow the rigid restrictions on diet and fluid intake and the strict timing schedule required for this method.

5.2.3. Outcome 3: Use of a “constipating” diet

The “folklore of medicine” also includes a belief that removing roughage and extra fluids from the diet will slow down or even regulate colostomy action and this is referred to as a “constipating diet” (Gazzard, Saunders & Dawson, 1978, p.642). Once again there are no controlled studies specifically relating particular diets to consistency and frequency of stools in people with a colostomy. This is surprising considering the strength of acceptance of this notion by both lay people and health professionals.

Grier, Postel, Jayse and Localio (1964) reported that regulation of diet is considered by many to be a primary principle in managing a colostomy, but their interviews of 50 patients with colostomies indicated that many of their food habits were more dogmatic than realistic. When describing foods that they avoided, most faithfully repeated the list noted in the particular booklet given to them while in the hospital. Although almost every patient in this study believed that diet effected the colostomy function and many considered that the amount of food was as important as the types of food eaten, not one of their 50 subjects had been successful in changing the basic pattern of colonic motility using dietary measures. Terranova et al. (1979) also found the method ineffective. They reported that of the 130 subjects who followed a constipating diet, 69% had more than 3 bowel motions daily.

Nevertheless, because of the wide held belief that a “constipating diet” helps to decrease colostomy output and the long history of use of this method it is included as an outcome in the decision instrument. The attributes for consideration by the decision maker would include whether they were willing to adhere to such a “constipating diet”.

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5.2.4. Outcome 4: colostomy regulation using medications

Medications have long been used to try to regulate stool consistency and bowel motility in individuals with or without a colostomy and are mainly directed at slowing or stimulating bowel motility, softening faeces or adding bulk to the stool. While there is no particular reason to believe that the action of these medications is different in a person who has a colostomy, what may be different is the frequency or regularity with which that person may use them. This is because a colostomy has no sphincter and the consequences of loose or frequent motions can be far greater than in a person who defaecates through their anus. Secondly, those who follow a “constipating diet” would need laxatives if they become too constipated.

The extent to which people with colostomies use these medications is not certain. Devlin et al. (1971) note that in their sample of 83 consecutive persons having colostomy surgery, the taking of medication bore little relationship to the number of colostomy actions per day. Thirty one percent had never taken any medication to control their colostomy, 29% took bowel medications regularly at least once per week, and 40% only took bowel regulation medication occasionally. They did not make any comparison with the individual’s premorbid bowel habit. Terranova et al. (1979) reported that people used constipating diet and occasional antidiarrhoeal drugs but in their results it seems that the method was ineffective since 69% had 3 or more motions daily. Gazzard et al. (1978) reported that 6 months after surgery 20% of respondents were taking medications to try to control their colostomy output. They did not state what these medications were nor whether they were successful.

In 1964 Grier et al.’s group of 50 patients had been told about kaolin and methyl cellulose bulk forming drugs, but only one person in their study actually used them. However 17 used laxatives regularly, usually as a weekly “health measure” or for transient constipation. In only 3 cases did the researchers believe the laxatives were an aid in management of the colostomy.
In summary, although an impression is gained that the taking of regular bowel medications is related to beliefs and values rather than to benefits, because medications have a potential to be useful by influencing bowel motility or stool consistency, they are included as an outcome in the decision instrument. The main attribute for consideration by the decision maker is whether they are prepared to take such medications on a regular basis. It also seems logical to consider the individual's premorbid bowel habit, for example, if a person has used a laxative regularly for years, it is likely they will also need a laxative after colostomy formation.

5.2.5. Outcome 5: The ‘trial and error’ approach to diet

As early as 1927, Gabriel recognised that a person with a colostomy may need to avoid certain foods which are liable to produce loose bowel motions. However, he proposed that, “one cannot lay down arbitrary rules: the only thing for a patient to do is to experiment and to generally avoid things which persistently upset him” (p. 1457).

This school of thought sees the whole matter of diet for a colostomy being very individual. Different foods affect individuals differently, so one food may cause diarrhoea in one individual but constipation in another (Samp, 1957). This is why dietary rules for colostomy management have been termed “arbitrary” by adherents to this school of thought. Rowbotham (1971) proposed that eating habits are “so personal and rooted in daily life that one should not expect an all-inclusive diet to be effective in many people” (p. 223).

Devlin et al. (1971) reported on a sample of 83 patients where 47% ate normally, which he defined as excluding less than three items from their usual diet. Sargeant (1966) also found that of 165 patients, 27% listed foods they could not eat. Gazzard et al. (1978) reported that of their 50 subjects, 56% avoided certain foods due to odour, flatus and liquid stools produced, but no patient had trouble choosing a suitable diet, and over 50% would eat anything on certain occasions.
The problem is that this method involves learning through error, and the errors may cause severe embarrassment, social isolation and psychological problems.

In summary, it seems that some people intuitively use the "trial and error" approach to diet and it is included as a fifth outcome in the decision instrument. This approach involves trying any foods, and if they cause problems such as diarrhoea, flatus or odour, then avoiding them in the future. Attributes for consideration by the decision maker include whether they are prepared to modify their diet and whether they are prepared to have "accidents" during the trial period.

5.2.6. Outcome 6: intraluminal plugs

In attempts to regain continence various types of intestinal occlusion devices have been developed. These include inflatable types, magnetic devices and tampon-like intraluminal devices (Donaldson & Northover, 1988; Goligher, 1986; Numanoglu, 1986; Schmidt, 1982). The most recent, the Conseal plug, is the one which offers the greatest chance of success but is still not suitable for all persons with a colostomy. However, since it is available free on the appliance scheme in NSW and was the only type available for subjects in this study, it is included as an option.

The Conseal plug is made of soft foam, coated by a water-soluble membrane which dissolves once the plug is inserted into the colostomy. The plug then expands, blocking the passage of faeces. Flatus can pass through, without the associated noise, and there is also a carbon odour filter. The plug can be worn up to 24 hours and is kept in place by an adhesive surface which holds it to the skin around the colostomy. It may be used alone or in any combination with bags, irrigation, medication and diet (Spencer, 1988).

Burcharth, Ballan, Kylberg and Rasmussen (1986) developed the plugs in 1984 and trailed them on 53 consecutive patients. Of these 30 irrigated and 23 did not. All were able to use the plug, with 86% becoming completely continent, 90%
being able to pass flatus noiselessly and 92% being able to pass flatus without odour. Some discomfort was felt by 15%. Those using the irrigation method were able to keep the plugs in longer than non-irrigators.

Depending on how the plugs are used, the length of time the plug remains in place may be an important factor in the decision. In NSW, a person is only entitled to 30 free plugs per month. If the plugs are the only appliance being used, then it is important that the plug be retained for 24 hours, otherwise the individual has to buy the extras.

Results from another study by Clague and Heald (1990) are less encouraging. This was a multi-centre study undertaken in the UK over four weeks and involving patients who had colostomies longer than 8 weeks. Of 100 patients, only 46 completed the trial. Reasons for discontinuing included leakage, discomfort and difficulty (usually related to extrusion of the plug). Of the 46% who completed the trial, 33% stated they had improved quality of life, but 10% were unsure. Non-irrigators kept the plugs in for an average of 9.8 hours, whereas irrigators could keep them in for an average of 20.2 hours.

The manufacturers recommend that their plugs should not be used until 6-8 weeks after colostomy construction (Airey et al., 1988). However, this stipulation has relaxed in subsequent years. Andersson and Baumgardt (1990) surveyed 27 former patients and asked when they believed people should be told about the plugs. Almost all believed the information should be given before the patient leaves hospital and half said it should be discussed pre-operatively. In their study only 1 patient used the irrigation method, and 67% used the plug by day and a bag the rest of the time. All stated that the plug was good because it avoided embarrassment due to noise (of flatus passing), odour and bulkiness of the bag.

In summary, the Consol intraluminal plug offers a relatively new style of management and is included as outcome 6 in the decision instrument. It can be used alone or in any combination with bags, irrigation, medications and diet.
Attributes for consideration by the decision maker include the desire to avoid wearing a bag on the abdomen, the desire to avoid noisy passage of flatus, the willingness to insert something into the colostomy and willingness to persevere with some possible discomfort in the initial stages. Decision makers must also be prepared to wait until the colostomy is properly healed before trying the plugs, and be prepared to pay for extra plugs if the free allowance is not sufficient for their needs on an ongoing basis.

5.2.7. Outcome 7: colostomy irrigation

The next outcome for consideration is colostomy irrigation, which is an enema given into a colostomy - an enema is by definition given into the rectum. In some literature a colostomy irrigation is referred to as a "washout" (Lockhart-Mummery, 1927, p.1457; Seargeant, 1966, p. 25), possibly because the water flows in and out, but that term is not used here since it implies mere cleansing of the bowel, whereas the real purpose in this context is to stimulate peristalsis so the bowel will evacuate its contents.

Colostomy enema (irrigation) was suggested by Pillore and Fine in France in the 18th century as a means of establishing more predictable bowel habits. The technique was revived by Miles in England (Aylett, 1978). However, the apparatus was somewhat primitive and it was redesigned by Binkley in the USA in 1927. The technique was strongly advocated (Gabriel & Lloyd-Davies, 1935; Lockhart-Mummery, 1927) and was popular both in England and the USA until Gabriel (1945) reported nine cases of colonic perforation resulting in eight deaths. Subsequently the merits of irrigation were debated in England (Anonymous writer in British Medical Journal, 1957 & 1958; Griffith, Philpotts, Espiner & Elthringham, 1976; Seargeant, 1966) but continued to be favoured in USA (Amdrup & Christensen, 1967; Benfield, Fowler & Barrett, 1973; MacLeod, 1972; Mazier, Dignan, Capehart & Smith, 1976) where a cleaner closed system method had been advocated by Binkley (1929 & 1952).
Until about 1970 the technique advocated was quite unsafe. It involved individuals inserting a thick rubber tube as far as possible into their colon (Watson, 1945), but later catheter designs were developed to try to reduce the risk of perforations, and included the Nigro catheter (1969), the Laird tip (1969), a catheter-nipple device (Land, 1970) and the Greer colostotip (Stuart, 1972). Today in NSW conetips (such as the colostotip), and not catheters, are issued free with all irrigation sets. The practice of using warm soap and water solution (Gabriel & Lloyd-Davies, 1935) has been superseded by the use of tepid tap water (Mazier et al., 1976) in keeping with the belief that this is also safer (Walls, 1994).

The advantages of irrigation include a decrease in the number of stools as well as a decrease in the amount of flatus, spillage and odour. Rowbotham (1975) commented that irrigation gives control, not over the colostomy, but over the timing of evacuations. Irrigation is often perceived to be a cleaner method (but not during the procedure), skin excoriation is almost eliminated and a more adventurous diet may be followed. Smaller, less conspicuous appliances may be used, including mini pouches, caps and the Conseal plugs. It has been proposed that if irrigation is started in the early post-operative period, the rapid achievement of faecal continence helps to overcome the psychological problems sometimes related to having a colostomy (Perbone, Paone, Postiglione, Botter, Oldani, Dall’Acqua & Tessera, 1993; Sanada, Kawashima, Tsuda & Yamaguchi, 1992; Stuart, 1976; Williams & Johnston, 1980).

Irrigation is safe in the long term in that it does not damage colonic mucosa (Galliani, Santi, Baratta & Patrizi, 1987), and does not affect full blood count, serum electrolytes concentration and serum urea (Williams & Johnston, 1980). The technique of irrigation appears to be safe provided modern cone tips are used and the individual receives adequate instruction concerning water temperature and other aspects of technique (Bertuzzi, Drudi & Mordente, 1985; Guinchi, Cacciaguerra & Drudi, 1985; Jao, Bert, Wendorf & Ilstrup, 1985).

Averaged over a week, the technique has been found to be no more time
consuming than using bags (Williams & Johnston, 1980) although this has been debated by others (Seargeant, 1966; Terranova et al., 1979). Certainly in Seargeant's study the procedure probably took much longer since the catheters then had no conetip to stop backflow of water during the procedure. Sanada et al., (1992) reported that the length of time to complete the procedure on an individual basis was the only real complaint that subjects had concerning use of irrigation. Attempts to find other means, such as foam enemas (Doran & Hardcastle, 1981) or other substances, such as prostaglandin E2 or bisacodyl, to speed up the process, have so far been unsuccessful (Christensen, Kjaergaard & Stadil, 1982; Kjaergaard, Christensen, Stadil & Anderson, 1984), although Sanada et al. (1992) reported a recent Japanese study using a glycerine enema which only takes 15 minutes for evacuation, as opposed to the usual 40 minutes when using water.

In NSW the cost of the various appliances is the same to the individual because they obtain supplies free through membership of the Colostomy Association of NSW (Inc). But the cost to the taxpayer, who finances the scheme, is variable depending on how many bags a person uses per month. In countries where users pay, irrigation is reported to be cheaper than using bags or plugs (Perboni et al., 1993; Sanada et al., 1992).

Some writers have claimed that, even when people are routinely taught to irrigate their colostomy post-operatively, compliance with irrigation falls after they leave hospital. But the reported 80% compliance is still fairly high (Terranova et al., 1979).

Noncompliance with irrigations was previously thought to be due in part to poor standards of domestic sanitation (such as rarity of inside lavatories). Some cited technical difficulties and aesthetics as reasons for not wishing to proceed with the technique. Certainly modern irrigation sets make the technique much easier and less messy than it was previously. The issue of compliance is significant. The term "to comply" means to yield or to act in accordance with another's wishes, so the
implication is that the treatment was ordered by someone else and the individual possibly did not really want to do it in the first place. In this context failure to comply may merely be the patient’s way of participating in the decision-making about their own lifestyle. The idea of irrigation simply does not appeal to some people.

For instance, Dini, Venturini, Forno, Bertelli and Grandi (1990) reported that 40 out of 509 subjects in their sample “refused to learn” the technique. Pringle (1984) commented that irrigation is “repulsive” to some, and Dudley (1978, p.1036) acknowledged that irrigation works, but strongly opposed its use for himself. He stated: “I do not want to see myself as a glorified flushing lavatory in reverse.” Clearly people who have such strong views should have the opportunity to choose another option. This idea of choosing a colostomy management method to suit individual preferences has evolved slowly.

In summary, colostomy irrigation involves administration of an enema into the colostomy daily, second daily or third daily to effect emptying of the bowel at a time deemed convenient by the individual and to allow a more adventurous diet and smaller appliances. Irrigation is included as outcome 7 in the decision instrument. The attributes for consideration by the patient include whether they wish to have control over the timing of their evacuations, whether they wish to follow a more adventurous diet and wear smaller appliances. They must be prepared to spend about 40 minutes daily or second or third daily performing the procedure. They must be prepared to insert a enetip into the colostomy, and they must not find doing the procedure too offensive.

5.2.8. Outcome 8: combinations of management methods

Early ideas about colostomy management were rigid. In the USA Binkley (1952) had decided, after many years of experience, that : “... every patient should be taught irrigation early in the post-operative period” and his colleagues seemed to accept this as usual practice. However in 1957 and 1958 an anonymous writer in
the British Medical Journal criticised them for their "almost unquestioning acceptance of the ritual of irrigation" (p. 448), but advocated an equally one-sided acceptance of the "natural evacuation" method.

Sometimes people were not considered completely rehabilitated if they wore an appliance, "with proper instruction and use of irrigations, most colostomy patients can eliminate the routine use of an appliance" (Sterling & McIlrath, 1970, p. 83), and those who soiled between irrigations were deemed to have failed. However, in 1971 Rowbotham publicly questioned the prevailing dogma which proposed that everyone with a colostomy could control it with irrigation and diet and ought not need an appliance. He urged his fellow surgeons to individualise care of persons in whom they had created a colostomy, to site the colostomy so that appliances may be worn if desired and to advise them of the range of options available "...even if the surgeon wants them to irrigate" and to allow everyone "the courtesy of wearing an inexpensive disposable appliance to collect faecal or gaseous discharge" (p. 223) regardless of whether or not they irrigated.

In Australia the opposite was occurring and Stuart (1972) asserted that there has been a tendency only to inform patients about the colostomy irrigation method if they request it. Since a person cannot choose a particular colostomy management option if they have never heard of it, the onus is clearly on the health professional to make sure the patient has all the information they need to make an informed decision.

Several prominent stomal therapy nurses also entered the debate about colostomy management. Jackson (1975) proposed that "nursing judgments must be based on patient cues" (p. 24). She further underlined the difference between "surviving" with a colostomy and "living" (enjoying life) after colostomy construction (p. 25). In 1977 Watt proposed that:

"Irrigation is not always the best way to manage a colostomy. The variety of products available to control leakage and odour give the patient a choice in how to manage the colostomy and still feel secure in social situations" (p. 444).
Smith (1978) questioned the rigidity and ritualism with which irrigation had become associated, pointing out that it was originally developed for the user's convenience. She further emphasised the need for independence and personal preference to be considered when decisions are made about colostomy management strategies. If an individual is not motivated to try a method, it should not be forced upon them.

These comments indicate that there is an option for using combinations of management methods. This notion is further supported by Williams and Johnston (1980) who carried out a prospective controlled trial comparing irrigation with "natural evacuation" and concluded that, "a flexible and common sense approach is required rather than rigid adherence to any single regimen" (p.109). Their ideas are reinforced by other writers such as Riley (1978), Bokey and Shell (1985), Plum (1990) and Walls (1990) who refer to the fact that the person with a colostomy may have choices involving a number of options. For these reasons, a combination of methods is included as outcome 8 in the decision instrument. Attributes for consideration by the decision makers include all the attributes mentioned earlier for each of the other outcomes.

5.3. Summary of outcomes & attributes derived from the literature

Information alone does not ensure good decisions. Because nurses may need to help patients to organise, appraise and use information when making decisions, a formal decision instrument was developed for this thesis in order to facilitate these steps when making a particular decision about long term colostomy management.

The development of this instrument is the matter of this Chapter. Literature about colostomy management methods was reviewed to enable currently and locally available methods to be named, described and discussed. While the original intention had been to perform a meta-analysis of data, unfortunately many of the papers reviewed were discussion papers and anecdotal reports rather than empirical studies, and while they provided interesting information, the data were not suitable for meta-analysis. Much of the data from the empirical papers were also unsuitable
due to methodological problems such as inadequate definition of variables making it impossible to compare findings. This was disappointing and highlights the need for more rigorously designed studies in the future to fill in the missing information, particularly about the role of diet and medications. An alternative strategy was implemented in which the papers were used to identify the relevant possible methods of colostomy management. These become known as the outcomes in the decision instrument. They are containment, training the bowel, use of a constipating diet, regular use of medications, the trial and error approach to diet, intraluminal plugs, colostomy irrigation and finally, combinations of the other methods.

The next step in designing the decision instrument was to identify the attributes from the same body of literature. These are the features identified as being relevant for consideration in relation to each outcome (management method) when an individual makes a decision. It will be recalled that the decision instrument used the Simple Multi-Attribute Rating Technique (Edwards, 1971), therefore the attributes are a crucial part of the instrument since they are the aspects to be rated and ranked by the patient as they make the decision. The previously described outcomes and attributes for inclusion in the decision instrument are listed in Table 5.1

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Table 5.1

The outcomes (methods for long term colostomy management) and relevant attributes identified for use in the decision instrument.

<table>
<thead>
<tr>
<th>OUTCOME</th>
<th>ATTRIBUTES FOR CONSIDERATION BY THE PATIENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Containment</td>
<td>Wearing a bag which will at times have faeces in it</td>
</tr>
<tr>
<td></td>
<td>Changing a bag intermittently as required</td>
</tr>
<tr>
<td></td>
<td>Allows a more adventurous diet</td>
</tr>
<tr>
<td></td>
<td>Involves time - intermittently as required</td>
</tr>
<tr>
<td>Training the bowel</td>
<td>Rigid diet and fluid restrictions</td>
</tr>
<tr>
<td></td>
<td>Regulation of timing of eating and drinking</td>
</tr>
<tr>
<td></td>
<td>Involves time - intermittently as required</td>
</tr>
<tr>
<td></td>
<td>Influenced by bowel habit prior to illness/operation</td>
</tr>
<tr>
<td>Constipating diet</td>
<td>Rigid diet</td>
</tr>
<tr>
<td></td>
<td>Involves time - intermittently as required</td>
</tr>
<tr>
<td>Regular medications</td>
<td>Regular medications</td>
</tr>
<tr>
<td></td>
<td>Involves time - intermittently as required</td>
</tr>
<tr>
<td>Trial and error diet</td>
<td>May have occasional 'accidents'</td>
</tr>
<tr>
<td></td>
<td>Involves time - intermittently as required</td>
</tr>
<tr>
<td></td>
<td>Influenced by bowel habit prior to illness/operation</td>
</tr>
<tr>
<td>Intraluminal plug</td>
<td>Involves inserting something into the colostomy</td>
</tr>
<tr>
<td></td>
<td>May be distasteful</td>
</tr>
<tr>
<td></td>
<td>Allows noiseless passage of flatus</td>
</tr>
<tr>
<td></td>
<td>Involves time - intermittently as required</td>
</tr>
<tr>
<td>Irrigation</td>
<td>Involves 40 minutes daily (or second daily or third daily)</td>
</tr>
<tr>
<td></td>
<td>Allows control over timing of evacuations</td>
</tr>
<tr>
<td></td>
<td>Allows a more adventurous diet</td>
</tr>
<tr>
<td></td>
<td>Involves inserting something into the colostomy</td>
</tr>
<tr>
<td></td>
<td>May be distasteful</td>
</tr>
<tr>
<td></td>
<td>Facilitates independence</td>
</tr>
<tr>
<td></td>
<td>Security</td>
</tr>
<tr>
<td></td>
<td>Convenience</td>
</tr>
<tr>
<td>Any combination of the above</td>
<td>Includes some or all of the above</td>
</tr>
</tbody>
</table>
The SMART decision technique requires that all possible outcomes and attributes be presented to the decision maker in an unbiased manner, so that they can rate and rank the attributes according to their own utilities and not those of others. Then after multiplying the attributes by the utilities, they sum the scores (of attribute x utility) for each outcome and select the outcome with the highest total score. The content material for this process - the information about outcomes and attributes - is crucial to its success, but the information in the literature was often ambiguous or missing. A decision was made to use a panel of experts in colostomy management to verify this writer's interpretation of the outcomes and attributes, to ensure that the information included in the instrument was both complete and accurate.

5.4. Delphi technique to verify outcomes and attributes

Verification of the outcomes and attributes was important because it had direct bearing on the structure of the problem as presented to the decision makers. Structuring of the problem can have a particularly powerful effect when decision makers, such as the patients with a new colostomy, are unfamiliar with the potential outcomes. Ignorance can, to some extent, be dispelled by fully informing patients, but care must be taken not to bias them by giving incomplete information or seeming to favour one outcome over another. There is no reason to believe that the patient's utilities should mirror those of the nurse. Different representations of the overall picture can lead to different decisions. If the structuring of the problem is wrong, for example because the outcomes or the attributes are not all presented, then a consequence would be that subsequent assessments of utilities and probabilities of various attributes occurring may be inappropriate and the overall computation using the decision instrument may be invalid (Wright, 1984).

A panel of experts in colostomy management was selected to verify the information obtained thus far. They were asked to judge whether the outcomes derived from the literature included all the currently and locally available methods of long term colostomy management and whether the list of attributes reflected the main issues a
decision maker would be expected to consider when selecting or rejecting a particular method of colostomy management.

5.4.1. The panel

The Delphi panel comprised 5 specialist stomal therapy nurses and 10 people who have had a colostomy for at least 5 years. To avoid the potential bias of selecting peers with similar views to the researcher, expert stomal therapy nurses were selected at random from the membership directory of the Australian Association of Stomal Therapy Nurses and contacted by phone to invite them to be on the panel. There were no refusals. Patients on the panel were a convenience sample selected on the basis that they had a colostomy for at least 5 years, had used a management method successfully for at least 12 months, and were willing and able to participate in the proposed process.

5.4.2. The process

Decision analysis usually involves iterative processes, whereby the decision analyst constructs a (provisional) representation of the problem and then seeks feedback from the decision maker or others, such as a panel of experts, to refine and develop the provisional structure until it includes all the outcomes and attributes which are required (Wright, 1984). Because of the iterative nature of the feedback process, and because the panel of experts were geographically distant, busy people, and therefore difficult to get together on a regular basis, it was decided to use a mailed Delphi technique to verify the outcomes and attributes from the literature review. Another perceived advantage was that using this technique views of individual panel members would not be influenced by group pressure. The process will now be described.

The Delphi technique is a method of data collection using questionnaires which are mailed to a panel of experts in “successive waves”, with feedback from previous questionnaires included with successive questionnaires (Seaman, 1987, p. 285).
The main aim of using this technique was the verification of the lists of outcomes and attributes derived from the literature, and this involved ensuring that the lists were complete and did not contain controversial items. This aim was achieved during the first two rounds. Subsequent rounds were used to eliminate overlapping attributes, to revise the wording to present the decision makers' perspective and to phrase all statements about attributes positively. After each round the results were summarised and returned to the panel so they could each see what the others had written. Further comment was sought. This process was repeated three times and is summarised in Figure 5.2 (over page) and below.

5.4.2.1. Rounds one and two

The aim of the first two rounds was to determine whether the lists of outcomes and related attributes derived from the literature review were complete and accurate. In round one panelists were given the lists and asked for deletions or additions and any relevant comments. The second round was a consolidation of information from round one and further comments. No extra outcomes were suggested by the panel. Comments concerned their beliefs about the effectiveness of the outcomes. A person with a new colostomy may choose any method they wish, but the colostomy may be "unmanageable", resulting in excessively frequent, fluid stools, excessive flatus, leakages and skin excoriation. The purpose of making a fully informed decision is not merely to select a method which the patient likes, but also one which will serve the purpose successfully. This information was not relevant here but was used when determining the probabilities. The first round mainly yielded attributes of individuals which might have a bearing on the decision. These included such attributes as age, ability, coexisting health conditions, physical facilities at home, and lifestyle. These characteristics may be factors for this decision, but they are attributes of the individual, not of the management outcomes, and thus were not incorporated into the instrument, but formed part of the exclusion criteria for the initial interviews. The results from these two rounds are displayed in Table 5.2.
Figure 5.3.
Flowchart Showing Summary of Delphi Technique

OUTCOMES AND ATTRIBUTES
DERIVED FROM THE LITERATURE REVIEW

ROUND 1
VALIDATION THAT OUTCOMES AND ATTRIBUTES FROM
LITERATURE WERE COMPLETE AND NOT CONTROVERSIAL

ROUND 2
CONSOLIDATION OF INFORMATION FROM ROUND 1
+ COMMENTS

ROUND 3
ELIMINATION OF OVERLAPPING ATTRIBUTES
REVISION OF WORDING TO PRESENT THE DECISION MAKERS’
PERSPECTIVE

ROUND 4
WORDING OF ATTRIBUTES REVISED SO THAT ALL
STATEMENTS WERE POSITIVE
Table 5.2
Attributes Remaining after the Second Round.

Involves a diet
Involves taking medications regularly
Involves wearing a bag which will at times have faeces in it
Allows control over timing of bowel evacuation
May affect appearance
Needs about 40 minutes for procedure either daily, second daily or third daily
Needs intermittent care for 5-10 minutes each time

5.4.2.2. Round three

Feedback from the second round had suggested that some panelists believed that 2 attributes related to appearance. This was an important aspect to resolve in order to keep the decision instrument as clear and simple to use as possible. Another concern was that the attributes needed to be worded so that they presented the issues from the decision makers’ perspective, hopefully assisting them to understand what was required of them in ranking and rating the attributes. So during round three panelists were asked to reword the attributes so they became statements of what the decision maker might need to do or to experience if they selected particular outcomes. The results are displayed in Table 5.3.

Table 5.3
Attributes Remaining after the Third Round.

Being restricted with what I eat and drink
Having my appearance affected
Having my bowel actions at a predictable time
Having to change the bags whenever they need it
Taking about 40 minutes daily to attend to my colostomy
Having a bag on my abdomen, sometimes with faeces in it
Having to take medicines to control my bowel
5.4.2.3. Round four

In the fourth round the panelists were asked to reword the attribute statements so they were worded positively. This idea arose because psychological research indicates that people favour options “stated positively” (Schwartz & Griffin, 1986, p.113), therefore to neutralise potential respondent bias, all the attributes were reworded and panelists were also asked to make any further suggestions they believed may be relevant. The resulting attributes are summarised in Table 5.4.

Table 5.4

<table>
<thead>
<tr>
<th>Attributes after the Fourth Round</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eating and drinking whatever I wish</td>
</tr>
<tr>
<td>Looking as normal as possible</td>
</tr>
<tr>
<td>Having my bowel actions at a predictable time</td>
</tr>
<tr>
<td>Having time to attend to my colostomy intermittently whenever it needs it</td>
</tr>
<tr>
<td>Spending about 40 minutes once a day attending to my colostomy</td>
</tr>
<tr>
<td>Having a bag on my abdomen - sometimes with bowel action in it</td>
</tr>
<tr>
<td>Taking medicines to control my bowel actions</td>
</tr>
</tbody>
</table>

5.4.3. Summary and conclusion of Delphi technique

By the end of the fourth round the aims had been achieved. That is, verification of the outcomes and attributes derived from the literature, and refinement of the wording of the attributes so they presented the decision maker’s perspective in a consistently positive way. There were few feedback comments from the fourth round. Thus it was decided to stop the Delphi process and to use the attributes as they were at the end of round four, and the outcomes as they were at the end of the second round. The next step in developing the decision instrument was to determine the probabilities for each of the attributes.
5.5. Determining probabilities of attributes for each outcome

Determining the probabilities for the decision instrument involved an estimate of the probabilities of the individual being able to perform or experience the attributes with respect to each outcome. For example, if a person places high utility on “eating and drinking whatever I wish”, what is the probability that each management method will allow them to experience this attribute successfully? Each of the attributes applied well to at least one method, but not to others.

5.5.1. The panel

With decision instruments such as SMART the probabilities are provided by the literature and by the professional (Edwards, 1977; Schwartz & Griffin, 1986) based on their expert experience and knowledge and their understanding of relevant studies. At this stage the panel of experts was reduced to include only the 5 stomal therapy nurses. It was reasoned that the contribution of the former patients was generally limited to knowledge of one person whereas the nurses had insight into experiences of groups of people. The panel of stomal therapy nurses met for face to face discussion, using the Delphi technique as previously described.

5.5.2. The process

During this process, probabilities were based on information from relevant literature, and then verified with the panel. Percentages were obtained from those papers which had been deemed sufficiently recent and “scientific” to be appropriate. In most instances the mean was calculated from the percentages from several studies. In some instances there was no relevant literature so expert opinion alone was used. This involved a discussion about data from the literature, and then asking the panel what they believed to be the probability of people successfully using a method which suited their utilities. Panelists estimated the probabilities independently then their estimates were discussed. In some cases
there was disagreement. If consensus could not be reached with the estimations of probabilities, a mean score across panelists was calculated.

It will be recalled that the need for “successful” management had been raised earlier (Section 5.4.2.1.). This idea was revisited and criteria for “successful” management were considered. The panelists defined success in various ways. For people who wore bags, success was defined as having 1-2 bag changes per day, having a stool of manageable consistency, and not passing flatus to the extent that it is embarrassing or troublesome. Successful use of medications was defined as obtaining the desired pharmacological effect with minimal or no undesirable side effects. For people wearing plugs success meant having the plug stay in place for the proposed length of time (this may be up to 24 hours if the person was irrigating daily, or lesser periods if the plugs are used in combination with bags). Success also required that the plugs not stimulate peristalsis to the extent that the plug was uncomfortable, bulging or extruded. For people who irrigated success meant having no leakages between irrigations.

5.6. Results: The probabilities of attributes for each outcome

The panel systematically considered the probability for each attribute in the context of each outcome — containment, training the bowel; use of a constipating diet; regular use of medications; the trial and error approach to diet; intraluminal plugs; colostomy irrigation; and combinations of methods. The results are reported below and are expressed as percentages.

5.6.1. Attribute 1: eating and drinking whatever I wish

The containment method allows people to eat and drink whatever they choose and change the bag whenever it needs changing. There are no studies which specifically report data on this method, but the percentage of non-irrigating people who did not change their dietary habits has been reported as 27% (Grier et al., 1964), 47% (Devlin et al., 1971) and 44% (Gazzard et al., 1978). An assumption
was made that they did not change their diet because they did not feel it was necessary, but this cannot be verified from the literature. Independently of this information, the panel had estimated the probability of a person using containment having 2 or fewer bag changes per day to be 35%, similar to the mean of the cited studies (39%).

By definition, a person who is attempting to train their bowel follows rigid restrictions on diet and fluid intake and follows a strict timetable so they cannot eat and drink whatever they wish. Therefore the probability for success in eating and drinking whatever one wishes using this method is 0%.

By definition, a person who is adhering to a constipating diet cannot eat high roughage foods, or drink large volumes of fluids, so (unless this is their favoured diet) they cannot eat and drink whatever they wish. Therefore the probability for success in eating and drinking whatever one wishes using this method is virtually 0%.

By definition, a person who is using a trial and error diet must eliminate any foods which cause loose bowel motions, flatus or odour, so (unless there is no food which causes these problems) they cannot eat and drink whatever they wish. Therefore the probability for success in eating and drinking whatever one wishes using this method is 0 - 100%.

---

3. This is the simple arithmetic mean of the three reported percentages and does not take into
While there are no specific studies concerning the effectiveness of regular use of medications alone for long term colostomy control, there are data to suggest that 45% of people following a constipating diet and using drugs have 1-2 bowel actions per day, as displayed in Table 5.5.

Table 5.5

Percentages of People with a Colostomy (Using a Constipating Diet and Occasionally Drugs) Reported to Have Varied Numbers of Bowel Actions/Day.

<table>
<thead>
<tr>
<th>Number of bowel actions per day</th>
<th>Percentage of people reported in study</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Grier</td>
</tr>
<tr>
<td>0 - 1</td>
<td>14</td>
</tr>
<tr>
<td>2</td>
<td>24</td>
</tr>
<tr>
<td>3-4</td>
<td>30</td>
</tr>
<tr>
<td>5+</td>
<td>32</td>
</tr>
</tbody>
</table>

Using these calculations, the probability for success (1-2 motions per day) using a combined method of diet and drugs was judged to be 45%. After considering these data the panel estimated that people who ate and drank whatever they wished but took regular medications might be a little less successful than those reported above, and the panel estimated the probability of success using that method to be 40% in the long term.

4. Based on data from Grier et al. (1964) n=50, Devlin et al. (1971) n= 78, Terranova et al. (1979) n= 130, Guinchi et al. (1988) n=40, MacLeod (1972) n=25.

5. This is the simple arithmetic mean of the percentages and does not take into account the sample sizes.
The *irrigation* method of colostomy management involves administration of enemas into the colostomy on a regular basis. Success is said to occur when the individual is continent between irrigations. The literature provides evidence that the degree of success of irrigations varies directly with the frequency of irrigations (Dini et al., 1991; MacLeod, 1972; Mazier et al., 1976) with daily irrigations being the most successful. The percentages of irrigators who are successful in staying continent using daily irrigations and eating whatever they felt like eating are shown in Table 5.6.

**Table 5.6**

Percentage of Irrigators Reported to be Continent with Daily irrigations when Eating a Normal Diet.

<table>
<thead>
<tr>
<th>Study</th>
<th>Year</th>
<th>n</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>MacLeod</td>
<td>1972</td>
<td>25</td>
<td>80</td>
</tr>
<tr>
<td>Terranova et al..</td>
<td>1979</td>
<td>210</td>
<td>84</td>
</tr>
<tr>
<td>Williams &amp; Johnston</td>
<td>1980</td>
<td>30</td>
<td>80</td>
</tr>
<tr>
<td>Laucks et al.</td>
<td>1988</td>
<td>80</td>
<td>68</td>
</tr>
<tr>
<td>Arithmetic mean</td>
<td></td>
<td></td>
<td>78</td>
</tr>
</tbody>
</table>

In MacLeod's (1972) study 80% of irrigators achieved continence and he proposed that diet made no difference but premorbid bowel habit did have an effect. Terranova et al. (1979) found that only 16% of subjects who irrigated had occasional irregularities due to enteritis or eating certain foods. Laucks, Mazier, Milson, Buffin, Anderson, Warwick and Surrell (1988) reported 100% who were always or usually continent but of these 68% said dietary indiscretions could occasionally cause problems. Williams and Johnston (1980) found that 80% of their subjects could eat everything they wished when irrigating.

The panel agreed that 78% was a reasonable estimate of the probability of a person being able to eat and drink whatever they wish and still successfully irrigating.

Clague and Heald (1990) reported a multi-centre study of 100 subjects in which the *intraluminal plugs* were only tolerated in 46%, and Spencer (1988) reported another multi-centre study with 75% success. There was no specific information
about diet in any of the literature about the plugs. The panel believed the probability of success with the plug only (without irrigation) and normal diet was only about 20%, less than the 46% who tolerated the plugs in Clague and Heald’s 1990 study, since that group included irrigators who would have a better chance of success. It is also less than the probability for those using containment since those people are considered successful with 1-2 bag changes per day whereas success with the plugs is defined as using one plug per day. The panel judged that the probability of eating whatever one wished and irrigating and wearing a plug successfully would be 80%. The results of the panel discussion concerning probabilities for the first attribute are summarised in Table 5.7.

Table 5.7

Probabilities for Successful Attainment of Attribute 1: Eating and Drinking

Whatsoever I Wish Using the Identified Management Methods (Outcomes).

<table>
<thead>
<tr>
<th>MANAGEMENT METHOD</th>
<th>PROBABILITY (%)</th>
<th>RATIONALE FOR PROBABILITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Containment</td>
<td>35</td>
<td>By definition people using this method eat and drink whatever they wish Panel estimate of success concurs with studies cited</td>
</tr>
<tr>
<td>Training the bowel</td>
<td>0</td>
<td>By definition people using these methods are not able to eat and drink whatever they wish unless no food upsets their colostomy</td>
</tr>
<tr>
<td>Constipating diet</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Trial and error diet</td>
<td>0-100</td>
<td></td>
</tr>
<tr>
<td>Regular Medications</td>
<td>40</td>
<td>Panel estimation done in relation to means of indirect references in literature</td>
</tr>
<tr>
<td>Colostomy Irrigations</td>
<td>78</td>
<td>Based on means from literature and accepted by panel</td>
</tr>
<tr>
<td>Intraluminal plug</td>
<td>40</td>
<td>Panel estimation based on percentages from literature, expert opinion and deduction</td>
</tr>
<tr>
<td>Irrigation plus Intraluminal plug</td>
<td>80</td>
<td>Deduced from indirect references in literature</td>
</tr>
</tbody>
</table>
5.6.2. Attribute 2: Looking as normal as possible

'Normal' was defined as not having anything obviously visible under the clothing. The panel considered that three outcomes which have particular bearing on looking as normal as possible are whether the person wears a bag or a plug and whether the person irrigates.

There was no literature specifically relating appearance to various management methods, however the panel estimated that people who used the methods involving the wearing of a bag - that is containment, bowel training, constipating diet, trial and error diet and regular medications - had an 80% chance of looking normal most of the time. Although they would intermittently have faeces collecting in their bag, most people could disguise this reasonably well with the use of low profile bags with modern flatus filters and prompt bag changes.

Despite the development of low profile bags, the panel of experts felt that people who irrigated, did not soil in between irrigations and wore a minibag, stoma cap or plug had the highest probability of looking normal most of the time. This was estimated to be 95% (this is higher than the probability of successful irrigation, since this present estimate only considers the dimension of appearance, and there are other reasons for failure of irrigation, such as odour or noisy passage of flatus).

Clague and Heald (1990) indicated that 46% of people could use an intraluminal plug successfully, and very few of their subjects (14%) were irrigating. The panel felt that approximately 40% of non-irrigators would be successful and therefore look normal with the plug.

Table 5.8 summarises these probabilities for attribute 2.
Table 5.8
Probabilities for Successful Attainment of Attribute 2: Looking as Normal as Possible Using the Identified Management Methods (Outcomes).

<table>
<thead>
<tr>
<th>MANAGEMENT METHOD</th>
<th>PROBABILITY (%)</th>
<th>RATIONALE FOR PROBABILITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Containment</td>
<td></td>
<td>Panel estimate</td>
</tr>
<tr>
<td>Training the bowel</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constipating diet</td>
<td>80</td>
<td></td>
</tr>
<tr>
<td>Trial and error diet</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Regular medications</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Regular irrigations</td>
<td>95</td>
<td>Panel estimate</td>
</tr>
<tr>
<td>with bags or plugs</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| Intraluminal plug alone | 40          | Based on literature and panel estimate |}

5.6.3. Attribute 3: Having a bag on my abdomen, sometimes with bowel action in it

Initially this seemed to be the same as the attribute about looking normal, but appearance is related to what others see and this attribute is related to what the individual knows about him/herself. There is no literature specifically addressing this matter, so the panel made estimates which are summarised in Table 5.9. By definition, with any method in which a bag is worn, there is a 100% probability of a person having a bag on their abdomen which sometimes has bowel action in it. With a method involving irrigation and a bag there is a 22% probability (that is, 100% minus the success rate for irrigation determined from the literature cited previously). There is by definition a 0% probability of having a bag on the abdomen if the intraluminal plug method is used.


Table 5.9
Probabilities for Successful Attainment of Attribute 3: Having a Bag on my Abdomen, Sometimes with Bowel Action in It, Using the Identified Management Methods.

<table>
<thead>
<tr>
<th>MANAGEMENT METHOD</th>
<th>PROBABILITY (%)</th>
<th>RATIONALE FOR PROBABILITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Methods in which a bag is worn</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Containment</td>
<td>100</td>
<td>By definition</td>
</tr>
<tr>
<td>Training the bowel</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constipating diet</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trial and error diet</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Regular Medications</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Methods in which a bag is sometimes worn</td>
<td></td>
<td>Panel estimation based on literature</td>
</tr>
<tr>
<td>Irrigation</td>
<td>22</td>
<td></td>
</tr>
<tr>
<td>Methods in which a bag is not worn</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intraluminal plug</td>
<td>0</td>
<td>By definition</td>
</tr>
</tbody>
</table>

5.6.4. Attribute 4: having my bowel actions at a predictable time

While the panel of experts all knew of people who had reported that their colostomy usually acted at a regular time, they did not necessarily believe in the concept of “training” advocated by Hughes and Wilson (1967). This was thought by the panel to be an area where scientific research might be of use. Timing of bowel motions was believed to be more related to regularity of bowel habits prior to illness. MacLeod (1972) found that 40% of people who had previously regular bowels had 1-2 bowel motions per day after the colostomy was made, but his study did not comment on the predictability of timing of the colostomy actions. There were no scientific studies to provide any probabilities about predictability of colostomy actions, and the panel estimated that the probabilities were only about 20% if the person had a previously regular habit and was returning to the same lifestyle. The highest chance of predicting timing was when bowel actions were forced, such as by use of irrigations or strong laxatives, but the latter were not
encouraged although panelists had no specific studies on which to base these views.

There were no studies on predictability using the containment method, constipating diet or trial and error diet and the probability was estimated by the panel to be 20% if there was premorbid regularity and less than 5% if there was premorbid irregularity.

There were no specific studies on the relationship between the use of regular bowel medications and predictability of timing of colostomy actions. However, it seems logical that forcing bowel actions by regular use of laxatives could lead to predictability of timing of those actions. The probability of this occurring was estimated by the panel to be about 80% if strong laxatives were used but far less (30%) if bulking agents were used.

The method which uses regular irrigations was believed to have the highest probability of causing predictable timing of colostomy actions. The irrigation stimulates the colostomy to act, and if the method is successful then there should be no other action until the next irrigation. Therefore, the probability of irrigations leading to predictable timing of colostomy actions is 78%, the same probability as successful irrigation.

There are no studies concerning the probability of people who wear intraluminal plugs having a predictable timing of colostomy actions. The panel estimated the probability to be 20% if there was premorbid regularity and less than 5% if there was not.

This information is summarised in Table 5.10.
Table 5.10
Probabilities for Successful Attainment of Attribute 4: Having my Bowel Actions at a Predictable Time Using the Identified Management Methods (Outcomes).

<table>
<thead>
<tr>
<th>MANAGEMENT METHOD</th>
<th>PROBABILITY (%)</th>
<th>RATIONALE FOR PROBABILITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Containment</td>
<td>&lt;5 6</td>
<td>Panel estimate: if premorbidly irregular bowel habit</td>
</tr>
<tr>
<td>Training the bowel</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constipating diet</td>
<td>20</td>
<td>Panel estimate: if premorbidly regular bowel habit</td>
</tr>
<tr>
<td>Trial and error diet</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Regular Medications</td>
<td>80</td>
<td>Panel estimate: if laxatives used regularly</td>
</tr>
<tr>
<td></td>
<td>30</td>
<td>Panel estimate: if bulking agents used</td>
</tr>
<tr>
<td>Irrigation</td>
<td>78</td>
<td>Based on literature about irrigation</td>
</tr>
<tr>
<td>Intraluminal plug</td>
<td>&lt;5</td>
<td>Panel estimate: if premorbidly irregular bowel habit</td>
</tr>
<tr>
<td></td>
<td>20</td>
<td>Panel estimate: if premorbidly regular bowel habit</td>
</tr>
<tr>
<td>Irrigation plus Intraluminal plug</td>
<td>78</td>
<td>Based on literature about successful irrigation</td>
</tr>
</tbody>
</table>

5.6.5. Attribute 5 : having to attend to my colostomy intermittently whenever it needs it

There are no studies specifically relating to this topic, but the panel estimated that the only people who were unlikely to have to attend to their colostomy intermittently were those with regular or infrequent colostomy actions and those who irrigated. The probability of having predictable bowel motions has already been estimated to be 20% if premorbidly regular and <5% if premorbidly irregular. The panel estimated that when using containment, bowel training, a constipating diet or a trial and error diet, the probability of having to attend to the colostomy intermittently is estimated to be 80% (if premorbidly regular) and >95% (if premorbidly irregular).

6. In the instrument, the calculations were made using the highest probability (5).
If a person is \textit{irrigating} the probability of having to change bags intermittently (that is between irrigations) is 22\% (100\% minus 78\%, the probability of successful irrigation as previously deduced from the literature).

There was a reported 46\% chance of the \textit{intraluminal plugs} being worn successfully, for up to 24 hours (Clague & Heald, 1990) so by deduction there would be a 54\% chance of the colostomy needing intermittent attention because the plugs were not successful. These results for attribute 5 are summarised in Table 5.11.

<table>
<thead>
<tr>
<th>MANAGEMENT METHOD</th>
<th>PROBABILITY (%)</th>
<th>RATIONALE FOR PROBABILITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Containment</td>
<td>80</td>
<td>Panel estimate: if premorbidly regular</td>
</tr>
<tr>
<td>Training the bowel</td>
<td>&gt;95</td>
<td>Panel estimate: if premorbidly irregular</td>
</tr>
<tr>
<td>Constipating diet</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trial and error diet</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Regular Medications</td>
<td>20</td>
<td>Panel estimate: if using regular laxatives</td>
</tr>
<tr>
<td></td>
<td>70</td>
<td>Panel estimate: if using bulking agents</td>
</tr>
<tr>
<td>Irrigation</td>
<td>22</td>
<td>Deduced from literature</td>
</tr>
<tr>
<td>Intraluminal plug</td>
<td>54</td>
<td>Panel estimate</td>
</tr>
</tbody>
</table>

\textbf{5.6.6. Attribute 6: taking medicine regularly to control my bowel actions}

By definition people using \textit{containment} do not try to control their colostomy, so the probability of taking medications to control the bowel would be 0\%.

By definition people seeking to \textit{train their bowel} do so by rigid diet and fluid intake and strict timing of food and fluids. When using this method they do not take regular medications, so the probability would be 0\%.

By definition people seeking to control their colostomy by using a \textit{constipating}
diet restrict their fluids and any foods with fibre and bulk. When using this method they do not take regular medications, so the probability would be 0%.

People using trial and error diet eliminate troublesome foods from their diet, do not take medications, so the probability would be 0%.

By definition those seeking to control their colostomy by use of regular medications are 100% likely to take regular medications for their bowels.

By definition, people using regular irrigations to control their colostomy do not take regular medications, so the probability is 0%.

Results for probabilities for Attribute 6 are summarised in Table 5.12.

<table>
<thead>
<tr>
<th>MANAGEMENT METHOD</th>
<th>PROBABILITY (%)</th>
<th>RATIONALE FOR PROBABILITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Containment</td>
<td>0</td>
<td>By definition</td>
</tr>
<tr>
<td>Training the bowel</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constipating diet</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trial and error diet</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Regular Irrigations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intraluminal plug</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Regular Medications</td>
<td>100</td>
<td>By definition</td>
</tr>
</tbody>
</table>

Table 5.12
Probabilities for Successful Attainment of Attribute 6: Taking Medicine to Control my Bowel Actions Using the Identified Management Methods (Outcomes).

5.6.7. Attribute 7: Spending 40 minutes daily attending to my colostomy

With modern appliances only irrigators would need to spend so much time on their colostomy in each session. Another aspect for discussion is the fact that irrigators do not all irrigate daily, and the 40 minutes may actually be spent second daily or even third daily.

The probability of spending 40 minutes at one time with other methods is almost 0% unless the individual has some other problem. Williams and Johnston (1980) reported that irrigators took 44-62 minutes daily and non-irrigators took 36-54
minutes daily attending to their colostomy, so there is a possibility that people using other methods may take approximately the same total amount of time, but in several smaller periods. Patients were advised that this attribute referred to an individual spending 40 minutes in one session attending to the colostomy, not several short sessions. The probabilities for successful attainment of attribute 7 using the various management methods are summarised in Table 5.13.

Table 5.13

<table>
<thead>
<tr>
<th>MANAGEMENT METHOD</th>
<th>PROBABILITY (%)</th>
<th>RATIONALE FOR PROBABILITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Containment</td>
<td>0</td>
<td>Panel estimate based on literature</td>
</tr>
<tr>
<td>Training the bowel</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constipating diet</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trial and error diet</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Regular medications</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intraluminal plug</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Irrigation</td>
<td>38</td>
<td>Panel estimate based on literature</td>
</tr>
</tbody>
</table>

5.7. Comments about the probabilities

Many of the probabilities were estimates, and some included a range dependent upon factors such as premorbid regularity. Where a probability was estimated to be less than a figure, then that figure was used for the calculation. For example, in Table 5.10 the probability for having bowel actions at a predictable time when using the containment method was estimated to be < 5% if the patient had irregular premorbid bowel habits, thus in any calculation relating to this attribute the figure of 5% was used.
5.8. Summary of the development of the decision instrument

Project 1 concerns the development of a decision analysis instrument to assist a person with a newly fashioned colostomy to make a decision about its long term management. A literature review was undertaken to structure the problem by identifying possible outcomes (management methods) and the related attributes of each outcome which might need to be considered by the patient when making their decision. The outcomes and attributes were then verified by a panel of experts including specialist stomal therapy nurses and former patients with established colostomies. The probabilities of an individual being able to perform or experience each of the attributes with respect to each outcome were determined from the literature and an expert panel of specialist stomal therapy nurses. This concluded the structuring of the problem.

The next step in a decision analysis process is for the decision maker, in this case the patient, to provide their utilities for the identified attributes. It will be recalled that a utility is an individual preference for a particular attribute.

5.9. Determining the utilities

Both elicitation and measurement of utilities for decision analysis pose a challenge and have not traditionally been “user friendly”. People sometimes have difficulty identifying and evaluating their own values and traditionally elicitation methods involve complex or difficult exercises (Keeney & Raiffa, 1976). It is not feasible to use such methods for people still in hospital recovering from major surgery and a more practical method is needed (Schwartz & Griffin, 1986).

Because utilities are abstract they are hard to quantify and certain assumptions have been made by those seeking to measure utilities, for example an assumption that utilities for a variety of attributes can be measured using a common scale. Mathematicians have devised sophisticated means to try to overcome these problems, however, Edwards and Barron (1994) proposed that simple, direct
methods will minimise errors when eliciting utilities and this may be more important than the employment of complex mathematical procedures once the utilities have been ascertained.

As discussed in section 4.3.2, the SMART method developed by Edwards (1971) has been demonstrated to be simple and robust (Edwards & Barron, 1994) and has been adapted for this study. Once the attributes are identified, the SMART method requires that they be rated and ranked, and this is how the utilities are elicited. The unique contribution of this study is the method used for the ranking, which employs a simple card sorting technique which was originally developed by Pascoe and Atkisson (1983) as a means for assessing patient satisfaction scores. The method will now be described.

5.9.1. The card sorting technique to determine utilities

The seven attributes of the outcomes (management methods) were written on 7 cards (3 cm by 8 cm). The probabilities of the individual being able to perform or experience each of these attributes using each of the management methods was written on the back of each card and on the master grid sheet which is included as Appendix Three. A sheet of white cardboard 45 x 30 cm was prepared with a vertical line 40 cm long. The bottom anchor of the line was marked with 0 and the words ‘Not at all important for me’. Single increments were printed up the line with multiples of 10 appropriately marked. The top anchor was marked 100 and labelled ‘very important for me’.

The cards representing the seven attributes were arranged on a table directly in front of the patients. They were asked to sort them using a two step process. The first step was to rank the cards in order of importance to themself, with the least important at the bottom and the most important at the top. The second step involved having the participant rate the absolute and relative importance of each of the dimensions to them. To do this they were asked to place the cards along the continuum represented by the vertical line on the cardboard sheet. Participants
started with the card lowest in their original rank order and progressively placed the cards. They were informed that the cards may overlap or be as far apart as they wished. The scale was a ratio scale, so a card placed next to 20 represented twice the importance as a card placed next to the 10 on the scale. During this second step they could deviate from their original ranking order if they wished. The number on the line next to the top border of the card represented their utility for that card. An example of the instruction sheet is included as Appendix Four.

Using the master grid sheet, the experimenter scored each attribute by multiplying the probabilities by the utilities which had been assigned by the individual using the card sorting technique. Next the experimenter summed the scores of each attribute within each management strategy. The management strategy with the highest score was the recommended management strategy for that individual.

5.9.2. Testing the Instrument

5.9.2.1. The aim
A pilot study was conducted to assess the practicality of using the decision instrument with post-operative patients with a newly fashioned colostomy.

5.9.2.2. The sample
The convenience sample which was used comprised 5 patients who, following the development of the instrument, presented to the Stomal Therapy Department and who met the inclusion criteria for Project 2 as set out in section 6.5. The subjects for this pilot were not included in Project 2.

5.9.2.3. The method
The decision instrument was administered as described in the previous section.

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7. Clearly the bottom or middle of each card could have been used as the measure. The decision to use the top of the card was purely arbitrary.
5.9.2.4. The results

Although no major problems were encountered during the pilot study, several practical issues were identified. The cardboard sheet was made smaller so that it fitted more easily on the patient's bed table. The writing on the cards was made larger and the size of the cards was changed to 5 cm x 10 cm. Four out of five patients felt they did not fully understand the whole structure of the problem until they saw the master sheet when the computations were being carried out. It was not appropriate to show them a master sheet grid during the procedure since the list of utilities down the side might influence their ranking, so in Project 2 the names of the outcomes, without the attributes, were written on a sheet and left in sight during the ranking and rating.

To ensure that the same information was given to each participant, the directions for the task were written in simple steps and read to them. People having difficulty were taken through one step at a time using the same written sheet (see Appendix Five). These amendments were included when the instrument was administered in Project 2.

5.10. Discussion and conclusion

The discussion concerning the development of the decision instrument pertains to two groups of issues. Firstly, there are various issues relating to long term colostomy management which have emerged during the literature review undertaken to structure the problem. The second group of issues concerns aspects pertaining to decision theory and have arisen from the development and pilot study of the decision instrument.

5.10.1. Issues related to colostomy management literature

The recursive nature of this process, including feedback to and from the panel, provided new insights into old ways of colostomy management, even for the
experts. The process provided a type of consciousness-raising exercise and uncovered beliefs and values held about certain aspects of management which need to be investigated further. For example, some panelists expressed disbelief concerning bowel ‘training’ in those with a colostomy, and some expressed negative feelings towards reliance on regular medications to stimulate or suppress colostomy activity, although they could not cite research as bases for these beliefs.

In 1982 Fischhoff (p.335) stated that:

“Decision analysis is orientated to picking the apparent best alternative rather than to assessing the adequacy of our knowledge, it may encourage us to act where ignorance dictates hesitation or continued information gathering.”

In this instance, the process of developing the instrument also involved an assessment of the adequacy of the knowledge base for long term colostomy management and found it wanting in several areas, particularly in relation to data about training the bowel, diet, medications and comparisons between various management strategies. This will hopefully lead to continued information gathering in a manner which will generate more practical answers for patients. Despite the revelations of major deficits in current knowledge, this exercise has created a much better information base for decision-making than had previously existed.

Although there is a large amount of anecdotal and prescriptive information about strategies for colostomy management, there is a relative dearth of precise information. Perhaps it could be argued that these are ordinary matters, relating to basic activities of daily life, and that individuals ought to be able to sort them out without requiring recourse to scientific studies. However, the patient with a new colostomy is frequently in a state of great stress, having had major changes to their anatomical, physiological and psychological status. These issues are fundamental. The individual is in a new and abnormal state and requires some direction. It seems, on the basis of the literature review, that much of the time patient instruction is based on a type of folklore, sometimes derived from anecdotal works which might even be described as dogma and rhetoric. The uncovering of such
matters is an indirect effect of this decision analysis process and may lead in the future to more appropriate studies about long term colostomy management. The direct effect of these shortcomings in the literature will be on the calculations when using the decision instrument in Project 2. However the decisions are based on the current state of knowledge.

Other aspects discovered during the determination of the outcomes were the insights which emerged from organising the literature chronologically. There were changes over time concerning how people in the western world are prepared to deal with their colostomy. These changes are not only tied in with changing social mores and attitudes, but also with technological advancements such as the development of much better colostomy appliances. Further comparisons of literature from different regions of the world demonstrated a greater acceptance for irrigation in North America than in any other region.

During the past thirty years there have been thirteen scientific studies comparing various methods of colostomy management and the results suggest that irrigation is the most advantageous. A total of nearly 3,500 subjects were involved in these studies, but despite these accumulated data, irrigation is still not widely practised outside North America. This is so, even in countries such as Hong Kong, Peru, Brazil and China, where people have difficulty acquiring ostomy bags (De-hong, 1990; Habr-Gama et al., 1990; Kwan, 1990). In NSW, less than 8% of members of the Colostomy Association ordered irrigation sets in 1995. It is not known why so few people choose this method, but there is a suggestion that the option is not given to many unless they ask about it. In Project 2 every person was explicitly told about irrigation, along with all the other methods. It was possible to work out what percentage of the total number of people having a colostomy made at the institution concerned over the period of the study were not able to use the irrigation method, and what percentage did not choose to use the method.

The literature revealed several debates. The most notable was the debate about the benefits of irrigation versus non-irrigation. Then there were opposing views about
whether or not a colostomy can be trained. Some considering colostomy training and bowel training to be the same thing, while others denied the ability to train a colostomy because, unlike the anus, it has no sphincter. The invention of the intraluminal plugs may provide an answer to this debate.

With regard to diet and medication, there was debate about whether diet helps at all, and then debate about which type of diet it should be; constipating, or trial and error with exclusion only of foods which have actually caused a problem. Then there is the disagreement about what people should be told about diet. There were comments that “every patient should be warned about some foods as potential problem causes” (Terranova et al., 1979, p.33) but also claims that people should not be warned of problem foods because the warnings tend to become “dogma” (Grier et al., 1964, p.1237). Unfortunately, the writers did not properly investigate which foods caused problems in patients. Nor has anyone investigated what patients believe they are meant to do when they are given lists of “potential problem foods”.

There are many unanswered questions about basic colostomy management. This study will answer some, such as the reasons people have for selecting or not selecting various methods of colostomy management. Other unanswered questions should form the basis of future research into the basics of colostomy management, including the specific nature of the role of diet and medications.

5.10.2. Issues related to decision theory

In this study the strategy used for measurement of utilities was deliberately made as simple as possible, utilising Edwards and Barron’s (1994, p. 310) “strategy of heroic approximation” in order to make the procedure reasonable for post-operative patients to handle. The visual, card sorting, ranking and rating technique was found to be simple enough for the patients to do within two weeks of surgery. It is inherently more interesting than a paper and pencil test and still brief and easily administered. There is some evidence that card sorting is less likely to lead to
systematic response errors such as acquiescent response set and global response
than is the case with written questionnaires (Pascoe & Atkinson, 1983). The
ranking is believed to have an organising effect on the patient's approach to the
rating task. According to Atkinson, Roberts and Pascoe (1983) the ranking round
helps to familiarise patients with the attributes before they rate them.

This decision analysis is based on several implicit “meta-assumptions” (Schwartz
& Griffin, 1986), of which the first is that all significant potential outcomes are
known. The use of the panel of experts has ensured that this is so. The second
assumption is that risks and benefits can be compared directly. The third
assumption is that utility for various outcomes can be measured accurately on a
single scale. The whole issue of elicitation and measuring utilities is a challenge,
and this may be the first time a card sorting method has been used to elicit utilities.

A major problem with SEU is the violation of an assumption caused when
probabilities and utilities are not independent, such as when an individual’s utilities
are influenced by the fact that they believe the attribute is unlikely to occur. In this
study the probabilities and utilities are independent because the professionals
(stomal therapy nurses) provide the probabilities and the patient provides the
utilities. This is a most appropriate division of labour. Furthermore the explicit
nature of this division of labour makes it obvious to the patient what is expected of
them. They are the only ones who can judge their utility for the attributes. This
division of labour also provides a structure for discussion during decision-making
so that only matters which are relevant to the decision are structurally “allowed”
thus avoiding and clouding or biasing of judgment.

5.10.3. Conclusion

This decision instrument facilitates decision-making because it assists patients to
simultaneously consider a range of variables relevant to their decision - the
possible outcomes, the attributes which need consideration, the probabilities of
each of the attributes and the utility for each attribute.
CHAPTER SIX

which outlines the methodology for Project 2 - a comparison of three decision-making methods to determine their effect on satisfaction and goal attainment.

This chapter outlines the methods employed to investigate the differences in outcomes between three groups using different decision-making methods. Issues raised in previous chapters are reviewed briefly to remind readers of the background to the study. Following a statement of the aims and research questions, there is a description of the methods employed. The statistical techniques used for the main quantitative analyses are introduced, together with information about the assumptions underlying their use.

6.1. Review of background information

In previous chapters it was proposed that working relationships between patients and nurses are changing to include more patient participation. Christensen (1990) found evidence that patients and nurses can and do work together in a general sense and proposed a model of nursing as a partnership with patients. But there is still some debate about whether patients should participate in decisions about their care (Cross & Churchill, 1982; Ornery, 1989). From an ethical perspective, patient participation is preferred (Thompson, 1990) but there is no convincing evidence that participation is linked to improved clinical outcomes (Steele et al. 1987). However, to dismiss participation solely because it does not improve clinical outcomes, indicates too narrow a focus on the physical aspects of patient care and ignores other major outcomes of decision-making such as satisfaction and autonomy which are defined from the patients’ perspective.

There is also some debate about whether patients want to participate (Waterworth & Luker, 1989) but evidence that patients do prefer mutuality in decision-making is provided by ongoing work using the Autonomy Preference Index (Smith & Garko, 1991) and by the work of Bennett et al. (1995).
Kim (1983b) provides a theoretical framework for understanding patient participation in making nursing decisions and is used as a theoretical underpinning for this study. She reports that, when her framework was applied to usual practice, there was little evidence of collaborative decision-making taking place between patients and nurses and she proposed that this may have been due to a lack of institutionalised processes for this to occur. It may also be that many nurses do not know any techniques to facilitate collaborative decision-making with patients.

Decision theory provides insights into such techniques, and it has been suggested by Schwartz and Griffin (1986) that decision analysis is the best technique for patient facilitating participation in decisions about their care. Because the focus of this study is decision-making between patients and their stomal therapy nurse as they seek to decide upon a method of long term colostomy management, the challenge is to devise a way of implementing decision analysis which is practical for use by patients who are still in hospital following major bowel surgery.

Project 1 has been reported and involved the rigorous development and piloting of a decision analysis instrument which specifically structures the decision about long term colostomy management using professional knowledge about possible outcomes (long term colostomy management methods), their attributes and the probabilities of those attributes being experienced with each possible outcome. Importantly, the decision instrument also provides an innovative and "user friendly" way for patients to contribute relevant information about their utilities for the various attributes. Finally, the instrument provides a rational way for relevant input from the patient and nurse to be combined to arrive at a decision. The decision analysis instrument developed and piloted in Project 1 was used in Project 2 which compared three treatment groups to determine the effect of differing styles of decision-making on goal attainment and satisfaction.
6.2. The research aim and questions

This study aimed to examine aspects of decision-making in stomal therapy nursing practice. In doing so it sought answers to the following questions. Are there differences in satisfaction and goal attainment between patients using three different decision-making methods with controlled levels and types of collaboration? Do patients prefer autonomy, delegation or mutuality when making decisions about their care? What happens when patients expect or prefer one type of participation in decision-making, but are placed in a situation where that type is not permitted or encouraged? How does patient participation affect outcomes from the patients' perspective? Would an institutionalised process, such as the decision analysis instrument developed in Project 1 facilitate collaborative decision-making between patients and nurses? Is the card sorting technique developed in Project 1 a practical and effective method to obtain relevant input from the patients in the early post-operative period?

6.3. Research design

The answers to these questions were sought by using an experimental design which involved three treatment groups, each of which were exposed to one of three different decision-making methods.

6.3.1. The Instrument Group

The Instrument Group made their long-term colostomy management decision using the decision instrument developed in Project 1. This group was considered to have high level participation. Although patients in the Instrument Group were later informed of the full range of management methods available, their management goals were set using the instrument.
6.3.2. The Discussion Group

The *Discussion Group* used a collaborative discussion between the nurse and patient for decision-making and this was considered to be another style of high level collaboration. Management goals were selected on the basis of the discussion. To ensure that collaborative discussion and decision-making took place, two independent judges assessed audiotapes of the discussions using predetermined criteria. To avoid any effect due to the presence of the tape recorder, it was present for all three groups, although only the tapes from the Discussion Group were used for the purpose of validation. The independent judges were both professional counsellors, selected because they each had several years experience in interviewing and negotiation with patients.

6.3.2.1. Criteria for a collaborative discussion

The criteria for recognising collaborative decision-making were derived from the work of Eisenthal, Koopman and Lazare (1983) who investigated mutuality in making treatment decisions as one dimension of the negotiated approach to clinician-patient encounters. In order for the decisions to be considered collaborative:

* The manner of initiating the decision-making phase of the encounter needed to be open-ended exploration rather than an authoritarian statement of a plan of action by the nurse;

* There had to be pursuit of consensus with the nurse actively seeking an expression of agreement with, and acknowledgement of, the treatment plan by the patient;

* Before decisions were made the patient had to verbalise some type of request or desire for information, and that request had to somehow match with the plans discussed, even if it was not the final decision made.

* A goal had to be set, that is, the decision reached had to be made explicit.

Criteria also included a global rating of the nurse's use of authority during the decision-making phase. Each of these criteria had to be met, and there needed to be
80% agreement between judges for inclusion of that decision in the study. If there was not evidence of collaborative decision-making that person was not used in the study. The first four discussions failed to meet the criteria and were not included.

6.3.3. The Advised Group

The Advised Group received advice from the stomal therapy nurse and was considered to have low level collaboration. Patients were informed of the range of management methods available but the nurse selected the goal, based on clinical judgment, and information from the patient which had surfaced during their interactions. The nurse set the management goals. Because Kim (1983a) found little evidence of collaborative decision-making in usual practice it is likely that the Advised Group most represents normal practice.

6.4. Sample selection

All patients with a newly fashioned colostomy attended to by the staff of the Stomal Therapy Department of Westmead Hospital (a 600 bed tertiary referral hospital) were potentially available for the study. Inclusion criteria stipulated the ability to give consent, so the participants needed to be adults (over 18 years) who could speak and understand English and who had the intellectual ability to understand the interview questions. Because the study was testing a real decision, not a hypothetical one, the patients had to have a colostomy located on the descending or sigmoid colon that could potentially be managed by any of the management methods. The person also needed the intellectual and physical ability to perform any of the management methods selected, so this criterion excluded those with poor manual dexterity, intellectual disability, severe or terminal illness, and those with illness or ongoing treatment which precluded any management method (for example, adjuvant radiation therapy to the bowel precludes management using irrigation). Only those who could reasonably be expected to return for follow up were included, so people from remote rural areas were excluded. Inclusion and exclusion criteria are summarised in Table 6.1.
Table 6.1

Summary of Inclusion and Exclusion Criteria.

Inclusion Criteria

Adult
Type of colostomy suitable for all management methods
Able to answer for self
Able to speak and understand English
Consent given
Manual dexterity sufficient for any single method of colostomy management
Intellectually capable of any method of colostomy management
Living near enough to return for follow up visits

Exclusion Criteria

Type of colostomy not suitable for all management methods
Unable to understand or speak English
Poor manual dexterity
Not willing to participate
Intellectually unable to answer questions
Not able to return for follow up
Terminally ill or too ill to participate in study
Pathological condition precluding any single method of colostomy management
Ongoing treatment modality precluding any single method of colostomy management

All patients attended by the staff of the stomal therapy department were interviewed using a structured interview schedule (Appendix Five) to ascertain their willingness and suitability to be included in the study, and secondly to determine their preferences and expectations about decision-making. Irrespective of their preferences and expectations about decision-making, patients who consented to participate in the study were assigned to one of the three treatment groups - Instrument, Discussion or Advised - until there were 20 patients in each group. This was done by allocating consecutive patients to groups on a rotating basis. Chronological allocation was determined according to the time of the initial contact with the Stomal Therapy Department, not the time of admission, nor the time of operation. Sample selection took approximately one year, since 51.6% of patients attending the department were excluded by the criteria, including 3 who refused consent, and one who died before interview. Due to these criteria the sample size is small, however statistical methods to handle the small sample size and large number of variables are discussed in Section 6.10.
6.5. The theoretical framework for the study

Kim's framework for collaborative decision-making in nursing was used as the theoretical framework for this study. The reader will recall that Kim's framework, as described in section 3.5., incorporates the context of the participants - clients and nurses - who bring to the encounter their various role expectations and attitudes, knowledge, personal traits and definitions of the situation. There is also the context of the situation which includes the organisation of decision-making in that institution and the type of nursing care decision involved. In Kim's framework the contexts of the participants and the context of the situation are the independent variables and they interact to produce the dependent variables which are called the primary and secondary outcomes. The primary outcomes are the level of collaboration and the nature of the decision, which is conceptualised in terms of its extensiveness, attainability and affective meaning for the patient rather than the discrete meaning of the decision made. The secondary outcomes arise from the primary outcomes and are goal attainment, satisfaction and autonomy.

6.6. Changes to Kim's Framework for this study

Because Project 2 concerned itself with the effect that different types of collaboration have on client outcomes of satisfaction and goal attainment. An adaptation of Kim's framework was developed, as shown in Figure 6.1. In this adapted version, the level of collaboration becomes the independent variable and is effected by allocating clients to three groups with differing methods of decision-making (one using the instrument, one having a collaborative discussion and the other being advised by the nurse). The client outcomes of satisfaction and goal attainment were the dependent variables. It was believed that the level of autonomy was dictated by the group to which the patient was allocated. The quality of the decision and the nature of the decision were explored in Project 3.

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8. The term "client" is used since this is the term used in most of Kim's work.
Figure 6.1.
Kim's Framework for Collaborative Decision Making in Nursing as Adapted for this Study

Context of Participant

Client Related Factors
- Sociodemographics
- Knowledge
- Experience
- Expectations
- Preferences

Nurse Related Factors
- Constant
- Depends on treatment group

Context of Situation

Organization of Decision Making
- Routinization

Nursing Care Decision Type
- Program Decision

Independent Variable

Level of Collaboration: 3 Treatment Groups

Dependent Variables

Nature of the Decision
Goal Attainment Satisfaction
6.6.1. Factors held constant: the nurse and the situation

An attempt is made to keep nurse-related factors as constant as possible. This is a complex matter and could never guarantee exactly the same treatment for each client. However, to minimise variability in knowledge and personal traits, the same nurse was involved in each decision being studied. The nurse’s role attitudes and definition of the situation were dictated by the treatment group to which the individual patient is allocated.

Because of Kim’s (1991a, p.15) findings that, “Nurses with a consumerist attitude provide a facade of allowing greater collaboration than patients perceive they actually have”, it was decided to have the two independent judges using predetermined criteria listen to audiotapes of the discussions and determine whether the nurse did have collaborative discussions and decision-making with those in the Discussion Group. This is outlined in section 6.4.2.1.

The context of the situation was held constant. The same type of decision was made each time, that is, selection of a long term management strategy for a newly formed colostomy. All patients were given information about their illness and treatment options. The severity of illness was fairly constant in that all had undergone major surgery involving colostomy formation and anyone considered too ill or with an obviously poor prognosis was excluded from the study. In all cases, the fact that a decision was needed was made explicit, and patients understood that decision-making was the aspect being investigated.

6.6.2. Factors not able to be held constant: the client

Obviously the client-related factors outlined in Kim’s framework vary with each individual, so in Project 2 these factors are measured and dealt with statistically in order to control for variation by treating them as potential covariates in the main analyses. Client-related factors were gathered during the initial interview and by using a modified version of the Autonomy Preference Index. Each of these data
collection methods will now be described.

6.7. Measuring client-related factors: the initial interview

Client-related factors were obtained from the medical record and through a structured interview (see Appendix Five). Data were grouped into logical clusters according to information derived from Kim’s work, and other literature as described in the previous chapters. The clusters relate to potential covariates to be used so as to statistically control data in order to keep client-related factors “constant” in the final analyses.

6.7.1. The sociodemographic cluster of variables

The sociodemographic variables were included because they are logically related to the “client-related factors” which are an integral part of Kim’s framework. Studies by Ende et al. (1988), Haugh and Lavin (1981) and Smith and Garko (1991) indicate that females and younger, better educated people are more likely to state that they wish to play a greater role in decision-making. The sociodemographic variables included gender, age, education level and occupation. Birthplace was included because the work of Kim (1991) and that of Smith et al. (1994) suggested some cross-cultural differences.

Gender was treated as a categorical variable and classified people as female and male. Age was the chronological age in years derived from the date of birth in the medical records, verified verbally and treated as a linear variable. Birthplace was treated as a categorical variable with two categories - Australian and other. Educational level was categorised into seven levels using the highest level attained, and then treated as a linear variable. Levels used were primary school, lower secondary school, upper secondary school, non-diploma technical or trade course, diploma, degree and postgraduate degree. Occupation was treated as a categorical variable, with two categories, those not in the work force and those in the work force.
6.7.2. The experience in the hospital system cluster of variables

The inclusion of this cluster was based on Kim's idea that: "persons having been exposed to many nursing care situations are more likely to have developed a strong sense of role expectations regarding their behaviours as clients than those whose sick-role exposure is new" (Kim, 1983b, p. 278). These variables included the amount of time ever spent in hospital (in weeks), and the number of months since the last admission to hospital. This latter variable was included because recency may render things easier to remember and therefore more influential in decision-making (Wright, 1984).

6.7.3. The prior knowledge cluster of variables

Kim (1983b, p. 278) indicated that, "the dependent role is often assumed by clients in situations requiring expert knowledge, especially in situations where clients perceive themselves to be inadequate with respect to the knowledge requirements for decision-making". Haugh and Lavin (1981) also referred to this perceived "competence gap" between patient and practitioner. The level of specific knowledge about colostomies and their management was assessed since it was possible that increased knowledge about a specific topic might make a patient more eager to participate in decisions concerning that matter. Two questions, addressed below, were asked - both are open ended so as not to bias the answers by providing cues.

6.7.3.1. Prior knowledge about colostomies

The purpose of asking "What do you know about colostomies?" was to determine whether level of knowledge influenced preference for participation in decision-making. Patients' responses to this question were categorised by two independent judges. Responses were written onto separate pieces of paper and each judge independently sorted them into three categories - no knowledge, vague knowledge and considerable knowledge. Inter-judge reliability was 99.5%.
6.7.3.2. Prior knowledge about colostomy management

The aim of asking “What do you know about how a colostomy is managed?” was to determine levels of prior knowledge about colostomy management methods. The responses were categorised as - no knowledge about any methods, knowledge about bags only, knowledge about bags and other methods. Again the two independent judges used the method outlined in the previous section and there was 100% agreement about the categories assigned.

6.7.4. The decision preferences cluster of variables

The decision preferences cluster of variables tie in with the client’s role expectations and personal traits (Kim, 1983b) and include both their expectations about level of involvement in decisions about the colostomy, and their global preference for involvement in decisions to be made about the colostomy.

6.7.4.1. Expected level of involvement in decisions

The question “How much involvement do you expect to have in decisions which will need to be made about your colostomy?” was posed in an open-ended fashion in order not to bias answers by giving cues. Answers were then categorised according to level of participation in the decision-making, taking care not to count receiving information as decision-making. The two independent judges were used, as described in section 6.3.2.1., and inter judge reliability was 98%.

This information was sought for several reasons. Firstly, because it forms part of what Kim called “clients’ role expectations” (1983b). Secondly, to see whether satisfaction was linked with expectations. For example, receiving less information than is expected may produce less satisfaction than receiving what was expected (Linder-Pelz, 1982). This question about expectations was included to determine whether random allocation to a treatment group which did not concur with expectations effected satisfaction.

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6.7.4.2. Global preference for decision-making

This variable forms part of what Kim called “clients’ personal traits” (1983b). Patients were asked “In general how much involvement do you prefer to have in decisions which are made about your colostomy?” Preference was indicated on a linear scale and treated as a linear variable. This item was included as a general item to check the validity of the API scales.

6.8. Measuring client-related factors: the modified API Scale

The development of the API as an instrument to measure collaboration in decision-making has already been reviewed in sections 2.4. and 2.5. A number of further modifications were introduced for this study.

1. Although the API items were maintained with three explicit statements, the wording was altered to reflect the specific stomal therapy situation.

2. The original items used in Smith and Garko’s work (1991) included statements such as: “You and your doctor should talk it over and decide together how frequently you need a check up”. In the version for the current study, the words “talk it over” were removed to tease out the fact of collaboration from the process of “talking it over”. Is it possible to collaborate in decision-making without having a discussion? In this study the treatment group which uses the decision instrument was conducted in such a way that the decision was based solely on the use of the instrument, not on a discussion. Despite this there was high level collaboration in decision-making without actually “talking it over”.

3. In Project 2 the API vignettes were not used. In previous studies they were used to distinguish between hypothetical situations of varying severity of illness and varying levels of relevance of patient input. This is part of what Kim refers to as the context of the situation. Because this study did not involve a hypothetical situation, and because the severity of illness and relevance of patient input are both
fairly constant, vignettes were not considered necessary.

In Project 2 all API items are scored from 1 = strongly disagree to 5 = strongly agree to allow a simple additive scale to score preferences for autonomy, delegation and mutuality. The following is an example of one item.

You should decide how frequently you need a colostomy check-up.

1 2 3 4 5
strongly disagree strongly agree

Your stomal therapy nurse should decide how frequently you need a colostomy check-up.

1 2 3 4 5
strongly disagree strongly agree

You and the stomal therapy nurse should decide together how frequently you need a colostomy check-up.

1 2 3 4 5
strongly disagree strongly agree

6.8.1. Pilot study to test adapted API

A pilot study was carried out to test for reliability and validity and to determine whether there were any problems in the administration of the scale. (The scale is shown in full in Appendix Six).

6.8.1.1. Reliability testing

Items were checked for test-retest reliability on a convenience sample of 50 patients, former patients and non-nursing staff members who were asked to take the questionnaires twice, the second time was two weeks after the first. The reliability score was calculated using Pearson product moment correlations. The correlation for patient preference items was 0.77 (df = 49; p<.01); for nurse
preference items $r = 0.80$ (df = 49; p<.01); and for mutuality preference items $r = 0.89$ (df = 49; p<.01). The scales were tested further for internal consistency reliability calculating the Cronbach alpha (Cronbach, 1951). The Cronbach alpha coefficient for patient preference items was 0.79, for nurse preference items was 0.78 and for mutuality preference items was 0.81. Overall, the modified API shows acceptable internal consistency and test-retest reliability for each of the three scores.

### 6.8.1.2. Validity testing

Concurrent validity was established by correlation with an empirically related global item appended to the instrument.

<table>
<thead>
<tr>
<th>Generally speaking I prefer to make my own decisions about my health care.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 strongly disagree</td>
</tr>
<tr>
<td>2</td>
</tr>
<tr>
<td>3</td>
</tr>
<tr>
<td>4</td>
</tr>
<tr>
<td>5 strongly agree</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Generally speaking I prefer that health care staff make decisions about my health care.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 strongly disagree</td>
</tr>
<tr>
<td>2</td>
</tr>
<tr>
<td>3</td>
</tr>
<tr>
<td>4</td>
</tr>
<tr>
<td>5 strongly agree</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Generally speaking I prefer that health care staff and I make decisions together about my health care.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 strongly disagree</td>
</tr>
<tr>
<td>2</td>
</tr>
<tr>
<td>3</td>
</tr>
<tr>
<td>4</td>
</tr>
<tr>
<td>5 strongly agree</td>
</tr>
</tbody>
</table>

The scores for these items were correlated with the means for the scale items for autonomy, delegation and mutuality. For autonomy $r = 0.76$ (df = 49, p<.01); for delegation $r = 0.81$ (df = 49, p<.01) and for mutuality $r = 0.88$ (df = 49, p<.01).

### 6.8.1.3. Further amendments suggested by the pilot study

Discussion with participants in the pilot study indicated that they tended at times to compare their responses with the other statements in each subset, and this made
their answers less spontaneous and perhaps introduced response bias. To minimise the occurrence of this response set in Project 2, each statement was typed on a separate page and incorporated into a flip chart so that it was less likely participants would compare answers with those given previously.

6.8.2. Administration of the adapted API

Each item was printed on a card 10 x 25 cm and placed into a flip chart. The possible responses (1 = strongly disagree to 5 = strongly agree) were written on a separate card and participants considered each item individually and pointed to the response of their choice, before the item card was flipped over to proceed to the next item.

Items were in subsets, each with three items presenting the idea in different perspectives: the patient decides, the nurse decides and the nurse and patient decide together. This arrangement minimised the potential for acquiescent response set. The fact that the scoring was always weighted, from 1 = strongly disagree to 5 = strongly agree, meant that a measure had been created which allowed aggregation of preferences for decision-making across sets (preference for the nurse to make the decision, preference for the patient to make the decision, preference for mutuality in decision-making) and also allowed comparison of the preference scores between the three sets.

6.9. The Outcomes : the dependent variables

Kim's secondary outcomes, goal attainment and satisfaction with the decision-making process, became the two dependent variables in Project 2. It can be noted that in Kim's framework autonomy is also a secondary outcome. In this study autonomy was predicated by allocation to one or other of the three treatment groups and the resultant level of collaboration inherent in the nature of these groups.
Measurement of the dependent variables - goal attainment and satisfaction with the decision-making process - occurred after 6 weeks and again after 18 weeks to assess for changes. Measurement methods are detailed in the following sections.

6.9.1. Measuring goal attainment

At the completion of the decision-making exercise a management method was selected for each participant and recorded on their interview sheet. This management method became the goal. At the 6 weeks and 18 weeks interviews the stomal therapy nurse assessed the level of goal attainment by asking participants to describe how they had managed their colostomy and by observing and discussing their current management methods. Those who did not attain their goal were questioned to ascertain why this was so. Goal attainment is simply categorised as goal not attained or goal attained.

6.9.2. Measuring satisfaction with decision-making

Patients were assessed at 6 weeks and at 18 weeks to determine their level of satisfaction with their opportunity to contribute during the decision-making process. Satisfaction was defined as an evaluative reaction resulting from interaction of the decision-making experience with the individual’s expectations (Pascoe, 1983, p. 187).

To measure satisfaction it was necessary to establish which type of expectation is used or to evoke a common type (Hunt, 1977) - that is, tell the subjects which type of expectation you want them to consider. Do you want them to compare their experience with what they expect to be the ideal, or the minimum acceptable or what they believe that they deserve? Because this Project aimed to determine which method of decision-making is most effective in nursing practice it was decided to ask subjects to use their ideal expectation when rating their level of satisfaction.
Many satisfaction scales are general and produce highly undifferentiated levels of reported satisfaction that fail to detect aspects that patients do not find satisfactory (Meterko, 1995). In Project 2 the interest was in the micro domain of the specific experience with the stomal therapy nurse when determining the choice of method of long term colostomy management. Because the interest was in one dimension, that is the level of participation in decision-making, a specific and direct measurement was appropriate and was expected to discriminate between differing levels of satisfaction.

An assumption was made that satisfaction is a continuum, from “not at all satisfied” to “completely satisfied”. A visual analogue scale was used for the rating. This was chosen because visual analogue scales contain no numbers or word descriptors, avoiding the ambiguity of value laden labels which may convey different meanings to different raters (Oberst, 1984). The distance of the markings from the endpoints was measured and assigned a number. 0 = “not at all satisfied”, and 5 = “completely satisfied”. The instrument used is shown in Figure 6.2.

---

9. Despite these precautions the measurement of satisfaction was still problematic. Initially there was little discrimination between subjects, with almost everyone indicating that they were very satisfied. This ceiling effect was noted after the first 20 responses and each of those respondents was contacted by letter and asked to reassess their level of satisfaction with the particular decision-making method they had used (see Appendix Seven). They were specifically asked if there was anything about how the decision was made which did not meet their needs or expectations, and whether the way the decision was made suited them. To avoid inconsistent treatment, the same information included in that letter was then given verbally to the remaining subjects when they completed their satisfaction assessment.
Figure 6.2

The Instrument to Measure Satisfaction.

Compare your decision-making experience with what you imagine to be the ideal situation. How satisfied are you with the opportunity you had to contribute your ideas and participate in decisions about how you will manage your colostomy? Please indicate your answer by placing a mark through the line below.

NOT AT ALL
SATISFIED

6.10. Analysis of data: multivariate analysis of variance

Following a general description of the subjects, the main research questions were answered with multivariate analysis using the computer package SPSS.

In the main analyses the level of collaboration (as determined by treatment group allocation) was the independent variable and the patient outcomes (satisfaction and goal attainment) were the dependent variables. Kim’s model for collaborative decision-making in nursing, and a review of other relevant literature indicated that some patient-related factors are also potentially relevant, however it is not known whether the random allocation of subjects to three treatment groups has controlled for the effects of these variables. Multivariate analysis of variance (MANOVA) is used to determine whether any of the patient-related factors are different between the groups, before the treatment. These factors are then termed the covariates and are statistically incorporated into the final analyses using multivariate analysis of covariance (MANCOVA). The use of these techniques will now be discussed.

MANOVA is a form of analysis of variance which enables inclusion of a number of dependent variables, and allows a test of the possible interactions among multiple dependent variables that cannot be evaluated if each dependent variable is treated separately (Huck, Cormier & Bounds, 1974). Furthermore, there are
advantages in the use of MANOVA as opposed to a series of ANOVAs (analysis of variance) where one ANOVA is conducted for each dependent variable. In this situation the use of MANOVA is a protection against Type I error (Tabachnick & Fidell, 1983). Use of MANOVA may reveal differences not shown in separate ANOVAs. Accounting for the interrelationships among the dependent variables allows investigation into whether the independent variables significantly affect an optimal linear correlation of dependent variable means. This process allows maximisation of group differences. (Bennett, 1989; Norusis, 1989; Tabachnick & Fidell, 1983).

An *a priori* decision rule was used when interpreting the MANOVA results. Multivariate significance was recognised when $p<.1$. In the absence of multivariate significance of $p<.1$ the univariately significant variables will be examined if they approach a significance of $p<.05$.

ANCOVA (analysis of covariance) is a special analysis of variance design that combines the power of multiple regression with an analysis of variance. The purpose of the ANCOVA is to reduce extraneous variation in the dependent variable due to the effect of separate variables on the groups being measured. Reducing or “controlling” this outside variation decreases the error sum of squares and increases the power of the test or the probability that a significant result will be found. Multivariate Analysis of Covariance (MANCOVA) is the multivariate extension of ANCOVA. In Project 2 it was used to achieve statistical matching between groups with regard to those variables where random allocation to the treatment groups had failed to achieve such matching.

**6.10.1. Assumptions underlying multivariate techniques**

6.10.1.1. Multivariate normality

MANCOVA is based on the multivariate normal distribution. This means that: “the sampling distributions of means of the various dependent variables in each cell are
normally distributed as are linear combinations of them” (Tabachnick & Fidell, 1983, p. 232).

Examination of box-plots for the variables in this study indicated that some of them were not normally distributed. This was due to the strong homogeneity of the samples which resulted in severely skewed distributions. According to Mardia (cited in Tabachnick & Fidell, 1983), MANOVA is robust to modest violations in normality provided they are created by skewness rather than by outliers, and the sample size is 20 or more with a few dependent variables. Because the data in this study meet these criteria, MANCOVA was used. In cases where non-normality was thought to be due to outliers, those outliers were removed from the data prior to analysis. Specific instances are discussed at the appropriate section of the results.

6.10.1.2. Homogeneity of variance-covariance matrices

The second assumption of MANCOVA is that the variance-covariance matrices in each cell of the design are sampled from the same population variance-covariance matrix. Box’s M test, which is based on the determinants of the variance-covariance matrices, provides a test that several covariance matrices are equal, noting that “this test is very sensitive to departures from normality” (Norusis, 1989, p.239). Box’s M test was used on all cells before proceeding with the multivariate analyses.

6.10.2. Levels of measurement

Those dependent variables which are measured at interval or ratio level are included in the MANOVA analyses, as are some ordinal variables since they are interpretable in MANOVA analyses. Categorical variables are by definition excluded unless they are capable of being reduced to only two categories of response which allows meaningful interpretation. This procedure allows categorical variables to be treated as “dummy” variables.
6.10.3. Calculating critical values

In the presence of a significant multivariate result, multiple comparisons will be carried out using the Bonferroni method. This method is based on the recognition that the more statistical tests are carried out, the greater the chance of a Type I error. Bonferroni showed that the Type I error rate for a family of hypotheses is at most the sum of the individual error rates. The Bonferroni method is an a priori test, that is the multiple comparisons are specified in advance of the data being inspected (Norusis, 1989).

6.11. Summary of Project 2

All patients who had colostomy surgery were assessed for inclusion using the stated criteria. The study was explained to those deemed suitable, they were given an information sheet and sign the consent form (see Appendix Eight). An initial interview was used to ascertain sociodemographic factors, decision-making preferences and expectations (using the modified API) and relevant medical history. This interview was completed as early as possible during hospitalisation.

The decision-making procedure in one of the three groups and the setting of goals was carried out before discharge from hospital and according to the respective protocol for that treatment group.

An appointment was made for a 6 week follow up interview so that the outcomes (goal attainment and satisfaction with the decision-making procedure) could be assessed. This time frame was selected because it approximates the time when most people would return to their normal activities after this type of surgery. An further appointment was made for an 18 weeks follow up interview so that the outcomes could be reassessed. This time frame was selected because colostomy management methods should be firmly established by this time.

A checklist was used to ensure that each participant fulfilled all aspects of the study
(see Appendix Eight).

This chapter outlined methods to find out more about patients' preferences, and expectations about decision-making, and to discover more about patients' levels of satisfaction and goal attainment after using different decision strategies. Results from these analyses are described in the next chapter.

6.12. Conclusion

This chapter outlined the methods employed to investigate questions about how decision-making might be enacted between patients and nurses, and the difference between three groups using three different strategies to make a decision about long term colostomy management. One of those methods is the innovative decision instrument which was developed and piloted in Project 1.
CHAPTER SEVEN

which presents the results for Project 2, including a description of the sample and identification of pretreatment differences between the groups which become the covariates in the analysis of differences in satisfaction and goal attainment between groups.

This chapter presents the results for Project 2 which investigated aspects of collaborative decision-making in nursing. Patients were randomly allocated to one of three treatment groups - Group 1 (Instrument) used the decision instrument which had been developed and piloted in Project 1; Group 2 (Discussion) participated in a collaborative discussion and decision-making exercise; and Group 3 (Advised) were advised by the nurse concerning long term colostomy management. In subsequent discussions in this chapter, groups will be referred to by the shortened terms shown above in parenthesis.

The theoretical framework of the study was an adapted version of Kim's work on collaborative decision-making in nursing. In this adapted version, the "nurse-related factors" and the "context of the situation" are held as constant as possible while the three groups use the different decision-making methods. However, because of the difficulty in holding "client-related factors" constant, MANOVA was used to make comparisons on the pretreatment "client-related factors" so that any pretreatment differences could be identified and treated statistically.

This chapter commences with a general description of the sample and is organised according to the clusters of variables outlined in Section 6.8. These are the sociodemographics; variables relating to experience within the hospital system; variables concerning prior knowledge about colostomies and their management; decision expectations and preferences; the modified API scores; and data about relevant medical diagnoses. Pre-existing differences in "client-related factors" between the three treatment groups are identified, discussed and subsequently incorporated as covariates in the final model for the analyses of the effects of the three treatments on the dependent variables - satisfaction and goal attainment.

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The question Project 2 sought to answer was whether there were differences in satisfaction and goal attainment between patients using three different decision-making methods. It also investigated whether patients prefer autonomy, delegation or mutuality when making decisions about their care. Furthermore, it explored what happened when patients expected or preferred one type of participation in decision-making, but were placed in a situation where that type was not permitted or encouraged.

7.1. Description of the sample

7.1.1. Sociodemographic cluster of variables

The sociodemographic variables are included because they are logically related to the "client-related factors" which are an integral part of Kim's framework.

There were 26 (43.3%) females and 34 (56.7%) males whose ages ranged from 22 to 88 years with a mean of 59.9 years (sd = 15.2 years). The majority were Australian born (76.7%). The remaining 23.3% were born in United Kingdom (15%), and then one each in Italy, Malta, India, Austria and New Zealand, and all had been in Australia at least ten years (range 10-47 years).
Table 7.1 sets out the highest educational level completed. It can be observed that most have completed secondary school (63.4%) with an additional 20% completing a trade or technical course. There are relatively few patients who have educational achievements higher than this (11.6%). This is consistent with the age of the patients, being typical for the general population in that age cohort, and also with the fact that some had been unwell for many years.

<table>
<thead>
<tr>
<th>Highest level of education completed</th>
<th>n</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary school</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Lower secondary school</td>
<td>25</td>
<td>41.7</td>
</tr>
<tr>
<td>Upper secondary school</td>
<td>13</td>
<td>21.7</td>
</tr>
<tr>
<td>Non-diploma technical or trade course</td>
<td>12</td>
<td>20.0</td>
</tr>
<tr>
<td>Diploma</td>
<td>4</td>
<td>6.6</td>
</tr>
<tr>
<td>Degree</td>
<td>2</td>
<td>3.3</td>
</tr>
<tr>
<td>Postgraduate degree</td>
<td>1</td>
<td>1.7</td>
</tr>
</tbody>
</table>

The majority of the patients (61.6%) were not in the paid work force due to various reasons set out in Table 7.2.

<table>
<thead>
<tr>
<th>Category</th>
<th>n</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabled</td>
<td>8</td>
<td>13.3</td>
</tr>
<tr>
<td>Retired or aged pensioner</td>
<td>26</td>
<td>43.3</td>
</tr>
<tr>
<td>Unemployed</td>
<td>3</td>
<td>5.0</td>
</tr>
<tr>
<td>Housewife</td>
<td>8</td>
<td>13.5</td>
</tr>
</tbody>
</table>

Of those who were employed, 8.4% were unskilled, 10.0% were semiskilled or in service industries and 6.7% were in professional or management positions (these categories were determined using 2 independent judges).
7.1.2. Hospital experience cluster of variables

Hospital experience was ascertained to test Kim's idea that those who have been exposed to many nursing experiences are more likely to have developed a strong sense of role expectations (Kim, 1983b), particularly if that experience was recent.

Most (88.3%) had previously been hospitalised, with a range of 0 - 300 weeks, and a median of 6.0 weeks. The number of months since the last admission ranged from 0 - 360 months, with a median of 20 months. The majority had considerable exposure to nursing experiences in recent times, but as is evidenced by the range for these two variables, the sample is very variable with respect to hospital experience.

7.1.3. Prior knowledge cluster of variables

It was proposed that a less participative role in decision-making might be assumed by those who perceive themselves to lack knowledge or competence (Haugh & Lavin, 1981; Kim, 1983b), so level of prior knowledge about colostomies and their management was assessed by asking open-ended questions during the initial interview.

The first question was "What do you know about colostomies?" and the answers were categorised by two independent judges using the method outlined in section 6.8.3.1. People who had not heard the word "colostomy" but had heard of people who "wear a bag" were included in the category of those who had vague knowledge. Table 7.3 sets out the categorised responses.
Table 7.3
Level of Prior Knowledge about Colostomies.

<table>
<thead>
<tr>
<th>Categories of knowledge about colostomies</th>
<th>n</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>No knowledge, never even heard the word</td>
<td>16</td>
<td>26.7</td>
</tr>
<tr>
<td>Vague knowledge (had heard the word)</td>
<td>27</td>
<td>45.0</td>
</tr>
<tr>
<td>Considerable knowledge (looked after someone or had a stoma previously)</td>
<td>17</td>
<td>28.3</td>
</tr>
</tbody>
</table>

Clearly, the level of prior knowledge about colostomies was poor, with only 28.3% having even the possibility of sufficient knowledge to participate confidently in decision-making.

Another open-ended question asked in the initial interview was: “What do you know about how a colostomy is managed?” (See Table 7.4). Again answers were categorised by two independent judges as previously described. Only a small percentage (5%) knew of management methods other than bags and 40% had no idea how a colostomy is managed. This included the 26.7% who had never heard of a colostomy. However, about half (55%) knew that people with a colostomy wear a bag.

Table 7.4
Percentage of patients with Various Levels of Prior Knowledge about Colostomy Management Methods.

<table>
<thead>
<tr>
<th>Level of knowledge about colostomy management</th>
<th>n</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>No knowledge about any methods of colostomy management</td>
<td>24</td>
<td>40</td>
</tr>
<tr>
<td>Knowledge about bags only</td>
<td>33</td>
<td>55</td>
</tr>
<tr>
<td>Knowledge about bags and other additional methods</td>
<td>3</td>
<td>5</td>
</tr>
</tbody>
</table>

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7.1.4. Decision preferences cluster of variables

This cluster contains two variables which tie in with patients' role expectations and personal traits (Kim, 1983) and include both their expectations about the level of involvement in decisions about the colostomy and their global preference for involvement in decisions.

Answers to the question: "How much involvement do you expect to have in decisions which will need to be made about your colostomy?" not only form part of role expectations, they were also used to test the relationship between expectations and satisfaction as proposed by Linder-Pelz (1982). They test to see whether satisfaction is affected if a patient is assigned to a treatment group where they do not have the level of collaboration in decision-making they had expected.

When categorising the answers, the independent judges were asked to be careful not to confuse information seeking with collaborative decision-making. This confusion was often expressed in the answers. For some patients, receiving information was the only way they expected to "participate in decisions". Almost every patient indicated that they expected health professionals to provide them with information about their care, but over a third did not expect to have any other involvement in decision-making, including no input into decisions. Conversely, almost half (46.7%) expected to ultimately make any decisions themselves. Table 7.5. sets out the results.

Table 7.5

<table>
<thead>
<tr>
<th>Expected Involvement in Decisions</th>
<th>n</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>No involvement in the decision, most expected information</td>
<td>21</td>
<td>35</td>
</tr>
<tr>
<td>Expect information and collaboration</td>
<td>11</td>
<td>18.3</td>
</tr>
<tr>
<td>Expect information and then to make decision myself</td>
<td>28</td>
<td>46.7</td>
</tr>
</tbody>
</table>
Patients were also asked "In general how much involvement do you prefer to have in decisions which are made about your colostomy?" The mean response was 3.2 (sd = 1.42); range: 0 = no involvement, 5 = total involvement. Almost a quarter of the respondents (21.7%) preferred to have no involvement and 18.3% preferred total involvement.

7.1.5. Revised Autonomy Preference Index (API) scores

The development of this instrument was described in section 2.5 and section 6.9. Individual scores were calculated for preference for autonomy (patient to make decisions), preference for delegation (nurse to make decisions) and preference for mutuality in decision-making. As Table 7.6 indicates, the highest mean preference score was for mutuality in decision-making, followed by preference for the nurse to make decisions and then finally preference for patient decision-making.

<table>
<thead>
<tr>
<th>Preference</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse</td>
<td>3.05</td>
<td>.72</td>
</tr>
<tr>
<td>Mutuality</td>
<td>4.02</td>
<td>.76</td>
</tr>
<tr>
<td>Patient</td>
<td>2.99</td>
<td>.86</td>
</tr>
</tbody>
</table>

Range: 1 = low preference; 5 = high preference.

7.1.6. Relevant medical diagnosis

Information about the diagnosis was obtained from the medical record and verified verbally with the patient. The sample was not homogeneous with respect to this variable. Five main groups of relevant medical diagnoses were identified as having necessitated the formation of these colostomies. The largest group (40%) had primary colorectal cancer, and the second largest group (21%) had an
inflammatory bowel disease such as Crohn's disease. A group of women with gynaecological cancer which had involved their bowel accounted for another 17%. A further 10% who had their colostomy fashioned because of radiation proctitis or colitis, clearly had a history of some type of cancer (usually bladder or cervical) needing irradiation. The remaining 12% had miscellaneous reasons for needing a colostomy, including neurological problems, trauma and faecal incontinence. There was no correlation between any of these five categories of medical diagnosis and any other variable, except gender which was naturally significantly related to those in the gynaecological category.

7.1.7. Goal attainment

An essential part of the decision process is the setting of a goal concerning which method of colostomy management would be used at least until the next appointment. At the 6 week and 18 week interviews the stomal therapy nurse assessed goal attainment by asking patients to describe how they had managed their colostomy during the preceding weeks and by observing their technique. Those who did not attain their goal were asked to explain why this was so, in recognition of the fact that failure to attain a goal may be due to reasons beyond the control of the patient. At the 6 week visit 63.3% had attained the goal and at the 18 week interview this had risen to 70%.

7.1.8. Satisfaction with the decision-making method

Satisfaction with the decision-making method was treated as a linear variable and measured on a visual analogue scale where 0 = not at all satisfied and 5 = completely satisfied. At the 6 weeks interview the mean score for satisfaction with the decision-making process was 3.9 (sd = 1.4). There was a "ceiling effect" with 30% rating their satisfaction above 4.8. When the ceiling effect was noted - after the first 20 responses were processed - a letter was sent to ask patients to reassess their level of satisfaction with the particular decision-making method they had used (see Appendix Seven). Subsequent patients were also asked to make sure they had
considered their satisfaction rating carefully. At the 18 weeks interview the mean satisfaction score was 4.1 (sd = 1.3). Again there was a “ceiling effect” with 33.3% rating their satisfaction above 4.8.

The satisfaction scores at 6 weeks and at 18 weeks were highly correlated (r = 0.94; p<.01) with satisfaction scores significantly higher at 18 weeks (t = 1.91; df = 59; p <.06). To explore these differences further a difference score was computed by subtracting satisfaction at 6 weeks from satisfaction at 18 weeks. This was called “satisfaction difference”. Only 8% of patients were less satisfied with the decision-making process at 18 weeks than they were at 6 weeks, 20% had the same levels of satisfaction and 72% were more satisfied.

7.1.9. Summary description of the sample

The study sample included 26 women and 34 men with a mean age of 60 years. Most (76%) had been born in Australia. Thirty two percent had been educated beyond secondary school and the majority (62%) were not in the paid work force since they were housewives, aged or disabled pensioners. Most (88%) had previously been hospitalised. Only 28% had more than a vague prior knowledge about colostomies and 40% had no prior knowledge about colostomy management. Approximately half (55%) had heard of colostomy bags but only 5% knew of other management methods. Virtually everyone expected to be given information about their colostomy, almost half (47%) expected to make decisions themselves, and only 18% preferred to make the decision themselves. Using the API the highest preference was for mutuality in decision-making (mean = 4.02), next highest was the preference for the nurse to decide (mean = 3.05) and lowest preference was for patients to make their own decisions (mean = 2.99).

Because of the heterogeneous nature of the group described above, there is no typical population profile with which to compare this sample. For example colorectal cancer is more common above the age of 60 years, whereas inflammatory bowel disease is more common in younger people. Colorectal cancer
is more common in males whereas gynaecological cancer can only occur in women. Nor is the sample necessarily typical of the colostomy population in a large metropolitan teaching hospital, since the particular large metropolitan teaching hospital in which this study took place has specialised units for colorectal surgery, radiation oncology, gynaecological oncology and trauma. However, except for the necessary correlation between gender and gynaecological diagnoses, the variable "relevant medical diagnosis" was not related to any other variable, so it would appear reasonable to generalise these findings to other populations of people with a newly formed colostomy.

It must however be noted that the sample is somewhat selected in the sense that they had to meet inclusion criteria (section 6.5.) to ensure that they were capable of participating in all aspects of the study and of using all methods of long term colostomy management. That is, the decision had to involve a real choice, and they had to be capable of making the decision and carrying out the method selected. It will be recalled that 51.6% of the patients attended by the stomal therapy department were excluded from the study because they did not meet the criteria. This indicates that roughly half the patients with a colostomy were unwilling, unable or unsuitable to participate in the study, usually because they were too ill to participate or to use all the identified management methods.

7.2. Pretreatment differences between groups: the covariates

It will be recalled that patients had been randomly allocated to three groups, each using different decision-making methods. The Instrument Group used the decision instrument which was developed in Project 1, the Discussion Group used a collaborative discussion and the Advised Group was instructed to use a colostomy management method selected by the stomal therapy nurse.

Despite random allocation to groups there is a possibility that there are still basic pretreatment differences between the groups with respect to the independent variables. That is, although it is possible to hold the "nurse-related factors" and
“context of the situation” fairly constant, there is no way to hold the “client-related factors” constant, and these variations may subsequently affect the dependent variables of interest. Therefore multivariate analysis of variance (MANOVA) was used to make comparisons on the clusters of pretreatment variables which are the “client-related factors” (sociodemographics; prior knowledge about colostomies; experience in the hospital system; and expectations and preferences about decision-making). Any differences would identify variables which need to be used as covariates in the analyses concerning treatment effects. These analyses also identify variables which were otherwise important and worthy of further investigation. Because the overall number of patients (60) is relatively small compared with the total number of variables (13), analyses were done with clusters of variables rather than individual variables, thus maintaining the power of the analyses (Norusis, 1989).
7.2.1. Investigation of sociodemographic variables

The cluster of sociodemographic variables was subjected to MANOVA. There was no multivariate relationship among the subset (Wilks Lambda $F = 0.75; \text{df} = 8,108; \ p = 0.64$), nor was any individual variable capable of univariate discrimination among the groups. Therefore none of these variables needed to be included as a covariate. These non-significant results are in Table 7.7.

<table>
<thead>
<tr>
<th>Multivariate Test</th>
<th>Value</th>
<th>$F$ (8,108)</th>
<th>$p$</th>
<th>Univariate F Value</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wilks Lambda</td>
<td>.89</td>
<td>.75</td>
<td>.64</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age (chronological)</td>
<td>1.65</td>
<td></td>
<td>.20</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>0.17</td>
<td></td>
<td>.98</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Educational level</td>
<td>0.52</td>
<td></td>
<td>.59</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational status (working vs all other)</td>
<td>0.34</td>
<td></td>
<td>.71</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 7.7
Multivariate and Univariate Results for Sociodemographic Cluster by Group (n=60)
7.2.2. Investigation of hospital experience variables

The cluster of variables concerning experience in the hospital system was also analysed using MANOVA to determine whether there were any pretreatment differences between the groups. Results are set out in Table 7.8.

Table 7.8
Multivariate and Univariate Results for Hospital Experience Cluster by Group

\( (n=60) \)

<table>
<thead>
<tr>
<th>Multivariate Test</th>
<th>Value</th>
<th>F (4, 112)</th>
<th>p&lt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wilks Lambda</td>
<td>.99</td>
<td>.20</td>
<td>.93</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Univariate F Value</td>
<td>p&lt;</td>
<td></td>
</tr>
<tr>
<td></td>
<td>df= 2,57</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of weeks ever spent in hospital</td>
<td>.27</td>
<td></td>
<td>.77</td>
</tr>
<tr>
<td>Length of time since last admission</td>
<td>.14</td>
<td></td>
<td>.87</td>
</tr>
</tbody>
</table>

There was no multivariate relationship among the subset and no single variable was univariately significant. Neither of these variables were used as a covariate in the main analyses.

It will be recalled that the range for number of weeks ever spent in hospital was 0-300 weeks, with a median of 6.0 weeks, and the number of months since the last admission ranged from 0 to 360 months, with a median of 20 months. Because these variables had both been demonstrated to have outliers, and because MANOVA is sensitive to outliers, it was decided to reanalyse these data after removing any values which lay outside 2 standard deviations from the mean. The results of the major analysis of this chapter remained unchanged after removal of the outliers.
7.2.3. Investigation of the prior knowledge variables

This cluster of variables concerns prior knowledge about what a colostomy is and how it may be managed. An \textit{a priori} rule (see Section 6.12) had set the level of alpha at 0.1 for multivariate analyses. Using this rule, a significant multivariate relationship was evident (Wilks Lambda \( F = 2.17; \ df = 4,110; \ p<.08 \)) and warrants further investigation. The results of the MANOVA are set out in Table 7.9. below.

\begin{table}[h]
\centering
\begin{tabular}{cccc}
\hline
\textbf{Multivariate Test} & \textbf{Value} & \textbf{F (4, 110)} & \textbf{p<} \\
Wilks Lambda & .86 & 2.17 & .08 \\
\hline
\textbf{Univariate} & \textbf{F Value} & \textbf{p<} & \textbf{Std. Discrim Function} & \textbf{Structure Coefficient} \\
Prior knowledge about colostomy & 4.55 & .02 & 1.02 & -.15 \\
Prior knowledge about colostomy management & 2.42 & .09 & -.02 & .53 \\
\hline
\end{tabular}
\caption{Multivariate and Univariate Results for Prior Knowledge Cluster by Group \((n=60)\).}
\end{table}

The level of prior knowledge about colostomies is univariately significant (\( F = 4.55; \ df = 2,57; \ p<.02 \)), and likely therefore to contribute to the observed multivariate effect. Means for each group are set out in Table 7.10.

\begin{table}[h]
\centering
\begin{tabular}{llll}
\hline
\textbf{Group} & \textbf{n} & \textbf{Mean} & \textbf{Standard Deviation} \\
\hline
Discussion & 21 & 2.38 & .59 \\
Instrument & 20 & 1.90 & .79 \\
Advised & 19 & 1.74 & .73 \\
\hline
\end{tabular}
\caption{Group Means and Standard Deviations of Scores for Prior Knowledge about Colostomy.}
\end{table}
Multiple comparisons of means using the Bonferroni method (family error rate alpha = 0.05, df = 57) indicated that those who were in the Discussion Group had significantly greater prior knowledge about colostomies than those who were Advised (t = 2.88). No other paired comparisons showed significant differences.

While inspection of the univariate results (Table 7.9) suggested that the three treatment groups did not differ with regard to the second variable in this cluster - prior knowledge about how a colostomy is managed (F = 2.42; df = 2, 57; p = .09), inspection of the structure coefficients suggests that this variable is contributing most to the observed multivariate significance (coefficient .53). This may be explained by the fact that these two variables are correlated (r = .76; df = 59; p < .01) in the overall sample and are fairly uniformly correlated across the three treatment groups. The correlation is strongest in the Instrument group (r = 0.80; df = 19; p < .01) and weakest in the Discussion group (r = 0.61; df = 20; p < .01), although still demonstrating a strong relationship. Because of these results both variables were included in the final model as covariates.
7.2.4. Investigation of decision preference variables

The cluster of variables concerning preferences for decision-making was analysed using MANOVA. There was no multivariate relationship among the subset (Wilks Lambda $F = 1.32$; df = 4,112; $p < .23$). The results of the MANOVA are set out in Table 7.11, where it can be noted that global preference for involvement in decision-making ($F = 4.03$; df = 2.57; $p < .02$) and preference for the patient to make decisions ($F = 3.68$; df = 2.57; $p < .03$) differentiated between the three groups at the univariate level. The means for global preference for involvement in decision-making are shown in Table 7.12.

<table>
<thead>
<tr>
<th>Multivariate Test</th>
<th>Value</th>
<th>$F$ (4, 112)</th>
<th>$p$</th>
<th>Univariate F' Value</th>
<th>df= 2.57</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wilks Lambda</td>
<td>.79</td>
<td>1.32</td>
<td>.23</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Expected involvement in decision-making</td>
<td>2.18</td>
<td>.12</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Global preference for involvement in decision-making</td>
<td>4.03</td>
<td>.02</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Preference for mutuality in decision-making</td>
<td>1.50</td>
<td>.23</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Preference for patient to make decisions</td>
<td>3.68</td>
<td>.03</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Preference for nurse to make decisions</td>
<td>2.53</td>
<td>.09</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 7.11
Multivariate and Univariate Results for Preferences Cluster by Group ($n=60$).
Table 7.12
Group Means and Standard Deviations of Scores for Global Preference for decision-making.

<table>
<thead>
<tr>
<th>Group</th>
<th>n</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Instrument</td>
<td>20</td>
<td>3.60</td>
<td>1.14</td>
</tr>
<tr>
<td>Discussion</td>
<td>21</td>
<td>3.48</td>
<td>1.36</td>
</tr>
<tr>
<td>Advised</td>
<td>19</td>
<td>2.47</td>
<td>1.54</td>
</tr>
</tbody>
</table>

These means were subjected to multiple comparisons using the Bonferroni method (family error rate alpha = .05 and df = 57). Only one comparison reached the critical level. The Instrument group had a significantly higher mean score for global preference for decision-making than did the Advised group (t = 2.59). Therefore since the groups were not the same prior to the different decision-making treatments, this variable was included in the covariate set.

The means of scores for preference for patient decision-making are set out below in Table 7.13.

Table 7.13
Group Means and Standard Deviations of Scores for Preference for Patient decision-making.

<table>
<thead>
<tr>
<th>Group</th>
<th>n</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Instrument</td>
<td>20</td>
<td>3.35</td>
<td>.89</td>
</tr>
<tr>
<td>Discussion</td>
<td>21</td>
<td>2.97</td>
<td>.82</td>
</tr>
<tr>
<td>Advised</td>
<td>19</td>
<td>2.63</td>
<td>.76</td>
</tr>
</tbody>
</table>

These means were subjected to multiple comparisons using the Bonferroni method (family error rate alpha = .05 and df = 57). Again only one comparison reached the critical level. The same pattern emerged, the Instrument group had a significantly higher mean score for preference for patient decision-making than did the Advised group (t = 2.71). Therefore this variable was also included in the covariate set.
7.2.5. Adequacy of the identified covariate subset

Investigation of the pretreatment variables - the "client related" factors - identified four variables which differentiated between the groups. To ensure that this covariate set is adequate for subsequent analyses of the dependent variables, a MANOVA analysis was performed including all four variables identified as potential covariates. When fitted there was found to be a significant multivariate relationship among the subset (Wilks Lambda F = 2.33; df = 8,108; p<.02), and as expected, each variable demonstrated univariate significance. The results of the MANOVA are set out in Table 7.14.

Table 7.14
Multivariate and Univariate Results for Variables Selected as Covariates by Group
(n=60)

<table>
<thead>
<tr>
<th>Multivariate Test</th>
<th>Value</th>
<th>F (8,108)</th>
<th>p&lt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wilks Lambda</td>
<td>.73</td>
<td>2.334</td>
<td>.02</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Univariate</th>
<th>p&lt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>F Value</td>
<td>2.57</td>
</tr>
</tbody>
</table>

Global preference for involvement in decision-making
Preference for patient to make decisions
Prior knowledge about colostomy
Prior knowledge about colostomy management

If the identified variables are sufficient when they are fitted as a covariate set, no multivariate significance should be observed among the remaining variables. The four previously identified covariates were introduced with all the other independent variables as factors. There was no multivariate difference (Wilks Lambda F = .65; df = 18,90; p<.85) among the "discarded" variables capable of discriminating between the treatment groups. Nor was any individual variable found to be
significant at univariate testing. Results are set out in Table 7.15.

Table 7.15
Multivariate and Univariate Results for Model Fitted with Four Covariates.

<table>
<thead>
<tr>
<th>Multivariate Test</th>
<th>Value</th>
<th>F (18,90)</th>
<th>p&lt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wilks Lambda</td>
<td>0.78</td>
<td>.65</td>
<td>.85</td>
</tr>
<tr>
<td>Univariate F Value</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>df= 2,53</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>1.31</td>
<td></td>
<td>.28</td>
</tr>
<tr>
<td>Education</td>
<td>1.53</td>
<td></td>
<td>.23</td>
</tr>
<tr>
<td>Gender</td>
<td>.24</td>
<td></td>
<td>.78</td>
</tr>
<tr>
<td>Occupation</td>
<td>.93</td>
<td></td>
<td>.40</td>
</tr>
<tr>
<td>Length of time spent in hospital</td>
<td>.09</td>
<td></td>
<td>.91</td>
</tr>
<tr>
<td>Months since last admission</td>
<td>.60</td>
<td></td>
<td>.56</td>
</tr>
<tr>
<td>Expected level of involvement in decisions</td>
<td>.16</td>
<td></td>
<td>.86</td>
</tr>
<tr>
<td>Preference for nurse decisions</td>
<td>.02</td>
<td></td>
<td>.98</td>
</tr>
<tr>
<td>Preference for mutual decisions</td>
<td>1.67</td>
<td></td>
<td>.20</td>
</tr>
</tbody>
</table>

7.2.6. Summary of Identification of covariates

Multiple analysis of variance was undertaken to check for possible pretreatment differences between groups. Because of the relatively small total number of patients (n= 60) relative to thirteen variables, the analyses were done with clusters of variables, rather than with individual variables, thus maintaining the power of the analyses. Pretreatment differences between groups were identified as: level of prior knowledge about colostomy; level of prior knowledge about colostomy management; preference for patient to make decisions; global preference for
involvement in decisions. These four pretreatment variables were used as covariates in the main analyses investigating the differences in satisfaction and goal attainment between the three treatment groups.

7.3. Differences in satisfaction and goal attainment between groups

This study sought to discover whether there are differences in satisfaction and goal attainment between patients using different types of participation in decision-making? The following analyses provide the answer to this question. In this study, the dependent variables are the patients' feelings of satisfaction with the decision process and their level of goal attainment. These were both assessed at 6 weeks and at 18 weeks after the three different decision-making conditions. The analyses included the four pretreatment variables as covariates.

7.3.1. Satisfaction with the decision-making at 6 weeks

Data were analysed to determine whether there was a difference in levels of satisfaction with the decision processes between the three groups, after accounting for the covariates. When the model was fitted with the four covariates there was no significant covariate effect (F = 0.58; df = 4.53; p< .68), however, a significant treatment group effect (F= 3.82; df=3.82; p< .03) was observed. The satisfaction means, adjusted for the non-significant covariates, are set out in Table 7.16 below.

<table>
<thead>
<tr>
<th>Group</th>
<th>n</th>
<th>Adjusted Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discussion</td>
<td>21</td>
<td>4.65</td>
</tr>
<tr>
<td>Advised</td>
<td>19</td>
<td>3.53</td>
</tr>
<tr>
<td>Instrument</td>
<td>20</td>
<td>3.59</td>
</tr>
</tbody>
</table>

Multiple comparison of means using the Bonferroni method (family error rate
alpha = .05, df = 53) indicated that the Discussion group was more satisfied than those who used the decision Instrument (t = 2.551) and the Discussion group was more satisfied than those who were Advised by the nurse (t = 2.656), but the levels of satisfaction were not different between the Advised and Instrument groups.

7.3.2. Satisfaction with the decision-making at 18 weeks

Data were analysed to determine whether after 18 weeks there was a difference in levels of satisfaction with the decision-making processes between the three groups, after accounting for the covariates. When the model was fitted with the four covariates there was again no significant multivariate covariate effect (F = .89; df = 4.53; p < .48). There was, however, a significant treatment group effect (F = 5.03; df = 2.53; p < .01). The means are set out in Table 7.17. Multiple comparison of means using the Bonferroni method (family error rate alpha = .05, df = 53) indicated that the Discussion group was more satisfied than those who used the decision Instrument (t = 3.093) and the Discussion group was more satisfied than those who were Advised by the nurse (t = 2.854), but the levels of satisfaction were not different between the Advised and Instrument groups.

<table>
<thead>
<tr>
<th>Group</th>
<th>n</th>
<th>Adjusted Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discussion</td>
<td>21</td>
<td>4.83</td>
</tr>
<tr>
<td>Advised</td>
<td>19</td>
<td>3.69</td>
</tr>
<tr>
<td>Instrument</td>
<td>20</td>
<td>3.61</td>
</tr>
</tbody>
</table>

Table 7.17

Adjusted Group Means for Satisfaction with decision-making at 18 Weeks.
7.3.3. Satisfaction consistency at 18 weeks

Satisfaction scores were higher at 18 weeks for all the treatment groups (see Figure 7.1).

Figure 7.1.

*Adjusted Means of Scores for Satisfaction at 6 Weeks and 18 Weeks by Group.*
A measure of consistency in satisfaction levels was computed by subtracting the satisfaction score at 6 weeks from the satisfaction score at 18 weeks. At the 18 weeks interview the consistency in satisfaction levels was not significantly different between treatment groups (F = .51; df = 2.57; p < .60). When the four previously identified covariates were introduced into the model there was still no between group difference (F = .67; df = 2.53; p < .52).

7.3.4. Goal attainment at 6 weeks

Goal attainment was assessed by the stomal therapy nurse at the 6 weeks and 18 weeks interviews by asking patients to discuss how they had been managing their colostomy at home and by observing their management techniques to see whether they were doing what they had set out to do. At the 6 weeks interview the patients’ level of goal attainment was not significantly different between groups (F = 2.24; df = 2.57; p < .116). However, when the four previously identified covariates were introduced into the model the difference between the adjusted means of goal attainment at 6 weeks became significant (F = 3.61; df = 2.53; p < .034). That is, when we account for underlying differences between the three groups on one (or more) of the covariates the groups do differ in goal attainment at 6 weeks.

Examination of the univariate covariate effects demonstrated that the significant covariates are prior knowledge about colostomy (p < .001) and prior knowledge about how a colostomy is managed (p < .009). Preference for the patient to make decisions (p < .996) and global preference for decision-making (p < .168) are not significant. The means for goal attainment at 6 weeks, adjusted for the covariates are set out in Table 7.18.

<table>
<thead>
<tr>
<th>Group</th>
<th>n</th>
<th>Adjusted Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discussion</td>
<td>21</td>
<td>.824</td>
</tr>
<tr>
<td>Advised</td>
<td>19</td>
<td>.631</td>
</tr>
<tr>
<td>Instrument</td>
<td>20</td>
<td>.447</td>
</tr>
</tbody>
</table>

Table 7.18. Adjusted Means for Goal Attainment (Range 0-1) at 6 Weeks by Group
Multiple comparison of means using the Bonferroni method (family error rate alpha = .05; df = 53) indicated that the only difference was between those who were in the Discussion group, who were more likely to attain their goal than those who were in the Instrument group (t = 2.856).

7.3.5. Goal attainment at 18 weeks

At the 18 weeks interview the patients’ level of goal attainment was significantly different between the treatment groups (F=5.54; df= 2,57; p <.006). When the four previously identified covariates were introduced into the model there was no covariate effect (F=.50; df= 4,53; p<.73), but the group effect remained (F=4.08; df= 2,53; p<.02). Adjusted means for goal attainment at 18 weeks are shown in Table 7.19. below.

<table>
<thead>
<tr>
<th>Group</th>
<th>n</th>
<th>Adjusted Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discussion</td>
<td>21</td>
<td>.79</td>
</tr>
<tr>
<td>Advised</td>
<td>19</td>
<td>.85</td>
</tr>
<tr>
<td>Instrument</td>
<td>20</td>
<td>.46</td>
</tr>
</tbody>
</table>

Multiple comparisons of means using the Bonferroni method (family error rate alpha = .05; df = 53) indicated that the Discussion and Advised groups were not different in goal attainment, however, the Instrument group was less likely to attain their goal than either the Discussion group (t =2.496) or the Advised group (t =2.805).
7.4. Expectation and preferences for involvement

The nature of allocation to each of the three treatment groups was such that inevitably patients would expect or prefer a level of involvement in decision-making which was not allowed by the nature of the group. This mirrors life, where patients with certain expectations or preferences deal with health professionals who have different ideas and philosophies. The purpose of this section is to explore what happened when such a mismatch occurred in this study.

In the initial interview patients were asked about their expectations about involvement in decision-making, with responses ranging from “no involvement” through “collaboration” to “expect to make own decision”. It is possible then to examine the two dependent variables - satisfaction and goal attainment - within each of the three groups across levels of expectation about involvement. Preference for involvement in decisions can be subjected to the same analysis as can scores from the API.

7.4.1. The Advised group

In the advised group neither goal attainment nor satisfaction were related to expectations or preferences about involvement in decisions, nor were they related to preference scores for the API.

7.4.2. The Discussion group

There was no significant difference in satisfaction or goal attainment related to expectations or general preference for involvement in decisions in the discussion group. However, on the API scores, there was a difference in levels of preference for delegation to the nurse between those who did and did not attain their goals at 6 weeks (F=8.79; df=1,19; p<.008) and at 18 weeks (F=5.50; df=1,19; p<.03). Those with a higher preference for the nurse to make decisions were more likely to attain their goal.

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7.4.3. The Instrument group

In the Instrument group there was a significant difference in goal attainment at 6 weeks relative to expected level of involvement in decision-making (F=3.428; df= 2.17; p<.06). Those who expected no involvement had the highest mean for goal attainment, followed by those who expected a lot of involvement and those who expected some involvement had the lowest mean for goal attainment. Multiple comparison of means was undertaken using the Bonferroni method (family error rate alpha .05, df= 17). This revealed that those who expected no involvement in decisions were more likely to attain their goal than those who expected a lot of involvement (t=2.62) but those who expected some involvement were not significantly different to either of the other two categories.

In the Instrument group at the 6 week interview there was also a difference in the level of satisfaction with the decision process according to expected level of involvement (F=3.92; df= 2.17; p<.04). The means are shown in Table 7.20. Bonferroni comparisons showed that those who expected high involvement were less satisfied than those who expected no involvement (t = 2.60). Those who expected some involvement had intermediate levels of satisfaction which were not significantly different to either of the other two groups. At the 18 weeks interview however, the difference in levels of satisfaction with the decision process was not significant (F = 2.65; df= 2.17; p <.09).

<table>
<thead>
<tr>
<th>Expected involvement</th>
<th>n</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>5</td>
<td>4.60</td>
</tr>
<tr>
<td>Small amount</td>
<td>4</td>
<td>4.04</td>
</tr>
<tr>
<td>Large amount</td>
<td>11</td>
<td>2.93</td>
</tr>
</tbody>
</table>

With regard to the API scale preferences within the Instrument group there was no significant relationship between autonomy (preference for the patient to make decisions) and preference for mutual decision-making for either satisfaction or goal
attainment. However there was a relationship between preference for delegation to the nurse and goal attainment at 6 weeks (F = 9.59; df = 1,18; p<.006). Those with a higher preference for the nurse to make the decisions were more likely to have attained their goal. Similarly there was a relationship between preference for the nurse to make decisions and goal attainment at 18 weeks (F = 6.8651; df = 1,18; p<.0173), with those with a higher preference for the nurse to make decisions still more likely to have attained their goal. Satisfaction at 6 weeks was correlated with preference for the nurse to make decisions (r = 0.59; p<.01) and satisfaction at 18 weeks was correlated with preference for nurse to make decisions (r = 0.78; p<.01).

Overall, in the Instrument group those who expected to have no involvement in the decisions or who preferred the nurse to make the decisions for them were most likely to attain their goal and to be satisfied with the decision-making method.

7.5. Summary of results and answers to some research questions

7.5.1. The sample

This chapter presented the results for Project 2 which investigated some aspects of collaborative decision-making in nursing. Sixty patients, each with a newly created colostomy, were randomly allocated to three groups using three different methods to make a decision about long term colostomy management. The Instrument Group used the decision instrument which was developed in Project 1, the Discussion Group used a collaborative discussion, and the Advised Group was instructed to use a colostomy management method selected by the stomal therapy nurse.

The patients included 26 women and 36 men with a mean age of 60 years. Thirty two percent had been educated beyond secondary school, and the majority (62%) were not in the paid workforce because they were housewives, aged or disabled pensioners. Most had previously been hospitalised. Level of prior knowledge
about colostomies and their management was poor with only 28% having more than a vague knowledge about colostomies and 40% having no prior knowledge about colostomy management. Fifty five percent had heard of colostomy bags, but only 5% knew of other management methods. Although almost everyone expected to be told information about the colostomy, and almost half (47%) expected to make decisions themselves, only 18% preferred to make decisions about the colostomy themselves. The highest preference was for mutuality in decision-making, next was the preference for delegation to the nurse and lastly the preference for autonomy with the patient making their own decisions.

According to Kim's (1983b) framework (Figure 3.1.) satisfaction with the decision process and goal attainment are two outcomes of collaborative decision-making and using an adapted version of Kim's framework (Figure 6.1.) the following questions, asked at the beginning of this chapter, were investigated.

7.5.2. Were there differences in satisfaction levels and goal attainment between the three decision-making treatment groups?

Analysis of these data indicate that those who used collaborative discussion to make their decision were more satisfied with the decision process than those in either of the other treatment groups. Those in the Instrument and Advised groups did not differ with regard to their satisfaction levels after 6 weeks and 18 weeks.

The picture is slightly different with regard to goal attainment. At 6 weeks those in the Discussion group were more likely to attain their goal than those in the Instrument group. At 18 weeks those in the Discussion and Advised groups were more likely to attain their goal than those in the Instrument group. This finding was contrary to the unstated expectations of the researcher who had anticipated that the use of the Instrument would lead to greater goal attainment than advice. Fortunately the patients' perspectives were sought in Project 3 using qualitative data, and this information helps to understand the unexpected findings in Project 2. The patients' perspectives are described and discussed in the following chapter.

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7.5.3. Was there any influence on satisfaction or goal attainment apart from the three decision-making treatments?

Goal attainment at 6 weeks was influenced by prior knowledge about colostomy and prior knowledge about colostomy management. Because of this influence on the main analysis, these variables were further investigated to more fully appreciate their role.

The level of prior knowledge about colostomies was generally low. People who had no knowledge about colostomies were found in all education levels, but knowledge did increase with increased education level. The interesting feature was that people who had never heard of a colostomy before were more likely to attain the goal set, but those who had considerable knowledge about colostomies were least likely to attain the goal set (see Figure 7.2.). This seems to be a strange relationship, but can be explained when one considers that the main thing that people knew about colostomies was that people with a colostomy wear a bag. Most people who did not attain their goal had been advised by the nurse or the instrument to use a method other than just wearing a bag, that is, the advice was not in accordance with their prior knowledge. It is possible that the firmly held idea that people with a colostomy wear a bag may have inhibited some people from trying other methods suggested by the nurse or by the decision instrument. These people who selected their management goal against the advice of the nurse or the decision instrument were acting autonomously.
Figure 7.2
Bar Chart Showing Level of Prior Knowledge by Goal Attainment at 6 Weeks

Prior knowledge of colostomy management
☐ Goal not attained at 6 weeks ☑ Goal attained at 6 weeks
7.5.4. What happened to levels of satisfaction and goal attainment when patients expected or preferred one level of involvement in decision-making but were allocated to a treatment group in which that method was not permitted by the experimental design?

In the Instrument group, those who expected no involvement were more likely to attain their goal than those who expected a lot of involvement, and those who expected some involvement were not different to either of the other two categories. Those who expected a lot of involvement were less satisfied than those who expected no involvement, and those who expected some involvement were not different to either of the other two categories. Those who preferred the nurse to make decisions were more likely to attain their goal at 6 and 18 weeks.

In the Discussion group those with higher preference for nurse to make decisions were more likely to attain their goal.

In the Advised group it made little difference what the patients expected or preferred - satisfaction and goal attainment were clearly mediated by factors which were not measured in this study.

It had been hypothesised that high level collaboration (including use of a collaborative decision-making instrument) would lead to higher levels of satisfaction and goal attainment, but this was not so. Results from Project 2 indicated that although high level collaboration involving collaborative discussion and decision-making led to high levels of satisfaction and goal attainment, high level participation using a decision instrument which did not involve collaborative discussion, did not lead to as high levels of satisfaction and goal attainment as occurred in the Advised group which had low level collaboration.

In order to appreciate the reasons for these findings it is necessary to turn to Project 3 which sought the patients' perspectives on these matters and which also

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investigated Kim's other primary outcome of collaborative decision-making - the nature of the decision. This outcome is conceptualised in terms of the extensiveness, attainability and affective meaning of the decision, rather than merely the option chosen. In Project 3 the nature of the decision was explored from the patients' perspectives by analysing the themes of decision-making evident in the words of the patients during the audiotaped collaborative decision-making discussions in Group 2, and some of the 6 and 18 week interviews with those in all three groups.
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*Project 3 which explores the patients’ ideas about the different decision-making styles used in Project 2, and the nature of the decisions they had made.*

In Project 2 the outcomes of goal attainment and satisfaction arising from different methods of decision-making have been investigated. People with a new colostomy, who needed to make a decision regarding its long term management, were allocated to three groups - Instrument, Discussion and Advised - employing three different decision-making methods. They were assessed at 6 weeks and at 18 weeks to determine whether they had attained their management goal and to what extent they were satisfied with the decision method used.

The analysis of data reported in the previous chapter indicated that at 6 and 18 weeks those in the Discussion group were more satisfied and also more likely to attain their goal than those in the Instrument group. The Discussion group was more satisfied than the Advised group, but there was no significant difference in satisfaction between the Advised and Instrument groups nor was there a significant difference in goal attainment between Discussion and Advised groups.

Project 3 comprised two parts. The first explored the patients’ ideas about the different decision-making styles used in Project 2. The second part explored one of the primary outcomes of decision-making in Kim’s framework (Figure 3.1.), namely the *nature of the decision*, which is: “conceptualised not in terms of the discrete meaning of the choices made, but in terms of the extensiveness, attainability and affective meanings of the decisions” (Kim, 1983b, p. 208). These terms are defined and discussed in section 8.3.4.

8.1. The research questions

Project 3 sought to discover the patients' views in order to answer the following questions. What was it about using the decision instrument which left people in that group least likely to attain their goal and less satisfied with the decision
process? Why were those who were advised by the nurse just as likely to attain their goal as those who used the collaborative discussion method? What was it about the collaborative discussion method which made it more satisfying than the other two decision-making methods? What was nature of the decisions they had made in terms of extensiveness, attainability and affective meaning?

Although there are formal methods for undertaking qualitative research, such as ethnography and grounded theory, a decision was made not to use these approaches which tend to be fairly rule-bound (Morse, 1994) but rather to use a more creative approach through a modified form of content analysis for elements of meaning from the words of the patients.

8.2. Methodology

8.2.1. Sources of data

Data for qualitative analysis was derived from three sources: the comments on the satisfaction scale; the 6 and 18 week interviews and the transcriptions of the audiotapes made during the decision-making exercise.

8.2.1.1. Comments on the satisfaction scale

Information about satisfaction with the decision-making method was obtained from the comments which accompanied the satisfaction scale. It will be recalled that a "ceiling effect" on satisfaction scores was noted after the first 20 patients' data were analysed and more detailed comments were sought through a letter which was sent to those 20 patients (Appendix Seven). To ensure uniformity, the same request was conveyed to the remainder of the sample during their subsequent interviews. Patients were asked to make comments about the method they had used, whether it had met their needs or expectations, and whether the method used had suited them. Comments about satisfaction were written on a separate sheet with the satisfaction scale, these comments for each group were then read and reread.
many times to determine emerging themes.

8.2.1.2. The 6 and 18 week interviews

The second source of qualitative data relating to goal attainment was the answers to open ended questions asked during the 6 and 18 week interviews. Specifically, some patients were asked to explain why they had not attained the goal set during the decision-making exercise. Others were asked why they had gone along with advice given, despite having previously expressed the view that they wished to make decisions themselves.

Reasons for not attaining the goal were given verbally and recorded verbatim by the researcher. These specific comments were the data for qualitative analysis when trying to gain an understanding of how that reason fitted in with expectations and decision methods for certain individuals within the three groups.

8.2.1.3. Transcriptions of the audiotapes

Qualitative data about the decision-making process came from transcriptions of the audiotapes which had been made to determine whether collaboration had indeed taken place in the Discussion group (see section 6.4.2). The transcriptions were used to obtain information about the nature of the decisions being made in terms of their extensiveness, attainability and affective meaning. This information was used to investigate what it was about the collaborative discussion method which made it superior to the other two decision-making methods with regard to satisfaction and goal attainment. The audiotapes from the other two groups were not useful for this purpose since the experimental design resulted in them containing little input from the patients.

The transcriptions for the Discussion group were first read several times for information about the extensiveness of the decision. Relevant excerpts were typed using a word processor so they could be rearranged easily as emerging themes.
were assigned categories. Transcriptions were then reread several times to ensure no themes had been missed. The same process was repeated when looking for themes concerning attainability and affective meaning.

8.3. Results

Direct quotations from patients are written in italics, and to ensure confidentiality the names used have been altered. The results are reported as answers to the research questions for Project 3.

8.3.1. Why were patients in the Instrument group less satisfied with their decision-making method than those in the Discussion group?

Comments about satisfaction revealed that, overall the instrument had not allowed patients in the Instrument group to meet their preference for a more interactive involvement. The two themes which emerged were: *I need to tell my story in my own words* and *this is not how I make decisions*. Each of these themes will now be elaborated, using the patients’ words.

8.3.1.1. *I need to tell my story in my own words*

For Barbara, the instrument was not sufficiently personal or interactive. She wanted more collaboration and stated that it *would be better if there was more discussion with the cards*. She needed to express issues in her own way, not in a manner which had been predetermined by someone else who might not really know or understand what type of information she required.

*I understand the cards have the information that you think I need to consider to make the decision ... but I like to run things by you in my own way and this did not allow me to do that.*

She did however recognise that it was a *good way to organise thoughts*, especially the sheet with all the colostomy management methods written on it.
Randy also felt:

... it has potential ... a helpful way to organise information. But if I hadn't had a flush out (irrigation) before doing it (the instrument), I think it would have been too confusing.

He felt it would be better as: an adjunct ... complementary to the whole thing. There should be the instrument and discussion. He also wanted to express his feelings in his own way, but felt that the instrument imposed too positive a structure on the choices. In Randy's case, the instrument did not allow expression of feelings, which in his case were negative:

It gave opportunity for input but I wanted to express myself ... not just sort out cards. You need opportunity for discussion, to talk about how you feel about things. Yes, not just what you like and don't like but to voice how you feel about it all ... yes that's important ... I wanted to whinge a bit ... I don't really want to do any of these things. The instrument implies some things are OK by me, when really I don't like any of them.

Anne felt the instrument method was too impersonal and too structured ... a bit artificial. It was as though the test made the decision ... not me ... and not you. She also expressed a long held mistrust of tests (which had started with a vocational guidance test in high school) and now transferred this mistrust to this situation. She worried that the instrument method might not detect some important aspect about her particular circumstances which would have been evident if she had a chance to talk about things on a personal level. She also worried that she might have made an error when sorting the cards, and she was not sure which order was right for her. She thought it was a bit hit and miss and worried what might happen if she got the cards all mixed up.

An emerging theme in these comments was the need to chat about things, express them in their own way and own words, to give the nurse the sense of how they were feeling. They felt the instrument was not sufficiently interactive, it did not allow sufficient flow of information from them and as a consequence it did not take into account idiosyncratic aspects which the individual believed might be relevant. On a positive side, the instrument was seen as a useful way to organise thoughts.
8.3.1.2. This is not how I make decisions

Some believed that the instrument was too rational, that it was imposing a decision strategy which was too foreign to them. Indeed, it does reflect a normative position and was selected in the hope that it might assist in making better quality decisions which included all options in an unbiased manner. But some, like Ken, perceived this to be a negative aspect. He felt it was not practical because it looks at oughts and possible. He said that for him one aspect outweighed all the others. He ... just couldn't be bothered with all that fuss. He made his decision using a method called "elimination by aspects" (Tversky, 1972). In this method if there was one aspect (attribute) a person does not favour about a choice, that whole method is eliminated from the range of possibilities. He did not want to consider his utilities for all the attributes of each method. Any method which involved fuss was not considered, even if it had many benefits.

Another argued that, despite its acknowledged benefit as a good way to organise thoughts, the instrument method was imposing an unwanted structure on her decision-making. Normally she goes by her gut feelings. She did not believe that the instrument might make a better decision than her intuition which she defined as a type of unmediated perception that a particular choice was right for her.

Con felt the instrument was incomplete and should make allowances for other circumstances. He criticised the instrument for not taking into account the fact that whatever he chose using the instrument still might not work, even though he wanted it to. However, there is a disparity between his feelings and the reality of the situation. The instrument is the only method which did explicitly (by providing percentages) take into account the fact that selected methods might not work. Graham found that the explicit inclusion of the probabilities was a hindrance because if he had not known the probabilities he felt that he would have been more likely to just go ahead and try other methods.
8.3.1.3. Summary

Although most people in the study were satisfied with the decision method used, these comments indicate that some people in the Instrument group were less satisfied than the others because their decision method was not sufficiently interactive or personal for them. The instrument's structure did not allow expression of feelings or idiosyncratic aspects which the individual might consider to be relevant. For some the dissatisfaction arose because it did not allow them to use their usual decision-making strategies. If these people had been in the Discussion group there may have been opportunity to ventilate their dissatisfaction during the course of the discussion and express the feelings or idiosyncratic aspects they considered to be relevant.

8.3.2. What was it about using the decision instrument which left patients in that group less likely to attain their goal than those in the Discussion group?

It will be recalled from section 7.5.4. that in the Instrument group those who preferred the nurse to make the decisions were more likely to have attained their goal at both 6 and 18 weeks. In fact, the nurse did not make the decisions for this group as patients' had to participate by providing utilities and then the decision instrument made the decision for them.

However, many patients using the Instrument did not like the decision it made. They liked the benefits associated with the decision, but they did not like the idea of performing the management method selected. This idea is essential in order to understand why some did not aim for the goal selected by the instrument.

In the Instrument group, it was revealed that there was a significant difference in goal attainment at 6 weeks relative to expected level of involvement in decision-making, with those who expected no involvement in decisions more likely to achieve their goal than those who expected a lot of involvement. This unexpected
finding is better understood after examining the following qualitative data, where the meanings associated with "a lot of involvement" are clarified.

8.3.2.1. Involvement in decisions and the right of veto

Most of the patients in the Instrument group who did not achieve their goal had in the initial interview expressed the expectation that they would make any decisions themselves, even if it meant refusing to comply with any selected treatment they did not like. These are comments from those individuals, together with their reasons for not attaining their goal.

Con, a retired senior police officer, referred explicitly to a right of veto, which he later exercised:

*I expect to be given the options and to discuss anything I don't understand and to be able to veto anything I don't like ... otherwise I'll be advised by you people.*

Although not using the word veto, Robert and Bill both held the same expectation. Robert reflected that: ... *Basically its up to me, isn't it. He did not use the method chosen because although he liked the benefits that method has to offer ... the thought of doing it is a real turn off.* The affective response to the instrument's decision outweighed the advantages offered.

Bill stated that he would *go along with most things ...unless it was something he did not want to do.* But after using the decision instrument, he would not consider any method other than the one he was already using (that is, containment, which is the immediate post-operative methods used for all patients). For Bill, containment was *satisfactory,* his emotional response was positive, so he did not want to be confused with unnecessary information about anything else.

Olive illustrated how past experiences clearly influence expectations about decision-making. Olive was an angry elderly woman with radiation proctitis necessitating a colostomy. She was angry because she believed the doctors had talked her into having the radiation, and she declared that in future she would not
go along with anyone else's advice unless I fully agree with it. She did not comply with the instrument's decision because she was not sure she fully agreed with what it suggested.

Margaret and Harry had both experienced long illnesses and each had previously had a temporary ileostomy. As a result of her experience and knowledge Margaret expected total involvement. To the extent that she stated adamantly: I'll do it my way. Harry announced that although he expected to be told what is happening, he would make his own decisions - I decide what I'll do, thank you! Neither used the management method selected by the decision instrument because both wanted to use containment, the method which most closely approximated their previous ileostomy management. Margaret felt that it would be simpler to stay with the method she already knew, notwithstanding the fact that she could have made things more convenient. Harry believed that because the colostomy could be managed with another bag he already knew enough about it all.

8.3.2.2. Summary

Patients who used the decision instrument were less likely to attain their goal because the instrument sometimes made a decision which they did not wish to take. Although the instrument ascertained their utilities in a general sense, they were unwilling to implement the management method selected. Some felt that the decision made using the instrument was not really theirs. Some who had expressed a desire for "a lot of involvement" in decision-making indicated that total involvement sometimes included non-compliance with a decision they felt was not theirs or which they did not like.
8.3.3. Why were those who were advised by the nurse just as likely to attain their goal as those who used the collaborative discussion method, even though they were not as satisfied with the decision method?

Although those in the Discussion group were more likely than those in the Instrument group to attain their goal at 6 and 18 weeks, there was no significant difference in goal attainment between those in the Discussion and Advised groups. However, the goal attainment in the Advised group seems unexpectedly high when one considers that in the initial interview some patients had expressed a preference for involvement in decisions, but because of the study design they had been dictated to by the nurse. Patients were more likely to follow the nurse’s advice than the advice of the decision instrument, notwithstanding the instrument was devised by nurses.

Patients in the Advised group were specifically asked why they had attained their goal and been fairly satisfied despite the fact that they had not been given the opportunity to participate in the decisions. To a large extent, the answers indicated goal attainment was tied in with confidence in the nurse which developed over the whole period of interaction, not just during the decision exercise. Furthermore, because the advice was effective, they had continued with it and been somewhat satisfied. Perhaps things would have been different if the outcomes of the advice had not been successful. Patients’ comments were used to understand this situation.

8.3.3.1. Confidence in the experts

Matthew, a retired labourer, had expected to be more involved in decisions, but wrote that he had no complaints about being advised because the nurse:

*seemed to know a lot about it and, more importantly what she told me to do worked. If it hadn’t I'd have come back and asked her to sort out something else for me.*
Rachel, a middle aged shop assistant made it quite clear at the initial interview that she would not be forced into anything. She did not mind being advised about what to do but if it was something I really hate(d) I just wouldn't do it. At the 18 week interview she was continuing with the advised method because she was happy with how things had progressed and added: if I wasn't you'd hear!

It is noted that in the Advised group there was a tendency for patients to expect to have to refer back to the nurse for guidance or advice if changes needed to be made, rather than sorting it out for themselves. The advice method, despite goal attainment and satisfaction, was associated with ongoing dependence on the nurse for decision-making over the long term.

8.3.3.2. Being given reasons for the advice

The level of satisfaction in all groups was frequently ameliorated by the quality of the relationship which had developed between the patient and the nurse. Indeed, even when people were shown that being advised by the nurse was clearly contrary to their stated preferences for autonomy or mutuality in decision-making, they sometimes defended the nurse for giving advice. For example, at the initial interview Lillian, a registered nurse, had stated that she expected full involvement and to be given all the choices, but instead of this, she was not given all the choices, she was advised to try irrigation and plugs. When interview she was questioned about her feelings about being told which method to use she replied that she was quite happy.

You actually told me that I can do that (irrigations and plug) but you were not that forceful with it ... you said well this is the thing for you because you'll be out there working ... blah blah blah. It's going to be more manageable and probably more appropriate for your lifestyle. But you sort of said it in a way ... like because you had reasons why it would be better for me, and how it would suit me. So it was not sort of pushed on me. That's why I didn't mind you telling me what to do.

The fact that the nurse gave reasons for the advice was important and contributed to compliance. As Mervyn, a retired butcher, explained:

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You have to have confidence in the experts - they know more about it than I do. They’ve done courses and have experience.

So he would listen to their advice, but if I had a problem with doing something I’d want to know their reasons for telling me to do it.

Nurse-given reasons seemed to rationalise and justify the apparent inconsistency of accepting advice without input despite having previously expressed an expectation of more involvement in decision-making.

8.3.3.3. The role of nurse advice

Janene also defended the nurse for advising her despite preference for autonomy. Janene reasoned that it was her post-operative mental state which had made the decision difficult. I was feeling pretty low at the time and I didn’t know what I wanted to do anyway.

Despite indicating in the initial interview in response to the API that they wanted to participate in decisions, some patients later revealed that they felt they were ignorant about what to do with the colostomy and needed to be told what to do. For example, Ellen’s management method failed, but she was not dissatisfied with the method of decision-making, since it was not the nurse’s fault that the method selected had not worked. When it was explained that whether or not the advice worked was a different issue to her satisfaction with the decision-making process, Ellen said she was satisfied with receiving advice because she had not known what to do and at least the nurse had given her some place to start. Likewise Betty who explained that she:

was glad, only too glad to be told. Because I didn’t know anything about it, so I didn’t know what to do or say.

The nurse’s manner helped, she was, so nice and kind ... talked and explained it to me.
The inconsistency of being happy to be advised despite generally preferring involvement was explained in several other ways. Hilmer claimed it was due to advancing age: *I put myself in their hands. You have to have faith. If I were a younger man I might want to make different choices.* But Tom, a tradesman in his early thirties, felt it had nothing to do with age, but was related purely to the expertise of the nurse: *I just leave it up to the nurse. I don't like people telling me how to do my job so I don't tell them either.* David, a young disc jockey, explained that, *at that time I was more interested in surviving ... in walking out alive and not being addicted to pain killers.*

Although in the initial interviews these people had a general cognitive commitment to making their own decisions, their priorities were different immediately post-operatively. David was glad of advice so he could focus his energy on more important matters. He was the only one to allude to the effects of the analgesics and other drugs. He felt they had altered his thinking and that he probably couldn't have made a good decision anyway.

8.3.3.4. I wanted to discuss what the choices meant to me

Another shortcoming of the Advised group's decision method, was that it did not allow people to express unusual experiences or reasons for wanting or not wanting to use various methods. The best illustration of this came from a young paraplegic man who did not comply at all with the advice he was given. Because he had a long history of chronic constipation, it was the nurse's opinion that irrigations would help him considerably. Before discharge from hospital he learned to do the irrigations, but he never used the method at home. At the 6 weeks interview he explained that before his accident he had been an enrolled nurse and had once had to administer an enema to an elderly man. He was asked whether he felt that experience had made him feel negative about enemas, and his answer indicated that his sentiments went far beyond this. Thinking about the enemas had made him think deeply about his whole situation:
You know instead of being the nurse looking after the patient, I'm the patient being looked after by the nurse, and you know, its just... something that you should get used to... but I don't think I ever will... I'll never ever accept it!

So the thought of using the irrigation method had stirred up thoughts and emotions which had not been able to be expressed at the time of the decision because there was no opportunity for discussion. The affective meaning of the decision can be quite unusual, unexpected and powerful, and needs discussion. This seems to be a major disadvantage of the Advice and Instrument methods for decision-making.

8.3.3.5. Summary

Patients were more likely to follow advice from the stomal therapy nurse than to use the method chosen by the decision instrument and this is related to confidence in the nurse's expertise, the manner in which the advice was given, and the quality of the relationship which had developed during all their interactions, not just the isolated decision-making episode. When questioned about the discrepancy between their preferences as stated in the initial interview and their comments after the decision was made, patients were ready to defend the nurse giving advice, claiming that they needed direction because they were old, ignorant or in a poor mental state at the time of making the decision. The overwhelming justification for continuing to follow the advice and to be somewhat satisfied was the fact that the advice was successful.

In those instances when the advice was unsuccessful, the patients returned to the nurse for further advice. The Advised decision method tended to foster this type of dependence. More than any other group they did tend to expect to have to come back to the nurse if changes needed to be made, rather than experiment with different methods independently. It was as though the nurse, in directive mode, had assumed ongoing control of future decisions somehow consequent upon this one.
8.3.4. What is it about the collaborative discussion decision making method which made it better than the decision instrument for satisfaction and goal attainment?

In this section, attention will be focussed on the positive characteristics of the discussion method. The relative success of the Discussion method arises from the high level of collaboration which enhances the nature of the decisions made. These terms - extensiveness, attainability and affective meanings - will now be defined and discussed. Thematic analysis of meaning of issues raised in the discussions allows insight into these aspects of the nature of the decisions for the Discussion group to demonstrate why the discussion method was the most effective in this study.

8.3.4.1. Extensiveness of the decision

Extensiveness refers to the scope of the decision - it tells us how far-reaching is the resolution which has been made. In this instance the scope ranged from decisions which kept management strategies as simple as possible to decisions which involved a combination of almost all possible colostomy management strategies. The decision to use containment was commonly made on the basis of keeping things simple, whereas complex strategies such as combinations of diet, medications and intermittent irrigations, were developed by those who expected problems and wanted contingency plans. Several themes emerged from the analysis of the transcripts of the audiotapes of the Discussion group. These were categorised broadly as decisions which aimed to keep things simple, and those which went beyond simplicity.

8.3.4.1.1. Extensiveness : keeping things simple

Sub-theme 1: Avoiding complicated management strategies

The most common theme to emerge was that of decisions being made on the basis
of deliberately keeping things simple to avoid complex management strategies. Often patients asked no questions about the more complex management methods, notwithstanding their obvious ability to use them. For example, Frank, a 76 year old retired precision tool maker builds intricate working models of machinery as a hobby. Despite his obvious manual dexterity and intelligence, he stated plainly that he wanted to do ... the simplest thing that will do the job properly. Those whose bowel management had always been uncomplicated assumed that colostomy management would likewise be a simple matter. Max, an 80 year old retired butcher, expressed this assumption when he commented:

_I've never had any problems in the past, this all came out of the blue. It all sounds a bit complicated. I think I'll just wear the bag and see what comes of it all._

Similarly Aldo, a retired labourer, chose dietary control because he reasoned that it is: _easier to just control your food._

Sometimes the desire for simplicity was based on past experience. For example, some patients had previously had a temporary ileostomy, a surgical procedure not unlike a colostomy, which can only be managed by wearing a bag. In this study, all but one of those who had previously had an ileostomy chose containment, the method which most closely resembles ileostomy management. Barbara argued:

_I really can't see myself spending all that time. I mean the ileostomy worked all day long, and it wasn't a bother, so I can't imagine that this will be either. I'd rather just get on with things._

This idea of _getting on with things_ was a recurring theme, made clear by Iris a 70 year old woman who still runs a cake decorating business. She dismissed dietary control because:

_I wouldn't want to ... unless it was, you know, very important ... to become a slave to diet. I wouldn't want too much interference. I think it becomes ... uh ... you become too aware of it. I've always done without being a slave to things. I'm a practical person and I just want to get on with my life._
When it came to discussing irrigations, she was worried that just as an enema enters the body, so the ritual of the procedure might enter her life and somehow take over, consuming too much of her time and efforts, making her unnecessarily conscious of her altered body function so that she was hindered in getting on with things in her life.

I don't think I'll do the irrigations. It's very invasive I think, isn't it? I mean I can see practical uses for it. I mean if people were travelling or not wanting to be bothered, you know. But I can't see that for me. It's too invasive, and too time consuming, and drawing too much attention to your condition. I don't want to be any more aware of it than I have to be.

Neither did she want to become one of those women who regale their friends with tales nor one of these people who are popping pills or carrying on. She wanted life to go on as nearly as possible as it had before.

Another aspect of the theme about keeping things simple concerned the belief that because bags were the most commonly used method of colostomy management, they were therefore the simplest option. This is illustrated by Jack, a 53 year old unskilled worker who selected bags because they were good enough for most people, and added that he considered himself not fussy. Lola, a housewife in her sixties, was one of several people who specifically asked: What would most people do? She based her decision on the assumption that because most people used the bags that must be the best or the simplest method. She added that she is not a fiddly person. It seems that methods other than containment were seen by some to be fiddly and fussy and a lot of unnecessary bother.

Sub-theme 2: Being natural

Another theme which emerged was the desire to keep things simple in the sense that they were basic and in particular natural. This included letting the bowel work to its own timetable, and if that failed, then using laxative foods rather than medications. Harry, a 66 year old retired labourer announced:
I don’t like stopping it from, you know, from coming out when it should come out, see. I think when it has to come out it should come out. But I do believe in prunes.

And Ken, a 46 year old furniture removalist, stated that attempting control by medications had no appeal to him because he could not see why one should try to control the bowel:

I think that’s the main part of the function, you go to the toilet when your bowel tells you to. I don’t think that you should be trying to override nature. I’ve got 46 years when I haven’t controlled my bowels ... so why bother now!

Ken was not alone in this view. Murray, a 33 year old painter who had suffered multi trauma in a motor vehicle accident had required a colostomy because of paraplegia and perineal tissue damage. The colostomy had been fashioned before he developed bowel problems, so his expectations were that bowel management could and would be as simple and natural as it had been in the past. In fact, despite his unnatural circumstances he was adamant that things be kept natural. He said he had gone off tablets since he had been in hospital and would rather just let nature take its course. He believed that: It’s totally unnatural to control your bowel. It should work when it needs to. He was asked whether his view would change if the colostomy acted at inconvenient times, but answered that if the bag is on it does not really matter, his works all the time and nobody else knows. He could not understand why anybody would go to so much trouble to do something which is completely unnatural. He reasoned that although he did not like his colostomy he did not dislike it enough to bother going to all that fuss. During his illness he had come to realise how important the body is and did not believe people should fiddle around with it unnecessarily. And that (irrigation) is bloody unnecessary!

Likewise Dennis, a 47 year old teacher who had both a urostomy and a colostomy, stated he would not agree to use medications regularly because he does not believe in pill pushing and trying to manipulate the body, because the body does a marvellous job on its own. Neither would he attempt dietary control because it
would take all the fun out of life. He also felt that irrigation was too much unnecessary fuss when:

... a bag is not a problem at all. It hangs down in between your legs there (indicates)... and even if it has some material in it ... I mean no one would know. Its no drama. I don't see why anyone would want to go to all that trouble. They should leave mother nature doing her job.

Looking natural or normal, especially looking normal to other people, was mentioned frequently. The notion that nobody else knows occurred during several of the 6 week and 18 week interviews. It was mentioned as a way of rationalising the decision to use containment. Carol, a 58 year old shop assistant who had a colostomy fashioned because of radiation proctitis, described her experience after 18 weeks when she had returned to work. She felt nobody had noticed her colostomy and she was an advocate of doing things naturally:

*I just think it works all right as it is ... If anyone at the shops has noticed it, they haven't told me. If I thought it wasn't working right I'd just eat some cabbage and that'd make it work right away.*

8.3.4.1.2. Beyond simplicity: covering all contingencies

Not everybody was motivated to keep things simple. A number of individuals made decisions specifically to cover all possible contingencies. In the analysis two sub-themes emerged. The first included those whose bowels had been difficult to manage pre-operatively, and the second included those who needed to make changes so the colostomy fitted in with their lifestyle. Examples will now be given for the extensiveness of decision-making in each of these types of decisions.

Sub-theme 1: Accommodating difficult bowels

Those for whom bowel control had been a complicated procedure pre-operatively were the most ready to devise an extensive plan with in built consideration of most possible contingencies. For many years Roger, a 22 year old with spina bifida,
had complicated bowel management. He had ingested large amounts of laxatives and spent weekly sessions having enemas, disempactions and manual evacuations. He asked that his mother be included in the discussion since she usually had to do all the mucky stuff.

Together they decided to try irrigations twice weekly, if that was not effective by itself he would continue to take the laxatives. If the irrigations worked, with no accidents in between, he would try the plugs. He enjoyed his food and was willing to alter his diet unless absolutely necessary, and he did not want to commence irrigations until after he had attended a forthcoming week long camp with his peers. All of this was planned before he left hospital, and before he even knew how his new colostomy was going to function. Because of their past experience, Roger and his mother had an expectation that the colostomy management would be complex, but did not consider their contingency plans to be too complicated because they offered the possibility of bowel control being easier, less messy and less time consuming than bowel management had been prior to surgery.

Wendy, now 46 years old, had become quadriplegic following polio vaccination as a child and provides another example of someone trying to cover all contingencies when making a decision about colostomy management. She confided that she deliberately ate very small amounts of food because she feared becoming too heavy for her aging parents and others to move her. Her colostomy was made to facilitate bowel care, but she anticipated that her old problem of constipation would continue. She refused to eat more food or to change the type of food eaten, but she did agree to take a fibre supplement and drink extra water each day. She decided she would have the home nurse do the irrigations regularly twice a week.

Sub-theme 2: Accommodating lifestyle

Some individuals had to think carefully about their usual lifestyle and how it would affect their colostomy management. This was illustrated by Robert, a 56 year old
council worker living on a farm. Robert's decision was extensive, not because his bowel management had ever been complicated, but because he felt his work circumstances might make even the simplest of colostomy management methods too difficult. Added to this, he was committed to keeping bowel management as normal as possible, even if it meant major changes to his lifestyle.

He would not consider control of the colostomy using drugs because: it should just happen normally. Then he described his circumstances at work as a labourer and truck driver, and the difficulties he would have changing his appliances. Always dirty from manual work, they had to rely on public toilets which were often filthy, vandalised or locked. He could not imagine trying to change a colostomy bag in such circumstances. He was advised that using the irrigation method should overcome this problem, as he could deal with his colostomy at home and then would not have to worry about it during the rest of the day. However, he was still greatly concerned because he believed the bowel should work when it wants to work.

After careful consideration of his situation he thought that he might retire from his council job and spend more time running his farm because then he could just go home when I needed to and suit my own schedule. He commented that he was thinking this way because of his age, he was ready for semi-retirement. Then he revealed his thoughts about the ultimate contingency:

They might not've taken all the cancer. I might still die. They haven't got the results back from the operation yet. ... But I've got to start trying to sort out in my mind what I could do if various things happen, and what I can't and won't do too!

At the 18 week follow up he was using the containment method. His extensive decision had resulted in the simplest possible management method, but he had retired from his council job, and was gradually increasing his work around the farm. Despite these major changes in his life he stated that colostomy management had been no problem.
Another example of an extensive decision to accommodate lifestyle was that of Gary, a 50 year old business manager with recurrence of rectal cancer, who had previously had a temporary ileostomy. He commented that with the ileostomy there were no management options, one could only wear a bag and empty it as required. He was pleased that with a colostomy he now had choices of management strategies. He still intended to continue to run his business and had a busy social life, including boating during the weekends. He believed that irrigation had the best chance of allowing him to continue these activities with as few interruptions as possible. He thought carefully before he made his decision:

I am a person of control ... I am almost certain to go down the irrigation path, but I would like to stabilise myself prior to doing any further changes. If that (irrigation) works, then I'd like to try the plugs.

Gwen, a 40 year old mother of two young children, also decided on an extensive contingency plan which had the potential to involve several management options so that she could resume working. She decided to use the bags first and experiment with diet. She did not want to resort to drugs unnecessarily:

If I can’t get it down to one change during the day time I’ll try the enemas ... I don’t want you to show me them now, I’ll come back for that if I need to. I’ll need to get it right before I go back to work. (Laughs) I’ll probably stay at home ‘til I’m confident it is OK.

Peter, a 34 year old paraplegic had suffered considerably from chronic constipation, including an episode which precipitated autonomic dysreflexia and resulted in him being admitted to an intensive care unit. He lived independently, but with some community nurse assistance. He expected he would need medications for his bowel, but was interested in the irrigations so he could deal with constipation if the laxatives failed. He saw it as a method to help me not to have to come to hospital. For him it was a way of increasing his independence.

8.3.4.1.3. Summary

Through dialogue, the members of the Discussion group were able to explore the management options and to select a method to suit their beliefs and detailed needs,
many of which were known only to themselves. When considering the extensiveness or scope of the decisions made, the most common idea to emerge was that of deliberately keeping things simple. This included two sub-themes: decisions which specifically avoided complicated management strategies and those which allow things to remain as natural as possible. For others the decision was comprehensive in order to cover all contingencies such as a difficult bowel or an unusual or busy lifestyle. There was such a range of circumstances, beliefs and needs, that without discussion it may have been difficult to select an appropriate method.

8.3.4.2. Attainability of the method chosen

Attainability refers to whether people are able to reach the goal set when a decision is made. In this case it refers to whether patients could successfully use the selected method of colostomy management, either straight away or with effort and practice. Those who clearly did not have the intellectual or physical ability to use all the methods had already been excluded by the study criteria at the time of the initial interview. Even though many were elderly they were fit enough to live independently and manage all other aspects of daily living and ought to have been able to manage all the methods of colostomy management.

A great advantage of being in the Discussion group was that patients had the opportunity to assess and discuss attainability as part of the decision process and thus air their concerns before selecting a method. Management methods believed to be unattainable were not selected, so generally speaking, once patients in the Discussion group had made their decision they tended to stay with the method selected. At the 6 week and 18 week interviews, people generally stated that there were no problems or that they were coping well.

During the discussions, management methods were not considered attainable if the individual felt the method would not work for them, or they were not able or not willing to use that method. Only one person in the Discussion group dismissed a
method by saying No, not for me! Knowing my bowels, it will never work. I wouldn’t put my wages on that one! There were however, people who felt they could not or would not attempt various methods. In exploring this aspect, three sub-themes emerged: I couldn’t do that; maybe I could do that; and maybe I could do that ... later.

8.3.4.2.1. I couldn’t do that!

Some people disclosed unapparent physical reasons which made certain methods difficult. One man with arthritis in his right thumb, chose containment as the simplest ... the best when it comes to hands. He felt it would be a struggle for him to use the flow controller on the irrigator and said he would only consider using it if there were exceptional circumstances because he simply did not think that he could do it.

More common were those who had psychological reasons for not attempting certain methods. Gerald, a 72 year old invalid pensioner did not think he could use dietary management because he liked his food and drink too much, and Anne suspected that she also did not have enough willpower.

Although some had a cognitive appreciation of the benefits of various methods of management, this was not matched by their emotional stance. They did not feel they could cope with some methods on an emotional level, thus such methods became unattainable. When John was told about irrigations he said I don’t think I could. After being reassured that he would be given full instruction and supervised practice he revealed:

I don’t mean that, I could do it. I saw what you did to me, but I don’t think I could do it to myself ... Honestly ... I know I couldn’t ... wouldn’t do that to myself. I’d rather eat any sort of diet or take any number of pills than do that. I couldn’t!

These sentiments were echoed by June, a 69 year old housewife who said: I like the results, but I couldn’t do it to myself. Similarly Doris, a retired barmaid liked
the idea of how it works, but did not like the idea of giving it to myself.

This discrepancy between cognitive and emotional evaluations of various methods was greatest for irrigation and plugs. Several people indicated that they found their intrusive nature daunting and did not feel they could insert the irrigation cone or the plug into their colostomy. For some the problem was the physical penetration of the devices: I don't like putting plastic things inside my body. Another asked: Do I have to put that white thing in very far? I don't think I could do that!

One young woman described how in the early post-operative days she was unable to even watch her bag being changed by the nurse, so when it was suggested she might try irrigations she replied adamantly:

I can't see myself putting that thing anywhere near my colostomy. I don't even use tampons! ... I think I'd be too ... (grimaces) ... to try anything like that.

For others the physical intrusion of the cone was compounded by the fact that the lengthy procedure would be an intrusion on the normality of their life. As mentioned previously, seventy year old Iris decided:

Its too invasive, and too time consuming, and drawing too much attention to your condition. I don't want to be any more aware of it than I have to be ... I just don't think that I could do it. I wouldn't do it.

Several proposed their age as a major factor for not attempting irrigation. They either thought that they would not be able to manage it physically, or they felt it was too much effort when their lifestyle was such that they were usually at home most of the time. One argued:

... not at my time of life. If I was working and more active ... I don't think I could do it.

But others who were working and were more active had a different reason to believe they could not do some methods. They felt they were too busy and could not fit the extra time into an already packed schedule. Terry, was a 60 year old bank manager involved in various community activities and committees at night.
He selected containment because his business lunches and dinners made dietary measures impractical, and he felt he simply did not have the time for irrigation:

*Time, the inconvenience of time. Work is already hard enough, without having to get up at say ... if you’re leaving home at seven ... to get up at half past five in the morning to do ... THAT! To hell with it, I’ll put up with what I’ve got.*

It can be seen that although a few people had physical reasons for not being able to use some management methods, the majority of reasons were psychological or emotional and included such things as weak willpower, strong aversions and feelings that particular methods were invasive, inappropriate to their lifestyle or impractical for them to use.

8.3.4.2.2. *Maybe I could do that*

Some people who thought they could not use particular methods had changed their minds by the time of the 6 week or 18 week interviews. Ken, aged 47 had initially refused to try anything other than containment and then had several embarrassing accidents. At the 6 weeks interview he asked to hear about the other methods again.

*So maybe I’ve just got to change my bloody attitude! ...Well you think that you know it all, but uh, it might not be so. You think you can’t or won’t do things but maybe you can and should!*

Similarly, Phyllis aged 40, believed she would not be able to use the irrigation method. However, when she returned to work using the containment method she found that her colostomy frequently acted at inconvenient times making embarrassing noises. By the 18 week interview she was using irrigation successfully.

Charles, who will be discussed more fully in the section about the evolution of more positive feelings, was initially horrified at the idea of irrigations, *Oh! I couldn’t handle that! Oh! No way!* But by the 6 weeks interview he had decided to try them and by the 18 weeks interview was using the method intermittently.
Others just kept delaying, putting off making any commitment to any particular method of management. People were unsure of whether the method was attainable, how they would cope, and how their bowel would react. They wanted to wait and see. This was despite being advised that their bowel activity was fairly certain to revert to the basic premorbid pattern. They were all ages, and in all types of living situations. A young mother decided to wait and see... you know... how it goes. And an elderly retired man said: we'll leave those things down the track a bit. A 64 year old taxi driver asked if he could take it step by step? And an 80 year old, retired clerk pondered:

_It's something to think about... I'm not ready to decide on anything yet... I don't know yet because I haven't had time to give it a great deal of thought and I'd need to think a lot about that one. This is the simplest. You keep giving me all the information and if I want to change in the future I'll know what is available._

Arthur, a 70 year old retired salesman, did have a contingency plan. He would only use the enemas if the diet didn’t work, because: _It's easier, and I'm new to all this. Later when I get a bit more... I might feel like trying something else. I've got the options now, and the opportunity to try something else if need be._

The fact that people did not change, usually meant that the initial method was successful, as explained by Aldo, a 71 year old retired manual worker:

_Oh yes, I know about enemas. In Europe people use this method a lot, even without this (points to colostomy). But if I learn and I can do it this way (using bags) and it's simple, why would I bother with this one? Why would I wish to complicate the situation?... I didn't ever really have to think about all of this before. Now I'll just have to wait a couple of months and see and then I'll make the decision. I'll try this one first (bags and diet) and then that one (irrigation) and then I'll make the decision._

At the 6 weeks visit, he had not tried the irrigations, and he never did because he said he felt it was unnecessary.
John, a 51 year old Maltese cleaner was one of the few to wait and see and then proceed with the next step. During the initial decision-making discussion he asked, Can I wait until I come to that bridge? He wanted to learn about all the methods including the irrigations, so he was taught in hospital and had all the equipment when he was discharged. At the 6 week follow up visit he said:

I haven't been using the ... drainage ... because I don't ... I haven't really needed it, you know? Because as soon as I eat, one pushes out the other.

He was also the only person to describe himself not proceeding because he was lazy. At the 18 week follow up visit he said he had tried irrigation a few times but it was time consuming, and at times frustrating. He described how:

one day I lay on the bed, I thought, I'll wait till it all comes out, so I lay there for about an hour. And nothing came. As soon as I put the bag back on it all came! And I get cranky because I've done all that and then I still have to do it twice.

8.3.4.2.4. Summary

This section on attainability refers to whether or not people felt they could successfully use the various methods. Three sub-themes were identified: I couldn't do that!; Maybe I could do that; and Maybe I could do that ... later. Patients revealed more psychological than physical reasons for believing that they could not use various management methods. Emotional responses played a great role in determining what they believed they could do. Personal preference and motivation also played a role. Some wanted to keep with the post-operative method the staff had instituted, thereby delaying the need to make any decision themselves. Regardless of their reasons and regardless of whether their beliefs represented reality, those in the Discussion group tended to attain the goal set, because their collaborative discussion had allowed them to identify and avoid selecting methods they believed to be unattainable.
8.3.4.3. Affective Meaning of the Decision

The affective meaning of a decision refers to those feelings evoked in the individual making the decision by an appraisal of the choices being discussed. In this context the patient is in a situation involving the threats posed by severe illness, surgery, changes to anatomy and physiology, and altered body image. The nature of the situation and the decision being made also focus attention on a subject normally taboo in general conversation. These factors all lead to the potential for strong emotional responses. It is not surprising that the feelings expressed covered a wide range, including shock, disbelief, nervousness, worry, disappointment, annoyance, resentment, fear, hatred, and revulsion during the initial making of the decision. At later interviews the feelings had generally become more positive. Although some expressed regret at making a poor choice, most felt happy, contented, enthusiastic, optimistic and even proud of their achievements.

Although a wide range of different types of affect were identified in the transcriptions of the audiotapes, and the subsequent interviews at 6 and 18 weeks, there was often only one example of each. However, three main sub-themes emerged and they had a type of chronological order. Anxiety and fear were often present in the early stages and when discussing things which had not yet happened. Once things had happened or been experienced there were strong feelings of aversion but eventually there was an evolution towards more positive feelings as people worked their way through their feelings, discussing and evaluating them. It was fortunate that there was access not only to the transcriptions of the discussion group, but also to the 6 week and 18 week interview notes, since without them this evolution would not have been noticed.

This section mainly considers data from the Discussion group. Those in the Advised and Instrument groups did not have opportunity to express their feelings during the initial decision process, indeed this was one of the identified shortcomings of those methods. The first two sub-themes look at the affective meaning of decisions made by those in the Discussion group, and how they
described or expressed them at the time of the decision when the audiotapes were made. However, at the subsequent interviews some from the Advised and Instrument groups did refer back to how they felt at the time of making the decision and some of that information is used in the third identified sub-theme.

8.3.4.3.1. Anxiety and fear

During the decision process some spoke of feeling nervous or anxious and could not identify exactly why they felt this way. But fear was the most commonly expressed feeling, and mainly involved a general fear that they would not be able to manage the colostomy. Typical comments were: I'm afraid I'll make a real hash of this; I'm just scared of the whole thing; I can't put my finger on it but I'm afraid of it.

Sometimes the fear was localised to some particular aspect of the decision or proposed management methods. When Brenda was shown the irrigation method, she said nothing, grimaced and shook her head. But when she saw the plugs she asserted: No way I'd wear that tampon! I'd be scared it'd get stuck and never come out! This fear was shared by others. An even greater number were scared the plugs would fall out at embarrassing moments. And Doris, an elderly retired barmaid had her own particular worry:

... it's too much like plugging up a sink or something. (Laughs)... and I think perhaps anything at all could happen while you are plugged up. You could have something go wrong and its plugged in and you know nothing about it until you pull the plug out.

A middle aged woman who still works as a registered nurse spoke of how her fear stemmed from her negative experiences with colostomy patients during her nursing practice.

That was my biggest fear of my life, when I first learned that there was such a thing as colostomy patients .. and oh ! Wow to ever have a colostomy! Horrific isn't it! And here I am! I hope I can manage it nursing wise and practical wise. Mentally sometimes I get a bit uptight about it. I’m scared of it and I hate it ... I really hate it!
In this sub-theme people expressed their feelings of worry or concern about imminent danger or difficulty in relation to their colostomy and the decision about its management. For some it was generalised anxiety or a fear of the unknown aspects of a new situation which had not yet been tested, but for at least one patient it was the return of an old fear based on things she had seen and learned in the past.

8.3.4.3.2. Strong feelings of aversion

A feeling of hatred of the colostomy and all the management methods was common, particularly during the first few days. This was strongly illustrated by Vera, a 62 year old housewife who cried intermittently when discussing the management options, stating that she hate(s) it all. "It's all as bad as the rest. I hate it all." She commenced with bags and used medications as necessary, but could not control the colostomy. She refused irrigations because she found them disgusting. Such feelings of disgust and repulsion were fairly common. Joan, a 74 year old pensioner was so overwhelmed by the whole idea of having to manage the colostomy that she just wanted to withdraw from the decision: "I just feel like going to bed and never getting up again."

Some people implied that they felt dirty and referred to dirt in the bag rather than calling it faeces. Others were more direct. At the 18 weeks interview one said:

> I can honestly say that I really felt dirty ... I like the irrigation, although its time consuming, it makes you feel lovely, fresh and clean.

Some people were shocked at the methods available. They had never imagined such things existed, let alone anyone suggesting that they might need to perform such acts upon themselves. Molly, a 68 year old housewife, stated loudly:

> No! No way! I'm afraid I do have some very definite ideas about these things!

Others were shocked, but not so vocal. These included June, a 60 year old
housewife. When the containment method was described she merely looked aghast, shook her head and then looked at her lap silently.

In this section we explored the strong feelings of aversion which were expressed when people considered methods of management which they strongly disliked or were unwilling to try. Confronted by something they found loathsome, some tried to withdraw. Others strongly refused on the basis of their dislike of the whole situation. These strong negative feelings were most common in the early post-operative period.

8.3.4.3.3. The evolution towards more positive feelings

Generally speaking, over time emotions became less negative. The experience of living with the colostomy decreased their initial strong aversion. The colostomy did not go away and they needed to confront it and deal with it. This evolution of expressed feelings is traced in many individuals.

At the 6 week interviews people from the Instrument and Advised groups were given an opportunity to discuss their feelings during the follow up interviews. Some reflected on their feelings about the choices they had made and words such as annoyed, disappointed and cranky were used. One man spoke of his embarrassment due to the selection of an inappropriate method, and another spoke of regret at not making a better choice during the decision-making exercise.

In a way I'm sorry. Because I had a few accidents... thinking back, I would have been able to irrigate. Had I realised how much better it is I'd have irrigated at night. Because we're late people, we stay up late anyway. So it wouldn't be anything to irrigate say at half past ten at night.

But at 18 week interviews most people were expressing far more positive feelings when they appraised their situation and how they were managing with the method they had selected. This is typified by Dennis who said It's no drama at least 5 times during his interview. Another observed that, life's too short to be worrying
about little things like that.

At the 18 weeks visit Con, a 60 year old retired senior police officer, confided that initially he was resenting the fact that he had the colostomy and had to make such decisions but then he realised that without it he would have died. He started to consider himself a lucky fellow and after that had no problems adjusting to or managing his colostomy.

At the 6 weeks interview Phyllis, aged 60 stated that she had begun to feel more confident, and Heather was quite proud of her achievements. I'm OK. I'm fairly impressed with how I've been managing. Its not really a hassle. Arthur, aged 70, was feeling comfortable ... I'm managing that part a lot better than I expected. At the beginning I felt I wouldn't manage, but that has been OK. Frank also felt that after 6 weeks he was handling it all pretty well. The bags ... and in my head.

Charles, a 60 year old retired businessman, had a urostomy for 17 years before requiring a colostomy due to radiation proctitis, so he was used to seeing a stoma on his abdomen and used to changing a bag. However when it was suggested that he might like to try irrigations he responded with shock.

AAGH! Oh my goodness! I wouldn't like that! I couldn't! I couldn't do that anyway! Oh! I couldn't handle that! Oh! No way!

Interestingly, by the 6 week follow up he had decided to try the irrigations and was instructed on an outpatient basis. By the 18 week follow up he was quite optimistic, although he confided that he still had some worries.

I hope that it works out because see then I can go out and not have any problems ... I get a bit concerned, I get a bit worried about it. ... It doesn't frighten me now. It did frighten me at the start, of course.

The nurse expressed surprise that he had been frightened, despite having had a urinary stoma for 17 years. He replied that he had been frightened when he first had to manage that too. He was not sure why, although he accepted it now, it had taken a long time to stop worrying about it.

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Mary, a 50 year old cashier in a licensed club, also expressed a range of emotions while she was making the decisions. Initially she confessed she was essentially very nervous about doing the whole thing. When irrigations were mentioned as an option she was quite apprehensive about her ability to manage and her dislike of the procedure, but stated that, If I really, really have to do it I would do it ... but if I don’t really absolutely have to do it I would prefer not to. As she progressed through the options she indicated she was becoming resigned to the fact that some things would have to be different. Concerning diet and medications she said, well if its got to be its got to be. But she selected containment because she felt more comfortable with it and reasoned ... isn’t that generally what people do? I’d like to just do what most people do... nothing special. At the 6 week follow up she admitted how terrified she had been, but could not identify exactly what she was terrified of. However, by the time of the 18 weeks follow up she confided that she was: ... feeling a lot better than I did ... you know ... and I know there is a light at the end of the tunnel.

David, a 30 year old disc jockey with Crohn’s disease spoke of his feelings immediately before the operation.

Everything was out of control. I couldn’t do much ... Spending 24 hours a day on the lounge, sleeping in maybe 20 minute spells for a total of maybe 2 hours per day. I was just existing ... I wasn’t living ... just existing.

During the decision-making exercise he stated that he would try drugs, if it (colostomy) needed it. That would put me in control. At first he did not want to try irrigations because he was scared he might damage something by poking around there. But he changed his mind by the 6 week visit and wanted to learn irrigation. By the 18 week follow up he had mastered the irrigation method of management and thought it was wonderful. I was in control ... Yes! Control! And this was very positive feeling for him because of his previous circumstances.
8.3.4.3.5. Summary

Although initial feelings were mainly negative, people generally appreciated the opportunity to discuss these feelings and in many people an evolution towards more positive feelings could be traced over the 18 week period. Not only did the discussion help people to select an appropriate method, the discussion also had a therapeutic effect since it allowed people to work through their feelings about the management options available.

8.4. Discussion and conclusion

In Project 2 people with a newly fashioned colostomy, who needed to make a decision regarding its long term management, were allocated to three groups - Instrument, Discussion and Advised - employing three different decision-making methods which systematically varied the level of collaboration. The analysis of data from these groups indicated that at 6 and 18 weeks those in the Discussion group were more satisfied and also more likely to attain their goal than those in the Instrument group. The Discussion group was more satisfied than the Advised group, and there was no significant difference in satisfaction between the Advised and Instrument groups, nor was there a significant difference in goal attainment between Discussion and Advised groups.

Project 3 explored the patients' perspectives. This involved analysis of reasons for goal attainment or non goal attainment, as expressed in the 6 weeks and 18 weeks interviews; patients' comments on satisfaction with the decision-making methods as expressed at the time of completion of the satisfaction scale; patients' comments from the transcripts of audiotapes made during the collaborative discussions. This analysis was deliberately kept as simple as possible and involved a straightforward content analysis for elements of meaning which were then organised into themes as they emerged from the data and based as much as possible on the logic of the patients.
Project 3 therefore was able to be used to provide answers to questions arising from the results of Project 2. What was it about using the decision instrument which left patients in that group least likely to attain their goal and less satisfied with the decision process? Why were those who were advised by the nurse just as likely to attain their goal as those who used the collaborative discussion method? What was it about the collaborative discussion method which made it more satisfying than the other two decision-making methods?

Patients in the Instrument group were less satisfied with their decision-making than patients in the Discussion group. Some commented that the Instrument was not sufficiently personal or interactive, and this led to diminished satisfaction with the decision-making method. They identified problems they had with the level and style of collaboration which had been imposed on them by the instrument. For some it seemed too unnatural and tended to make different decisions to the ones they thought they would have made if left to their own decision strategies. Patients in the Instrument group were also less likely to attain their goal than those who made their decision using a collaborative discussion. Because they did not wish to take the decision made using the instrument, some exercised their right of veto, reclaimed decision-making autonomy by setting and later seeking a goal of their own choice.

Patients in the Advised group were less satisfied, but just as likely to attain their goal, as those who used the collaborative discussion. Patients were more likely to follow the advice from the nurse than the advice from the instrument, despite the fact that the instrument was designed by nurses. According to the patients, this was related to the quality of the relationship with the nurse which contributed to confidence in the nurse’s expertise so they felt positive about the manner in which the advice was given. Some reported the importance of being given reasons for the advice. However, satisfaction was lessened by the lack of opportunity to express feelings and ideas. Generally speaking, many patients in the Advised group were happy with the situation and instead of viewing it as parentalism, they interpreted it as a delegation of decision-making.
Overall the collaborative discussion method was the most effective for increasing satisfaction and goal attainment. In the Discussion group the high level of collaboration allowed the participants to structure the decision as they wished, provided the nurse could contribute ideas considered important. Through dialogue they were able to identify and explore the extensiveness, attainability and the affective meaning of choices before selecting a goal. Although many patients' feelings were initially negative they had usually changed to more positive sentiments by the 18 weeks visit. This method of decision-making led to the highest levels of satisfaction and goal attainment. Autonomy was replaced by mutuality.

It was disappointing that the decision instrument was not as effective as had been expected. However, the analysis of qualitative data presented in this project made it clear that the instrument is still potentially useful, but it needs to be used in conjunction with discussion. Another possibility is that it needs to include other attributes for consideration, such as feelings about inserting objects into the stoma.

It must be noted that the use of the instrument in Project 2 was to some extent contrived in the sense that discussion was purposely disallowed. The research design allowed participation - the giving of utilities by the participants - without discussion. This was done to test whether the notion of “talking it over” which Smith and Garko (1994) had incorporated into their concept of mutuality, was indeed an integral part of collaborative decision-making. Certainly for these participants such “talking it over” interaction was crucial. In terms of Kim’s framework (1983b), the research design was limited in the nature of the decision because participants were unable to express and explore their perceptions of the extensiveness, attainability and affective meanings of the decisions.

There were elements of each of the three decision-making methods which were identified as useful to patients when making their decisions. In an ideal situation the patient needs information and a structure for the decision process, these can easily be provided by a decision instrument, and were appreciated by many of the
patients interviewed in this study. But there is also a clear desire for people to be able to discuss issues from their own perspective and using their own words, and to override the decision of the instrument if it cuts across some aspect which is important to the individual.

From this qualitative data it became clear that there is also a case for patients having the option to solicit advice in relation to the decision in circumstances when they feel unable to understand or process information being presented. This ties in with ideas proposed by Righter (1995) who explored issues relating to uncertainty during an ostomy experience and the role of the stomal therapy nurse. She proposes that the stomal therapy nurse acts as “a credible authority” who has the expert knowledge and potential to facilitate patient coping by using individualised education, counselling and support (including support with decision-making) to construct a sense of order and predictability for both patient and family.

In this thesis, three different decision-making methods were deliberately used in as pure a form as possible in order to determine how those methods compared with each other. On the basis of the meanings which have surfaced from the qualitative study, a further study is now warranted, combining the features of each method which have been identified as contributing separately to satisfaction and goal attainment.
CHAPTER NINE

in which the study is reviewed and there is discussion of its findings and how they may be applied in nursing practice

Nursing has been criticised for practising from a traditional rather than a research-based foundation, yet many “grand” nursing theories and their related research projects contribute little to clinical nursing because of difficulty in applying their findings to the immediate questions which challenge practice (Gray, 1994). This is not to say that such “grand” theories are not important. They have the potential to shape how we view nursing, and perhaps in altering our perspective, to allow us to see things which were previously hidden. However, in order to advance nursing practice, there needs to a balance between research which influences how we view nursing on a “macro” scale and that which influences how we view practice on a “micro” scale.

This study sought to strike such a balance. It investigated a persistent, important situation which arises in the daily practice of stomal therapy nurses as they assist patients with newly formed colostomies to make decisions about which long term management method they will use - in terms of the above argument this is the “micro” scale. This study investigated the problem within a collaborative decision framework (Kim, 1983b) which had been structured from a perspective derived from a “macro” view of nursing as a partnership (Christensen, 1990).

Some may say this is a complex way to look at a seemingly simple situation, but nursing practice is becoming increasingly complex. This is due in part to changes in the nature of illness and its treatment, and to the rapid expansion of health care technology and information. There have also been changes in the nature of working relationships between patients and nurses in the direction of working partnerships.
In this partnership context, patients and their carers are increasingly called upon to participate in decisions about their care. The patient is depicted as “an expert in the particularisation that is himself” (Stevens, 1979, p 216), but who may not have the relevant “facts” or experience in the matter under consideration, and who is often feeling stressed at the time when nursing care decisions need to be made. The nurse is seen as an agent, facilitating the patient’s work of decision-making, communicating information pertinent to the patient’s problem, and using communication strategies to collaborate and negotiate with patients. The notion of patients and nurses having separate but complementary work is an assumption underlying the present study.

Because Kim’s (1983b) framework for collaborative decision-making in nursing focusses on a specific aspect of that complementary work it is used as a framework for Project 2 which investigated the effect on satisfaction and goal attainment of three different types of decision-making. Kim proposed that when the patient and nurse enter into the partnership to make a nursing care decision they are influenced by their individual contexts which include role expectations, knowledge, personal traits and their own definition of the situation. How these two individuals interact is also influenced by the context of their situation which includes the organisation of decision-making in that particular place and the type of nursing care decision which is being made. The combination of individual and situational contexts leads to a level of collaboration which at its lowest level is characterised by complete domination of decision-making by one party (usually the nurse) and at its highest level is characterised by both parties equally influencing the decision-making.

9.1. The aims of the study

This study explored aspects of decision-making in nursing practice. In Chapters 2 and 3 a review of literature about changed working relationships between patients and nurses raised questions about the way decision-making might be enacted within those relationships. Do patients prefer autonomy, delegation or mutuality when making decisions about their care? What happens when patients expect or
prefer one type of participation in decision-making, but find themselves in a situation where that type is not permitted or encouraged?

Although Steele et al. (1987) proposed that patient participation in decision-making has not been demonstrated to effect clinical outcomes as measured from the health care professional’s perspective, this study concerned the outcomes from the patient’s perspective. Are there differences in goal attainment and satisfaction with decision-making between patients using different types of participation in decision-making?

Work using Kim’s framework for collaborative decision-making in nursing suggested that collaborative decision-making is not common in usual practice and Kim proposed that this might be because there are no institutionalised ways for nurses to include patients in decisions or because nurses may not know how to include patients in decisions. This raises the question of whether an institutionalised process, such as a decision instrument, would facilitate collaborative decision-making between patients and nurses? Would a simple technique such as card sorting be practical or effective as a means of obtaining relevant patient and nurse input into decisions in the early post-operative period?

9.2. Overview of the three Projects

The unique contributions of this study arise from the three component projects which were used to answer the above questions. It is not intended to review all the findings of the three projects since they are detailed in the body of the text. However, some critical aspects will be described and discussed to identify how they make a significant contribution to existing knowledge in various fields, and how the findings may influence future nursing research and nursing practice.

These three projects make unique contributions to existing knowledge in several distinct fields. The literature review in Project 1, essential to the development of the decision instrument, contributes to the understanding of stomal therapy nursing
practice by systematically considering and organising current knowledge about long term colostomy management and also by identifying gaps in current knowledge which need further research. Projects 1 and 2 both contribute to knowledge in the field of decision theory through the development and use of a card sorting technique to elicit utilities of people usually unable to participate in decision analysis because of the difficulty of thinking clearly after major surgery. Project 2 contributes to the understanding of collaborative nursing practice and the understanding of outcomes of collaborative decisions. This new knowledge builds on and extends previous work in these areas. Projects 2 and 3 contribute to knowledge about patient preferences for participation in decision-making, an area which has previously been developed in the health communications literature. Projects 2 and 3 explore issues related to patient satisfaction and its measurement. Each of these contributions will be described and discussed more fully within the context of the relevant project.

9.2.1. Project 1: development of the decision instrument

Studies concerning collaborative decision-making in nursing indicate that although nurses generally recognise that patients have much to contribute to decisions about their own care, collaborative decision-making is not evident in usual practice.

Decision theorists (Carroll & Johnson, 1990; Fischhoff, 1983; Schwartz & Griffin, 1986) have advised that the best way to increase the patient’s role in decisions is to use techniques known as decision analysis which require the professional to define and structure the problem, identifying attributes which might be relevant when making the decision, and the probabilities of each attribute occurring with each of the possible outcomes. The patient needs to determine their utilities - individual preferences for particular outcomes. This information is then combined using a formula which usually maximises utilities to make the decision.
9.2.1.1. Review of Project 1

This project involved the development of a formal decision instrument based on a simple multiattribute rating technique (Edwards, 1971), to be used in the early post-operative phase of the patient's stay in hospital. This instrument requires the nurse to present research-based information relevant to the problem, to structure the problem and then take the patient through a process of sorting a series of cards, thus ranking and rating the attributes under consideration in order to clarify patients' utilities. This information is then used within the decision instrument to make the decision and set management goals. This instrument is a new application for decision theory in an area which has previously been considered impractical because usual techniques for eliciting utilities are too abstract and too difficult for most patients to use immediately post-operatively.

The development of the instrument involved an extensive literature search to identify currently and locally available methods of long term colostomy management. These were termed outcomes: containment, training the bowel, constipating diet, regular medications, trial and error diet, irrigation, intraluminal plugs and any combination of the above. Further review of the literature identified attributes, characteristics of the management methods which might cause a person to select or reject that method. The attributes include aspects relating to wearing a bag which at times may have faeces in it, dietary modifications, having time to care for the colostomy either intermittently or in periods of about 40 minutes, having occasional accidents, having control over bowel function, inserting a device into the colostomy, taking regular medications and others.

A Delphi technique, involving 5 expert stomal therapy nurses and 10 patients, was used to verify the outcomes and attributes and to make the instrument more "user friendly" by reducing the number of items for consideration and expressing them in a way which reflected the users' perspectives.
Literature was analysed to calculate the *probabilities* of the individual being able to successfully manage the colostomy using the various methods, and then the expert nurse panel was used to verify these probabilities and to estimate probabilities wherever there were none available in the literature. A pilot study was carried out and evaluated and the instrument amended accordingly. The instrument was then used as one of the two methods of collaborative decision making in the second project.

9.2.1.2. Contribution of Project 1

The instrument is unique in that it systematically considers “taken for granted” aspects of lifestyle after colostomy formation. During the process of developing the instrument, the literature review uncovered deficits in knowledge about possible outcomes for those with a colostomy. It was disappointing to discover that although there was a large amount of anecdotal and prescriptive information about strategies for colostomy management, there is a relative dearth of precise research based information. Although there have been studies comparing various methods of colostomy management they have had major flaws in their design - no control groups, no clear operational definitions, and too strong a reliance on retrospective assessments.

The literature review revealed several ongoing debates about colostomy management. The notion of “bowel training” was taken for granted in some of the literature but disputed elsewhere and caused considerable discussion among the members of the Delphi group. This notion warrants close and controlled scrutiny. There was controversy concerning the role of diet, with some proposing that diet made no difference, some advocating a “constipating” diet, and others advocating a “trial and error” approach. There was also debate about how patients should be educated about diet. Some proposed that everyone be warned about potential problem foods, while others felt patients should be left to work things out for themselves. There was further controversy about whether medications should be used regularly, and about the types considered useful.

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The use of irrigations was the method about which there is the most published systematic study. However, despite accumulated data suggesting it to be the most advantageous method, it is still not the most widely practised, with only 7% of members of the NSW Colostomy Association using it in 1997. Some writers (Stuart, 1972) have suggested that this is because the method is not offered to people on a regular basis. However, in Project 2, all methods were systematically offered in an unbiased manner to all patients, and still only 17% selected irrigation. Reasons patients gave for not selecting irrigation included the effectiveness and comparative convenience of modern appliances, and the fact that many of the patients were at an age when they spent much of their time at home, so having control of the timing of their bowel actions was not a major issue. Although they appreciated the benefits of the irrigation method, these benefits were not aspects of particular importance in their circumstances. Some indicated that the procedure was repulsive to them, others indicated that it was too much fuss when containment might achieve as good a result or they did not like inserting things into their body (interestingly this attribute had been eliminated during one of the Delphi rounds, but may need to be reintroduced if the instrument is further developed).

While decision analysis aims to select the apparent best alternative, the development of the decision instrument led to an assessment of knowledge about the subject and found it to be inadequate. There is a need for properly designed prospective studies which focus on various ideas about “training”, diet, medications, bowel actions, irrigation and appliances to develop a more precise information base so that nurses can confidently provide more reliable information about the probabilities of outcomes after colostomy surgery.

The literature review and the Delphi technique both identified the role played by beliefs and values of expert stomal therapy nurses, particularly in relation to ongoing debates about the use of diet, regular medications, and the irrigation method. The beliefs and values held by nurses need exploration, open discussion and either verification or challenging because they influence management decisions, particularly in situations when patients are not given opportunity to
collaborate or when patients choose to delegate decision-making to the nurse.

This is the first time a card sorting technique has been used to elicit utilities in a direct manner. It was proposed as a practical means for a situation in which patients in the early postoperative period might not be able grasp more sophisticated or complex strategies because of their particular circumstances so soon after major bowel surgery. When implemented, the method was found to be useful. No person was unable to rank and rate the attributes at the time of the exercise. Overall it seems to be a successful method for eliciting utilities in the post-operative period, and this is a major step forward involving the application of decision analysis in a practical nursing context.

9.2.2. Project 2: an assessment of satisfaction and goal attainment after using three different decision-making methods

The concept of working partnerships, with the nurse as an agent, facilitating the patient’s work of decision-making by communicating relevant information and using techniques such as decision analysis, discussion or advice giving, gives impetus to the second project in this study.

9.2.2.1. Review of Project 2

Three modes of patient-nurse interaction - decision analysis, collaborative discussion and advice giving - are investigated to determine their relative merits in contributing to satisfaction and goal attainment.

This Project validated and extended Kim’s framework for collaborative decision-making in nursing, by adapting it and using it in a prospective experimental design. In the adapted version the level of collaboration became the independent variable and this was effected by allocating sixty patients to three groups with differing methods of decision-making - Instrument, Advised and Discussion. The nature of the decision, and patient outcomes such as goal attainment and
satisfaction become the dependent variables which were assessed at 6 and 18 weeks. Attempts were made to keep the nurse-related factors and the situational factors constant, and to statistically deal with the client-related factors (through covariate analysis) so that more could be learned about the effects of different levels of collaboration on goal attainment and satisfaction. Those who used collaborative discussion to make their decision were more satisfied with the decision process than those in either of the other two groups. The picture was slightly different with regard to goal attainment; those in the Discussion and Advised groups were equally likely to attain their goal, and significantly more so than those in the Instrument group.

9.2.2.2. Contribution of Project 2

This Project makes a contribution to knowledge about collaborative practice in nursing through exploring three possible roles of the partners and the effects of these varying levels of collaboration on patient outcomes.

Project 2 also makes contributions to stomal therapy practice by exploring patients’ prior knowledge of colostomies and their management, which was found to be low. Patients with no knowledge about colostomies were found in all education levels, but as education increased the percentage of patients who had some knowledge increased. Those who had some knowledge almost always expressed it using the term “wearing a bag”. In fact the term “colostomy” seemed to be synonymous with “wearing a bag”. Many patients never spoke of “colostomy” without adding the word “bag”, for example: “my uncle had a colostomy bag”. It was a foregone conclusion that people with a colostomy also had a bag. Even those who had heard of a colostomy bag usually had no ideas about how it might look, or how it might function. These findings point to a great need for education of the general public to develop their understanding of this subject.

In Project 2 expectations about level of involvement in decisions influenced goal attainment but this depended on the group allocation. It will be recalled that
patients were randomly allocated to the groups, irrespective of their previously stated expectations and preferences concerning involvement in decisions. In general, preference for involvement was related to expectations about involvement in decisions. That is, patients generally expected what they preferred. When they were allocated to a group in which they did not experience the level of involvement in decision-making that they expected and preferred, patients sometimes reclaimed their decision-making autonomy and did not try to attain the goal set during the decision exercise. When their expectations and preferences were congruent with the groups allocation, they did not reclaim autonomy.

These findings are consistent with the work of Bennett et al. (1995) who used a grounded theory approach to investigate patients’ perspectives in decision-making and proposed a model of mutuality in decision-making which they state “arises out of and feeds back into a background of patient expectations” (p.5). They proposed that if there is poor information exchange in relation to the individual’s expectations, this influences the amount and quality of mutuality in decision making and may lead to reclaiming of autonomy.

The finding that those in the Discussion group were most satisfied with the decision method used is also in agreement with the work of Bennett et al. (1995). Their informants indicated that the critical process affecting decision-making was the exchange of information. That is, they recognised that information ought not to be merely dispensed by the health professional, but that it needs to be a two directional flow. They identified themes of information exchange which included the provision of options, some indication of how a decision might be reached (a decision trail), and the incorporation of a holistic view of the patient as a person. Although members of all three groups in Project 2 received the same information about colostomy management methods, in the Advised group that flow of information was one way, from the nurse to the patient, and in the Instrument group the information from the patient to the nurse was structured and may not have been interpreted by the patient as representing a holistic view. Although the instrument considered utilities, it did not take feelings into account. The
collaborative discussion group alone used a method which fulfilled all the criteria for satisfactory information exchange (as described in Bennett et al.'s 1995 model) and it is this which was explored in Project 3.

9.2.3. Project 3: exploring reasons for differences in satisfaction and goal attainment

This third Project was undertaken to ascertain the patients’ perspectives on the three decision-making methods and their ideas about the nature of the decisions made.

9.2.3.1. Review of Project 3

The patients’ perspectives concerning the decision-making methods and the nature of the decision made helped to answer certain questions which had arisen in Project 2. What was it about using the decision instrument which left people in that group least likely to attain their goal and less satisfied with the decision process? Why were those who were advised by the nurse just as likely to attain their goal as those who used the collaborative discussion method? What was it about the collaborative discussion method which made it more satisfying than the other two methods?

These questions were answered using a modified form of content analysis, searching for elements of meaning which were sorted into emerging themes.

Thematic analysis of comments indicated that patients in the Instrument group were less satisfied with that decision method because it was not sufficiently interactive or personal. Its structure did not allow expression of feelings or idiosyncratic aspects which the individual might consider to be relevant, nor did it allow patients to use their usual decision-making strategies.

Patients were more likely to follow the advice of the nurse than that of the decision
instrument and they attributed this to confidence in the nurse's expertise, the quality of the relationship which had developed during their interactions and their beliefs that they needed direction because they were old, ignorant or in a poor mental state at the time of making the decision, and the nurse was a credible authority. The overwhelming justification for continuing to follow the advice and to be somewhat satisfied was the fact that the advice was successful. When the advice was not successful patients tended to return to the nurse for further help rather than to try to solve the problem independently.

The collaborative discussion method was considered to be more effective than the decision instrument for satisfaction and goal attainment. To gain insight into the reasons for these findings, Kim's (1983b) concept of the nature of the decision being reflected in its extensiveness, attainability and affective meaning was used as a framework for thematic analysis. The extensiveness referred to the scope of the decision. Through dialogue, patients in the Discussion group were able to explore management options and make a decision appropriate to their beliefs and detailed needs, which were often unusual and revealed only through the discussions. Attainability referred to whether they felt they could successfully use various methods. A great advantage of the Discussion method was the opportunity afforded to assess and discuss attainability openly, and to raise concerns before selecting a method. Patients revealed more psychological than physical reasons for believing they could not use certain methods. Emotional responses, personal preferences and motivation all played a role. Compliance with the goal set during the decision exercise was high because the discussion had allowed them to identify and avoid selecting those methods they believed to be unattainable.

The affective meaning of the decision referred to the feelings evoked in the individual by their appraisal of the choices being discussed. Fear of failure to cope with the management methods being discussed was the most commonly expressed emotion. Other initial feelings were mainly negative and included disgust, repulsion and hatred of the options offered, as well as shock, resentment, annoyance and disappointment at finding themselves in a situation where such
decisions were necessary. However, patients generally appreciated the opportunity to discuss these feelings and at later interviews the feelings had generally become more positive and many felt happy, contented, enthusiastic, optimistic and even proud of their achievements. Those not in the Discussion group did not have the opportunity to express these feelings during the initial decision process, indeed this was one of the identified shortcomings of those other two decision methods.

At this stage, it is relevant to mention the notion of autonomy. In this study the level of collaboration was an independent variable, determined by the group allocation. An assumption had been made that the level of autonomy had been determined in the same manner and would parallel the group allocation. This was not found to be the case. Patients in the Instrument and Advised groups who did not like the decision made for them reclaimed their decision-making autonomy by setting and later seeking a goal of their own choice. This was consistent with the work of Bennett et al. (1995) who found that the only situations in which patients reclaimed decision-making was when the doctor-patient interaction and information exchange was unsatisfactory. For some, this situation arose because the decision method employed was foreign to them or did not cater for some idiosyncrasy. This aspect highlighted the need to encourage discussion and a two way flow of information, even when the rational choice seems fairly obvious to the health professional. The patient is the expert on him/herself, and must be given opportunities to reveal what they consider to be relevant aspects.

9.2.3.2. Contribution of Project 3

The major lesson from this Project was the importance of information exchange as a two directional process. Mutuality was selected as the most popular patient preference, regardless of its mode of implementation through group allocation, but the treatment group which included discussion was clearly the most successful collaborative mode.

"Talking it over" was found to be an integral part of mutuality, despite the fact that
there are other ways of extracting relevant information from individuals. Patients in the Instrument group were less than completely satisfied because the instrument was not sufficiently interactive or personal. Its structure did not allow expression of feelings or idiosyncratic aspects which the individual might consider to be relevant.

Project 3 makes a unique contribution to knowledge about collaborative decision-making in nursing by looking at measurable outcomes from the patients' perspective. In other studies reduction in clinical factors such as anxiety (Fortin & Schwartz-Barcott, 1987) or analgesic use (Bringsjord et al., 1987) are investigated rather than the patients perspective which involves feelings about the nature of the decision.

Patients were more likely to follow advice from the nurse than from the decision instrument and this was found to be related to confidence in the nurse's expertise, the manner in which the advice was given and the quality of the relationship which had developed during all their interactions, not just the decision-making episode. These findings are consistent with the work of Smith and Garko (1991) who proposed that decisions are not isolated acts and that context is an important determinant of the way in which a decision process is enacted. The findings also concur with Bennett et al.'s (1995) work which concluded that: "Mutuality is an outcome nested in the situation and context of particular relationships" (p.14). It seems that the relationship between the nurse and the patient may be more effective in contributing to goal attainment than a rational structured presentation of possible outcomes, their attributes and probabilities. This aspect warrants further discussion.

It was only through the collaborative discussions that patients were able to present their ideas about the attainability and affective meanings of the decisions. Those who used only the research based criteria outlined by the decision instrument, made a choice which seemed optimal to the nurse but may have seemed suboptimal to the patient because it may not have incorporated an aspect which was important
to them. In developing the decision instrument in Project 1, great care was taken to include only those studies which were deemed "scientific" as opposed to prescriptive, anecdotal reports. But once the patients in Project 2 were exposed to this carefully selected, modified and structured information they frequently chose not to treat it in a similarly scientific manner. Rather, they allowed their emotions and beliefs to dominate the ways in which they treated incoming information. The Discussion group was the only truly "patient-centred" approach, because it had enough flexibility to allow the patients to mould the decision process to suit themselves, whereas each of the other two methods provided a predetermined structure based largely on the views of professional nurses.

The decision instrument was grounded in rationalism (the practice of treating reason as the basis of belief and knowledge), based on the assumption that people should want to maximise their utilities and choose whatever is "best" in a rational sense. The approach was essentially cognitive. Although the decision instrument asked patients to prioritise utilities, it elicited this as a cognitive function as distinct from emotion and volition. The patients were not asked how they felt about the various methods, neither were they asked whether they were motivated to use them. The collaborative discussion group was the only one to transcend the cognitive aspects with affective means of dealing with the decision, and this was clearly more satisfying for the patients because it was more in tune with their way of knowing and dealing with information when making decisions. The challenge then is to devise ways of combining the professional's role of providing information with the patients' ways of dealing with it. Clearly the collaborative discussion process has an important role in such activities since it is a major way of discovering the patients' reality and their agenda. Perhaps different attributes, which accommodated these notions, could have been developed for the instrument.
9.3. Emerging Themes

Several overarching themes emerged from the analysis of the three projects comprising this thesis. They include ideas about rationality and the quality of decisions, emotions and feelings, and a focus on how decisions are made. Each will now be discussed briefly.

9.3.1. Rationality and the quality of decisions

It is difficult to judge the quality of a decision. People often call something a “good” decision if the outcome is “successful”, but the same outcome can be achieved through the toss of a coin as through vigilance and careful consideration of options. To judge the merit of a decision on the outcome ignores the process. One finding of this study is that the process of decision-making is very important.

It was acknowledged at the beginning of this study that people tend not to have good decision-making skills, but it was thought that this was because they lacked the knowledge and strategies to improve them. This was why the decision-making instrument was devised, to show patients how to deal more comprehensively with all the known information in an easy way. Why? Because rationally speaking that is how the best quality decisions are made, by considering the widest range of possibilities, taking into account the probabilistic nature of decisions, and not being biased.

From the perspective of health professionals, this is a logical approach. The importance of health professionals supplying accurate information about health care is an undeniable part of their job. It is also important that they know enough about how decisions are made to be able to assist people who seek such help. However it is clear from this study that the imposition of unwanted decision strategies can be counterproductive. Why did the Instrument group have the lowest level of goal attainment and satisfaction? Clearly, it was something to do with the process. The Instrument was giving patients the opportunity to participate, but was
based on assumptions about rationality which many of them did not share.

It seems that many decision makers are not rational. People have diverse motivations which do not contribute to the maximisation of utilities. This instrument lacks the facility for the individual to make an emotional response and this was the type of interaction that many wanted. The “talking over” was more important to them than having specific relevant input into the decision in the form of prioritising their utilities. Patients wanted to describe their feelings about the options. Why was this so important? What is it about feelings that makes it important to express them to others?

9.3.2. Emotions and feelings

Because patients made it clear that they often wanted the opportunity to express their feelings in their own words, it is necessary to reflect on emotions and feelings and the role they play in making decisions.

Feelings are the phenomenological experience of emotion. As the name suggests, feelings are tied in with bodily processes, and yet they are intuitive and personal. One cannot really know how another person is feeling unless they communicate somehow, for example with spontaneous gestures, body language or words. These ways of communicating feelings were observed with many of the participants interviewed during this study. To communicate one’s feelings verbally requires a deliberate appraisal of them. This appraisal triggers off affective memories and the replaying of emotions. This was illustrated by the young paraplegic man who was reminded of his past life when he was giving, not receiving enemas. The recollection reminded him how much he hated his current situation. His response to irrigation as an alternative management method was emotional.

Insights into the role played by the expression of feelings can be gained from the work on emotions by Crawford, Kippax, Onyx, Gault, and Benton (1992). These
authors proposed a social psychological theory wherein expression and discussion of feelings raises the individual’s consciousness of their feelings and allows them to incorporate them into emotions as a way of constructing self. That is, the individual is constructing self as a person who feels certain things because of certain experiences. In essence the current study finds the individual reaffirming who they are and where they fit in with the new, probably unexpected notion of managing a colostomy. When viewed in this way, expression of feelings is not only a process, it is also agency, an intervention to assist in this new construction of self.

Qualitative findings from this study have demonstrated that the affective meaning of an alternative can be a powerful force. In the 6 weeks and 18 weeks interviews people in the Instrument and Advised groups revealed that they had wanted to express their feelings, and those in the Discussion group usually did express them. Patients had forms of reasoning which were not cognitive nor hypothetico-deductive. There were bodily ways of knowing what they could or would do. But feelings and emotions are traditionally seen as irrational. Solomon, (1983, p. 9) points out that:

Since the earliest of Western thinking, the meaning of human existence has been sought in the calm reflections of rationality ... The passions, on the other hand, have always been treated as dangerous and disruptive forces, interrupting the clarity of reasoning and leading us astray.

This particular context of making a decision about long term colostomy management is emotion laden because it involves certain threats, to body image and to self-esteem, and occurs within a context of general societal taboos. Use of the Instrument alone denied the opportunity to express feelings at a time when many had quite intense feelings, and it seemed artificial and unsatisfactory and as though something had been imposed upon them.
9.3.3. How decisions are made

What decision-making strategies do people use when they did not have one imposed on them? Insight into this question comes from revisiting the transcripts and analysing them from a different perspective, and trying to classify the decisions in terms of other strategies identified in the decision theory literature.

According to Simon (1978), “satisficing” is the dominant decision-making strategy. Simon proposed that people do not usually go to the trouble of considering all the alternatives and their attributes, they look for a course that meets a minimal set of requirements, that is “good enough”. To be satisfied a person does not necessarily have to optimise their utilities, “satisficing” is all that is required. One participant’s answer was almost a definition of this strategy. He wanted to do the simplest thing which will do the job properly. “Satisficing” can be used as an explanation for why some patients are content to follow advice, rather than find all the information themselves. For them it is “good enough” to find an expert and do what that person suggests. If satisficing is a dominant strategy for people in general, then this may be why so many people in the Advised group were “satisfied”.

Another common method of decision-making is “elimination by aspects” (Tversky, 1972). This involves the sequential narrowing of choices by eliminating anything which has an unacceptable aspect. Overall the decision may be inferior, but it is superior with regard to that aspect. If that aspect is the major consideration for that individual, then the decision is logical from their perspective. Many examples of this were found in the transcripts. People dismissed various methods by saying things like, that sounds too complicated. This strategy was particularly common with the irrigation and plug methods, people frequently deciding against them on the basis of certain aspects, such as, I don’t like putting plastic things inside my body!

Others used a strategy which relies on the perceived salience of one of the
alternatives. Salience refers to the extent to which the person is attracted to a particular option on the basis of information given (Pierce, 1993). For many of these patients, the wearing of a bag was the most salient method. It was the one about which they had prior knowledge, the one which was routinely implemented by the staff post-operatively. It was the only method they had all tried by the time the decision had to be made.

Still other people make impulsive decisions. One patient referred to the fact that she usually relies on her gut feelings and another spoke of her intuition. When questioned about their reasons for the method selected they had no idea, no real strategy. Others resorted to buck passing, asking the nurse What do you think? and What do you recommend? They had to be led into the decision.

Procrastination was also evident, with people making comments which indicated they did not want to make a decision just yet. I think I'll wait and see ... you know ... how it goes. It is noteworthy that vigilance, a thorough consideration of alternative courses of action, an evaluation of costs and risks, analogous to unemotional, rational SEU theory (Janis & Mann, 1977) was only evident in one decision outside the Instrument group.

Most research about decision strategies is descriptive, and this is why there is a considerable body of knowledge about how people make unaided decisions using the decision strategies outlined in the previous paragraphs. This study was different because it was experimental and the decision strategy was manipulated. For some, a foreign strategy was imposed on their decision-making. Although, technically speaking, the instrument imposed a better quality decision - because it weighed up more aspects about each alternative - it was counterproductive when some patients chose not to implement the decision, and were not satisfied with the process of the decision-making encounter.
9.4. Limitations of the study

9.4.1. Generalisability

This sample included people requiring colostomy formation due to colorectal and gynaecological cancers, inflammatory bowel diseases, radiation colitis and proctitis, neurological disorders, trauma and incontinence. Thus it represents the main reasons for colostomy formation in adults. The particular mix of diagnoses is not relevant since the underlying medical diagnosis was not found to be related to any of the independent or dependent variables (except gynaecological cancer which was logically related to gender). However, the results are not generalisable to all persons with a new colostomy.

The sample was selected on the basis of inclusion and exclusion criteria to ensure that patients were physically and intellectually capable of using all the available methods of colostomy management and of participating in all aspects of the study. That is, the decision had to involve a real choice, and they had to be capable of making that decision. More than half (51.6%) the people with newly fashioned colostomies were not suitable. They included those who refused to participate in the study, who spoke little or no English, were neonates or children, were too ill (usually having a palliative colostomy), were intellectually or physically incapable of participating. Thus any findings are generalisable to adults with a sigmoid colostomy who are able to speak English, and are physically and intellectually capable of using any method of colostomy management.

Pieper (1996) made an interesting observation that patients who are physically and mentally incapable of participating in research projects are systematically excluded from most ostomy related research projects. However, such individuals make up a considerable percentage of those needing this type of surgery, and they should be included in studies so that data more truly reflects the total picture. How to do this remains a great challenge.
9.4.2. Implementing the three treatments

In this study patients with a newly fashioned colostomy were allocated to three treatment groups according to the chronological order of treatment by a member of the stomal therapy department. There were some problems with the implementation of the treatment groups which warrant discussion.

9.4.2.1. The Discussion Group

Audiotapes were used to ensure that encounters in this group were really collaborative discussions, and this proved to be very important. The interviewer experienced considerable difficulty in the early stages developing skills to facilitate collaboration. Four trial interviews were taped and when assessed using the criteria adapted from the work of Eisenthal et al.(1983), they were found not to be collaborative decisions. Data from these discussions were not used in the final analysis, but provided an excellent learning experience for the interviewer.

Despite the interviewer's cognitive commitment to mutuality, it was too easy to have a friendly chat and then to dominate and prescribe. The problem was not one-sided. Despite stating that they wanted to participate in decisions, and knowing that they were meant to be in a collaborative discussion group, patients were often quite content just to chat, then to receive information and be advised. Patients usually had to be drawn into the decision process. This fully supports Kim's (1983a) early findings that there was a general attitude for professional dominance and control and that people were content to receive information and instruction rather than collaborate. It also supports Kim's comments when she compared expressed attitudes with practice and found that "patients tended to be in the informative mode while nurses wanted them to be in the collaborative mode" (Kim, 1991a, p. 11).

The audiotapes of these discussions were invaluable for ensuring that collaboration took place, and later for providing some qualitative data to further explain some of
the quantitative findings. However, the use of audiotapes was not without its problems. An inconspicuous recorder was used but some patients were still clearly very nervous about their conversations being recorded, notwithstanding assurances that only the researcher would listen to the tapes. Patients sometimes spoke to the recorder rather than to the interviewer. When the recorder was put to one side to make it less obvious, some tapes were difficult to transcribe because parts were inaudible. One of the earliest tapes failed to record anything, so that person was excluded from the study because this failure was not realised until the end of the decision-making discussion.

9.4.2.2. The Instrument Group

Use of the Instrument was greatly hindered by the constraints of the experimental design which specified that it be used without collaborative discussion, and that detailed information about the management methods be given after the Instrument imposed its decision rule. These constraints were designed to see whether it is the act of participating (in this case, by contribution of utilities) or the "talking things over" which contribute to satisfaction with collaborative decisions (Smith & Garko, 1991). In this sense, the situation was artificial, and this was observed and commented on by some of the participants. The difficulties encountered in operating in this artificial context highlighted the fact that "talking things over" is an integral part of collaboration. Patients did not just want to convey information deemed relevant according to the instrument, they wanted to use their own words to convey their feelings about the choices offered. This method was collaborative in the sense that the Instrument outlined the attributes for consideration, and the patient prioritised their utilities, that is, both parties contributed to the decision. But the instrument was not sufficiently, nor spontaneously, interactive. Being listened to, and having the opportunity to talk about feelings were seen as an integral part of the collaborative process which was not allowed in the Instrument group.

Although people found the Instrument a useful way to organise their thoughts, several rebelled against the fact that the Instrument imposed a decision rule. Some
wanted to make the decision in their own way. It was not a mutual decision for them because it did not take into account some aspect they considered to be important. A major problem with the instrument was that it wrongly assumed that users would operate on a rational level and be motivated to use any method deemed optimal by the instrument. This was not the case. Without discussion the only recourse for some users of the instrument was noncompliance with the decision rule. This was their way to reclaim autonomy in decision-making.

The fact that it was so hard for the nurse to collaborate in the Discussion group and so hard not to collaborate with the Instrument group leads to the conclusion that there was a need for a group which used the instrument and collaborative discussion. In such a context the instrument becomes a decision aid, something to help clarify things, rather than something used to impose a decision rule. Such an arrangement allows the instrument to work with the expert, rather than replacing them (Carroll & Johnson 1990). In this type of situation the instrument is used to make it clear “what information the patient requires and the expected outcomes of the various alternatives - and how they will affect their ... quality of life”, (Schwartz & Griffin, 1986, p. 227) but the patient ultimately makes the decision.

The fact that the interviewer also found the instrument to be a useful tool for organising thoughts raises the possibility that such a tool might be more useful for the professionals, to help them structure their information and discussions rather than it being used solely by the patients. A further project is planned in which a group will use a combination of a decision instrument as an organising tool, together with a collaborative discussion so that patients have the opportunity to have access to the researched base knowledge and also to explore issues from their own perspectives.
9.4.2.3. The Advised group

Both interviewer and patients found it relatively easy to assume their roles in this situation. Both had been socialised into these roles through their other interactions in the hospital system. The pervasiveness of these roles and associated attitudes is demonstrated by the fact that there was no difference between goal attainment in the Advised and Discussion groups - patients were just as likely to do what the nurse told them to do as to do what they had selected collaboratively.

9.4.3. The measurement of satisfaction

A number of ways of defining and measuring patient satisfaction have been described in the literature. Davis and Hobbs (1989) defined satisfaction as "the extent to which patient treatment expectations are fulfilled", but this definition is at odds with much of the other published reports. Thompson (1986), Linder-Pelz (1982) and Linder-Pelz and Streuning (1986) all indicated that expectations play a finite but ill-defined role in satisfaction levels reported by patients. Locker and Dunt (1978) proposed that expectations change over time, and Williams (1994) argued that often patients hold no clear expectations.

However, satisfaction has some relationship to expectations, and expectations are modified during the illness experience, including the discomforts experienced by the individual and the ultimate success or failure of the treatment. Exactly how these factors are involved and how they are interrelated is unclear and warrants further research. If satisfaction is viewed as an evaluative reaction resulting from the interaction of the decision-making experience with the individual's expectations, then those who did not get what they expected should all have been dissatisfied. But in this study, often they were satisfied. Perhaps the failure to fulfil expectations results in lessened satisfaction but it is artificially elevated by general satisfaction which is derived from other factors, such as confidence in the experts and faith and the positive nature of the relationship which had developed.
Ovretveit (1992) argued that patients perceive a health service in relation to what the individual feels it should provide, what they realistically expect it will provide, and what they think they need. However he argued that most people are not aware of their expectations until they are not met. A similar idea was developed by Parasuraman, Berry and Zeithaml (1991) who proposed that “customers” have a “zone of tolerance” which extends between adequate and desired levels of service expectation, and proposed that it is only when service falls outside this zone of tolerance that service is perceived to be unsatisfactory. This was borne out by some of the participants when they spoke of their right of veto.

During the past ten years there has been a progressive increase in the rigour and complexity of research into patient satisfaction, but much of the literature argues for multidimensionality of patient satisfaction measures. This is not the issue in the current study, which looked at one dimension only, that is the level of satisfaction with regard to the decision-making exercise.

Not only were there some problems with conceptualisation of satisfaction but also with its measurement. A visual analogue scale was chosen to avoid the ambiguity of words and numbers and to minimise acquiescent response bias (Oberst, 1984). At the 6 week assessment a “ceiling effect” was noted, with 30% of participants rating their satisfaction above 4.8. In order to try to improve the discrimination of the measure a letter was sent to all those who had already completed the 6 weeks interview, focussing their attention on the purpose of the measure and inviting further comment (Appendix Seven). To ensure uniformity of treatment, the same invitation was given verbally to all subsequent participants when filling out the satisfaction measurement scales.

Despite these actions the satisfaction ratings remained fairly high. Whilst it is not unusual to have high undifferentiated levels of reported satisfaction in general scales (Scott & Smith, 1994), this measure was both direct and specific and therefore greater discrimination was expected. Possible reasons for this phenomenon can be divided into three categories: social psychological artifact,
limitations of the measure, or that levels of satisfaction were *actually* high.

Possible types of social-psychological artifacts include: social desirability response bias, tendencies to ingratiate oneself with staff, the Hawthorne effect, cognitive consistency pressures to make satisfaction ratings congruent with one's continued participation, and experimenter bias since the evaluator is affiliated with the service (Pascoe, 1983). Any of these may have occurred. Having someone who is not on staff administer the satisfaction measure could have avoided some of these artifacts.

Possible limitations of the method chosen to measure satisfaction include failure to assist the participants to differentiate between satisfaction with their opportunity to participate in decision-making and satisfaction with other aspects of the encounter. If the measure had been done as a verbal interview rather than as a pencil and paper exercise, these issues could have been teased out. Ware, Snyder, Wright and Davies (1983) identified a number of factors which influence patient satisfaction. These included such things as humaneness of care, technical quality of care, and efficacy / outcome of care, which if present can create a feeling of overall satisfaction which might artificially increase satisfaction with another aspect such as decision-making. The three features listed above were mentioned by patients when discussing satisfaction, and it did seem that they had influenced their satisfaction with the decision-making process. It may be that people had difficulty discriminating between various distinct characteristics of the encounter. There were also participants whose dissatisfaction seemed to be reflecting an overall dissatisfaction with life circumstances and, as has been reported, this was stated explicitly by some patients.

It may be argued that the satisfaction measure may have been more accurate if satisfaction had been assessed immediately after the decision making episode, rather than at the 6 week interview. Perhaps their recollection was better than what actually happened. However, there is a counter argument that with a construct such as satisfaction what one remembers at 6 and 18 weeks is a more important
outcome than what one thought at the time, if indeed they are different. It must be noted that with this particular measure there was consistency over time and satisfaction scores at 6 and 18 weeks were highly correlated (r = 0.94, p<.01) indicating temporal reliability. There was also a correlation between satisfaction and goal attainment at 6 weeks (r = 0.46, p<.01) and at 18 weeks (r = 0.47, p<.01), which could be taken as a measure of concurrent validity of the satisfaction measure.

It may have been that the “ceiling effect” was not a reflection of inaccuracy of measurement, but the level of satisfaction was actually high. Smith and Garko (1991) had found that in the absence of mutuality, delegation was the preferred option, and the participants in the Advised and Instrument groups may have considered each of these methods to be more satisfying than making the decision themselves.

Because satisfaction rating is a personal evaluation it is intentionally subjective and attempts to capture something which cannot be known by observing. It does not ask “how much?” but “was it enough for you?” In this sense it is a measure of the patient as well as the decision process. This raises an interesting question worthy of future research or discussion. If one aim is to improve satisfaction, should the decision-making method be changed or should patients’ expectations and preferences be changed?

9.5. Contributions to the API and to Kim’s Framework

The following section describes contributions made by this study to two theoretical models, the modified API and Kim’s framework for collaborative decision-making in nursing.

9.5.1. The Autonomy Preference Index (API)

Results from the modified API indicated that, in the specific context of this study,
patients most preferred mutuality in decision-making, followed by delegation, and finally patient decision-making. These results are consistent with those of Smith and Garko (1991) and others who had replicated their study in the USA, UK and Australia (Smith et al., 1994). However, the use of this version of the API takes their work further since it was being administered to people who are actually ill rather than in an hypothetical situation.

Smith and Garko (1991) had identified two post hoc variables, severity of illness and relevance of patient input into the decision. They reasoned that the role a person wishes to take in a decision might vary according to whether the illness is major or minor, so they introduced a series of vignettes depicting situations with increasing severity of illness, and then asked about preferences for decision-making. They found that doctor and patient preference scores decreased with increasing severity of illness, but preferences for mutuality in decision-making increased with increasing severity of illness. In this study, the severity of illness was fairly constant for all patients since all had undergone major bowel surgery. The other post hoc variable was the relevance of patient input into the decision. There are some decisions which are so technical that the patient can contribute little, but there are others which involve patient values and experiences and considerable input is relevant. Not surprisingly, Smith and Garko found that patients want to contribute most when their input is most relevant. In this situation, there was a need for high level of patient input concerning the various management methods available. The same pattern of preferences emerged in this study as in the hypothetical situation, so in that sense this study validates work conducted to date using the API.

The other important difference in this version of the API was that the notion of “talking it over” (which is integral to Smith and Garko’s (1991) items representing mutuality) had been removed from the items. This was done in order to tease out the fact of collaborating from the act of “talking it over”, to see whether people still chose collaboration without that aspect included. The preferences were unchanged. It may be that patients took it for granted that when decisions are made
by “you and the nurse together” there will be a certain amount of “talking it over”. This was tested by looking at qualitative comments from those who were in the Instrument group. In this group “talking it over” was purposely removed from the collaborative process. The decision was based purely on the results from the decision instrument. Although the decision was collaborative, in the sense that the patients did contribute information, it was obtained without discussion. It is noted that a number of patients in the Instrument group commented that the lack of discussion made the situation seem artificial. For them, the notion of “talking it over” is integral to their idea of collaboration, and this finding serves to validate that aspect of the API.

After working with Smith and Garko’s team, Bennett et al. (1995) proposed that the meaning of patient autonomy has not been well defined from a patient perspective, and investigated the issue using a grounded theory approach to obtain that perspective. They identified that information exchange is a critical process and needs to provide options, demonstrate a decision trail and incorporate patient involvement. Patients reclaim autonomy in decision-making when these processes are deficient. This is consistent with the findings of the present study, however this study advanced those ideas further in that the type of information these patients wanted to exchange was not just that which was relevant to the practical aspects of the decision, but also related to their feelings about the options available. The expression and discussion of feelings is one agency through which the patient constructs a version of self which is consistent with the decision made and the decision process used (Crawford et al., 1992), and if this self is not consistent within the decision-making process, then decision taking is unlikely to occur.

9.5.2. Kim’s framework for collaborative decision-making in nursing

This study validated and extended Kim’s framework for collaborative decision-making in nursing by using it in the context of a prospective experimental study. Results indicated that the components of Kim’s framework serve to logically
explain the phenomena observed in this study.

Previously reported studies using Kim’s framework had investigated such aspects as whether or not collaborative decision-making occurs in usual practice, the context of the participants (nurse and client) and the context of the situation in collaborative decision-making in nursing practice. A cross cultural study (Kim et al., 1993) looked at attitudes of the participants and factors which explain these attitudes. One group of studies (Kim, 1987) looked at the effects of collaboration on various outcomes, and in 1988, Kim investigated collaborative decision-making as an interactive process. The present study adapted Kim’s framework to investigate some aspects not previously tested.

This study involved the use of a different scale - which included a mutuality option - when assessing clients’ and nurses’ attitudes towards decision-making. When Kim (1991) investigated what was termed “consumerist” attitudes of participants towards decision-making, she used a scale developed by Haugh and Lavin (1981). Reported in a study entitled “Practitioner or Patient - Who is in Charge?”, this work had been undertaken from a perspective which sees decision-making as a control issue, so that either the patient or the practitioner is “in charge”, and if one has more control, then the other has less. This premise is challenged by a counter argument that there is not a fixed amount of power in a relationship (Smith & Garko, 1991).

Although Haugh and Lavin explicitly discussed the need for both parties to “negotiate an acceptable set of terms for the relationship” (p.213) their scale did not offer the option for mutuality, it only offered a choice about who should make decisions, not one about how decisions may be made. This is not appropriate for use in Kim’s model which is specifically seeking to explain a negotiated experience. In this study, when the option for mutuality in decision-making was included among the preferences, its popularity demonstrated that the client outcome of autonomy was not as important as mutuality. Autonomy was reclaimed by those who were dissatisfied with the decision process.
Bennett and Irwin (1997) explained this phenomenon from a different angle. They proposed that power is attributed to information and knowledge but when mutuality is introduced as an option, the technological base of knowledge has its supremacy challenged by the introduction of new ways of knowing, which can be termed social knowledge. This is what happened when the API was adapted to include an option for mutuality and also when patients in the Discussion group demonstrated they had other, different knowledge which was as important to their decision as the “facts” which the nurse knew and conveyed to them about colostomy management.

The second way in which this study advances Kim’s framework stems from the experimental design. A major argument against patient participation in decisions about care arises from the criticism that no direct link has been demonstrated between patient participation and improved outcomes (Steele et al., 1987). A counter argument is that this situation only applies to outcomes as defined by the professional, such as control of blood sugar levels or stabilisation of blood pressure. In Kim’s (1983b) framework these types of outcomes are the goals. However, there are other outcomes defined within the patients’ perspective - satisfaction and perceived level of autonomy - and in holistic nursing care these are just as important as outcomes relating to physical health.

This study advanced the understanding of Kim’s (1983) framework by focussing attention on the relationship between what the framework depicts as the primary and secondary outcomes of collaborative decision-making. By controlling the level of collaboration in this study it was possible to investigate how differing levels of collaboration affect some client outcomes. This study demonstrated that outcomes such as satisfaction and a sense of mutuality or partnership may be as important to the patient as is attainment of physical well-being.
9.6. Conclusions and implications for clinical practice

The first group of general conclusions relate to stomal therapy nursing practice. This study revealed that members of the public have generally poor understanding of colostomies and their management and often require education in relation to these matters. Unfortunately, knowledge about colostomy management is largely based on anecdotal information and warrants further investigation in order to develop a more precise information base so that nurses can confidently provide more reliable information about the possible outcomes of colostomy management methods. In the light of these comments, beliefs and values of stomal therapy nurses need exploration and discussion since they are often based on a type of “folklore of nursing” yet have the potential to strongly influence patients in their decisions.

The second group of conclusions relates to decision-making in clinical practice. If a clinician wishes to structure a commonly occurring decision problem in such a way that all the possible outcomes, attributes and probabilities are made available to the patient, then a decision instrument using card sorting to elicit patient utilities is practical and may be useful. However, a decision instrument will probably be more effective in terms of patient satisfaction and goal attainment if it is coupled with a collaborative discussion. In this way the decision instrument is truly a decision aid in that the instrument does not make the decision, but provides a conceptual framework for use by both parties.

This study has demonstrated that decisions made using collaborative discussion are the most likely to be satisfying to patients. This is evidence that patient participation is of benefit to the patient. Both collaborative discussions and nurse advice are likely to lead to goal attainment, but the acceptance of nurse advice is mediated by confidence in the nurse, and/or a lack of confidence in “the self”. If nurses wish to advise patients it seems they must prove themselves to be a credible authority during their interactions with patients. If patients expect or prefer one level of involvement in decisions but that level is not allowed, they may reclaim
their decision-making autonomy unless they have confidence in the other party, or have the opportunity to explore the decision’s extensiveness, attainability and affective meaning.

Studies investigating the level of collaboration in usual nursing practice reported that, although nurses stated that they believed in collaborative decision-making, it was not evident in practice (Kim, 1983a). This study further demonstrated that it is easier to be directive or to give information than it is to engage in collaborative decision-making. There is therefore a need to train nurses to be in the discussion mode so that they become dialogical rather than directive and/or information-givers.

Collaborative decision-making involves a two way exchange of information, and this may reveal that the patient does not make decisions using the same types of strategies as the nurse. It may be useful for the nurse to explain other decision strategies to the patient, particularly in relation to the decision under consideration, but it is not the role of the nurse to tell the patient what their values or utilities should be. If nursing practice is to be truly collaborative then nurses must be willing and able to negotiate and to accommodate a holistic view of the patient, not merely focussing on the clinical outcome of the decision.
REFERENCES


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References marked with an asterisk indicate studies included in the modified meta-analysis.


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APPENDICES
PLEASE NOTE

The greatest amount of care has been taken while scanning the following pages. The best possible results have been obtained.
APPENDIX ONE

The original Autonomy Preference Index decision-making preference scale (Ende, Kazis, Ash & Moskowitz, 1988) and Smith & Garko’s (1991, p.22) revised API scale.

Responses are made on a 5 point scale, strongly agree to strongly disagree.

**Original Version**

**1.** The important medical decisions should be made by your doctor, not by you.

**2.** You should go along with your doctor’s advice even if you disagree with it.

**3.** When hospitalized, you should not be making decisions about your own care.

**4.** You should feel free to make decisions about everyday medical problems.

**5.** If you were sick, as your illness became worse you would want your doctor to take greater control.

**6.** You should decide how frequently you need a check-up.

* scored: 5, strongly agree to 1, strongly disagree

**scored: 5, strongly disagree to 1, strongly agree

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**Revised Version***

1. Important medical decisions should be made by your doctor, not you.
2. Important medical decisions should be made by you, not your doctor.
3. Important medical decisions should be made by you and your doctor together after talking it over.

4. You should go along with your doctor’s advice even if you disagree with it.
5. You should not go along with your doctor’s advice if you disagree with it.
6. If you and your doctor disagree you should talk it over and decide together.

7. When hospitalized, you should not be making decisions about your own care.
8. When hospitalized you should be the one making decisions about your own care.
9. When hospitalized you and your doctor should talk over decisions about your care and make them together.

10. You should make decisions about your everyday medical problems.
11. Your doctor should make decisions about your everyday medical problems.
12. You and your doctor should talk over your everyday medical problems and make decisions together.

13. If you were sick, as your illness became worse you would want your doctor to take greater control.
14. If you were sick, as your illness became worse you would want greater control.
15. If you were sick, as your illness became worse you would want more discussion and mutual decision making with your doctor.

16. You should decide how frequently you need a check-up.
17. Your doctor should decide how frequently you need a check-up.
18. You and your doctor should talk it over and decide together how often you need a check-up.

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*all items scored: 5, strongly agree to 1, strongly disagree*
APPENDIX TWO

"Scientific" studies concerning colostomy management methods
<table>
<thead>
<tr>
<th>Authors</th>
<th>Year</th>
<th>Title</th>
<th>n</th>
<th>Country</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Terranova, O., Sandei, F., Rebuffat, C., Marvotti, R. and Bortolozzi, E.</td>
<td>1978</td>
<td>Irrigation vs Natural Education of Left Colostomy - A Comparative Study of 340 Patients</td>
<td>340</td>
<td>Italy</td>
<td>Follow up of all patients attending clinic. Descriptive statistics of both groups.</td>
</tr>
<tr>
<td>Stuart, M.</td>
<td>1976</td>
<td>Colostomy Irrigation. It’s Role in Improving the Colostomate’s Quality of Life</td>
<td>10</td>
<td>Australia</td>
<td>Mail questionnaire two years after teaching technique. Descriptive - percentages and some qualitative data.</td>
</tr>
<tr>
<td>Authors</td>
<td>Year</td>
<td>Title</td>
<td>n</td>
<td>Country</td>
<td>Comments</td>
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<tr>
<td>Palselius, I.</td>
<td>1992</td>
<td>Irrigation for Regulation of Colostomy Function</td>
<td>97</td>
<td>Sweden</td>
<td>Selection method not stated. Some patients assessed with natural evacuation and irrigation. Describes results of each method.</td>
</tr>
<tr>
<td>Perbone, C., Paone, A., Postiglione, C., Oldani, S., Dall’acqua, S. and Tessera, G.</td>
<td>1993</td>
<td>The Cost Benefit of Transtomal Irrigation: A Multi centre Study in Northern Italy</td>
<td>98</td>
<td>Italy</td>
<td>Selection method not stated, implies consecutive patients at Clinic. Describes costs in time, money, diet and compares irrigation and non-irrigation but not statistically.</td>
</tr>
<tr>
<td>ATTRIBUTES</td>
<td>Containment</td>
<td>Training</td>
<td>Constipating Diet</td>
<td>Regular Medications</td>
<td>Trial and Error</td>
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<tr>
<td>Eating and drinking whatever I wish</td>
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<tr>
<td>Looking as normal as possible</td>
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<tr>
<td>Having my bowel actions at a predictable time</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Having time to attend to my colostomy</td>
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<td></td>
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<td></td>
<td></td>
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<tr>
<td>intermittently whenever it needs it</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Spending about 40 minutes attending to my</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>colostomy daily / second daily or third daily</td>
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<tr>
<td>Having a bag on my abdomen sometimes with</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>bowel action in it</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Taking medicine to control my bowel actions</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>
APPENDIX FOUR

Instructions given to patients when administering the decision instrument.

These cards have statements on them. If you can put them in order of importance to you, we can use this information to decide which method of colostomy management suits you best.

STEP 1

RANK the statements in order of importance to you.

Put the most important at the top and the least important at the bottom.

STEP 2

RATE the statements on the cards by putting them next to the numbers on the vertical line on this poster.

Start with the one you had ranked as most important.

The number next to the top border of the card represents its score.

They may overlap.

You may change your original order.

STEP 3

Now we will look at the back of the cards and multiply the numbers there by the numbers on the vertical line next to the cards. Then we will add up the score for each method and the one with the highest score is the one that is best for you.
APPENDIX FIVE
Format for initial interview

INITIAL INTERVIEW

Have you ever been in hospital before?

_________________________________________________________________________

When? (Years)

_________________________________________________________________________

Approximate total length of stay(s)

_________________________________________________________________________

What do you know about colostomies?

_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________

What do you know about how a colostomy is managed / looked after?

_________________________________________________________________________
_________________________________________________________________________

How much involvement do you expect to have in decisions which will need to be made about about your colostomy?
Generally speaking:

How much involvement do you prefer to have in decisions made about your colostomy?

<table>
<thead>
<tr>
<th>None</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
<td>5</td>
</tr>
</tbody>
</table>
TREATMENT GROUP ALLOCATION:

NAME:

AGE:

GENDER:

HIGHEST LEVEL OF EDUCATION COMPLETED:

PLACE OF BIRTH:

OCCUPATION:

RELEVANT MEDICAL HISTORY:
APPENDIX SIX

Amended form of API used on a flip chart in Project 2. There was only one statement on each page of the flip chart and patients pointed to the number which best represented their view.
DECISION PREFERENCES

1. When hospitalized, you should be the one making the decisions about your own care.
   1    2    3    4    5
   strongly agree neutral disagree strongly disagree

2. When hospitalized, you should not be making decisions about your own care.
   1    2    3    4    5
   strongly agree neutral disagree strongly disagree

3. When hospitalized, you and the staff together should make decisions about your care.
   1    2    3    4    5
   strongly agree neutral disagree strongly disagree

4. You should make decisions about your everyday colostomy related problems.
   1    2    3    4    5
   strongly agree neutral disagree strongly disagree

5. The stomal therapy nurse should make any decisions about your everyday colostomy related problems.
   1    2    3    4    5
   strongly agree neutral disagree strongly disagree

6. You and the stomal therapy nurse should make decisions together about your everyday colostomy related problems.
   1    2    3    4    5
   strongly agree neutral disagree strongly disagree

7. You should decide how frequently you need a colostomy check-up.
   1    2    3    4    5
   strongly agree neutral disagree strongly disagree

8. Your stomal therapy nurse should decide how frequently you need a colostomy check-up.
   1    2    3    4    5
   strongly agree neutral disagree strongly disagree
9. You and the stomal therapy nurse should decide together how often you need a colostomy check-up.

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>strongly agree</td>
<td>agree</td>
<td>neutral</td>
<td>disagree</td>
<td>strongly disagree</td>
</tr>
</tbody>
</table>

10. You should go along with the stomal therapy nurse’s advice about your colostomy even if you disagree with it.

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>strongly agree</td>
<td>agree</td>
<td>neutral</td>
<td>disagree</td>
<td>strongly disagree</td>
</tr>
</tbody>
</table>

11. You should not go along with the stomal therapy nurse’s advice about your colostomy if you disagree with it.

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>strongly agree</td>
<td>agree</td>
<td>neutral</td>
<td>disagree</td>
<td>strongly disagree</td>
</tr>
</tbody>
</table>

12. If you and the stomal therapy nurse disagree about your colostomy management you should make decisions about it together.

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>strongly agree</td>
<td>agree</td>
<td>neutral</td>
<td>disagree</td>
<td>strongly disagree</td>
</tr>
</tbody>
</table>

13. Important decisions about the management of your colostomy should be made by you, not by the stomal therapy nurse.

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>strongly agree</td>
<td>agree</td>
<td>neutral</td>
<td>disagree</td>
<td>strongly disagree</td>
</tr>
</tbody>
</table>

14. Important decisions about the management of your colostomy should be made by the stomal therapy nurse, not by you.

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>strongly agree</td>
<td>agree</td>
<td>neutral</td>
<td>disagree</td>
<td>strongly disagree</td>
</tr>
</tbody>
</table>

15. Important decisions about the management of your colostomy should be made by you and the stomal therapy nurse together.

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>strongly agree</td>
<td>agree</td>
<td>neutral</td>
<td>disagree</td>
<td>strongly disagree</td>
</tr>
</tbody>
</table>

Thank you for your time.
APPENDIX SEVEN

Letter sent to patients when “ceiling effect” on satisfaction scores was noted.

Stomal Therapy Dept
c/- ward D3a,
Westmead Hospital, 2145
10th May, 1995.

Dear

Recently you took part in a study about different ways that may be used to help people make decisions about how to manage their colostomy.

You were in a group which : (one of these was included)

a) used a card sorting system to make the decision, and later was given information about various methods possible
b) had a collaborative discussion
c) was advised by the stomal therapists to use a particular method of management, but given information about other methods.

Although you indicated that you were generally satisfied with the method used, I am interested to know whether there was anything about the way the decision was made which did not meet your needs or expectations.
At this point I am not asking whether what you decided on is working, but whether the way the decision was made suited you. And any comments you would like to make about the way the decision was made.

Do not feel that you will offend if you wish to indicate that you were less than completely satisfied. The aim of the study is to find out which is the best way of making such decisions, and in order to do that your honest opinion is needed.

Please fill in the enclosed form and mail it back as soon as possible in the stamped addressed envelope provided. If you need to discuss this with me, please phone 6336333 + page 1139 anytime between 8:30 am and 5:00 pm on weekdays.

I have numbered these forms so that I know whose comments go with which group.

Yours sincerely,

Julia Thompson.
APPENDIX EIGHT

Information sheet
Consent form
and
Checklist
People with a new colostomy often have difficulty making decisions about how to look after it. I am conducting a study to see whether there is a more effective and practical way to help people make these decisions.

If you agree to participate you will be asked to:

* Be interviewed about your attitude to making decisions (approximately 15 minutes)

* Participate in a decision-making exercise about colostomy management (approximately 5 minutes)

* Be interviewed in 6 weeks and then 18 weeks time concerning the effectiveness of the decision which you made during the decision-making exercise above.

No identifying information will appear on any of the information obtained from you. Some interviews may be audiotaped. All data will be tabulated, analysed and reported anonymously.

This research could yield useful information that could be of help to others in the future. It may also benefit you at this time. There are no known risks involved in this study.

You may refuse to participate in this study or discontinue participation at any time without prejudice of any kind or effect on the care provided.

You may contact Julia Thompson (Clinical Nurse Consultant in Stomal Therapy at Westmead Hospital: phone 633 3333 + page 1139) at any time if you have any questions about this research.
CONSENT TO PARTICIPATE IN STUDY ABOUT COLOSTOMY MANAGEMENT DECISIONS

Investigator: Julia Thompson

I, ___________________________________________ of ___________________________________________

have read the information about being a participant in the research project entitled, "An investigation of collaborative decision-making between nurses and people with colostomies", and any questions I have asked have been answered to my satisfaction. I agree to be interviewed for this research project. I understand that the interview will be recorded in writing and on audiotape but that my identity will not be revealed without my written consent to anyone other than the researchers conducting the project. I may withdraw my consent at any time or choose not to talk about any particular topic. I agree that the research data gathered in the interview may be published, but that my name will not be used and that I will not be identified in any way. I acknowledge that I have received a copy of this form and the participant information sheet, which I have signed.

Signature of the participant __________________________________________

Signed ___________________________________________ (investigator)
APPENDIX NINE

Letters sent to members of Delphi Group
Dear

I am developing a decision aid to assist people with a new colostomy to make a decision about which longterm management method to choose. You will recall that recently I asked if you would help me by sharing your opinion about some ideas. Thank you for agreeing to participate.

You are now part of a panel which includes 5 stomal therapists and 10 people who each have a colostomy. I will be sending you each a series of questionnaires. After I receive all the replies to this first round I will summarise what you have all written and then send the summary back to each of you for comments. This process will continue until all the tasks have been accomplished.

To develop this decision aid I need your help to:

a. Determine which longterm management methods are currently available to people in N.S.W. who have a colostomy.

b. Determine which attributes of each of those methods would influence a person to want or not want to choose that method.

c. Calculate the probabilities of each attribute as it applies to each method.
I have read widely on the subject and it seems to me that in N.S.W. today the management options for longterm colostomy management are:

1. CONTAINMENT: this means the person just wears an appliance and collects the output, making no attempt to control the volume or timing of the motions.

2. 'TRAINING' THE COLOSTOMY - using diet, fluid restrictions & timing

3. CONSTIPATING DIET AND LAXATIVES AS REQUIRED

4. REGULAR MEDICATIONS SUCH AS BULK FORMING AGENTS

5. 'TRIAL AND ERROR' DIET

6. REGULAR IRRIGATION

7. INTRALUMINAL (CONSEAL) PLUG

8. ANY COMBINATION OF THESE

Do you have any comments to make about these?

CAN YOU THINK OF ANY OTHERS? Please describe them.
The literature identifies the following attributes/features of these methods as being important when a person decides which method to choose. They are in no particular order.

1. INVOLVES WEARING A BAG WHICH WILL AT TIMES HAVE FAECES IN IT
2. INVOLVES A DIET
3. INVOLVES MEDICATIONS
4. TIME FACTORS
5. FACILITATES INDEPENDENCE
6. ALLOWS CONTROL OVER TIMING OF EVACUATION
7. SECURITY
8. CONVENIENCE
9. MAY CAUSE SKIN IRRITATION
10. AFFECTS APPEARANCE
11. SAFETY
12. ALLOWS USERS TO SOCIALISE
13. COST
14. INFLUENCED BY PERSONS BOWEL HABIT BEFORE ILLNESS /OPERATION

IN YOUR OPINION ARE THESE THE FEATURES OF THE METHODS WHICH WOULD CAUSE A PERSON TO CHOOSE OR REJECT THE MANAGEMENT METHODS LISTED?

Please add to or delete and write comments next to each attribute/feature as you think appropriate.
Please return your comments in the stamped addressed envelope provided, within a week if possible. The next round will be sent a few days after all your comments are received.

If you have any questions or difficulties with this please do not hesitate to contact me either at work (02 6336333 + pager 785) or at home on 02 6300882.

Thank you for your assistance.

Yours sincerely,

Julia Thompson
Dear

Thank you for your prompt response to round 1.

THE MANAGEMENT METHODS

No extra management methods were suggested by the panel.

Thank you to those people who shared their feelings about the various methods.

Most of you believe that 'training' is only possible for those who were 'regular as clockwork' before the illness or operation.

There is a general belief that diet helps somehow but is very individual. There was a strong feeling against laxative abuse but in favour of bulkforming agents if they are needed.

Irrigation was seen as useful for those who wanted to do it.

Plugs were seen as a good idea, but nobody had experienced much success with them so far.

One person commented that the less fuss a person makes of their colostomy, the more likely they are to get on with their life.

THE FEATURES / ATTRIBUTES OF THE MANAGEMENT METHODS

The following extra attributes were received in response to the first round questionnaire.

AGE

LIVING SITUATION (PHYSICAL FACILITIES)

COEXISTING HEALTH CONDITIONS

ONGOING TREATMENTS (CHEMOTHERAPY OR RADIOTHERAPY)

ABILITY (PHYSICAL AND MENTAL)

INDIVIDUAL PREFERENCES

LIFESTYLE (SEXUAL PARTNER, HOBBIES, SPORTS, WORK)

PSYCHOLOGICAL 'HANGUPS'

BODY IMAGE

These were not included in the instrument since they are attributes of the individual, not of the management methods. However they were noted and will be discussed further.
The following attributes were removed from the list:

ABILITY - PHYSICAL AND MENTAL - persons deemed not capable of using all the methods of management will be excluded from the study as per exclusion criteria.

AGE - is not a factor, if the person is able.

INDIVIDUAL PREFERENCES - by definition not a factor using a normative decision instrument method.

COEXISTING HEALTH PROBLEMS - can be derived from the records and according to the exclusion criteria, would exclude patient from study if it interfered with any type of management method.

ONGOING TREATMENTS (CHEMOTHERAPY AND RADIOTHERAPY) - can be derived from the records, and would exclude person from study if it interfered with any type of management method.

LIVING SITUATION - rarely relevant these days as most people now have a bathroom or access to same. This information will be sought from participants in the study, to see if it is a factor.

LIFESTYLE - people with all manner of lifestyles use each method successfully.

COST - same for all methods now as free to patients through Colostomy Association.

ECOLOGY - all methods involve use of some type of plastic appliance which has to be disposed.

FACILITATES INDEPENDENCE - could apply equally to all methods.

SAFETY - all methods are safe if patient is taught properly.

SKIN IRRITATION - uncommon now due to modern skin barriers.

BEING ABLE TO SOCIALISE - possible using any method.

BOWEL HABIT PRIOR TO ILLNESS/OPERATION - can be asked elsewhere and used in the study, but is an attribute of the individual, not an attribute of management method.
The remaining attributes are:

INvolves a diet

INvolves taking medications

INvolves wearing a bag which will at times have faeces in it

ALLOWS control over timing of bowel evacuation

May affect appearance

NEEDs about 40 minutes daily or second daily in bathroom

NEEDs intermittent care for about 5-10 minutes each time

Please comment

If you are having problems knowing what is expected of you, please ring and discuss it with me. Send your answer in the enclosed envelope, within a week if possible.

Thank you

Julia Thompson
Dear

Thank you for your prompt response to round 2.

These are the attributes which remain.

INVolves a DIet
INVolves taking MEDICAtions
INVolves wearing a bag which will at times have faeces in it
ALLowS controL oVer TIMIng of bowel evacuation
MaY AffecT affeRance
NEEdS abOut 40 MInutes daily or seCond daily in baThroom
NEEdS inTermittent care for about 5-10 minutes each time

Do you think that any of these overlap?
In order to make these more meaningful to the patient, please rewrite them so they describe something the individual with a new colostomy might have to do or to experience if they used the relevant method of colostomy management.

For example: INVOLVES A DIET could be
BEING RESTRICTED WITH WHAT I EAT AND DRINK

Once again I would appreciate your reply in the enclosed envelope within a week.

Yours sincerely,

Julia Thompson
Dear

Thank you for your prompt reply to round 3.

These are the statements about the attributes.

BEING RESTRICTED WITH WHAT I EAT AND DRINK
HAVING MY APPEARANCE AFFECTED
HAVING MY BOWEL ACTIONS AT A PREDICTABLE TIME
HAVING TO CHANGE THE BAGS WHENEVER THEY NEED IT
TAKING ABOUT 40 MINUTES DAILY TO ATTEND TO MY COLOSTOMY
HAVING A BAG ON MY ABDOMEN, SOMETIMES WITH FAECES IN IT
HAVING TO TAKE MEDICINES TO CONTROL MY BOWEL.

PLEASE COMMENT ABOUT THE WORDING OF THESE STATEMENTS

Again, please reply within a week if possible, using the enclosed envelope.
Yours sincerely,

Julia Thompson.

279
Dear
Thank you for your reply to round 4.

These are the statements I am planning to use on the decision aid. You will notice they are phrased as positively as possible.

EATING AND DRINKING WHATEVER I WISH

LOOKING AS NORMAL AS POSSIBLE

HAVING MY BOWEL ACTIONS AT A PREDICTABLE TIME

HAVING TIME TO ATTEND TO MY COLOSTOMY INTERMITTENTLY WHENEVER IT NEEDS IT

SPENDING ABOUT 40 MINUTES ONCE A DAY ATTENDING TO MY COLOSTOMY

HAVING A BAG ON MY ABDOMEN - SOMETIMES WITH BOWEL ACTION IN IT

TAKING MEDICINES TO CONTROL MY BOWEL ACTIONS

Do you have any comments or alterations to make?

You may recall that when I sent the initial letter one of the tasks was to calculate the probabilities for each of the management methods. Because this process of rounds of questionnaires is rather slow I have decided to use a different method to obtain opinions for that section. This means that this is the last round of questions for you in regard to this matter.

Thank you for your help. When the decision aid is fully developed and has been tested, I will let you know how it went. Again, please use the envelope provided and send it back within the week if possible.

Yours sincerely,

Julia Thompson.
APPENDIX TEN

During the course of the study aspects of the work were presented at various colloquia, research interest groups, seminars and conferences, the major presentations are listed below.


Thompson, J.M. (1995). Patient and nurse: mutuality in decision-making. Who is the expert on what?" Presented at a symposium on patient involvement in decision-making at 14th World Council of W.O.N.C.A. - the Association of Practitioners of Family Medicine, Hong Kong, 14-6-95.