

**THE BENEFITS OF HEALTH CARE BEYOND HEALTH: AN
EXPLORATION OF NON-HEALTH OUTCOMES OF HEALTH
CARE**

M. R. Haas

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Department of Public Health and Community Medicine

Faculty of Medicine

University of Sydney

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Preface

The sources of written information used in this thesis are the publicly available databases MEDLINE, CINAHL, PSYCHINFO and ECONLIT. Ethics approval for the research described and reported in Chapter 5 was obtained from the Central Sydney Area Health Service Ethics Review Committee and for that described and reported in Chapter 6 from the University of Sydney Human Ethics Committee. All research participants received written information sheets regarding the objectives and process of research and signed consent forms were received from all participants. I declare that the entire thesis is original work carried out by me, Marion Ruth Haas. None of the work carried out for this thesis has been submitted for any other degree.

Summary

Recent interest in identifying and measuring health outcomes represents an advance in our understanding of how health care for individuals should be evaluated. However, the concept of health outcomes has mainly focussed on improvements in health status. Non-health outcomes of health care may also be important to patients. In this thesis, four tasks were undertaken with the aim of identifying non-health outcomes and establishing the extent of their relevance and importance to patients. First, the illness experience literature was reviewed to identify potential non-health outcomes. Seven categories of non-health outcomes were identified: information, being treated with dignity, being able to trust the health care provider, having distress recognised and supported, participating in decision making, legitimisation and reassurance. Second, to gain an in-depth understanding of these concepts, topic-specific literature was reviewed and synthesised. Third, in order to confirm how relevant and important the concepts were to patients, a qualitative study was conducted with each of two different groups of health service users. Broadly, patients considered that all the non-health concepts were relevant, although the extent to which they were important varied. Fourth, to test the relative importance of the seven concepts, a Stated Preference Discrete Choice experiment in the context of general practice was conducted. This study showed that most people thought their GP demonstrated behaviour likely to result in the production of non-health outcomes. The results showed that although all the non-health outcomes were, to some extent, preferred by respondents, trust was most important, followed by legitimisation and recognition of and support for emotional distress. Once again, these results point to the importance of context in the evaluation of health care from the patient's perspective. While still being perceived as positive aspects of health care, the provision of information and acting autonomously or participating in decisions about their health care were the non-health outcomes considered least important by patients.

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Chapter 1

Introduction

Chapter 1 Introduction

1.1 Background

In the past 10-15 years, health care systems, services and programs across the developed world have focussed attention on the evaluation of outcomes of health care. Such evaluation (sometimes called the “outcomes movement”) has been conceptualised as involving the weighing up of the health gains and costs of health care programs and services so that outcomes valued by individuals and populations are maximised. Ideas of costs and outcomes are important as they raise questions of what is valued and what should count as an outcome, or as a positive outcome of health care.

The primary idea underpinning the health outcomes movement is that it is important to understand and evaluate health care using information from patients and other users of health care. In assessing the performance of health care systems, what should be counted is what individuals and populations get out of a service (in the case of individuals) and the system (in the case of populations). This idea is consonant with health system objectives articulated by both international and local organisations.

The World Health Organisation (WHO) lists three important goals for health systems: good health, the responsiveness of services to people’s needs; and fairness of financial contribution. [1]Similarly, NSW Health’s recently published “Strategic Directions for Health” recognises the importance of improving health outcomes, increasing responsiveness to consumers, efficiency and equity. [2]Such objectives suggest that these organisations recognise that users of care and the community value both health outcomes (health gains) and non-health outcomes (outcomes beyond health gains). If health care providers, both individuals and organisations, want to offer the type of health care needed and valued by

patients and other users (i.e. patient-centred health care), it is necessary to examine which aspects of care patients and other recipients of health care services consider relevant and important and which they prefer. Such evaluation requires an understanding of patients' experiences, an assessment of which aspects of care they consider important and an estimation of which combination of factors they prefer. The information generated by such an evaluation will allow planning and delivery of health care that reflects patients' values and, as such, their needs. This thesis aims to undertake such an evaluation.

In the remainder of this chapter, some reasons why health outcomes, evidence-based medicine and patient satisfaction do not fully meet the objective of patient or consumer responsiveness will be discussed. At the end of the chapter, the concept of non-health outcomes will be introduced and the reasons for and conduct of the research for the thesis presented. First, however, it is necessary to define how these terms are being used in this thesis.

- Health: Prior to any discussion of how health services affect the health of those who use them, it is important to define the meaning of health. The definition of health has changed over time and different meanings of the term have gained popularity over time and depending on the context in which they are used, the objective of defining the concept and the theoretical orientations of the user.
- Health outcomes: Health outcomes are changes to the health status of an individual or population which can be attributed to a particular treatment or intervention. Outcome measures are often those concerned with morbidity and mortality but have been measured most broadly as changes in health-related quality of life (HRQOL) and most narrowly as changes in clinical tests (e.g. blood pressure, cholesterol level).
- Evidence based medicine (also called evidence-based healthcare): EBM has as its focus the application of treatments or interventions for which there is evidence of more gain in

health outcomes than harm and (in theory) an acceptable relation between productivity and cost.

- Patient satisfaction: Patient satisfaction measures are an established method of assessing patients' perceptions of service quality. Although the measurement of patient satisfaction normally involves asking patients to rate the service they have received, its domain is narrowly defined, usually by providers or researchers rather than by patients themselves. The range of issues typically covered includes access, waiting times, hotel and other environmental issues, communication and technical quality of care. Patient satisfaction is normally measured using a questionnaire.
- Non-health outcomes: Non-health outcomes are effects (consequences) of health care which, while they may be directly related to clinical and/or health status (i.e. instrumentally), may also be valued by patients per se (i.e. in and of themselves).

1.2 Health

As the meaning of health is complex and subject to change, so is the definition. The importance of the meaning of health in relation to this work is in its relationship to health care and the impact of that care on health status, health outcomes and non-health outcomes. The medical definition has, explicitly or implicitly, been the most widely used in relation to the outcomes of health services although the World Health Organisation's (WHO) definition of health has been widely used outside of this narrow paradigm. Recently, recognition that health can have many components (depending on who is defining it and their aim in doing so) has led to the development of definitions that include medical, social and spiritual aspects of health. [3]One such definition is that developed by Australian Aborigines - "not just the physical well-being of an individual, but...the social, emotional and cultural well-being of the whole community in which each individual is able to achieve their full potential as a human being thereby bringing about the total well-being of their community. It is a

while-of-life view and includes the cyclical concept of life-death-life cycle” {(NAC-CHO), 1997 #680.

The changes to the definition can be partly explained by changes to how and why organised health care has operated. The dominance of the medical model of health, which can be defined as “the absence of disease or disability” comes from a time when care and (perhaps) cure were perceived as the only roles of doctors and other health care providers. It is also an extension of what has been called a “naturalist” concept of health [4] which holds that health, as freedom from disease, represents normal functioning where normal means as the body is designed to function. Thus, this definition of health can be seen to be related to the Cartesian notion of the body as a machine. [4] The definitions include mental as well as physical health and distinguish between disease, illness and function (these definitions will be discussed in some more detail in the literature review of the experience of illness (Chapter 2, p28).

Although health care is officially directed at illness (the individual’s perception that she or he is suffering), the emphasis of medicine on diagnostic tests and technological interventions suggests that it may place equal importance on attacking disease (a condition which can be attributed a specific, universally agreed diagnosis, in which the body’s structure or function is disturbed or deranged). There have been many criticisms of the medical model such as its lack of adaptability to emotional or psychiatric disorders, its lack of emphasis on preventing illness and promoting health and its ignorance of the social, cultural and economic factors which influence and mediate both the definition and expression of health and illness. [5, 6] However, it is still the model used in relation to most acute health care and has been important in defining and underpinning priorities for health research and the development of new ideas for health care.

Away from the confines of health care, the WHO definition of health has found much favour although it too has been criticised. The definition of health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” [5] represents a holistic model of health. Although criticised as being impossible to achieve and unmeasurable, the WHO definition has influenced many people and organisations interested in preventive health care and health promotion and, in time, many health care providers. One reason for its wider acceptance is that serious and successful attempts have been made to measure physical, mental and social health and the concepts have been found to be valid and reliable. [7] Subsequently, definitions of health have included physical and mental health but social health has been largely dropped as part of the meaning of health. This appears to be because social factors (defined as participation in social activities and interpersonal interaction) have been considered as external factors which influence health but should not be considered an independent dimension of health itself. [8]

Criticisms of the WHO definition (summarised by Larson), include:

- No definition of the meaning of well-being;
- Lack of awareness of cultural differences in the definition;
- Lack of awareness of the influence of social structure on social well-being; and
- The unrealistic idea that complete well-being is achievable. This may mean that most people are in constant need of health care or that the definition is ignored and the medical model favoured. [9]

A more recent definition of health has been termed the wellness model. In this model, health is defined as an internal experience or feeling that is either present or absent in individuals [10] or, more explicitly, as “optimal personal fitness for full, fruitful creative living”. [11]

In this definition, health is portrayed as being able to overcome illness by having a reserve of strength. The main criticism of the wellness model is the difficulty in measuring wellness which is a subjective concept and likely to vary with age, experience and cultural context. For example, a person may be healthy according to the medical model but perceive that they have a low level of well-being, which may manifest as a poor quality of life with which the individual is unhappy. [5] In relation to traditional outcomes of health care, the question which needs to be asked is whether happiness or perceived levels of quality of life affect an individual's response to a disease and therefore the care of disease? Or are there other potential outcomes of health care more in line with perceived happiness or quality of life which should be captured? These are legitimate research questions which, along with other questions of the extent to which health promotion is aided by addressing (for example), issues such as reserves of health, are underpinned by this definition of health.

The wellness model of health has been seen by some as representing an ideal. [9] A more practical concept of health is represented by an individual's perceived ability to adapt physically and mentally to the environment in which they live. [12] In this definition, health is related to all types of stresses and how individuals cope with this in terms of interacting with their environment. [13] Good health is represented as the product of "a harmonised relationship between man and his ecology". [14] A number of other authors have produced similar definitions which emphasise factors such as adjustment, balance, successful functioning within an environment and the ability to thrive. [11, 15] Illness is therefore defined as an inability to function and disability as the perception of a gap between an individual's ability and the demands of the environment. [16]

One important strength of the environmental definition of health is that its emphasis on balance allows for the outcomes of both health care and health promotion to be considered as relevant and important. Using this definition, the objective of health care is to restore the balance between an individual and his/her environment while that of health promotion is to prevent imbalance occurring. However, as with the wellness model, although the ideas such as balance and continuing adjustment are logical and appealing, there are obvious difficulties in identifying and measuring them, mainly because they are such broad concepts and are culturally specific. Further, care must be taken when using this definition to recognise the extent to which a characteristic feature of the human race has been their tendency to modify, transform or devastate their environment constantly and rapidly. Thus, it is unlikely that any individual will be in perfect balance with their environment at a particular time – at best, humans are likely to be adapted in terms of their health to a former environment which will only be partly existent when health is measured. [4]It also follows that it is a matter of opinion whether the body or the environment requires change to restore the required balance. It may be a matter of the relative dominance of either a natural science or a social science paradigm that will determine which change (to the body or the environment) is likely to be endorsed.

From the above it can be seen that, apart from the medical definition of health, the other definitions have been criticised for being too idealistic and therefore unmeasurable. Twaddle [9]has proposed that notions of health can be conceived as lying along a continuum where death (perfect disease) is at one extreme and ideal health (perfect health) is at the other. The point at which “normal” health lies along this continuum is decided by society, that is, it is determined by social norms. This, in turn, is determined by, for instance, society’s (current) attitude to the environment and the extent to which health technology is seen to be desirable, that is, the values of the time.

1.3 Health outcomes and evidence based medicine

There is a substantial literature on the benefits and methods of measuring the extent to which health care produces changes in health; [17]. [18] [19-23]Indeed, one of the most impressive advances of the outcomes movement has been an expansion in the number and type of health outcomes that providers, managers and funders of health care are willing to consider. [17]Such outcomes as functional status, emotional health, social interaction, cognitive function and degree of disability extend the definition of outcomes far beyond clinical signs and symptoms. However, they all assume that the only benefits of health valued by patients are those directly related to health status or health gain.

Much of the growth in the measurement of health outcomes can be attributed to an increasing awareness of the need for evidence-based health care. The search for evidence aims to identify and measure the processes of care or interventions which are most likely to lead to positive changes in health status; [24] [25-29]Again the emphasis is on changes to health, with the result that the evidence is limited by what has been researched or agreed by experts (and so, to some extent on what is considered “worthwhile” to investigate) and is largely restricted to the “technical” process of care, such as which procedures or drugs to use. The most valuable evidence is considered to be that generated by randomised controlled trials (RCTs). However, inclusion in RCTs is usually limited to individuals who fulfill strictly defined criteria, thus excluding the majority of patients who have social or health-related characteristics which are considered likely to reduce the power of the study. [20]Therefore, the focus of evidence-based health care - offering clinicians the best available information about diagnosis and treatment for an “average” patient - cannot take into account individual factors (e.g. social and emotional) governing a particular patient’s health or his or her needs or preferences. [24]In addition, the evidence-based approach is centred

on the needs and values of health care professionals, because it focuses on the expert's interpretation of the evidence and may not capture all that is relevant to the needs and values of patients. [30]

The emphasis on outcomes can be seen as a logical component of a "quality cycle" in health care which includes baseline measures of patient status, monitoring of progress and finally the measurement of what the care has achieved (the outcomes of care). [17] Ideally, feedback is then used to improve the structure of health care services and the processes they employ to care for patients, with improvements in these two areas expected to result in improved outcomes for patients. Thus, the outcomes movement has claimed to be a patient-centred process of improving the way health care is delivered. However, the extent to which the measures of outcome commonly used reflect the preferences and values of patients has been questioned;. [20, 31, 32]

1.4 Patient satisfaction

It is widely recognised that understanding the patient's perspective on the processes and outcomes of care is an important issue in the evaluation of health care. [33, 34] Health care funders, managers, planners and providers have sought patients' opinions on or their evaluations of care for a number of reasons: as part of a desire to improve accountability; to identify deficiencies; to raise the standard and quality of care; to improve responsiveness to consumers; to monitor health care seeking behaviour; to improve patient compliance with care; and to improve outcomes of care;. [35-38]

For the purposes of health care evaluation, the concept of patient satisfaction has been proposed as an appropriate measure of health outcome from the patient's perspective.;;;;; [39]; [36]. [40] [41-45] The objectives of measuring patient satisfaction have been described

as being to:

- describe health care from the patient's perspective;
- measure the extent to which the process of care meets the objectives of care; and
- measure the extent to which the process of care is related to the outcomes of care. [46]

However, as will be discussed in detail in Chapter 2, it is questionable whether the measurement of patient satisfaction fulfills these goals. While patient satisfaction might, on the surface, have an agreed meaning, when the detail of the concept is examined, it appears to have different connotations for different people. In addition, the concept of patient satisfaction is not unidimensional and contains several sometimes disparate elements, which, depending on how it is operationalised and measured, may lead to different results.

1.5 Non-health outcomes

While health gains (improvements in the health status of individuals) are likely to be very important to patients, to restrict the definition of benefits to health gains alone would be to adopt an unnecessarily narrow view of what health care might be expected to produce or achieve. Moreover, it seems unlikely that patients and health care professionals will use exactly the same criteria to judge success; what health professionals think of as improvements may be neither relevant nor important to patients. [47]For example, while the outcome of screening programs for genetically inherited diseases or defects has traditionally been measured as the number of affected births prevented, women or couples being screened may also perceive increased information, the ability to make a better-informed choice or even the chance to be screened as relevant and important outcomes of a screening program;. [48, 49]Similarly, a person with a chronic disease may consider that, in addition to health outcomes such as preventing deterioration or enhancing physical function, benefits such as receiving reassurance or being able to trust his or her doctor are just as relevant and important;. [50, 51]2000 #450].

In addition, the process of care may produce a series of effects which, while not health outcomes, are part of what happens as a result of health care. These non-health outcomes are increasingly being recognised as important to patients and may be included among the objectives of a health care service or system. For example, in NSW, a recently released document lists as objectives the desire that health care will produce a number of non-health outcomes for individuals, including being able to make decisions about their own care, receiving information upon which to base decisions about their health management, being able to provide feedback and being able to make complaints. [2] In terms of the evaluation of health care, health and non-health outcomes (intentionally or unintentionally produced) are outputs of the production of health care and inputs to the production of health, utility and/or well-being. Utility is a word used by economists which represents an abstract measure of the satisfaction or happiness a consumer receives from a bundle of goods – that is, a consumer is likely to prefer a bundle or combination of goods which provides more utility than an alternative bundle or combination. [52]

While there is little doubt that health outcomes are important to and valued by patients, the definition and measurement of a broad range of outcomes (i.e. both health and non-health outcomes), has been somewhat limited. While progress has been made in developing and using measures of health outcomes and health status indices to measure changes, other potential benefits to patients or recipients of care such as knowledge gained, the ability to choose or satisfaction with care have not been subject to rigorous investigation, in terms of their importance or value to individuals. [20] The result has been that, to a large extent, health outcomes are regarded as the only legitimate outcomes of health care. Even where non-health changes are produced intentionally, (e.g. ensuring that patients are well-informed or reassured may be some of a service's objectives), changes to these outcomes are not always measured as part of the evaluation of the service.

1.6 The need for research into non-health outcomes

Hence, the importance and value of aspects of non-health outcomes have not been examined in a systematic way. The fundamental questions that will be addressed in the thesis are:

- What non-health outcomes of health care are relevant to patients?
- What non-health outcomes of health care do patients consider important?
- What non-health outcomes of health care do patients prefer?

Relevance refers to the extent that a concept is considered applicable or germane to the topic. Importance concerns the idea that a concept carries weight, that it is significant to an individual. Preferences involve the identification of the relative importance of one concept to another. Thus, an individual may consider a particular non-health outcome to be relevant to health care, but not classify it as important. The same person would be unlikely to prefer the same non-health outcome to all or even most others. At the other end of the spectrum, another individual may consider the same non-health outcome to be both relevant and important and prefer it to others.

In the remainder of this thesis, the conduct and results of an evaluation of the non-health outcomes of health care are reported. An interdisciplinary approach will be used to examine the questions listed above. Such an approach is necessary for methodological reasons as well as to do justice to the numerous theoretical and disciplinary frameworks in which work to date on non-health outcomes has been conducted. At this stage, it is important to note that the evaluation of health care is being considered as it occurs at a personal (i.e. patient or client) level. That is, the thesis does not consider the implications of the production of health or non-health outcomes from a societal perspective and outcomes which can be conceptualised as occurring at a social level (e.g. social capital or equity) are not considered.

In the first section, consisting of Chapters Two and Three, a number of theoretical and conceptual issues concerning non-health outcomes are outlined. In Chapter Two, a synthesis of the literature reporting on the relevance and importance of non-health outcomes for patients and a non-statistical cluster analysis of this literature is presented. This is followed by a critical discussion of previous work in identifying and measuring patients' perspectives, including non-health outcomes. In particular, the concept and measurement of patient satisfaction will be examined. In Chapter Three a different set of literature is used to identify each of the concepts from the previous chapter and to review their use in health care research. A proposed typology or framework of how such non-health concepts are experienced by patients and their relationship to health outcomes is described at the conclusion of the first section of the thesis.

The second section of the thesis consists of Chapters Four, Five, Six and Seven. In Chapter Four the methodological means by which the typology will be examined empirically is presented. Justification for the use of both qualitative and quantitative research methods will be advanced. In particular, the use of qualitative methods to assess the relevance and importance of non-health outcomes and the quantitative methods to examine patients' preferences for these non-health outcomes will be presented. The results of the empirical work are presented in Chapters Five and Six. Firstly, the results of a study exploring the relevance and importance of non-health outcomes with two groups of people – people with chronic renal failure and women in the age range recommended for cervical screening - are reported. Secondly, Chapter Six reports on the use of Stated Preference Discrete Choice Modelling (SPDCM) to elicit the preferences of health care consumers for the chosen non-health outcomes of health care in relation to their decisions about attending a general practitioner. The final chapter (Chapter Seven) concludes the thesis with a general discussion about the following: the applicability of the typology outlined in Part One to the

results of the subsequent empirical studies; the feasibility of using qualitative and quantitative methods to gauge what patients want from health care (i.e. what they think is pertinent and significant and what they prefer); the relationship of these findings to those of other published studies; and the implications of the results for the measurement of the outcomes of health care.

PART ONE

IDENTIFYING NON-HEALTH OUTCOMES IN THE LITERATURE AND EXAMINING THEORETICAL AND CONCEPTUAL ASPECTS OF NON-HEALTH OUTCOMES

Chapter 2

Identifying non-health outcomes in the literature

Chapter 2 Identifying non-health outcomes in the literature

2.1 Introduction

To set the scene for the studies conducted as part of the proposed research into non-health outcomes of health care, this chapter will draw together evidence from the literature about the relevance and importance of non-health outcomes to patients and some strands of previous research which had as their broad goal an improved understanding of the processes and outcomes of health care from the patient's or recipient of care's perspective.

First, the results of a search for evidence about the relevance and importance to patients of non-health outcomes are reported. This is followed by a critique of the extent to which health outcomes and measures of patient satisfaction in particular have included the non-health outcomes identified in the literature. Potential solutions to the problems of identification and measurement are outlined at the end of the chapter.

2.2 Identifying potential non-health outcomes in the literature

2.2.1 Introduction

Previously, much of the evidence for the relevance and importance of non-health outcomes has come from literature which, while based on research developed and implemented with the best interests of patients in mind, has not generally been explicitly undertaken from the patient's perspective. However, the "illness experience" literature and articles and books written by patients about their health and health care are potential sources of information which originate from patients' experiences. Both sources were used to inform the tasks reported on in this chapter. First, the conduct and results of a broad literature review are described. Then a non-statistical cluster analysis (also called typologising) [53] is used to identify non-health outcomes from the literature. Finally, seven concepts which emerged from the synthesis of this research are identified and described briefly.

There is a long history of sociological and anthropological inquiry regarding the sick role and the role of the patient. It is within this literature that research regarding illness experience has been conducted and this research largely falls within that literature. Before discussing the literature in general, it is appropriate to define disease and illness more thoroughly. Both brief and detailed definitions have been proposed. For example, Susser [54] has proposed that:

- Disease is a physiological/psychological dysfunction; and
- Illness is a subjective state of the person who feels aware of not being well.

Broader definitions have been proposed by Kleinman and colleagues [55] who suggested that:

- Diseases are abnormalities in the structure and function of body organs and symptoms. They are biophysical events and the prime concern of medical practitioners; and
- Illness refers to experiences of disvalued changes in states of being and includes how the sick person and members of the family or wider social network perceive, live with and respond to symptoms and disability.

Margolis [56] has suggested that disease is a morbid or abnormal state of some sort, defective or deranged in relation to some condition of healthy functioning even if there is no complaint or complainant while illness is best described as disease states palpable to the patient in virtue of his or her symptoms.

The most famous thinker on the sick role was Parsons [57] who related illness not only to biology but to its role in changing a person's ability to function at work and in the wider community (their social roles). Parson's central premise is that the

presence of illness (and its biological, functional and social implications) must be sanctioned by the medical profession who are the gatekeepers of the social norms and values prevailing in any society. If society, through doctors, determines that an individual's illness is acceptable as such, it also acknowledges that person as being sick. In this way, being sick is a social category. One of Parson's most notable contributions to the issue of being ill and adopting a sick role was his notion that in doing so, an individual has certain rights and obligations. Being accepted as sick, meant, according to Parsons, that a person has the two rights: to forego his or her normal social obligations (e.g. at work or home) and to not be held responsible for the illness; and two obligations: to get well and to seek and cooperate with medical assistance.

However, other researchers have pointed out that many (perhaps most) experiences of illness are never seen by a medical practitioner. Instead, individuals rely on previous experience or the advice of non-medical family members and/or friends to cope or treat the symptoms. [58] Such advice may ultimately lead to a consultation with a medical practitioner but it also serves to legitimise the illness in the eyes of non-medical or lay people. Friedson, [59] argues that the extent to which a person is allowed by society to take on a sick role depends on the seriousness of the illness (or disease) and its perceived legitimacy. If an illness is perceived as temporary (ie treatable illness where a person could be expected to recover) an individual's sick role, and hence the legitimacy of the benefits associated with it, is termed "conditional"; if the illness is incurable, the role is described as "unconditionally legitimate" because getting well is seen to be beyond an individual's control; and where the illness is not accepted as legitimate (or is stigmatised), the role is termed "illegitimate". It is important to note that which individuals and illnesses are categorised in these ways are both societally- and historically- specific. For example, mental illness has moved from being illegitimate in the eyes of many

to being either conditional (e.g. if it is considered that a person with depression could and should be treated) or unconditionally legitimate (e.g. schizophrenia is now regarded as a chronic condition which can be treated but not cured).

A major finding from the illness experience literature is that patients conceive of or conceptualise illness differently from doctors and other health care professionals. [60] While patients attend to pain, discomfort, interference with function and an overall sense of well-being, health care professionals tune into the logic of making a diagnosis, searching for learned, consistent patterns of symptoms which may indicate an underlying disease state. How and why patients respond to their perceptions of illness depends on the context in which they live and work. Thus, the environment in which patients have learned about illness and disease is much more variable than the medical, nursing and allied health professional training undertaken by those who diagnose and treat disease. Yet, individuals are able to accurately appraise their own state of health as exemplified by the high level of correlation between self-assessed health status and future care-seeking, disability and mortality. [61] Why this should be so is not known.

The historical inattention to illness relative to disease has been suggested as contributing to patient non-compliance with treatment, patient and family dissatisfaction with traditional health care, rising numbers of legal claims relating to medical malpractice, mounting consumer criticism and increasing reliance on non-traditional health care (alternative medicine). [55]

The importance of this body of work for the research reported in this thesis is that taking account of patients' perceptions of illness as well as more traditional medically-based notions of disease allows consideration of the importance of factors which impact on

alleviation, control and containment of symptoms and prevention of secondary conditions and disabilities rather than only cure. [60]The recognition that health care professionals have many opportunities to assist individuals beyond traditional patterns of care is evidenced by an increasing emphasis on evaluating patient-focussed outcomes, functional outcomes and satisfaction with care. There is also widespread interest in understanding why people consult health care professionals for healing rather than cure and in identifying, measuring and valuing the psychosocial aspects of care and in implementing illness interventions alongside interventions aimed at diseases. [55, 60]

2.2.2 Methods

A literature search was conducted on MEDLINE, CINAHL, PSYCHINFO and ECONLIT using key word combinations of the following: health care, patient, responses, perceptions, perspective and quality. In addition, the relevant chapters of eight books were identified. The references of each of the articles and books were scanned for additional literature. Each of the articles and chapters was read by the candidate and a decision was made to include it if it met one or more of the following criteria:

- focussed on the patient's or user's perspective;
- discussed theoretical or empirical work about one or more non-health outcomes of care;
- used qualitative research methods to investigate non-health outcomes empirically;
- was a personal description of an individual's own experiences with health care, including their perceptions of relevant and important non-health outcomes.

As the articles and books were read, separate lists of health and non-health aspects or outcomes of health care were created for different health care settings or types of care discussed in the article or book. A non-statistical cluster analysis was then used to group the identified consequences of health care into interrelated sub-groups. Cluster analysis involves

a search for similar patterns and characteristics in the data and the sorting of elements of data into categories;. [62, 63]Along the same lines, typologising is a method of grouping ideas to form ideal types which have similar characteristics. [53]The formation of categories or types assists in making sense of abstract and/or complex ideas. The candidate and another researcher undertook the cluster analysis of the initial list of items. The aim of the analysis was to group items on the list which appeared to have shared or similar meanings. The first step was to remove items which were clearly health outcomes. Then, items which clearly had similar meanings were grouped together in clusters. Thus, for example, information and knowledge (preventive care), understanding terminology and hospital rituals (acute care), understanding the cause (cancer), information regarding progress and advice regarding coping (rehabilitation following stroke) and adequate, timely and reliable information (general care) were grouped together. The final step was to name the clusters (see Table 2).

2.2.3 Results

In total, 70 articles, books and book chapters were identified. Of these, 33 were excluded because they did not meet the inclusion criteria. Fifteen were excluded because they did not include qualitative research as part of the empirical work undertaken or reported, 10 were excluded because they did not represent patients' perspectives and 8 did not discuss non-health outcomes. A wide range of health care settings were discussed or evaluated. Twenty-nine (78%) of the included sources of information reported the results of empirical work. The remaining eight articles all used references to empirical work to discuss the feasibility or desirability of using non-health outcomes in the evaluation of health care. Twelve articles featured a general discussion of health and non-health outcomes from the patient's perspective; [64]; [65]; [66]; [67]; [68]; [69]. [70] [71-75]

Table 1 shows the country of origin of the article or book, characteristics of the patients involved, the methods used and the type/s of care covered. Nearly twice as many articles

(15) covered non-health outcomes for one or more chronic conditions compared with the number discussing non-health outcomes in relation to acute care (8).

Table 1. General characteristics of the 37 included articles and books

Country of origin	USA (16); UK (13); Europe (7); Australia (1)
Patient characteristics	Adults, men and women except for 1 article on breast cancer
Characteristics of methods used	Sample sizes: range 8-94 for individual-based methods such as interviews; 63-66 for focus group-based research. Respondents were recipients of care and their relatives. Usually, only one non-health concept was described/investigated.
Types of care	Number of articles/books
General care	5
Acute care	8
Chronic care	16
Care of the elderly	1
Cancer care	3
Screening	2
Psychiatric care	2

The non-health aspects of health care discussed in the articles are listed by type of care in Table 2. In this table, services described as screening services have been expanded into preventive and diagnostic services and services for chronic conditions have been expanded into chronic care, rehabilitation for stroke and palliative care services.

Table 2. Non-health aspects of care by type of care as discussed in the 37 included articles and books

Type of care	Benefits (positive)	Limitations (negative)
Preventive care	Relief Reassurance Avoidance of distress Information and knowledge Changes in function (sexual, social, family) Input to decision making	Anxiety Stress Depression Guilt Regret Disappointment Distress
Diagnostic services	Understanding, Reassurance Having result	Non-understanding Anxiety Uncertainty
Acute care	Input to decision making Understanding terminology Understanding purpose of hospital rituals Successful recovery Accessible and specific information Reassurance	Disempowerment Anxiety Anger Dependency, loss of control Social isolation Lack of therapy Lack of assistance with self-care

Cancer	Understanding the cause Sharing decisions and “the fight” Helpful communication Psychosocial function	Shock Horror Fear Helplessness Anger Despair Grief Depression Unhelpful communication
Chronic conditions	Having illness verified (certainty) Legitimation Understanding the cause Appraisal of options (choice) Discussion and advice Information and knowledge Given confidence in ability to cope Being cared for (personal interest in welfare) Being in control Reassurance about skills Ability to devise own regime, prepare, plan for care Trust Hope Improvement in social, sexual image and function (coping)	Being labelled Non-legitimation Anxiety Unrealistic hope Unnecessary tests
Rehabilitation (following stroke)	Social/family adjustment and participation Emotional well-being Confidence in ability Information re progress Advice re coping Involvement of carers/supporters Facilitated independence Self-direction. Personal autonomy	Lack of therapy Unhelpful communication Non-involvement of carers/supporters Fear Anxiety
Palliative Care	Information Hope Being cared for	
General Care	Trust in providers Honesty and fairness in provision of care Participation in decisions Intuitive care Individualised care Enhanced self-awareness Adequate, reliable, timely information Facilitating independence	Incompetent care Inconsistent or lack of information Non-involvement in decisions Lack of respect Lack of professionalism Being mechanical, doing the minimum Rushing, being “over-efficient”
Psychiatric care	Empathy Listening Trust Respect in provision of care Information	

Many process and non-health consequences or outcomes of care were identified and/or measured in evaluations of health care from the patients’ perspectives. In most areas of care, consequences such as information, knowledge, reassurance, input to decision

making/sharing decision making and anxiety appeared, either as positive or negative aspects or (rarely) as both.

A few consequences were listed only in respect of one area of health care. Examples include successful recovery (as judged by the patient) which was only mentioned in connection with acute services (e.g. surgery) and relief and guilt which were listed as consequences of screening programs. However, some consequences were mentioned in relation to more than one, but not all areas of health care. An emphasis on psychosocial function and helpful/unhelpful communication as outcomes were aspects mentioned in connection with the evaluation of screening, cancer care and rehabilitation services. Choice, legitimation, being labelled, unrealistic hope, the ability to devise the patient's own regime and being cared for were identified as consequences of care for chronic disease, disability and palliative care services and lack of therapy was mentioned in connection with acute and rehabilitation care.

Some non-health consequences overlap with or are very similar to each other. For example *choice* overlaps with or is implicit in *being involved in decision making* and *discussion and advice* may also fall within this category. *Knowledge* and *understanding* are very similar concepts and there are many aspects to understanding which are specific to the type of care being considered (i.e. understanding of what). *Being cared for* may include, among other things, individualised care, empathy, listening and respect. The extent of overlap and similarity of meaning between many of the listed consequences of care led to the decision to undertake the cluster analysis.

Most of the consequences identified in the literature are positive. That is, they are regarded as beneficial outcomes of care. For example, reassurance is the act of restoring an

individual's confidence and autonomy is immunity from the arbitrary exercise of authority. However, the presence of emotional distress (i.e. disappointment, regret, shock, despair, horror, grief, anger and guilt) is a reminder that there are some consequences that are less positive than others. This is not to say that attempts should always be made to avoid them; while unpleasant, they may be inevitable and ultimately necessary and useful for many people to experience as they learn to cope with an illness or a disability. Information and knowledge are usually regarded as positive consequences, that is, as benefits of health care. However reducing a patient's uncertainty and increasing their understanding, learning and reasoning may not all be positive as patients may experience some negative reactions in response to changes in information and knowledge. In Table 3, items are grouped in the major categories to which they were assigned by the cluster analysis. Items in italics are ones described in the literature as a being a negative outcome of health care.

Table 3. Grouped items of non-health aspects of care

Reassurance	Information and knowledge	Participation in decision making	(Recognition of and support for) emotional distress	Being able to trust provider	Being treated with dignity	Legitimation
Knowledge Having test result Certainty Good communication Given confidence in ability to cope Hope <i>Uncertainty</i> <i>Unrealistic hope</i>	Understanding of illness and care Having test result Good communication Choice Appraisal of options Empathy <i>Not understanding</i> <i>Poor communication</i>	Input to decision making Shared responsibility Sharing the 'fight' Good communication Appraisal of options Choice Advice Being in control Facilitated independence <i>Disempowerment</i> <i>Dependency</i> <i>Loss of control</i> <i>Poor communication</i> <i>Helplessness</i>	Enhanced self-awareness <i>Disappointment</i> <i>Regret</i> <i>Shock</i> <i>Horror</i> <i>Despair</i> <i>Grief</i> <i>Anger</i> <i>Guilt</i>	Trust	Personal interest in welfare Being cared for Individualised care <i>Lack of respect</i> <i>Lack of professionalism</i>	Certainty <i>Being labelled</i>

Thus, the inference to be drawn from the literature reviewed so far is that the aim of health care professionals should be to provide care which is most likely to maximise the positive and minimise the negative non-health outcomes of care for patients. By behaving in ways

which result in the production of a combination of preferred non-health outcomes, health care professionals increase the likelihood that health care will be acceptable to patients and consumers, will enhance its effectiveness through increased compliance and promote the patient's concerns and interests through acting humanely and ethically. The cluster analysis produced ten groups of items which are listed and briefly described in Table 4.

Table 4. Potential non-health outcomes

Outcome	Description
Autonomy/participation in decision making	Independent decision making (i.e. free from unwanted influences).
Being treated with dignity	Being treated as a person of worth, high standing or as one whose values are esteemed.
Recognition of and support for emotional distress	Health care professional empathises with less severe aspects of distress which are often considered "normal" in coping with the diagnosis and treatment of medical conditions.
Function	Being able to perform usual activities.
Information and knowledge	The provision of information which increases understanding.
Legitimation	Having ideas, feelings and perceptions about ill-health validated.
Pathological distress	Distress (e.g. depression, anxiety) which is severe enough to be clinically recognised and measured.
Reassurance	Health care professional provides a response designed to restore confidence and reduce anxiety.
Relief	Respite from physical and/or psychological symptoms of illness.
Trust in health care provider	Belief or confidence in the honesty, integrity, reliability and justice of health care professional.

In the second phase of the cluster analysis, it was decided that the items listed under the labels relief, function and pathological distress could be considered health outcomes and these were removed from the analysis. This left seven items: reassurance, information and knowledge, autonomy/participation in decision making, recognition of and support for emotional distress, trust in health care provider, being treated with dignity and legitimation. Table 5 shows, within each care type, which non-health outcomes were identified and/or discussed.

Table 5. Number of articles (% of total in each type of care) describing non-health outcome by type of care

Type of care	Non-health concept						
	<i>Information</i>	<i>Participation in decision making</i>	<i>Support for emotional distress</i>	<i>Treated with dignity</i>	<i>Reassurance</i>	<i>Being able to trust provider</i>	<i>Legitimation</i>
<i>General</i>	1 (25)	1 (25)	2 (50)				
<i>Acute</i>	8 (100)	4 (50)	6 (75)	3 (37.5)	3 (37.5)	1 (12.5)	
<i>Chronic</i>	9 (60)	11 (73)	6 (40)	1 (7)	4 (27)	3 (20)	4 (27)
<i>Elderly</i>			1 (100)			1 (100)	
<i>Cancer</i>	2 (66)	1 (33)	3 (100)	1 (33)		1 (33)	
<i>Screening</i>	1 (50)	1 (50)	2 (100)			1 (50)	1 (50)
<i>Psych.</i>	1 (50)	1 (50)	1 (50)	1 (50)		1(50)	1 (50)

Note: Articles may describe more than one non-health concept.

2.2.4 Conclusion

The results of this preliminary examination of the evidence for non-health outcomes indicate that there are a number of potential outcomes apart from health outcomes which patients consider important. Some of the non-health consequences, particularly those described as limitations of care, are difficult to separate from the outcomes of the diagnosis or of the illness itself. For example, many of the outcomes listed in relation to preventive care and cancer care such as anxiety, shock, fear and anger may be as much a reaction to the results of a test or to confirmation of the illness as they are to the care itself. Because of the nature of ill-health and health care, it may be impossible to completely separate the consequences of the illness from those of the care in many circumstances. However, the consequences identified represent a potential set of non-health outcomes which are important to patients. That is, they may form part of the bundle of health care goods that consumers prefer.

If the literature shows that patients consider non-health outcomes as potentially important enough to consider including them in any evaluation of health care, it is important to understand the extent to which they are currently part of such evaluations. The next section

(Section 2.3.1) describes the extent to which non-health outcomes have been included in the

measurement of health outcomes, particularly health-related quality of life (HRQOL). In the following section (Section 2.3.2), the emphasis is on a critical evaluation of the concept of patient satisfaction, as it is the measure most commonly used to evaluate health care from the patient's perspective.

2.3 Critique of health outcomes, including HRQOL and patient satisfaction in relation to non-health outcomes

2.3.1 Health outcomes and HRQOL

The “father” of the quality movement, Donabedian, [76] introduced the idea of evaluating the quality of care by assessing the standards of three factors– structure, process and outcome. The assessment of structure has been translated into standards for facilities and amenities, including hotel services and staffing. Process was traditionally assessed by observing standards set and included such issues as infection control, patient and staff accidents and discharge processes, auditing the type and amount of care given for a particular condition against an industry standard, technical competence, access and waiting times. More recently, quality of care has been assessed using comparisons of written or observed practice with detailed procedures and protocols for care, including care plans, pathways and benchmarks, many of which have been developed using evidence from research. According to Donabedian, [76] who regarded the assessment of the quality of care as the most valid form of evaluation, examining the quality of care also included assessing outcomes of care, which he defined as “the effects of care on the health status of patients and the population”. Donabedian included changes in a patient's behaviour, knowledge and satisfaction with care in his definition of health status. However, while measures of patient satisfaction are widely included in the assessment of the quality of care, it is less common to include behavioural changes as part of such assessment.

Changes to an individual's health (status) are important outcomes of health care for patients. For example, cure, relief from pain or improvement in function are significant outcomes, particularly of acute care interventions or services. Improvements in quality of life are also well-recognised outcomes of care which came to the fore in health care as care for chronic diseases improved. Particularly in the case of cancer, improved treatment resulted in much longer survival for many people who, prior to advances in care, could have expected to die within a relatively short time of their diagnosis. As the advances in care were largely due to the use of chemotherapy and radiotherapy, both of which produce side effects, it became obvious that people living longer might not always be doing so in full health. Thus, HRQOL measures were developed to take account of the effects of treatment on the quality of life of patients.

Although there is no standard definition of HRQOL, over time, the domains or dimensions of HRQOL have come to include physical, psychological, social and functional factors. HRQOL measures have been used to identify changes in quality of life resulting from disease and/or treatment, to defend or dispute various therapies and to choose between therapies for a particular disease. [77]Because of their use in addressing these issues, HRQOL measures largely reflect the priorities of clinicians, that is, they are disease-oriented. That these priorities are not necessarily the same as those of patients has been illustrated by Woodend et al, [78]who showed that cardiac outpatients and staff of a hospital cardiac unit ranked aspects of quality of life very differently. For example, on a scale from 1 to 26, staff rated depression (1), chest pain (3) and medical complications (7) much higher than patients did (15, 22 and 19 respectively), while patients ranked side effects of medications (9) much higher than staff did (17). In another study, [79]women with metastatic breast cancer ranked the relative importance of items concerning general health and disease. General health items such as mobility, family relationships and physical activity

were ranked higher than disease-specific items. Thus, it seems that HRQOL measures may capture neither the breadth of experience of patients nor their perception even of health outcomes let alone any indication of the relative importance of their experiences of illness and health care.

In addition to improving health outcomes, including HRQOL, health services or programs may have aims such as preventing ill-health (e.g. by offering screening), or maintaining good health (e.g. by preventing deterioration of chronic conditions such as diabetes) or providing palliative care. Screening, while producing positive health gains at a population level, results in negligible immediate improvements in health for the individual. Being screened, however, may involve processes such as providing information or reassurance which aim to produce outcomes for patients (e.g. a better informed patient or a reassured patient). While outcomes of care for chronic conditions and palliative care may not be as easily defined as gains in health, they may be able to be measured in terms of maintenance of health or prevention of deterioration in health. In addition, if other aspects of the health service or program are relevant and important to patients, for example being provided with information, being supported emotionally or being treated with respect and dignity, they should be considered as potential outcomes and therefore measured in any evaluation of the program or service.

2.3.2 Patient satisfaction

Measures of patient satisfaction have been developed primarily so that patients could furnish health care providers and services with feedback on the quality of health care provided to them. Particularly in relation to chronic illness, patients are an essential source of data about how a health care provider or service functions. [80]Although the proponents of patient satisfaction are rarely explicit about the purpose of measuring patient satisfaction, its

measurement can be observed to have one or more aims. Measuring patient satisfaction may be considered to be part of the acquisition by health care services of descriptions of the experiences and perceptions of patients and the community. Such feedback could be used to modify existing services and/or plan new ones). [81]It may be employed as a measure of the quality of the process of care and used to identify problems and suggest solutions. [76]Patient satisfaction has also been used to compare different health care programs or systems, to identify which aspects of a service need to be changed to improve patient satisfaction and to assist organisations in identifying customers likely to choose not to return. [82]Finally, in its most recent metamorphosis, patient satisfaction has been proposed as a measure (from the patient's perspective) of the outcome of care;. [36, 40]Those who measure patient satisfaction do so in the expectation of acquiring knowledge about individual consumer's opinions of and preferences for aspects of health care services which can be used to improve the organisation and delivery of care, thus making health care more responsive to consumers. [37]However, the theoretical underpinnings of the concept of patient satisfaction are under- developed and the framework within which patient satisfaction has evolved is considered by some to be in need of review and overhaul;;. [35, 37, 38, 43]

2.3.3 What is patient satisfaction?

i) Where did the notion of patient satisfaction come from?

Patient satisfaction has its roots in ideas of consumer satisfaction, dissatisfaction and complaining behaviour which, in turn, began with concerns over the extent to which buyers should be protected from sellers. [83]Increased interest in the measurement of patient satisfaction has been directly influenced by the rise of consumerism with its emphasis on creating a customer service-oriented culture and on promoting individual choices and preferences;. [46, 80]

ii) How has patient satisfaction been conceptualised and operationalised?

The dominant definitions of consumer satisfaction involve comparison of what is expected with what is actually received. [84]That is, a consumer is satisfied if he or she receives what was expected. When reality is not as good as expected, dissatisfaction results. A related definition involves comparing outcomes to a standard derived from experience. [85]That is, consumers use experience to develop a standard expectation, or a notion of what they should receive from a good, brand or service and satisfaction (dissatisfaction) occurs if the actual outcome is the same (different) from the standard expectation. Although the dominant definitions appear to work well in most everyday consumer contexts, alternative definitions have been developed for specific conditions in which they will apply as well if not better than the dominant ones. For example, the normative deficit definition compares outcomes to what is culturally acceptable, [84]the equity definition compares gains as part of a social exchange (i.e. if the gains are unequal, the loser is dissatisfied; [86, 87]and the procedural fairness definition holds that satisfaction results from a perception that the outcome has been received as a result of being treated fairly. [88]

The interpretation of the results of measuring patient satisfaction has implicitly accepted the dominant definitions. Thus, most measures of patient satisfaction assume that patients have prior beliefs or expectations about health care and that they will use these expectations to evaluate their care. [42]The degree to which patients are satisfied or dissatisfied with the health care they receive has been thought to influence whether a person seeks medical care, reveals important information, complies with treatment and maintains a relationship with a health care professional;. [45, 89]Each of these factors separately can be seen to be important if individuals are to receive care at the right time, if good communication between patient and provider is to be established so that treatment and any necessary follow-up can

be organised and enough trust is present that the patient will comply with the recommended treatment. However, the factors individual patients use to decide the extent to which they are satisfied remain largely unknown. [82] That is, the attributes which individuals use to decide their level of satisfaction have not been investigated; thus, the relative importance of individual factors has not been assessed.

The most common tool used to measure satisfaction is a self-administered questionnaire. [36] A number of universal (or generic) measures of patient satisfaction have been produced. [36] In addition, many health care providers and services have developed measures specifically designed to evaluate local practices and policies. Although the emphasis on individual attributes varies depending on the setting (e.g. public versus private facility, doctor's surgery versus hospital), at a minimum most measures of patient satisfaction attempt to capture the respondent's impression or evaluation of the environmental and structural features of the care, the extent of accessibility and convenience, and interpersonal relationships with and clinical competence of staff (including information provision and communication). Some measures include items regarding charges, continuity of care and outcomes of care. A range of questionnaire techniques is employed for patient satisfaction surveys. Many surveys list the factors patients are to assess and then ask respondents to indicate on a Likert scale the extent to which they were satisfied with a particular aspect of care, hospital or hotel services. Other surveys use a combination of closed and open-ended questions.

2.3.4 Criticisms of patient satisfaction

Criticisms have been levelled at the concept of patient satisfaction as well as at the methodology, interpretation and use of patient satisfaction tools.

i) Problems with the concept

As Sitzia and Wood [46] point out, it is logical to assume that some discussion about and resolution of the conceptual and theoretical issues of a construct (such as patient satisfaction) have been achieved before measurement problems are tackled and the ideas tested empirically. However, this sequence of events has not occurred in relation to measuring patient satisfaction. Despite its acceptance by health care providers and managers as a measure of quality of care, patient satisfaction lacks a solid conceptual base;. [37, 38, 46] Until the meaning of satisfaction is explicitly defined, the tools used to measure it and the results produced will be open to criticism on the grounds that the patients' perspectives gained may be partial or misleading;. [90-92]

Research over a number of years has raised concerns about the relationship between expectations and satisfaction. Despite the dominance of the expectations-satisfaction model, a number of studies have failed to show any straightforward relationship between patients' expectations prior to their experience of health care and their subsequent responses to patient satisfaction tools;. [42, 93, 94] For example, one study showed that while the effect of expectations was significant, independent of other variable, in explaining satisfaction, they explained only 8% of the variance in satisfaction. [42] In a qualitative study, women undergoing surgery for cancer were asked about their pre-operative expectations and, at follow-up, about the extent to which these had been met and the extent of both satisfaction and dissatisfaction with care. Prior to surgery, many women could not articulate pre-operative expectations about care and, following their recovery, there did not appear to be a relationship between prior expectations, the extent to which they had or had not been met and the extent to which respondents described themselves as satisfied or dissatisfied. [94] Thus, the nature of expectations, what influences their formation and how they are used (or not) by patients in understanding and/or valuing their health care experiences are yet to be completely understood.

Measures of patient satisfaction have been used to provide both descriptive (i.e. to describe what happened) and evaluative (i.e. to assess positively or negatively) results. Both issues are potentially problematic. First, surveys and questionnaires are limited in their ability to provide patients with the opportunity to describe their experiences and perceptions of health care because they incorporate only those aspects of care considered worthy of inclusion by their designers. Most instruments are devised by health care professionals or academics working in the field. [34] Thus, patients are forced to limit descriptions of care to aspects of their experiences which may or may not be those they would choose to describe.

Second, while qualitative methods of assessing patient satisfaction have garnered more expressions of dissatisfaction or critical evaluations of providers or services than traditional surveys, overall, any method of evaluation which asks patients how satisfied they are produces high levels of positive responses. Among the possible reasons for such consistent results are the existence of a high level of passivity among patients, an unwillingness to express negative opinions about providers or services they have no previous experiences of or believe are doing their best under difficult circumstances and a fear that anything less than a positive evaluation may undermine their chances of receiving good care in the future;. [38, 94] Further, each individual patient is both central and essential to the production of the outcomes of care. Recognising the important part she or he plays in the process of care, a patient may be, on the one hand, reluctant to criticise, believing that personal inadequacies or idiosyncrasies may be (part of) the cause of any negative experiences or, on the other, anxious to justify the considerable time and effort he or she has invested in the care experience by reporting high levels of satisfaction. [46]

Third, traditionally, patients have been taught that being passive and accepting of the superior knowledge of health care professionals is the type of behaviour required by a “good” patient;. [34, 38]Moreover, people who are ill are likely to be vulnerable and more willing to accept advice or assistance offered or recommended. Thus, individuals may not develop the capacity to act as a consumer of health care services in the same way as they would of other services such as being sold a car or having a tap mended. Modern health care is an extremely complex and technical series of events. The more technical the nature of the care, the less likely a patient will consider him/herself able to form a legitimate opinion of it and the more likely s/he will excuse mistakes or make allowances for negative experiences;. [38, 94]

A final conceptual problem lies with the assumption that dissatisfaction is the opposite of satisfaction and the two concepts lie at either end of a continuum. That this is not necessarily the case is demonstrated by results of research which show that patients are able to be both satisfied and dissatisfied with the same aspects of care. For example, they may be generally satisfied or have a positive overall view of the clinical competence of a doctor, but still be able to pinpoint dissatisfying experiences or negative characteristics of the care provider;; [90, 95]Avis et al 1994;;. [38, 94]

ii) *Problems with measurement, interpretation and use*

Problems with the measurement of patient satisfaction are not problems of survey design as many reliable tools have been developed;. [36, 96]However, surveys may not always be the most appropriate tool and other, potentially more appropriate ways of gathering information from patients have been limited in their application.

Surveys, questionnaires and structured interviews are limited in their capacity to capture many of the nuances which may be important to patients in the provision of health care. A number of researchers have recommended increased use of qualitative methods such as unstructured interviews or content analyses of patients' writings in combination with observational techniques as potentially useful in understanding the patient's perspective and providing a more comprehensive and therefore accurate description of his/her experiences; [38, 44-46, 80] Further, the attributes included in measures such as surveys should be informed by the results of qualitative research so that the characteristics of health care considered important by patients are taken into account. [38] The extent to which qualitative research has informed the development of surveys is difficult to assess. While this has been the case in the development of a number of the generic surveys, [97] the extent to which locally developed tools have relied on input from patients is unknown and may be limited.

Although patient satisfaction surveys allow respondents to choose a level at which they rate a particular aspect of care (e.g. excellent, good, poor, very poor, etc.), there is little evidence that individuals assess aspects of care only in these ways. For example, if a patient does not consider that they are knowledgeable enough, she or he may not be willing to express any opinion of (some aspects of) her or his care. As patient satisfaction surveys do not usually allow for non-evaluation or multiple evaluations (e.g. a "don't know" answer), any rating by a patient of an aspect of care about which they do not consider themselves sufficiently "expert", or about which they have mixed feelings, may not be valid.

As Scott and Smith [37] have pointed out, the scores given by patients to each of the aspects of care they are asked to consider are assumed to be comparable; that is, if a respondent rates one aspect as poor and another as good, the aspect with the lowest score is assumed to be the

one considered most in need of improvement by patients. However, the fact that an individual evaluates a particular aspect of care negatively does not necessarily mean that this is the aspect of care they would prioritise as needing to change. For example, a patient may rate the standard of food as “poor” and that of communication as “good”. However, their preference may be for communication to be improved to “excellent” before or instead of food improving to “good”. Thus, respondents’ strengths of preferences or priorities for change are rarely taken into account. If measures of patient satisfaction are to be used to gain feedback from patients about which areas of health care are in most need of attention, then an appropriate method for valuing and weighting patients’ preferences needs to be developed.

Another issue to be considered in the measurement of patient satisfaction is the inter-relatedness of inputs to and outcomes of care. If both satisfaction with care and gains in health are considered outcomes of care, and measured separately as consequences of care, then problems of double counting may arise if the inputs to one (health gain) are also inputs to the other (satisfaction). For example, as noted in a previous section, the provision of information as part of good communication is a widely accepted item commonly included in measures of patient satisfaction. Acquiring information has also been shown to be positively related to gains in health. Thus, if information is an input to satisfaction as well as an input to health gain, using satisfaction and health gain as separate measures of outcome will result in information being counted twice. [37]

2.4 Potential solutions

Rather than attempt to repair or redesign the concepts of health outcomes (including HRQOL) and patient satisfaction, it may be more useful to focus research on what processes and outcomes of health care patients believe are important and that they value. Although

some dispute the need to separate process and outcome, all agree that a list of attributes relevant to the evaluation of health care might include such non-health constructs as being reassured or achieving self-determination, which are part of the process of care. [98]

Some previous research has suggested factors which patients consider important. For example, Fitzpatrick and White [99] proposed that health care should be evaluated in terms of attributes such as producing knowledge and understanding, hope, reassurance, support, dignity and control. Other studies, focusing on the patient-provider relationship and communication between patients and health care professionals have identified the use of warmth and friendliness, taking account of concerns and expectations, clear-cut explanations and use of medical jargon as aspects of provider behaviour which may be important to patients. [82]

Some preliminary work regarding how patients ascribe value to (i.e. evaluate) their experiences of health care is promising. In describing the results of this work, Williams et al [92] suggest that two aspects of the patients' perspective of health care should be separated. That is, positive and/or negative *descriptions of experiences* should be distinguished from positive and/or negative *evaluations of the services* providing the care. Patients, on being asked about their experiences with health care will generally provide descriptions in which positive and negative values are attributed to those experiences. For example, a patient may describe his or her appreciation of the information about procedures and results given by hospital staff (positive) or she or he may describe how medication produced unpleasant side-effects. In some instances, (e.g. on being questioned about how the experience occurred or what s/he thought of the incident) a patient may also provide statements which allow an assessment of the extent to which the service (as opposed to the experience) is evaluated as positive or negative on the (perhaps partial) basis of such experiences. For example, the

description of how the information was given may include a statement about how much it assisted in the patient's understanding (positive) or the description of medication-induced side-effects may be accompanied by a statement about the need for staff to ask questions about possible reactions to medication (negative). In other words, the research suggests that patients may describe a negative experience but not evaluate the person or service which led to such an experience negatively (and vice versa). Williams [92] suggests that the reason that patients separate the experience and the evaluation can be found in the concepts of duty and culpability. Duty refers to what a professional or service should or should not do, while culpability pertains to the extent to which an individual or agency is at fault if it fails to do things it should or does things it should not. [92]

2.5 Conclusion

A number of reasons have been proposed as providing explanations or justification for why users' views should be taken into consideration. First, there is a view that patients or recipients of health care are consumers in the same way that they are also consumers of supermarket goods. The consumerist ethos stresses patient choice, professional accountability and responsiveness to consumer preferences in line with the view that patients will be able to use their power in the market to make appropriate choices. [100]A second view, related to the first, is that while every individual user may not be able to articulate his or her opinions, they should be taken into account by advocates for patients. Such advocacy may be pursued in a general sense by "citizen advocates" or by the representatives of specific support groups (e.g. those set up to advocate for services for particular diseases, such as diabetes, or groups of users such as pregnant women). [34]

A third reason is connected to the legal and ethical implications of the notion of informed consent. At the simplest level, informed consent is concerned with an individual patient's

understanding and choice regarding medical intervention (e.g. a surgical procedure). However, broadly speaking, it is also concerned with the extent to which health care professionals are responsible for a patient's welfare more generally. Thus, some professionals emphasise the holistic nature of health care and the need to take account of users' views and preferences; [101] [24, 102-105] Such considerations are brought into greater relief by the shift in prevalence from acute to chronic diseases in developed countries and the resulting transformation in the delivery of health care services. People with chronic diseases or long-term disabilities play a more active role in their own health care. Such involvement has been highlighted by the ongoing reduction in hospital length of stay, with concomitant increased use of community or home-based care, both of which rely for their success on the active participation of patients and, often, their families and carers.

The final reason for including patients' perspectives is concerned with the development of comprehensive measures of quality and outcome in relation to the evaluation of health care. A broad assessment of the extent to which health care achieves its goals should not only include measures considered relevant and important by professionals, managers and funders, such as clinical effectiveness, efficiency and equity, but also include benefits or outcomes relevant and important to patients. Including the preferences of patients as well as professional perspectives will help ensure that changes to health care delivery reflect all the potential outcomes. It is from this standpoint, the comprehensive evaluation of health care, that this examination of potential non-health outcomes is undertaken.

Currently, there is no evidence to suggest that the measurement of health outcomes or patient satisfaction surveys are particularly accurate in taking the patient's perspective into account. In considering the involvement of patients in the evaluation of their health care, careful thought must be given to the objectives for their involvement (why ask patients?)

and the most appropriate methods to use (how to ask patients?). In answering the first question, it is necessary to distinguish, for example, between such reasons as wanting to know what should be changed, the priorities for change and the likelihood of an individual re-using the service or recommending it to another. The response to the second will depend on the answer to the first. For example, the method of asking patients may differ depending on whether the information is required to plan a new service, change a specific aspect of a service or monitor changes made previously.

However, before patients' preferences can be examined in detail, an in-depth understanding of what is meant by each of the non-health concepts identified in this chapter and the circumstances under which they are more or less important needs to be developed. In Chapter Three, the results of a process of identifying, reading and synthesising peer-reviewed literature which examined the theoretical and/or conceptual basis of each non-health outcome are presented. The aim of this exercise was to gain a better understanding of the theoretical and conceptual basis for each non-health outcome and to assess the extent to which each had been examined in relation to health care and to each other. In this way, knowledge of what each concept meant in theoretical terms and the extent to which they were interrelated was gained.

Chapter Three

A model of non-health aspects of health care

Chapter 3 A model of non-health aspects of health care

3.1 Introduction

In this chapter, each of the non-health outcomes introduced in Chapter Two is defined and discussed in some detail. The literature used to categorise and synthesise the non-health outcomes was obtained by searching the databases MEDLINE, CINAHL, PSYCHINFO and ECONLIT, using as a primary search term the name of the non-health outcome (e.g. trust, reassurance) combined with the terms health, health care and theory. Specific criteria were not developed for inclusion of identified articles as the task undertaken in this chapter was not perceived as a critical appraisal of the literature but rather a broad exploration of it.

Within this chapter, the discussion of each concept is, as far as possible approached using similar headings. One or more definitions are proposed and the aspects of research which will be covered in the section are outlined. In particular, the research into each concept will be reviewed in terms of how patients have perceived or experienced the concept and how health care providers have operationalised the concept. Any special issues concerning each concept are also covered. Each section concludes with a discussion of the relationship of the concept to the other non-health concepts under consideration and a summary of the main issues raised in relation to the concept. However, as the amount of relevant research into each concept varied considerably, some concepts, notably dignity and legitimisation and labelling, are not covered in the same detail as has been possible with others. The number of articles identified for each non-health outcome provide some indication of the extent to which they have been the subject of scholarly research. Table 6 shows the number of articles collected and reviewed by topic. Patients' participation in decision making stands out as the most researched topic, followed by information. Reassurance, trust and recognition of and support for emotional distress are represented by approximately 30 articles each and dignity and legitimisation have been the subject of a small amount of research.

Table 6. Number of research articles by non-health outcome

Non-health outcome (topic)	Number of articles identified and reviewed
Participation in decision making	72
Information	53
Reassurance	30
Trust	27
Recognition of and support for emotional distress	27
Dignity	8
Legitimation	6

3.2 Reassurance

3.2.1 Introduction

Reassurance has been defined as a response, designed to restore confidence and decrease anxiety, to patients who are observed to be uncertain about their health (or some aspect of their health) and the potential outcomes of health care intervention/s;. [106, 107]Teasdale; [108, 109]has conceptualised reassurance in three distinct ways: as an optimistic assertion; as a purposeful attempt to restore confidence; and as a state of mind. The first two can be seen as processes, both of which seek the third (the outcome) as their goal. Generally, providing reassurance seems to involve a combination of verbal and non-verbal behaviours.

Empirically, reassurance has been examined (and, to some extent measured) from a number of perspectives. The effect on anxiety reduction of verbal statements of reassurance has been compared to the presence of companions. [110]The effect on reassurance of diagnostic investigations and doctors' emotional expressivity has also been considered;. [111, 112]As a process, it has been assessed from nurses' and patients' perspectives;;. [106, 109, 113]The extent to which obtaining reassurance was part of patients' expectations or intentions (*ex ante*) has been examined;;. [114-116]Other research has identified reassurance as one of the important effects of health care experiences as varied as breast cancer screening, palliative care, well-child care and participation in clinical trials for breast cancer treatment (*ex*

post);;. [113, 117-119]False reassurance and the rate and determinants of failure of reassurance and the reasons for non-reassurance have also been studied;. [120, 121]

3.2.2 How do patients perceive or experience reassurance?

It has been suggested that the presence of others, particularly experts, may be sufficient to reassure patients. However, other research [110]has shown that verbal or physical manifestations of reassurance are also required to reduce anxiety and enable patients to feel reassured. A limited amount of research has investigated the extent to which patients or consumers believe they need reassurance.

The extent to which people expect to be reassured as a result of a health care encounter or their intention to seek reassurance from health care providers (e.g. the extent to which they consider its provision part of the “duty” of the doctor or other health care provider) has been the subject of some research. How important reassurance is to people may be related closely to the context in which care is sought. For example, Michie and colleagues [114]reported that 50% of clients who attended genetic counselling expected to be reassured as a result of the intervention (of these, 38% did not receive the reassurance they were expecting; in addition, 42% of those not expecting reassurance did receive it). Reporting receiving reassurance was found to be associated with a greater reduction in anxiety if it had been expected than if it had not. Explanation and reassurance (along with emotional support and investigation and treatment) were common requests that patients had of their GP in a study conducted in the UK. [115]Other contexts in which reassurance may be expected is when care is sought on behalf of others (e.g. by parents or guardians on behalf of children or by carers on behalf of those receiving rehabilitation or palliative care). Chan [116]found that 85% of parents and/or guardians expected that their doctor would reassure them regarding their children’s health in relation to care for upper respiratory tract infections.

Reassurance has also been considered as an outcome of care. Bakker and colleagues [118] found that women attending breast screening reported that it had a positive effect on feelings of reassurance at three weeks post-screen (48% were reassured a great deal, 36% quite a bit and 4% a little bit). Similarly, most people attending a follow-up oncology clinic reported that the most valuable outcome from their perspective was that of reassurance. [122] However, it is not clear how much reassurance was provided by the attendance itself and how much by a good result (i.e. clear screen or no sign of reoccurrence of cancer). Women who used well-child care in rural USA identified reassurance for themselves as an important benefit of the care provided to their children. [119] Interviews with people who had attended an Accident and Emergency Department as a result of serious injury revealed that touch, having company and information were paramount in providing patients with reassurance. [123]

There has been surprisingly little research into how patients experience or describe feelings of reassurance. It has been discussed as resulting in an enhanced ability to cope and decreased anxiety. [124] In research which examined patients' experiences of reassurance, [113] the process was described by respondents as involving empathy (i.e. patients believed that nurses understood what they were experiencing), receiving information and becoming knowledgeable, experiencing a tone of voice or touch which was perceived as being "humanistic" and caring, feeling they were in a trusting relationship and being encouraged to be optimistic.

3.2.3 How is reassurance provided?

Buchsbaum [125] described reassurance both as an outcome of a process and as part of processes which have as their goal relief of anxiety and restoring his/her sense of autonomy. The process of reassuring a patient consists of uncovering the meaning that the perceived illness has for him/her, empathising with him/her, addressing his/her need for information

and providing a clear message about the results of the consultation. Teasdale [108]describes the range of possible actions as broad, including verbal reassurance, information giving, touching, referral to other experts and the use of other sources of data.

In one of the earliest examinations of the concept, French [107]described several behaviours which a nurse should do to be reassuring and a patient should do to become reassured. For nurses, these included explaining, familiarising, touching, counselling and diversional techniques (although it is doubtful whether the last can be considered a valid technique for reassurance). Boyd [106]asked fifteen nurses to describe their efforts to reassure patients. Nurses responded to patients' uncertainty or distress by offering information (factual or theoretical), physical comfort, being present, listening, assuring patients of their rights, projecting a calm confident manner and sharing patients' emotions. Such actions were broadly aimed at relieving anxiety by enabling patients to identify options, make better decisions, endure difficult times, understand their experiences and communicate more effectively with others.

Teasdale; [108, 109]described reassurance as entailing giving information predicting a safe outcome plus the use of personal support to help patients feel better. Assuring the patient means that a pledge or promise is given. First, the health care professional must believe that the patient feels anxious or afraid. Words are then used to convey optimism and hope (e.g. using phrases such as “everything will be alright”, “you will be fine” and/or, “the (doctor) will look after you”, employing a confident but soothing tone). These words may include factual information, but such information alone will not necessarily reassure the patient. A nurse may reassure (i.e. tell) a patient that removing stitches will not be painful, but if the patient does not believe him/her, he/she will not be reassured. Optimistic assertion may also be used as part of a more purposeful intervention, described below.

If a deliberate intervention is to be used to restore confidence, the health care professional must first be convinced that the patient is worried or anxious. Some authors assume that this is almost invariably the case (i.e. that if a person consults a doctor about a new or changed condition, he/she is likely to feel threatened and be in need of reassurance). [126]

Cooper [126]described seven aspects of care which may contribute to reassurance: taking a careful history; undertaking a physical examination; using diagnostic investigations; addressing specific anxieties; providing an explanation for and information about the symptoms and/or signs; emphasising the positive aspects of treatment; and offering ongoing support. Sapira [127]and Kathol [128]offered some specific variations on these aspects in cases where the objective was to provide reassurance for symptomatic but benign or “non-organic” disease. The first two (history and examination) remained the same. The third aspect (diagnostic investigations) may be present depending on the presenting symptoms or illness. Kathol [128]expanded on this and suggested the following steps: assuring the patient that serious illness is not present; suggesting that the symptoms will resolve; advising a return to normal activity; considering non-specific treatment; and offering ongoing support (e.g. follow-up). This final step is the same as that suggested by Cooper. [126]

3.2.4 Non-reassurance

A special issue in relation to reassurance is that of non reassurance. That is, some patients do not become reassured (i.e. they remain anxious) despite the fact that their health may be “normal” and/or they have undergone a process of reassurance, including receiving information, discussing the results and their opinions and being given persuasive reasons for accepting that the results were normal. Many health care professionals believe that clinically unnecessary diagnostic investigations should be avoided on the grounds of cost and potential for harm. [111]Others believe that an investigation should not be classified as unnecessary if it reassures the patient. [129, 130]Howard and Wessely [111]point to conflicting evidence in

the literature. For example, angiography may or may not reassure patients with normal coronary arteries. [131-133]One explanation for the non reassurance of some patients may be that patients may be in hospital because reassurance from their GP has failed. They are therefore more likely to be resistant to reassurance in general, including that resulting from “negative” investigations.

In a study of patients undergoing heart tests, 21 of 38 patients were still anxious after a normal result, including three who were just as anxious as before the test. Although the sample size was small, the determinants of reassurance failure appeared to be the pre-test presence of symptoms and the specific circumstances of patients, including past experiences. Although a poor quality consultation was unlikely to be associated with reassurance (1/13), a good consultation technique was not significantly more successful (3/9). [120]Such results may also be partly explained by underlying neurosis and depression which investigations will not address. “Non-reassurance” was described by Warwick [129]as affecting patients who were already prone to obsessiveness. Interventions such as information, further tests and follow-up appointments intended to provide reassurance may have the unintended effect of furnishing patients with evidence that their anxiety is warranted. Such effects may also occur (albeit to a lesser extent) in patients not prone to obsessiveness.

3.2.5 How is reassurance related to other health and non-health outcomes?

It is clear from the information presented above that reassurance is associated with other non-health outcomes. The most obvious is one aspect of emotional distress usually described as anxiety or worry. However, other aspects of emotional distress such as guilt may also be a pre-cursor to the identified or felt need for reassurance. Teasdale [108]considered that in order for the process of reassurance to occur, the patient must first be identified (by him/herself or by another) as being anxious, worried or otherwise emotionally distressed.

The process itself has been described as trying to calm a patient who is anxious, worried or

distressed. [109]Fareed [124]considered that one of the main reasons for offering reassurance was to assist patients in coping. Anxiety was also a pre-cursor to patients having heart tests being offered reassurance. The quality of the reassurance given by the doctor did not affect the post-test anxiety of patients as most were reassured by factors such as the results of the test and not by the consultation. [120]There is also the possibility that reassurance may unintentionally increase anxiety in some patients. [121]However, it is not always possible to link reassurance and anxiety. Thomas [122]reported that while few people (8%) attending a follow-up oncology clinic reported that they felt anxious at the thought of their impending attendance, 92% reported that they were always or usually reassured.

Information is a very important component of the process of reassurance which has been described by a number of authors (see above). Buchsbaum [125]includes addressing the patient's information needs as one part of the process of reassuring patients. Timely and meaningful information can assist in dispelling fears and reducing anxiety. Fareed [113]describes information as potentially one of the main components of eliminating fear of both the known and the unknown. Information here is also taken to mean explanation of things that are not clear or are too complex to understand without further information. Valori et al, [115]in using principal components analysis to examine the extent to which patients agreed with a large number of statements, found that patients frequently intended to seek explanation and reassurance when they attended their GP. In this instance, explanation and reassurance concerned information and relief from worry that the GP could give immediately; it did not mean referral for further investigation.

Patients have indicated that developing a trusting relationship is an important element in reassurance. [113]Trust was developed through a combination of experiencing nurses'

behaviour, observing the knowledge and skills they demonstrated and the development of rapport which allowed some but not all patients and nurses to have such a relationship. Legitimation is also associated with reassurance. Legitimation refers to a patient's perception that s/he is truly ill being accepted and verified by some more objective means (e.g. by a test result or diagnosis). Despite the negative connotations of a diagnosis or the prospect of pain, patients may still feel relief at their concerns having been justified. [126]

3.2.6 Summary

Reassurance is clearly an important aspect of health care from patients' and providers' perspectives. However, for the purposes of this thesis, only the patients' perspectives will be taken into account. That is, being reassured will be the concept under consideration. However, within the concept of being reassured, it is necessary to differentiate between reassuring actions or statements and a feeling of being reassured. Although a number of definitions have been proposed, Teasdale's three-way concept of reassurance as an optimistic assurance, a purposeful attempt to restore confidence (both actions) and a state of mind (feeling) is the clearest;. [108, 109] Despite its importance, there is little consistent evidence from the literature about how to ensure that patients do feel reassured or the relationship between imparting reassurance and its effect on patients' health.

3.3 Information and knowledge

3.3.1 Introduction

There are a number of reasons why information gathering and exchange and the acquisition of knowledge are essential dimensions of health care encounters for both provider and recipient of care. They are used to understand the causes, effects and prognosis of a particular condition for an individual, to define and clarify the choices and options available, to make judgements about the quality of care, to make decisions about future health care and to assess the outcomes of care. Although information has always been a vital ingredient in

health care, the balance between provider and recipient of care in collecting and exchanging it has been slowly changing. There are many reasons for such change, including:

- an increased amount of information about diseases and treatment is known and available in the public domain;
- an increased emphasis on using the best evidence available means that information is regarded as a crucial pre-requisite to gaining understanding and knowledge, considering choices and making decisions;
- in Western countries, the ongoing development of screening, including genetic screening and the increasing prevalence of chronic illness require long term understanding and management by both provider and recipient of care; and
- the potential for patient participation in decisions regarding screening and chronic disease care has changed the amount, type and way information is delivered.

3.3.2 The patient's perspective

In this section, three aspects of patients' perspectives regarding information will be presented. First, evidence that patients prefer some information to no information is provided. Second, there is some evidence that patients prefer more rather than less information. Finally, evidence about the effect information has on patients will be summarised.

i) Some information is preferred

There is no doubt that most patients want information. According to Waitzkin [134] patients almost always want as much information as possible. Research by Haug and Lavin; [135, 136] confirms this as well as noting that many patients believe that the availability of information is a right. Beisecker and Beisecker [137] found that patients wanted as much information as possible about a wide range of subjects (e.g. what signs and symptoms mean, diagnosis, treatment, reasons for and the effects of medication, further referral, return to work and need for hospitalisation). A limited amount of research has investigated the types

of information patients want (e.g. information about the nature and sequence of events (procedural) versus information about the feelings and sensations (sensory)). [138]In a meta-analysis of this literature, Suls and Wran [139]concluded that providing a combination of procedural and sensory information was beneficial. Even in the case of terminal illness, research with patients indicates that most want to be told the truth. [140]Although there is a widespread perception among patients that they have a right to information, such is not the case among health care professionals. Recent research by Osuna et al [140]showed that only a small proportion of health care professionals (9%) agreed that information on prognosis should always be given to the terminally ill, while 80% agreed with the statement when it was qualified by only if the patient will understand and accept the situation. Two percent thought the patient should never be informed of his/her prognosis.

Despite the availability of so much information and the potential for acquiring vast amounts of knowledge, it is also important to acknowledge that there is no such thing as full information or knowledge as all recipients of information will infer different meanings from it and, in the giving and receiving of information, impartiality will be lost. Nowhere is this clearer than in genetic counselling. In a qualitative analysis of the factual information given to parents and prospective parents and their perceptions of the information, Lippman-Hand [141]found that clients and counsellors often translated numerical information (e.g. 2% probability of conceiving an affected child) into a more manageable form (e.g. very low or quite high), thus implying a value judgement. What represents enough meaningful information for recipients to be sufficiently knowledgeable, consider the options and make decisions is likely to vary between individuals and situations. There is also a body of research about the philosophy of language which has attempted to understand the extent to which communication depends on decoding information or on drawing inferences from the context in which the communication is delivered. [142]Recent advances suggest that the

recipients of information tend to draw inferences, so that communication can be seen as a process by which communicators selectively present information in order to induce recipients to infer the intended meaning. [142] Thus information exchange is an inherently biased process.

ii) More rather than less information is preferred

Considerable research effort has been devoted to examining the kinds of information patients want about different aspects of their condition and the options open to them. This may depend on individual characteristics of patients. Armstrong, [143] has divided patients into those who search for and demand more information about their condition (called “monitors”) and those who deliberately avoid information (called “blunters”). Other research has differentiated between patients on the basis of coping styles: those who engage in problem-focussed coping may require more information while those who use an avoidant coping style may prefer as little information as possible. [144] Patients and doctors may differ in their perceptions about what information is most important or necessary. In a study of diabetic patients, both patients and doctors identified that information about injections and the impact of the disease on lifestyle were important. However, doctors thought that information about complications was more important than did patients, while patients were more concerned with diet restrictions, which were not considered an important problem by doctors. [145] What information is considered most useful is likely to vary with the condition. For example, Scholmerich et al [146] found that patients with Inflammatory Bowel Disease (IBD) wanted information on the possibility of remission and of developing cancer. Using an open-ended survey design, De Jesus et al [147] found that day surgery patients needed more information than they were given about possible complications of the anaesthetic and the procedure and preparations for surgery (e.g. the fasting procedure). Similar findings have been reported for other surgical patients. [148]

In interviews with people with multiple sclerosis about a recent exacerbation of their condition, participants identified three types of information needs: information about the physical symptoms they experienced at the onset of the attack; information about the emotions they experienced at the onset and during the exacerbation; and information about the drugs they received during and after the exacerbation. [149] People with a chronic condition have an ongoing need for information about the changing aspects of their disease. The families of a group of people who were cared for in a palliative care centre in France were asked (after death had occurred) about their need for information before their relative died.. [150] Although staff considered that they provided information about the patient's disease status and the efficacy and adverse effects of the treatment, fifteen per cent of families considered this information unsatisfactory because the language used was too technical or insufficient time was devoted to it. For example, many relatives considered that the prognosis was not dealt with well enough. Cancer patients and their families identified treatment options, experimental treatment and referrals as the most important types of information [151]

iii) The effects of information

In the exchange of information, both giver and receiver have the potential to be affected. In this section, the effect of information on patients will be considered. The most important and obvious effect of information (i.e. the output from its exchange between giver and receiver) is an increase in knowledge (often on the part of both contributors). While there is no doubt that all information has the potential to enhance the knowledge and understanding of the recipients, it is important to consider how much information patients want or need to meet what purposes. This is a difficult area to research as while it may be the case that many patients seek care at least partly to meet their need for information, they are less likely to have a clear idea (*ex ante*) of what information will be most useful until they have received some and can judge its usefulness in the light of their knowledge and the decisions they

make (*ex post*). However, many research participants have identified the need for more information than they received, thus expressing a need to acquire more knowledge. [134]In the discussion above regarding people with multiple sclerosis, [149]the gaps in information were in those aspects of the condition identified by participants as requiring increased understanding. The effects of such knowledge may include decreased anxiety and increased ability to adjust to and cope with the condition. More generally, increased community knowledge about conditions may also assist in planning health care services and in the greater acceptance of people with long-term conditions in the community. Clarke and Smith [152]have shown that knowledge of stroke increases over time in patients, their spouses and other family members and that a better knowledge of stroke was related to improved functional outcomes for patients.

To some extent, knowledge may be important for its own sake. Hebert et al [153]state that the purpose of information is not only to enable people to make informed choices about health care and other aspects of their lives, but also to inform them of their situation. It can be argued however, that even if knowledge is not used immediately to make a decision, it will almost always be used in future decision making (although this may not take the form of any action, but may be a decision to take no action). Mooney and Lange [48]report the importance of information about reproductive risks to women whether or not they had considered aborting an affected foetus. Therefore, an important effect of information is the clarification of choices open to patients.

It is also important to consider that information may evoke both positive and negative reactions. It is usually assumed that information and the knowledge gained from it will have a positive effect on patients. However, patients' relative lack of information has sometimes

meant that doctors and other health care professionals have sought to protect them from

well-recognised negative effects of information. This has been (and may still often be) the case when giving information about cancer and other terminal illnesses. Health care professionals (and sometimes family and friends of patients) have justified giving the patient less information than was available on the grounds that it would cause anxiety and loss of hope and the will to live, thus harming the patient;. [153, 154]Indeed, some doctors will go to incredible lengths to tell the truth about a terminal condition and the treatment without divulging the exact nature of the illness, making use of many strategies and tactics such as evading questions, denial of exact information and euphemism. [154]There is also evidence that how much information is considered desirable is culturally specific. [153]However, Janis [155]argued that information is useful even if it produces anxiety for patients because it allows them to rehearse the stressful events they may be about to experience, thereby enabling them to cope better.

Screening is a more recent development of health care where the resulting information may produce negative effects. Such effects are complicated by the fact that a positive result of screening is usually only an indication of an increased risk of a disease (in contrast to early detection, where a positive result is indicative of disease at an early stage) and there may be true and false positive results from screening. As was noted above, [141]recipients of information about the results of a screening test will infer different meanings from it and information given in terms of probabilities is particularly difficult for many people to understand. A false positive result is almost certain to produce unnecessary anxiety in the recipients of such information and despite its ultimately being negative, an individual's attitude to and beliefs about his/her health may change forever as a result of such an experience.

Genetic testing is a particular example of the potential for information to produce negative effects. An increased understanding of the part genetic inheritance plays in the development of different diseases, in particular, the work on the Human Genome Project, has resulted in many new tests being available. The results of such tests are, for the most part, confined to information and enhanced knowledge, as in many cases interventions are not available. One way in which the information may be used is in making reproductive decisions, although, as noted above, such decisions are complicated by the need to translate numerical probabilities into meaningful words. In some cases, depending on the type of inheritance, the results of a DNA test may indicate that a person has a 100% chance of inheriting the condition. In a small number of conditions, such information may lead to early detection and treatment, but in others the information may produce the knowledge only, without any possibility of intervention in the future. It is unlikely that such knowledge will be regarded as wholly positive even by those who want to know everything. [49]

3.3.3 The delivery of information

i) Methods of information delivery

Information to patients may be freely offered or given by a health professional, or it may be sought by the patient (e.g. from a health professional, written source or electronic means such as radio, television, video or the World Wide Web). A number of studies have demonstrated that patients accept that doctors and health professionals are the most important, authoritative and desirable sources of information about their condition;. [146, 156]However, as the amount and type of information needed by patients may vary, not only between individuals, but also within individuals (i.e. with different illnesses or at different stages of their illness), health professionals are not the only source of information. For example, eighty percent of patients with Inflammatory Bowel Disease (IBD) reported that they wanted information in addition to that given them by their doctor (62% wanted additional written information and 18% wanted additional information from self-help

groups). No participant reported that they had received too much information. Research among stroke patients and their families revealed that a structured information program increased their knowledge more than information they were given by individual health professionals or information they garnered along the way. [152] As health related messages become more common and the information required by patients or potential consumers more complex, there may be a need in some circumstances to devise unusual ways of reaching sections of the population. The use of photographs with accompanying descriptions (called photoessays) (for breast cancer screening for Afro-American women) or interactive electronic systems (for prostate cancer treatment options) are two means that have been evaluated;. [157, 158]

ii) How much is the right amount?

How much information patients want is likely to be patient, condition and context specific. What is clear is that generally patients want more information than doctors and other health care professionals believe is enough or in some cases are prepared to give them.

In developing an information booklet for patients about anaesthesia, Garden et al [159] found that their professional colleagues held diverse views about the amount of information to provide. Most thought that excessive detail would frighten patients and many had doubts about the ability of patients to make sense of the information, to remember it or to incorporate it into their knowledge of risks and benefits. In comparing three information sheets graded as minimal, standard and full, Garden et al [159] found that there was no significant difference between the groups receiving the sheets in respect of their levels of anxiety (although there was a trend towards increased anxiety in the minimal group), but that patients' knowledge scores increased significantly when they received the full information sheet. The percentage of patients who found the information frightening rose as the degree of disclosure rose and after viewing all three sheets, many patients thought that

the minimal sheet contained too little information and the full sheet contained too much. In a trial of breast cancer patients' psychological distress on receiving one of two information packages (standard or condensed) or nothing prior to their first attendance at a tertiary cancer centre, [160]it was found that while the packages did not affect their distress level, most women preferred to receive a package. The condensed package was as useful and as easy to understand as the standard package. Ninety percent of patients with inflammatory bowel disease preferred detailed information about all items listed on a questionnaire or at least on the essential items they selected. [146]

iii) Information seeking by patients

Information seeking behaviours are actions used to obtain knowledge of a specific event or situation. [161]Information seeking behaviour on the part of patients has been recognised and legitimised relatively recently. An increase in knowledge and available information about the complex interaction between health care and health status may have led to increased health seeking behaviour. However, the knowledge of family, friends and others with similar conditions as well as written information has always been available, even if the latter has not been as accessible as it is today, and many patients must have sought out such sources. In 1990, Beisecker and Beisecker, [137]in analysing recorded consultations between 7 physicians and 106 adult patients in an outpatient rehabilitation setting, found that patients averaged 3.4 information seeking comments per consultation (range 0-24 per patient). Thirty patients made no attempt to seek information. This was despite the fact that all patients had previously indicated their desire for information.

The information seeking behaviour of women who were referred to a colposcopy clinic at an urban hospital were studied at three time intervals (at time of referral, prior to the colposcopy examination and immediately following the examination). [161]Women asked an average of 6.3 questions and 42% requested an information sheet (women had to phone

and arrange to have the sheet mailed to them). Women who asked questions and requested the information sheet were more likely to have a preference for information as measured by the Krantz Health Opinion Survey (KHOS). [162] However, there were no differences between information seekers and non-seekers in scores on the Survey of Feelings (SOF) which is a measure of positive and negative emotions associated with stressful situations). [161]

Telephone interviews were conducted with people who had contacted a cancer information service (CIS) to examine the information seeking behaviour of patients with cancer and family members. [151] Of 257 participants, 49% called the CIS just after diagnosis and before treatment, 31% called during treatment, 41% called between treatments or after treatment was completed and 20% called more than once. Fifty-four per cent sought information from 3 or more sources, 30% consulted 2 sources and 16% contacted the CIS only. Other sources included books, medical journals, magazines, pamphlets (73%), family and friends (40%), patient support groups (12%), the American Cancer Society or other organisations (11%) and hospitals or cancer centres (6%). Fredette [163] found that information seeking was a major coping device for 11 of 14 women interviewed about their experience of breast cancer. They obtained knowledge through reading, questioning health care personnel, attending cancer education and support programs and talking to other patients. Seventy-eight per cent of women drawn from a population sample and interviewed by telephone indicated that they had actively sought information on breast cancer detection from doctors and health care professionals, [156] 14% had sought this information from health care organisations, 19% from friends and relatives, 22% from television and 49% from magazines. In attempting to find out information about an exacerbation of their condition, patients with multiple sclerosis sought out doctors, nurses, pharmacists and therapists more often than they sought written information or the National Association for

MS. [149]HIV-positive people also sought information from doctors first and then from support groups and friends. [164]

In one of the few qualitative studies of information seeking behaviour, Weijts et al [165]audiotaped 32 consultations between gynaecologists and women. It was reported that most information-seeking actions concerned the nature or process of treatment and were formulated by women in a straightforward way, resulting in equally straightforward responses from the gynaecologists. However, in seeking information about the causes of their health-related problems, women tended to be less direct and often requested information in a way that elicited an inadequate response from the physician.

iv) Quality of information

Entwhistle et al [166]have examined four published checklists concerned with the quality of information given to consumers. Entwhistle and her colleagues consider that there are a number of criteria against which the quality of information can be judged. These are: [166]

- Relevance. For example, information about available options. Whether this should include all possible options or just those that may be available to the patient within the service they are currently attending is open to debate. Patients may feel deprived if they do not have access to all possible options. On the other hand, their knowledge may increase the pressure on a health service to provide more choice or increase the availability of effective interventions. Information about outcomes is also an important criteria. It is recognised that this is likely to focus on a narrow range of health outcomes and thus information should also be included about the uncertainties and gaps in this information. Local availability of information and the processes adopted by local services also represent relevant information, as does information about further sources of information.

- Accuracy. Although this criterion would seem to be universally appropriate and desirable, on what basis accuracy can be judged is less certain. Consideration needs to be given to whether accurate information consists of the most up-to-date and reliable research evidence (and whether it takes into account the standard or level of evidence available) or of its application to an individual's situation. While some would consider that it is vital to give patients information about the best research evidence currently available, the uncertainty inherent in applying such results to individuals' situations makes the interpretation of the information problematic. Not only will an individual patient respond differently to the recommended procedure, local variation in skills and processes will also contribute to different patient responses.
- Accessibility, comprehensibility and usability. How the information is presented and in what form will have an impact on how the quality is judged. Language, literacy levels and the impact of disability should be taken into account when designing information packages. Reliance on a variety of sources of distribution may also enhance access to the information. As well as variety of presentation (e.g. language, tables, graphs, pictures) the way in which information is framed must also be considered. The order in which information is presented, how and which types of information are presented together, whether messages are presented in positive, negative or mixed terms and the ways in which probabilities are expressed are variations which may affect comprehensibility. Additional educational and/or counselling services may be necessary to assist patients to access, comprehend and use the information.
- Acceptability. As well as for reasons of comprehensibility, information may not be acceptable for cultural, social or political reasons.
- Resource implications. Not only does the development and production of information packages consume resources, but the consumption and use of the information may also have resource implications down-stream. For example, patients who have acquired

information may need more time than usual to discuss it with their doctor or they may demand additional and/or more costly interventions.

3.3.4 The relationship between information and other non-health outcomes

It should be obvious from the discussion above that, from a patient's perspective, receiving some information represents a fundamental outcome of an encounter with health care (either an individual provider or an organisation or service). Therefore, it is not surprising that information is mentioned in connection with all health and non-health outcomes. Where authors and researchers differ is in the reasons they give for patients wanting or being entitled to information. For some, information is an end in itself, a right of patients and theirs to do with as they please. For others, information is an input to patient decision making or to patients' coping strategies. For others, information improves patient compliance and/or outcomes.

i) Information, anxiety and reassurance

Early studies, carried out after numerous reports that patients were dissatisfied with and anxious about the amount of information they were receiving, showed that increasing the amount of information patients received seemed to decrease anxiety;;;. [167-170]However, more recent results have not been as promising [142]and, given publication bias, the relationship between information and anxiety is not likely to be as strong as the 1970s researchers thought. Teasdale [142]believes that one reason for this may be the reliance of the studies on a decoding model of communication which assumed that information should be given in a neutral or even protective manner so as not to cause the patient more anxiety than necessary. Teasdale [142]suggests that cognitive re-framing (in which information is given to patients in a way that suggests they have some control over how they view the forthcoming event) may assist patients to be less anxious. Sainsbury [171]suggests a three stage process: patients should become aware of the meaning they attach to an event; they should recognise that the event may not be as threatening as they first thought and believe

that it may be less harmful; and they should test this against reality. This may be thought of as a process of self-reassurance.

Felton and Revenson [172] describe the same process in people with chronic conditions as cognitive restructuring and define it as “efforts at finding positive aspects of the illness experience”. It may consist of endeavors such as making positive comparisons, maintaining an optimistic outlook and redefining the illness to cast it in a better light. Seeking information may assist all of these efforts.

Teasdale [142] argues that health professionals are rarely neutral when giving information. They almost always have personal views which colour the amount of information they give as well as the language they use in order to stimulate a specific response in patients. Todd and Still [154] have described the tactics used by GPs to disclose information, prompt patients to ask questions or evade disclosure in dealing with terminally ill people. While extreme disclosers did not use reassurance, it was widely used by the others (prompters and evaders) to assist either in talking about the terminal illness or in evading such a discussion at all. Similarly, euphemism was used by both disclosers (e.g. in leading up to the topic of cancer) and by evaders (e.g. in avoiding the word altogether). All such tactics were described by their perpetrators as part of their attempts to reduce anxiety and reassure patients.

ii) Information and decision making

It is a common assumption that the most important reason a patient needs information is in order to assist him/her in making a decision. In the section on decision making, the difference between problem solving and decision making will be discussed. [173] Beisecker and Beisecker [137] have speculated that patients may need more information for decision making than for problem solving and that this may manifest itself only during a longer

encounter (e.g. a minimum of 20 minutes). Manfredi [151] found that 38% of people who received information from a cancer information service felt that it had been helpful in making treatment decisions and that 67% of these people believed that the information had enabled them to explore all the options and choose the right one. A smaller proportion used the information to seek a new physician or a second opinion (12%) and 10% indicated that it had helped them to decide for or against a specific treatment.

3.3.5 Summary

Information may be considered an important prerequisite for, precursor to or be provided concurrently with reassurance, coping with emotional distress and decision making. Patients require information about the medical or health-related problem they have presented with and its manifestations. They also need information about the options or choices that are available and the risks and benefits of these. Despite the evidence that patients want more information than health care professionals think they do, most patients regard their doctor as the most important source of information, although increasing use is being made of other sources of information such as support groups, lay experts and electronic sources (the World Wide Web etc.) As the initial if not the only source of information, doctors and health professionals may need to be prepared to provide patients with factual information. The quality of the information may play an important part in its usefulness to patients. In considering the impact of information, differences in how patients use information between those who (passively) receive and those who (actively) seek information need to be explored.

3.4 Trust in health care professionals

3.4.1 Introduction

Trust (a firm belief or confidence in the honesty, integrity, reliability and justice of another person or thing), [174] is considered by some to be at the core of medical and healthcare

practice. Usherwood [175] considers that trustworthiness is an attribute expected of all professionals, including health care professionals. It involves at least two people, one of whom is likely to be in a more dependent position than the other. [176] While some have defined trust somewhat narrowly as expectations that words, promises or written statements can be relied on, [177] other, broader definitions have also been proposed. For example, trust has been defined as an attitude of confidence in someone or something, this attitude being bounded in time and space and can be broken. [177] Although not identical, trust is related to concepts of faith, belief and hope. [177] Meize-Grochowski [177] traces the origins of the word to Old English, Gothic and German origins where it meant or means (respectively) faithful, agreement or pact and with a sense of comfort, cheer, encouragement. Although these are different meanings to the dictionary ones, they are related.

In relation to healthcare, trust is sometimes defined more specifically. For example, Byrne and Thompson [178] define it as a feeling of safety in sharing one's own thoughts and feelings with another. This definition could be extended to include the fact that in the course of receiving care, patients are often asked to expose (i.e. share) their body with a health care provider. Pask [179] characterises trust on the part of patients as a belief that they will not be harmed. Cassel [180] considers the moral enterprise of medicine to be grounded in a "covenant of trust". Evidence for the existence of interpersonal trust in the patient-provider relationship can be seen in the willingness of patients to disclose personal information. [181] Respecting patients' confidentiality and putting their interests before that of the health care professional are ways in which trustworthiness is demonstrated. [175]

Thus, the development of trust is a function of individual personality traits or personal experience, the characteristics of the person or entity to be trusted and the context, including

previous interactions with the same or a similar person, in which the interaction occurs. [182]

3.4.2 The development of patients' trust in healthcare professionals

As social animals, humans have a basic need to develop trust in other individuals, in the wider society and in the environment in which we live. [183]It forms the basis for many interpersonal relationships. [179]As a learned characteristic, the ability to develop trust requires its experience in infancy [184]and a familiar world. [185]By being able to trust others and the world around them, individuals gain confidence, optimism, faith that the world can satisfy their needs and a sense of hope for the future. [186]

Arrow [187]noted that trust was necessary in healthcare because, to a large extent, treating or curing a patient involves a process of care (the production) from which the patient (who when treated and/or cured is the product) cannot be excluded and whose co-operation is, in fact, vital. Trust has been described as necessary for effective care, by reducing patient anxiety, assisting patients to gain information and knowledge (including effective communication), recover or gain control over their health;. [179, 188]

The development of trust has been studied in a range of health care settings. The development of trust in GPs has been defined as needing a period of time over which the doctor demonstrates integrity, competence, consistency and commitment. [175]In a study of the needs of women undergoing surgery for breast cancer, the women's need for trust was fulfilled when they considered themselves satisfied with the information they were given as well as with practical assistance, personal treatment and emotional support. [189]Similarly, a study of women who sought medical care in relation to domestic violence found that they defined a good patient-provider relationship in terms of a complex interaction of trust,

compassion, support and confidentiality and importantly, a lack of trust would dissuade women from seeking necessary care.. [190]

Trust alters a relationship, including the power positions within that relationship. Because it involves depending on others, it also involves the possibility of betrayal and risking harm to oneself. [176]Meize-Grochowski [177]has listed a number of consequences of the development of trust including a sharing of feelings, the development of a therapeutic relationship, openness and honesty between individuals and the reinforcement of trust in other people or the environment. Consideration of these outcomes indicates how important trust is in respect of healthcare which is characterised by interactions between two or more people. Such consequences also point to the reciprocal nature of trust in healthcare. Mechanic considers that trust is an investment in the continued possibilities for human growth and learning. As such, trust in healthcare facilitates patient disclosure and cooperation in treatment, making unhealthful behaviour easier to modify and reducing the likelihood of disputes, complaints and lawsuits. [188]

3.4.3 The dimensions of trust

As trust involves the development of confidence in another, its dimensions (i.e. aspects of behaviour or factors which contribute to its development) include the projection or perception of expertise in another, [191]the display of consistent, predictable actions by another (i.e. reliability) and the notion that it is able to be broken. [177]Semmes [192]has described the factors which contribute to trust as the demonstration of caring, empathy, respect, shared information, familiarity and sincerity.

It has been proposed that trust is engendered by health care professionals being competent, caring, consistent and reliable and maintaining confidentiality. Trust may be produced and

strengthened by full disclosure;. [188, 193]Trust is built slowly by the accumulation of positive experiences. [182]For example, a perception that providers had sufficient technical skills, continuity of care and accessibility of the staff were factors which contributed to a feeling of trust among women undergoing surgery for breast cancer. [189]

It has been suggested that patients may take it for granted that healthcare professionals are worthy of trust (i.e. a stereotypical view of doctors and nurses) and that this will be maintained unless an individual professional proves untrustworthy (e.g. by failing to disclose that a complication has occurred or that a mistake has been made). Thus, individuals may continue to trust people in general (including healthcare professionals) while not trusting a specific person or vice versa.

Thorne and Robinson [194]have suggested that the taking for granted of health care professionals' trustworthiness is naive trust and that for people with chronic illness this type of trust represents the first phase in the development of a health care relationship. It is followed by disenchantment and finally by a guarded alliance, both of which represent predictable shifts in patients' trust of health care professionals.

3.4.4 Lack of trust (distrust, violation of trust)

The capacity for trust to be broken has been mentioned as one of its dimensions or characteristics. This characteristic is a function of the dynamic nature of trust. Slovac [195]found that trust is particularly fragile because negative events are visible, carry greater psychological weight and credibility and therefore overshadow events likely to engender trust.

Trust is most likely to be tested in a crisis such as during serious illness or in an emergency. Wrong or doubtful information and broken promises have been shown to produce feelings of distrust in patients. [189]A violation of trust can result in hurt, anger, humiliation and even retribution. [188]Moreover, it may also lead to poorer health outcomes if the resulting wariness, doubt and anxiety delays necessary healthcare as a patient sorts out whom to trust and turn to for help. [196]It has been suggested that broken or violated trust may be repairable but the extent to which this is possible is not certain. [196]

3.4.5 The relationship between trust and other non-health outcomes

In light of the view of some that trust lies at the core of the patient-professional relationship, it is not surprising that a case can be built for trust and the other non-health concepts discussed in Chapters Three and Four to be closely interrelated. For example, a process of care where patients are treated with dignity, have their emotional distress recognised and believe that health care professionals take account of their (the patients') perspectives seems more likely to result in patients developing trust in health care professionals than if the opposite had occurred. Further, if, over time, health care professionals demonstrate that the information and reassurance they provide is correct and they are prepared to respect patients' preferences with respect to decision making, it seems reasonable to assume that patients are more likely to regard them as trustworthy than if they did not act in this way.

3.4.6 Summary

In the context of health care, trust seems to be the result of a provider demonstrating over time technical and interpersonal (e.g. caring, compassion) skills coupled with the development of confidence in the professional's ability to act in the best interests of the patient. It can be recognised by a patient after they have tested a provider in some way and once they have experienced their care over time. It is important to recognise that the

development of trust is context-specific and depends on a patient's circumstances, perception of risk, personal characteristics and access to information.

The development of trust seems to be an iterative process, particularly where chronic conditions are concerned or where repeat visits are necessary (e.g. for check-ups, follow-up or repeated screening). The process of developing trust within the context of health care is potentially quite difficult as the relationship between patients and health care providers is a relatively casual one compared with other human relationship, such as that between family members.

3.5 Dignity

3.5.1 Introduction

The Australian Concise Oxford dictionary defines dignity as “true worth, excellence, of high standing or estimation”. It has also been described as “the quality of being worthy of esteem or respect” (WordPerfect Thesaurus). The term is closely associated with integrity which means “a state of wholeness”. Taken together, the terms suggest a moral obligation on the part of health care professionals to ensure that patients retain their dignity and integrity which, for individual patients, are part of, or an expression of, his/her values and wishes. [197]In the context of health care, dignity has been described as referring to an individual being able to maintain self-respect and feeling and seeing to be valued by others. [198]Being treated with dignity can be likened to being treated with non-judgemental respect which Usherwood [175]has described as unconditional positive regard.

3.5.2 Being treated with dignity

Although research undertaken from a patient's perspective commonly mentions dignity or being treated with dignity as an important aspect of the process of care, in the mainstream

eminence in relation to the topic of dying may have occurred because in developed countries the process of dying is no longer a purely natural process or considered inevitable, but can be delayed almost indefinitely by high technology care. [199] Thus, when and how a person dies is often able to be controlled and moral and ethical arguments about maintaining a sense of the individual's values (and hence his/her dignity) have been developed to counter such control. One result of this concentration on research about dying with dignity is that the concept has not been widely studied in relation to other treatments not directly connected with dying. One exception is the reported results of a conference on healthcare [200] in which the participants identified respect for the dignity of the human person as an individual and social being as one of three dominant values underlying the provision of healthcare. (The others were respect for pluralism and difference, and accountability.) Respect for dignity requires that every person is respected because they are human, regardless of social, health or economic status. [200] Similarly, the Swedish government, in a report on priorities in healthcare, described a framework for setting priorities which was underpinned by human dignity (as well as need, solidarity and cost-efficiency). The human dignity principle is that all people have the same dignity and equal rights regardless of their personal characteristics or function in the community. [197] Being treated with dignity is an acknowledgment of the inherent worth of the patient as an individual human being. Recently, Lothian and Philip [198] have identified the provision of information and the quality of interactions between patients and health care staff as key issues in enabling older people to feel that they were being treated with dignity.

3.5.3 Dying with dignity (a dignified death)

Despite the fact that considering dignity only with respect to dying and death represents a narrow portrayal of the concept, examination of the literature provides some clues about a more generalised concept and why dignity may be important in all aspects of the delivery of

healthcare. Just as dying with dignity has come to symbolise effective and ethical terminal care, [201]so caring with dignity or treating with dignity may represent effective and ethical care more generally.

Dignity (in the case of dying) is, to some extent, associated with controlling one's own fate, that is, with maintaining autonomy. That is, if a person dies (or is treated) in accordance with his or her wishes, that is according to his/her choices, dignity is maintained. The maintenance of autonomy requires compassion, truth, the right to make decisions and excellence of care. [202]The processes entailed in protecting dignity have been described as ensuring that patients have as much self-control, privacy, attention and support as s/he desires. [201]However, dignity also requires that the person administering the treatment respects the values or wishes of the patient, whether they are able to exercise control, indeed whether they are conscious or unconscious.

No discussion of dying with dignity would be complete without mentioning assisted suicide, euthanasia (different though related terms), or, less emotively, self-chosen death. [203]The major reason for mentioning it is that the majority of people who choose, over a long period of time and with much deliberation and discussion, to end their lives (assisted in one way or another by another person and usually by chemically induced means) mention the desire for a dignified death as one of the important motivating factors in such a choice.

3.6 Legitimation and labelling

3.6.1 Introduction

Goffman's work on stigma and the management of self has been influential in researching the experience of illness. He distinguishes between "virtual social identity" (i.e. the stereotypes devised about people and their characteristics) and "actual social identity" (i.e.

those attributes an individual actually possesses). How likely stigmatisation is to occur depends on visibility (the extent to which the signs of illness are recognised by others), awareness (the extent to which and the amount others know about the illness) and obtrusiveness (the extent to which interaction is impeded). [204] Ideas of legitimation in relation to care from professionals are most closely related to the awareness aspect described by Goffman. Visibility and obtrusiveness are less likely to be taken into account by health care professionals in relation to diagnosis and treatment as they are used to the idea of not being able to observe a disease process, more attuned to subtle signs and symptoms and more able to overlook and accept a certain level of interference with interactions which result from disease.

The relevance of this work for the following discussion of legitimation is that Goffman and others have contributed to an enhanced understanding of the enormous stake patients have in how illness and its causes are constructed. Achieving legitimation is necessary to access entitlements (including appropriate health care services), elicit sympathy, avoid stigma and promote self esteem. [60, 204]

Depending on the perspective adopted, telling an individual that s/he has a particular diagnosis may help or hinder her/him. For example, there is disagreement in the literature about the benefits and harms associated with detecting and treating hypertension and it has been suggested that labelling an individual as having hypertension may increase absenteeism and impair psychosocial function;. [205, 206] On the other hand, individuals who have been feeling unwell or experiencing symptoms for some time may need the legitimation of a diagnosis for emotional relief and validation of perceptions and feelings, [207] as well as for leave of absence. [208] Thus, labelling means telling someone they have a particular diagnosis and may be reinforced by adding treatment to the telling process, [206] while

legitimation is a process of recognising and confirming that an individual has experiences which represent sickness. [208]Legitimation generally has the effect of proving to individuals that their problems are real, not imagined, [207]and are socially sanctioned or acceptable.

Labelling (in the definition above) refers primarily to individuals who are unaware (until labelled) that they have any health problem, while legitimation refers to those individuals who require society's sanction or authorisation of their actions (e.g. to take leave from work). This categorisation can be clearly demonstrated in relation to chronic illness when individuals are sometimes referred to, for example, as "a diabetic" or "an asthmatic" in the same way as others might be referred to by their profession (e.g. "a plumber" or "a teacher"). A second type of labelling refers to persons who know they are sick. Such labels as schizophrenia, leprosy, and HIV may have negative social consequences. Generally, labelling is viewed less positively than is legitimation, although they are not inseparable (e.g. an individual may have his/her feelings of ill-health legitimated by a doctor and the label provided may prompt behaviour which was not contemplated until the label was received).

Another form of labelling associated with health care relates to pejorative terms sometimes applied to patients. For example, patients may be labelled as "difficult", "manipulative", "angry" or "unintelligent". Such labelling is unkind, fails to acknowledge an individual's uniqueness and may determine or influence the manner in which s/he is treated in the future. For example, a person labelled "difficult" or "unintelligent" may be deemed incapable of understanding information or making decisions and thus be denied the standard of care s/he is entitled to. [198]

3.7 Recognition of and support for emotional distress

3.7.1 Introduction

Depending on the perspective adopted, emotional distress may be characterised either as a normal reaction to stressful life events which is usually followed by the development of coping mechanisms, or as an umbrella term covering aspects of clinically diagnosable psychological disorder such as depression and anxiety. [209] Serious psychological disturbances are more likely to be recognized and treated and changes in them due to treatment are accepted as having an impact on health status. Further, emotional distress has been recognised as having an impact on health related quality of life (HRQOL) and has been included in many measures of HRQOL;. [47, 77] Therefore, an individual's emotional distress is more likely to have been assessed and alleviated in health care settings which treat diseases which are the subject of HRQOL assessments (e.g. cancer and some chronic conditions);. [201, 210] Nevertheless, there are very many health care settings where HRQOL is not routinely considered as one of the outcomes of care. There are also some points in the course of care for cancer and other chronic diseases (such as during diagnosis or when treatment decisions are being made) when emotional distress may be present to the extent that it has an impact on a patient's health and/or well-being. These are points at which uncertainty (and therefore emotional distress) is most likely to be present (Christman et al 1988 ED3). For the purposes of this thesis, the less severe definition of emotional distress will be used. However, it is difficult to define a clear demarcation between severe and less severe aspects of emotional distress.

The subject of emotional distress is (not surprisingly) most commonly dealt with in relation to the theoretical foundations of psychology. Even in the psychological literature, emotional distress in relation to health care has been overwhelmingly concerned with its manifestations

in people with cancer and other chronic diseases; [211]; [212]; [213]. [214] [209, 215-218] Baer [219] has described the alleviation of emotional distress as an important function of patient care.

3.7.2 The patients' perspective

Behan and Rodrigue describe emotional distress as consisting of depression, anxiety and anger. [215] Depression, anxiety, anger, hopelessness, fear, grief, loss, guilt and self-blame are described by Roth and Robinson [218] as common signs of emotional distress experienced by many people with chronic conditions. Distress is likely to occur when an individual perceives that some aspects of his/her environment are potentially damaging, threatening or challenging. [220] Patients may describe emotional distress as feeling “nervous” or having “nerves”. [221]

One of the effects on patients of emotional distress may be a loss of ability to think critically and therefore a diminished ability to make rational decisions. Higher levels of distress are likely to occur when an individual perceives that a threat, damage or challenge is being posed. The diagnosis of a serious disease and/or the need for a complex procedure or hospitalisation are examples of potentially distressing ingredients. Psychologists have long recognised that distress may reduce reasoning ability and depress the capacity of an individual to process information. [222] Scott [217] found that women who were very anxious prior to having a breast biopsy were compromised in their ability to reason (as measured by the Watson-Glaser Critical Thinking Appraisal (CTA)). [223] Spertus et al [224] found that emotional distress, including a history of repeated episodes of distress, had a detrimental impact on patients' abilities to manage subsequent health problems, including chronic pain.

3.7.3 The measurement of emotional distress

As emotional distress is most commonly measured by psychologists, a valid, reliable scale or checklist is the most common means of identifying it. Two of the most common are the Profile of Mood States (POMS) [225] and the Spielberger State Anxiety Inventory. [226] The POMS is a 65 item mood adjective checklist which uses a 5-point Likert scale ranging from “not at all” to “extremely” to measure tension, depression, anger, vigour, fatigue and confusion. A total mood disturbance score is calculated by summing the five negative moods from which the score for the positive mood, vigour, is subtracted. A third measure which is mentioned in fewer studies is the Beck Depression Inventory (BDI). [227] The Hospital Anxiety and Depression (HAD) scale [228] measures anxiety and depression during the previous week.

3.7.4 Recognising and managing emotional distress

Good et al [229] report that while many psychiatric disorders are unrecognised in primary care, the extent to which less severe aspects of emotional distress are recognised is unclear. However, the situation may change when the person already has another diagnosis [221] as the diagnosis may have a bearing on the strength of emotional distress. Cassileth et al [230] found that apart from people with chronic depression, no group of patients with chronic diseases differed significantly from the general public or from each other on six psychological variables (anxiety, depression, positive affect, emotional ties, loss of control and global mental health), indicating effective psychological adaptation among people with chronic disease. Severity of the disease was associated with greater distress, no matter what the diagnosis was.

The emotional difficulty of treatment for infertility was rated higher than the physical difficulty of the treatment by patients, nurses and physicians. [214] However, specific

aspects of the treatment were rated as more or less emotionally difficult by patients and professionals. For example, the initial interview and broaching the subject of adoption was considered less stressful by patients than by professionals, whereas having treatment in the home was rated as more stressful by patients than by professionals. Further, while both patients and nurses rated an interrupted IVF program, a negative pregnancy test, the onset of menstruation or a miscarriage as equally emotionally distressing, physicians rated these events as less distressing than others such as the subject of adoption.

It is well documented that people with cancer often suffer emotional distress and that at some points in the course of cancer patients are more likely to suffer distress (e.g. diagnosis, treatment, advanced disease and recurrence) {Lenburg, 1979 #558; Moorey S, 1988 #648; [231, 232]}Uncertainty may play a major role in the development of distress following a health care encounter. [233]}However, the ability of cancer specialists to recognise distress remains unclear.

One out of five oncologists rated distress in patients in a manner consistent with patient ratings. [232]}Oncologists tended to under-rate the patient's distress and were mostly satisfied with their performances during interviews with patients. In contrast with this finding, Sensky et al 1989 [234]}found that few oncology patients rated themselves more tense, anxious or depressed after an outpatient consultation with an oncologist; those who did were more likely to have been given bad news.

Some clues as to why clinicians and patients might differ in their ratings of distress were explored in a study of how patients present to health care professionals (i.e. their personality and emotional affect). [211]}Both physicians and non-physician observers rated people with hypertension to be less anxious and in better emotional health than people with normal

blood pressure levels. Hypertensive people may give a false impression of being happier or less distressed than they really feel. Another point of difference might be the extent to which professionals are prompted to recognise emotional distress by verbal or nonverbal cues from their patients,. [219, 235]

In an interesting study of emotional distress among disabled elderly people, Newsom and Schultz [236] found that 40% of the recipients of care reported some distress in response to the assistance they received from their spouse. Fatalistic attitudes (i.e. passive response to a problem), low self-esteem and lower perceived control were the predictors of negative emotional reactions to help received among 288 spousal pairs. However, the extent of emotional distress prior to care, or at the beginning of care, were not known and age and physical disabilities were also significant predictors of emotional distress. The findings indicate that help *per se* may not always alleviate emotional distress, but that specific assistance to, for example, regain a feeling of control may be more important.

“Mild” emotional distress is usually perceived as being alleviated by the use of coping mechanisms. People use many strategies or tactics in coping with emotional distress, some of which are associated with greater relief from distress (e.g. confrontation, redefinition and seeking direction) or less relief (suppression, stoic submission, passive behaviours) (Weisman and Worden 1977, Burgess et al 1988 see ED7). Behan and Rodriguez [215] found that increased emotional distress (as assessed by a number of psychological measures) was the most salient predictor of the use of passive coping strategies by people with cancer. Possible explanations for these findings are that the scales used are more likely to detect a higher level of, or more profound emotional distress which is less easy to ameliorate and that those people who were still emotionally distressed had not been

successful in alleviating their distress even if they had previously adopted a more positive coping style.

Uncertainty may also play a part in the type of coping strategies used. Patients who experienced more uncertainty following a myocardial infarct used more passive methods of coping, although in this study those patients who used positive or confrontational strategies were more distressed at discharge from hospital than those who adopted a passive style. [212]

The way in which health care professionals attempt to assist people to cope or deal with emotional distress is dependent on their background and training. There is no doubt that some training in recognition of and counselling about emotional distress is necessary for professionals in prolonged contact with people with chronic conditions and those who are terminally ill. Kinzel [213] advocates the use of truth telling about health-related issues using supportive communication (including empathy, legitimation, support, partnership and respect). Empathy is based on an awareness of the patient's emotional reaction and a willingness to acknowledge it. Legitimation refers to the validation by the professionals of the patient's emotions, while support, partnership and respect involve reassurance about assistance, including the patient in decision making and acknowledging the patient's vital role in coping with the task ahead. However, there is limited empirical support for interventions to alleviate emotional distress. Vaneldereren et al [237] found that a post-hospitalisation health education program for people with chronic heart disease, consisting of weekly two-hour group sessions over an eight week period and one follow-up session, had no effects in either the short- or long-term, on emotional distress.

Usherwood [175] refers to the use of empathy as a means of general practitioners recognising distress and supporting patients. Empathy is conceived as consisting of two related aspects: understanding how the patient is feeling and taking action to demonstrate this. Patients will provide health care professionals with both verbal and non-verbal cues about their emotional state and health care professionals demonstrate empathy by observing the emotional state of the patient, acknowledging their (the patient's) feelings and asking questions about them.

3.7.5 How is emotional distress related to other health and non-health outcomes?

Emotional distress is closely related to the other constructs defined and examined in this chapter. On the one hand, it may occur in conjunction with or as a result of involvement in decision making and/or receiving information and becoming knowledgeable. An individual may also become distressed as a result of not being treated with dignity and/or not having his or her ideas about illness or health legitimated. On the other, the distress may be relieved by the same processes, as well as by receiving reassurance or feeling reassured. Emotional distress (or specifically anxiety) on the part of patients is often a trigger for health care professionals to give reassurance. Most research begins with the assumption that reassurance will reduce distress and although the evidence is ambiguous, it is constrained by the small number of studies and their reliance on quantitative methods for measuring distress; [109, 118, 119, 122, 123]

The effect of information (including type, amount and timing of information) on emotional distress is commonly studied and while most studies show that people who desire and receive information use their increased knowledge to cope with their health problems, the evidence is still somewhat equivocal; [48, 134, 152-154] Although there are only a small number of studies published, there is reasonable evidence that if patients want to and are able to have input to decision making regarding their health care, they are less distressed;.

[93, 238-240]The situation is complicated however, by conflicting evidence about the amount and levels of distress experienced by patients whose decisions have failed or not resulted in the outcomes hoped. Recent studies have shown that earlier fears that patients would not be able to cope with failed treatment decisions are largely unfounded. Patients use different types of coping methods to deal with failure. That is, they see the decision as the only one open to them, or they do not perceive that there was a decision at all. [241]

3.7.6 Summary

Emotional distress is a common reaction to many aspects of illness and health care. Health care professionals are less likely to recognise that patients are distressed than patients are to report emotional distress. However, evidence of the effect emotional distress has on health outcomes is unclear, as is the effectiveness of interventions designed to alleviate distress. Therefore, patients may be as well off if health professionals recognised and empathised with their distress (i.e. were perceived as being caring and compassionate) as they would be after a specific intervention.

3.8 Participation in decision making

3.8.1 Introduction

Decision making in health care involves complex interactions between the personal characteristics of an individual, the social context in which the decision is being made and the importance of the choice to the individual. Decision making is a process, the results of which are one or more choices. Many fields of inquiry have investigated aspects of decision making, including mathematics, statistics, philosophy, economics, political and social science, business and marketing. Making decisions and choices about all aspects of life are features of human behaviour considered important, even vital, as such behaviour not only reveals what individuals want or value, but, as choices and decisions involve interacting with other people, they also have an impact on other individuals and on society in general.

3.8.2 Decision making in health care

Much discussion about decision making in health care has been prefaced by more general consideration of autonomy as a concept and specific consideration of its application in health care. In the context of health care, autonomy is defined as individual control of decision making and other activities. [198] Thus, decision making and, in particular, the patient's or consumer's role in decision making has been framed as a sub-set of a broader philosophical dialogue. For example, an increasing perception that patient autonomy (defined as self-determination) is important is, in turn, seen as influencing the promotion by nurses of actions that will enhance patient involvement in decision making and improve patients' control over their lives. [242]

It is well recognised that health care may jeopardise individual autonomy. The problems for which an individual has sought assistance may render her/him vulnerable (physically and/or emotionally). Dependence on the expertise of health care professionals for (among other things) information, advice and access to other parts of the system may reduce the control s/he has over some aspects of life. Thus, patients may not be able to "exercise as much power over their destinies as anyone can". [243] According to Meyer, decision making is a key component of autonomy - it is one of the repertoire of skills available to an autonomous person. Lothian and Philip [198] suggest that older people in particular are easily disempowered in health care settings and that this is more likely to occur if patients and their carers are not given adequate information or the opportunity to understand their diagnosis and to make choices about their care.

Byrnes and Long [244] note that there is a hierarchy of decision making within a health care encounter or consultation. From least to most participation by patients, a doctor may:

- Instruct the patient (i.e. about the diagnosis or treatment regime to follow);
- Make a decision and tell the patient what it is;
- Sell his/her decision to the patient;
- Present a tentative decision, subject to change;
- Present the problem, seek suggestions and make a decision;
- Define the limits of a problem and ask the patient to make a decision; or
- Permit or insist the patient makes his/her own decision.

It is considered by many that input to decision making regarding their own health and health care is likely to be more beneficial than harmful for the recipients of care. Entwistle et al [166] have summarised the main reasons for potential benefits. First, decisions by patients may lead to more effective health care more appropriate to their needs. This is more likely to be the case when individual preferences are required to judge the utility of short versus long term gains or where one course of action carries a risk of a bad outcome. For example, O'Meara et al [245] found that patients viewed a high risk of a swollen painful leg (the result of deep vein thrombosis treated with heparin alone) as more desirable than a small risk of intracranial haemorrhage and death (the result of adding streptokinase to the treatment regime). Second, some benefits, such as being convinced that the chosen course of action is correct and responding more positively to treatment, may be more immediate. However, there is also the possibility that courses of action chosen by patients will result in more anxiety and distress than if the choice had been left to the doctor and that a less than optimal treatment result may be more distressing to a patient who made the decision him/herself. Proponents of evidence-based medicine advocate that decisions should be made based on evidence about outcomes. However, it should be recognised that possible outcomes may be viewed differently by patients and clinicians. How risks are judged, the weight given to different complications and side-effects and how short-term versus long-term outcomes are

viewed will vary between individuals depending on their experiences, attitude to risk and the importance they attach to particular aspects of health and well-being. [246]

3.8.3 Patients' preferences for participating in decision making

A number of studies have examined whether and to what extent patients want to make health care decisions autonomously. Participants of a study undertaken in Vancouver [247] indicated that maintaining some form of participation in decision making (sometimes by asking the physician for more information about the diagnosis and management of the condition, sometimes by taking more time to make choices) was important. Ende et al [248] developed and tested the Autonomy Preference Index (API), part of which was designed to measure patients' preferences for making decisions. Patients attending a University-based primary care clinic in the USA scored an average of 33.2 on a scale of 0-100 where the pre-testing definition of preferences for decision making were: 0 = very low, 50 = neutral and 100 = high. Relative youth, higher health status and higher educational attainment were associated with respondents having higher preferences for making decisions while being separated or divorced, having lower occupational status and regarding an illness as potentially severe were associated with lower preferences for making decisions. In surveys of people newly diagnosed with cancer and members of the general public, Degner and Sloan [249] found more patients (59%) than general public (9%) wanted doctors to make treatment decisions on their behalf. The proportion who preferred a collaborative role for patients and doctors was similar for both groups (29% patients, 27% general public).

In a qualitative study, 12 patients (men and women, all hospital inpatients for chronic medical conditions) [250] discussed the ways they were involved in decisions concerning nursing care. The authors found that the patients were not keen to participate in decision making; instead, they wanted to "stay out of trouble". Perhaps partly because a major

decision (i.e. to be admitted to hospital) had just been made, participants in this study described themselves as having to accept the situation (e.g. by finding out the rules and complying with routines), trusting the nurses and other health care professionals and having confidence that the staff would do their best for each individual. In contrast to this study of a relatively short term event, Weissman [251] examined the interactions over time between doctors and parents involved in making a choice about home or hospital dialysis for children. The study concludes that choices about where to conduct dialysis were mainly determined by referring to criteria set up by doctors, including their opinions of the families; thus doctors tended to control the decisions. However, over time, much negotiation and conflict took place; thus original decisions could be modified, especially towards parents' desires for hospital dialysis. The results of these studies (and others quoted in them) suggest that patient preferences for making decisions is not strong. However, such studies have not differentiated between decisions about different aspects of health care (e.g. which diagnostic tests to order versus which treatment option to have versus when to begin treatment).

It has been suggested that there are two aspects to participation by patients in decision making; participation in problem solving and participation in decision making. [173] Patients undergoing angiograms at a Canadian hospital wanted problem solving (diagnosis, determination of treatment options, find information regarding risks and benefits and the likelihood of these) to be done by the doctor alone (60%), mostly by the doctor (30%) or by doctor and patient equally (8%). Fewer, however (approximately 75%) wanted to be involved in decision making such as deciding how acceptable risks and benefits were to an individual and which treatment option was the right one (50% doctor and patient equally, 12%-20% mostly by patient and 8%-10% patient alone). The results of this study and another like it [252] suggest that major roles for clinicians include giving patients sound information which will assist them in making choices and supporting them in making

difficult decisions. Gafni et al [253] also suggest that arriving at a treatment decision should be the result of a combination of the physician's knowledge and the patient's preferences. There is also some suggestion that the type of illness and decision may affect patients' preferences for decision making. One study [254] showed that patients wanted to share major decisions with their doctor, but wanted less involvement in minor decisions. Patients who had recent experience with serious heart conditions also wanted more involvement in decision making than people with no previous experience of heart disease or those with diabetes.

3.8.4 The effect of the patient-provider relationship on decision making

That there is often an unequal division of power between doctors and patients has long been recognised; the study of this as a social phenomenon is the particular province of sociologists interested in health and illness. Parsons [57] described this inequality of power as both legitimate and functional because doctors would use their power responsibly to benefit patients and patients would also gain by complying with doctors' interventions. However, this notion has been challenged by others including Freidson [255] who considered that the worlds of patients and doctors were so different that there was always the potential for conflict; patients and doctors may define a health problem very differently, so there may not be agreement about possible solutions. Freidson [255] makes an important distinction between medicine's expertise in the technical sphere and the patient's expertise (and right to make choices) as a moral one. Here there are echoes of the problem-solving (i.e. technical) and decision making (i.e. moral choices) distinctions of Deber and Kraetschmer [173]

However, medical expertise has largely dominated choice in health care. Short [256] suggests that such domination may be due to a combination of the decision rule and the notion of technological imperative. This means that faced with uncertainty, doctors feel

safer in diagnosing a well person as sick than vice versa. Thus, an equivocal test result is more likely to be categorised as abnormal than normal and clinical signs are more important than how the patient feels (psychologically, emotionally etc.) in deciding whether or not a person is sick. The technological imperative can be stated simply as “when the technology is available, use it”. However, there is little evidence that patients disagree with this type of decision making by providers. Doctors and patients have been criticised for overvaluing medical treatment relative to non-treatment in a desire to do whatever is possible, rather than what is likely to have the most beneficial effects on health. [256] However, this criticism ignores the possibility that doing everything possible (or being seen to do so) even when explicitly faced with a low probability of success (healthwise) may be perceived by patients as positive per se. Ryan [32] found that women and couples perceived doing everything they could to conceive and have a child as one of the benefits of IVF.

As illustrated by Ryan’s study, [32] patients and providers may have differing ‘worldviews’ which may influence how they perceive decision making about health care. For example, one worldview may be that doctors are the experts and therefore, their advice should be followed. However, another may be that while doctors have technical expertise, the patient is the real expert in his or her health and a two-way decision making process is appropriate. One way in which differences in worldviews can be observed is by examining the communication exchanges between providers and patients. Meredith [93] described surgeons’ use of clinical-diagnostic terminology (e.g. survival rate, complications) while patients used words and phrases closely tied to ways they might expect to manage life after surgery (e.g. how long before I can carry out normal activities, how long will I need to be away from work?).

Investigation, from a psychological perspective, of the doctor-patient relationship has been an important source of ideas about decision making. According to Beutow, [257]the relationship has three main elements: manner, information transfer and decision making. Further, mutual (or shared) decision making is assumed to be the aim of doctor-patient decision making practice as it empowers both patient and doctor and assists in the resolution of patient concerns and improvement in health outcomes, including increased compliance. However, it is also recognised that the degree to which mutuality is practised may vary with context. For example, patients with predominantly physical problems or serious illnesses may not prefer to have the same amount of input to decision making as other types of patients. Dowrick [258]points out that the way in which decision making in health care is viewed depends upon who is observing it. For example, while GPs in the United Kingdom generally have characterised decision making as a team effort between doctor and patient, sometimes as a meeting of experts, patients have on the whole not had this view, except in the case of long-term involvement with a GP. On the other hand, sociologists have tended to view decision making as a means of gaining or maintaining power, with doctors and patients battling over the direction and outcome of a consultation. It is not clear, therefore, that patients perceive their role in the same way as professionals or academic commentators. One danger of this lack of congruence (for patients) is that when health care professionals' expectations that every patient desires some input to decision making are unfulfilled, the patient may be labelled non-compliant. Such a position may be similar to that which a patient might have been in if input to decision making had been denied and she or he was then not compliant with an intervention s/he did not agree with. [259]

Among the many facets of the patient-doctor relationship, communication has been examined as a possible determinant of the quality of decision making. [260]Beutow

[257]and Dowrick [258]also view communication (i.e. listening and information giving,

empathising etc on the part of patient and/or doctor) as vital to decision making and its perceived quality. That context is important is illustrated by the results of a study investigating women's decisions about breast cancer screening over a one year period. About 55% of the women remained consistent while 25% became more positive and 20% less positive in their attitudes towards screening. Those who became less positive were less inclined to rate the opinions of a doctor as important, to have been discouraged from screening by a family member or friend or to perceive that they lacked people in their social network with whom they could discuss the issues. Although a doctor's recommendation may be an important trigger to a positive attitude, this study suggests that active communication by same-age peers may reinforce positive attitudes. Thus, in this context, social networks or contacts seem to be influential. [261]

Meyer [243] has described bilateral (shared) decision making in health care as “the essence of the partnership between the autonomous patient and the health care professional”. One of the (shared) requirements for such a partnership is the exchange of information. Other requirements of both doctor and patient may include being truthful and open (including not withholding information) and being committed to the improvement of the patient's health. Such a commitment includes acting according to agreed goals, such as providing a referral to a specialist (doctor) or altering his or her lifestyle (patient) at least until any benefits are outweighed by disbenefits. Finally, both doctor and patient must develop a fair and accurate view (i.e. recognise the limitations) of health care professionals and the care they are able to provide. [243] Thus, participation in the decision making process is seen as the right of an autonomous person.

It has been suggested that there may be therapeutic effects for patients who participate in shared decision making. [238] On one hand, such participation may enhance well-being by

promoting a sense of control and of being treated humanely. On the other hand, the information necessary for participation may result in increases in anxiety. Ninety-six patients referred for removal of a ureteral calculus participated in a study examining the effect of information and participation in decision making on anxiety. Anxiety levels did not change for participants assigned to the study group (received information and participated in decision making). Those who were not assigned to participate in decision making experienced a decline in anxiety levels. This is an especially interesting finding as a large proportion of the control group perceived that they had received information (59%) and participated in decision making (46%). [238]

In a study of patients' and providers' views of participation in decision making regarding surgery, patients were generally not critical of their providers. However, a significant number did not feel that their need for information or participation had been met. Providers were perceived as directing the consultations towards their agenda (i.e. that clinical priorities took precedence over other patient concerns, which were often seen by the providers as trivial) and lack of time was perceived as a barrier to weighing up the pros and cons of the situation in preparation for decision making. [93]

In the research described above, the assumption is made that providers generally regard patients as competent and are happy to participate in shared decision making, albeit under conditions that they largely control. However, Britten [239] found that a number of doctors described some patients (e.g. those who asked questions which were perceived to be not relevant or who questioned or did not fully comply with the doctor's directives) in derogatory terms. Such patients were perceived as being disqualified from participating in decision making because they did not conform to the doctor's norms of how patients should act (i.e. to the medical worldview).

Most empirical studies have concluded that while it is natural for the doctor or other health professional to lead the decision making process, most patients perceive this as guidance leading to a mutually agreed upon or co-operative decision;;;. [247, 262-264]It has also been suggested that the amount of mutuality is likely to vary with the context e.g. in an emergency, there will be little opportunity for patient participation in decision making while the leadership of the process might move towards the patient as an illness became chronic. [265]Wiens [242]developed a framework within which nurses can assist patients to develop and/or maintain control through decision making. Nurses can assist patients who are in the process of making decisions by considering alternatives, listening to concerns and accepting the patient's decision as valid (including their decision to rely on others to make the decision). This represents an attempt to assist patients in controlling the process of decision making.

3.8.5 Special cases - decisions in respect of elderly people and end of life decisions

As more people in the industrialised countries of the world live to old age and as technological advances increase the possibility that the end of life can be delayed, decision making in respect of health care comes to the forefront of the many issues facing patients and their families. The process of ageing has been characterised as one of decremental decline leading to gradual social withdrawal, less control and more dependence. Because participation in decision making assumes that a person will be both capable and rational, elderly people (who may be more likely to be perceived as either not capable and/or not rational) may not become involved or be allowed to become involved in decision making regarding their health care to the same extent as younger people. Davies [266]has suggested that promoting individualised care, improved patterns of communication and breaking down organisational barriers in hospitals, hostels and nursing homes all have a part to play in

encouraging older people to maintain autonomy, including participating in decision making. Being responsible for making a decision (i.e. selecting clothes) was found to increase nursing home residents' self esteem. [240]

Recently, the palliative care literature has included contributions related to living wills and advanced medical directives. These are generally formulated when a person is relatively well. The case of decision making in the advanced stages of illness has not been the subject of a great deal of research. In a longitudinal study of seven patients admitted several times over a 3-8 month period to a palliative care unit, Barry and Henderson [267] found that over time patients wanted to become more active in the decision making process. Patients perceived any discrepancies between preferred and actual forms of decision making as moving away from more active participation on their part. The physical status of patients did not appear to be related to their decision making preferences. Even patients who know that decisions at the end of their life are likely to be difficult (both in terms of which decision to make and who will make it) seem to want to retain the right to change their decisions over time. Pfeifer [268] described such actions (by people with chronic lung disease considering mechanical ventilation) as watchful waiting about the circumstances and specifics of their future care. Although discussions with patients and families are useful, surrogate decision making does not always coincide with the patient's stated wishes. Research with doctors involved in treating patients with chronic lung disease suggested that all were in favour of a shared method of decision making. While timing, style and delivery varied, most doctors framed information in such a way as to influence patients' decisions. [269] That is, they used technical rather than lay terms, presented information which supported their clinical judgement regarding probable health outcomes and emphasised positive or negative aspects of the intervention to "lead" the patient towards a decision.

3.8.6 Summary

It is clear that decision making is a key aspect of health care for most, if not all patients. However, it is not clear to what extent patients wish to be totally autonomous in making decisions or how they perceive shared decision making as an alternative. The impact on decision making of personal, social and specific contextual aspects as they relate to individuals making health care decisions is very complex. However, all the non-health concepts described in Chapter Three have the potential to influence or be influenced by decision making.

3.9 Conclusion: a model of health and non-health outcomes of health care

This chapter has described in detail a number of potentially important non-health outcomes of health care: information, reassurance, trust, support for emotional distress, being treated with dignity, having the presenting problem legitimated and participating in decision making about health care. Using this information, a model of how health and non-health outcomes of care are related to both the presenting problem and an individual's interaction with the health care system (usually in the form of one or more health care providers) has been developed and the hypothetical relationship between non-health outcomes has been described.

Table 7 illustrates the range of outcomes an individual may gain from health care. In addition to "traditional" clinical outcomes such as improved health status, slower deterioration or prevention of the problem, an individual may also gain other outcomes such as improved knowledge, reassurance, participation in decision making, trust, emotional support and being treated with dignity. As can be seen from Table 7, some of the non-health outcomes are directly related to the presenting problem (information, knowledge and reassurance about the presenting problem). Other non-health outcomes can be characterised

as “process” outcomes as they relate to the interaction between an individual and the health care system independent of the actual presenting problem (participation in decision making, trust, emotional support and dignity).

Table 7. Outcomes of seeking health care

	Health outcomes	Non-health outcomes
Related to presenting problem	Improved health status <ul style="list-style-type: none"> • Removal of problem • Relief of problem • Prevention of problem Slower deterioration of presenting problem Improved ability to cope with presenting problem	Information about presenting problem Reassurance about any/all aspect/s of presenting problem
Related to interaction with the health care system		Participation in decision making about presenting problem Trust in health care provider/s Being treated with dignity Emotional support from health care provider/s Having any/all aspects of presenting problem legitimated

Although there is support in the literature for the significance of each of the non-health outcomes described in the model above, how important they are to patients dealing with health care decisions is not clearcut. Further, there is little evidence about their importance relative to each other and to what extent patients prefer one or more non-health outcomes. Examining the importance of non-health outcomes to patients and their relative importance presents some measurement challenges. How patients view non-health outcomes will be to some extent dependent on the context in which they consider each concept. For example, the reason they are seeking or receiving health care (e.g. minor or major problem, acute or chronic condition) and in which setting they present for care may have a bearing on how

important each non-health outcome is to them. Moreover, it is unlikely that a simple question (e.g. how important is reassurance to you?) will reveal the full range of patients' notions, convictions or opinions about a non-health outcome. Therefore, qualitative research is most likely to be useful here. However, determining the relative importance of non-health outcomes requires that they be weighed up one against the others. Such an exercise requires patients to consider how they would trade-off their preferences for each non-health outcome and necessitates a quantitative research tool.

In the next section of the thesis, a qualitative study will examine the importance of non-health outcomes to patients and a quantitative study will assess patients' preferences for them (i.e. how they would trade-off).

PART TWO

METHODOLOGICAL ASPECTS AND EMPIRICAL EXAMINATION OF NON- HEALTH OUTCOMES

Chapter Four

Using qualitative and quantitative methods to examine the relevance and importance of non-health outcomes to patients and their preferences for non-health outcomes

Chapter 4: Using qualitative and quantitative methods to examine the relevance and importance of non-health outcomes to patients and their preferences for non-health outcomes

4.1 Introduction

This chapter will provide an overview of the methods used in this section of the thesis, where the conduct and results of two empirical pieces of work will be reported. Chapter Six consists of an account of research which used a qualitative method (in-depth interviews) to assess how important non-health outcomes are to two groups of people – people with chronic renal failure and women in the target age range for Pap smears. In Chapter Seven the results of research using a quantitative method (Stated Preference Discrete Choice Modelling) to examine the preferences of people (in this case a community sample) for non-health outcomes are reported.

Although many researchers have theoretical reasons for using either quantitative or qualitative methods (e.g. their beliefs about what social reality is and how it should be studied), there are also practical reasons for choosing either or both methods. Put simply, different research methods are appropriate for different research questions – so that preferences for one type or the other, or a combined approach, are based on an understanding of the circumstances of the research and the technical issues faced by the researcher. While it is becoming both more common and acceptable to use qualitative and quantitative methods as complementary research strategies, their use in examining a particular issue requires clarification and explanation in the context of the specific research being undertaken. Thus, this chapter has three aims:

- To explore the use of qualitative methods of research in understanding patients' experiences, particularly the relevance and importance of any aspects of their experiences;

- To examine the use of Stated Preference Discrete Choice Modelling in understanding the importance of different aspects of non-health outcomes and patients' preferences for them;
- To clarify the reasons for using qualitative and quantitative methods in this thesis.

4.2 Using in-depth interviews to investigate the relevance and importance of non-health outcomes to patients

4.2.1 Overview

Qualitative research, to a large extent, sets out to describe, understand and explain a particular phenomenon. The paradigm is characterised by a range of mainly non-numerical methods which are used to generate data (in-depth interviews, focus groups discussions), to study naturally occurring events (observational fieldwork, audio/video recordings) or to analyse independently produced documents (document or textual analysis). Although it involves the use of distinctive vocabularies (drawn from its disciplinary traditions including anthropology, sociology and social psychology), the trademark of qualitative research is its emphasis on context and the ways in which the situation or setting influence the factors or phenomenon being studied. [270]The influence of the various disciplines has led some commentators to insist that qualitative research draw on pre-existing, relevant bodies of theory. However, others have shown that, although the application of theoretical perspectives can allow arguments to be extended and add value to the findings, many pieces of qualitative research, particularly in health services research, may shed light on structures, processes and outcomes without drawing on or seeking to refine any particular theoretical perspective. [270]Such is the case in this study.

Qualitative research techniques are used to capture the meanings, definitions and descriptions of events by those who experience them. That is, research of this kind seeks to discover the nature of phenomena as they are perceived by people, to understand the

meanings they attach to the phenomena in the context of their lives and thence how they make decisions and take action. [271]

Understanding human experience as perceived by the individual him- or herself requires the researcher to have personal interaction with the individuals (and, in some instances with the context in which their experiences occur) so that he or she can hear what people have to say and observe how they behave in a particular situation. By interpreting the words used by people in describing their experiences, researchers are attempting to understand the interpretations individuals themselves have given to what happens to them in a particular situation. In-depth interviews provide a means of gaining access to events and activities which cannot be observed directly by the researcher. It is undertaken with individuals on their own, although in some circumstances, interviews with couples or a larger group (e.g. family) may be appropriate.

4.2.2 Planning and undertaking in-depth interviews:

The purpose of interviewing is to find out from people things that cannot be observed. In particular, feelings, emotions, thoughts and intentions cannot be observed, and neither can individuals' ideas about what meanings they and others attach to events and situations and how they interpret and understand their reactions to them. Thus, in-depth interviewing begins with the belief that the perspective of others is meaningful, able to be understood and valuable.

In-depth interviews are often described as open-ended, giving the impression that they are unstructured, rambling episodes during which the interviewee is free to talk about anything and everything. Nothing could be further from the truth. Although interviewees are generally given greater freedom to introduce topics and to respond to questions in a broad non-directed manner than in a structured interview, a well-designed in-depth interview will

provide a framework within which the interviewee can speak comfortably, honestly and accurately about the issues which are applicable to the objectives of the study. This does not mean that the interview guide, produced to prompt the interviewer to introduce potentially relevant topics, is unimportant; the point is that, as well as being detailed has an open-ended method, thus allowing the researcher to concentrate to issues which are important to the research participants and facilitate the exploration of different perspectives.

There are three approaches to in-depth interviews, each of which serves a different purpose, and therefore requires a different technique. [53]The informal conversational interview or unstructured interview often takes place within the natural flow of daily activities – it is most commonly used as part of an observational study and may also be called a life-history interview. [271]However, it can also be used in more formal situations such as clinical or focus group settings. The general interview guide approach (sometimes called focused or semi-structured interview) involves the preparation of a set of issues or topics to be discussed with each participant. The interviewer uses the list to make sure all topics have been covered, but the order in which they are covered and the wording of specific questions are not determined in advance. Thus, the order, wording, probing and additional topics or questions are settled as the interview proceeds[53];. [271]The standardised open-ended interview (also called a structured interview) consists of a set of questions which are carefully worded and organised in a sequence so that each interviewee is led through the same questions in the same order. Common reasons for designing a standardised interview schedule are the need to use multiple interviewers, to collect specific data in a comprehensive way and when time for interviewing is limited. As the purpose of conducting interviews for the purposes of the thesis was to explore each non-health outcome as a topic, a general interview guide approach was used.

4.2.3 General interview guide approach

An interview guide is a list of questions, issues or topics that the interviewer wishes to explore during the interview. They serve as a reminder and checklist so that the same general information is obtained from all participants. Within the area of each issue or topic, the interviewer is free to ask additional questions, probe and build on a different issue raised by a participant. This style of interview, should, in the hands of an experienced interviewer, resemble a conversation in its spontaneity and flexibility. The strength of the general interview guide approach is that it allows the interviewer to maximise the time available for each interview by carefully preparing for and adhering to the topic list, but at the same time enables individual interviewee's experiences and opinions to emerge. It also provides participants with some opportunity to emphasise or elucidate the issues that are important to them. The following (Table 8) is the interview guide used in the research with women about Pap smears, the results of which are reported in Chapter Six. The questions or checklist are in bold and suggestions for probes or additional questions are dot points.

Table 8. Interview guide for Pap smear interviews

Do you have regular Pap smears?

- How long have you been having Pap smears for?
- Who does your Pap smear?
- How/why did you start having Pap smears?
- Was anyone/anything particularly influential in this decision?

How do you decide when to have another Pap smear?

- own initiation?, reminder from doctor/Pap test register?
- some other method? (reminder from own doctor, friend, media, someone with cervical cancer)

Has anything ever discouraged you from having a Pap smear?

- ?lack of time, embarrassment, forgetting, fear of results, discomfort of the examination, indignity, fees, doctor's advice

Has anyone ever talked to you or given you specific information about having a Pap smear?

- Who?
- What?

Once you have had your Pap smear, do you think about the results of the test?

- What do the results of the Pap smear mean to you?

Have you ever had any positive results/worrying results from a Pap smear?

- how was this dealt with/handled by doctor/health professional?
- how did you handle it?
- Could/should things have been done differently?
- Did it change your attitude to having a Pap smear?

Have you had any particularly positive or negative experiences connected with having a Pap smear?

- What could/should have been done differently (ie to make the experience easier or more positive for you?)
- Have you ever been embarrassed or experienced discomfort when having a Pap smear?

Have you always had your Pap smears done by the same provider?

- Why?
- Does the sex of the person doing the Pap smear make any difference to you? How?

What part does trust play in your relationship with your (Pap smear provider)?

- How do you decide/work out that someone is trustworthy?

Does your (Pap smear providers') personal manner influence your thinking about whether or not or when to have a pap smear?

- If yes, how?
- If no, why is it not influential?

Have you ever discussed Pap smears with other people who are important to you?

- e.g. partner, sister, brother, mother, father, daughter, son, close friends, workmates
- How much do you think they are in favour of or opposed to your having Pap smears?

No matter what type of interview is used, careful consideration must be given to the types of questions to be asked. Which type of questions is chosen depends on the topic to be explored and the way in which it is decided to approach it. [53]For example, questions can be asked about a person's experience or behaviour (e.g. "what did you do when the results were shown to you?"); their opinions or values (e.g. "what is your opinion about having a Pap smear every two years?"); their emotional responses (e.g. "how did you feel when you found out about the abnormal result?"); about their knowledge (e.g. "what women's health services are available in this area?"); about what is seen, heard or sensed in another way (e.g. "what did you see when you looked at the scan?"); and background or demographic questions (e.g. age, education, occupation etc). These last are often routine questions to which standard answers are required.

While there may be good reasons for asking specific or closed-response type questions, truly open-ended questions allow the interviewee to select his or her response without being guided by the words used in the question. Thus, a question such as "how did you feel about going back for another Pap smear?" allows the participant to consider using their full

repertoire of responses, while "how annoyed were you at having to go back for another Pap

smear?” potentially restricts the respondent into answering only about the amount or degree of annoyance they felt. Questions may be asked about present, past or future events or experiences and how the questions are sequenced is flexible.

It is important to begin each interview on a comfortable footing. Although there are many ways in which this can be undertaken, a common approach in health services research, where participants may be questioned about potentially private or intimate details regarding their health, is to carefully explain the general nature of the research and how the researcher intends to conduct the interview. Issues of consent, confidentiality and how the data (e.g. tape-recording, interview transcript) will be handled and stored should be discussed. The way these initial processes of research are conducted will set the tone for the entire interview as well as help establish rapport between the interviewer and interviewee. [271]

Rapport and comfort will be further established during the first few questions and answers or exchanges between researcher and respondent. Many experienced interviewers recommend beginning an interview with a general, non-controversial question (e.g. “how long have you been having dialysis?”; or “how did the CAT scan go?”) and then move onto questions about feeling, opinions and knowledge. Putting these questions in the context of an actual experience is a good way of assisting participants to feel comfortable about revealing their emotions or knowledge.

Probing is used to elicit more detailed information on a topic. It can be used to clarify how a participant understood or felt about an issue or to ask for more information about the new issue raised by the interviewee. Questions such as “tell me more about...” or “what did you have in mind when you said...” are example of probes.

Pilot testing the questions is a useful way of ensuring that interviews elicit the sorts of responses needed. In the context of open-ended interviews, pilot testing may take place in the first few interviews and result in the schedule being refined in terms of number, type and sequence of questions. Pilot testing also allows refinement of introductory and transition questions and/or statements and probes as the responses of participants may introduce issues which the researcher had not previously considered.

4.2.4 Analysing qualitative data

The aim of data analysis is to find meaning in the information collected. [271]It is the process of systematically organising information so that it can be examined for ideas or issues relevant to the research question. Qualitative analysis commonly requires that the data be collected and analysed (at least in a preliminary manner) simultaneously, to allow ideas that emerge from the data to influence future interviews. [271]Such a process is termed inductive analysis, meaning that possible explanations are not hypothesised prior to the data collection. In contrast, in deductive analysis potential explanations for events are put forward before data is collected in the expectation of refuting or confirming the hypotheses. Therefore, qualitative research moves from observation to hypothesis without imposing a priori categories or concepts from the researcher's own knowledge onto the process of data collection. [272]In practice, some deductive analysis may take place in qualitative research, particularly at an advanced level of analysis.

Although there are a number of ways in which the process of inductive analysis can be sequenced, the steps involved are similar. For example, all methods require that the data be coded, although when in the analysis sequence this is done and how the codes are derived may differ. Codes can be derived from the actual words used by respondents, from the research questions or from a theoretical framework. Codes may be developed by counting individual words or sentences used by respondents, by searching for particular ideas or

concepts as they are expressed by participants or by identifying broad themes, which are often ideas or concepts linked together. Thus codes may fall into categories representing different aspects of the research context and questions. Examples of potential code categories include the situation or circumstances of respondents, their perspectives on their situation, the activities they have undertaken or the relationships they describe.

Once codes are developed and the data has been coded, steps are taken to explain the meaning and ideas that have emerged from the words which have been spoken by respondents. Such steps include developing descriptive and/or general statements about a concept, idea or theme, searching for data which both confirms and refutes the general statement, refining ideas or themes and producing and justifying an explanation for each idea or theme. Computer software may be used to assist in the initial stages of coding, particularly in grouping words or sentences to form ideas or themes. However, while such aids are extremely useful in storing and managing data, they cannot replace analytical thinking processes of human researchers.

Every qualitative researcher will, over time, develop one or more ways of undertaking data analysis that they favour. The method used by the candidate in the analysis of the research reported in Chapter Six is one that has been adapted from Collaizzi, Patton and Minichiello;. [53, 271, 273]The non-health concepts examined and described in earlier chapters form a theoretical framework within which the data from in-depth interviews was coded. Each interview transcript was read and summarised so as to condense the data thus making it easier to differentiate information relevant to the research questions from other information. Case summaries such as these are developed by asking questions such as “what issues are raised by the interviewee?” “what are some of the possible reasons for this explanation or event?”. [271]From the summaries, issues and explanations were grouped

together to form themes. The transcripts were then searched for statements which fitted each theme and explanations for the ideas expressed by informants were developed. Both supporting and non-supporting statements were identified. Finally, ways in which the themes related to one or more of the non-health concepts were elucidated and the results are presented under the non-health outcome headings using direct quotations from the interview transcripts to support the findings.

4.3 Using Stated Preference Discrete Choice Modelling (SPDCM) to assess the importance of non-health outcomes to patients and their preferences for them.

4.3.1 Overview

SPDCM has been widely used in marketing and transport and environmental economics as a means of investigating complex discrete choice problems. It draws on three major developments in research methods: discrete choice modelling, stated preference methods and qualitative research. Discrete choices are those which involve indivisible goods such as some consumer durables (e.g. car, washing machine), residential location, occupation or travel mode. The methods are consistent with Random Utility Theory (RUT) in economics and psychology, [274]and with a Lancasterian approach to consumer theory. [275]RUT states that utility is comprised of a systematic (observable) component and a random (unobservable) component. Lancaster's theory states that a consumer good can be disaggregated into a number of characteristics or attributes, each of which contributes to utility. For example, a car might be described in terms of characteristics such as size of engine, safety features, colour and time to delivery. Although utility is not directly observable, if the choice to consume a good or not can be observed from actual (revealed preference) or hypothetical (stated preference) data, discrete choice modelling methods can be used to estimate an index of utility from the observed choices. In this way, preferences

for complex multi-dimensional goods can be studied and the contribution of each attribute to the choice to consume the good or not can be estimated. Thus, SPDCM would enable a manufacturer to assess the relative value or importance of a car's characteristics to consumers.

Since the late 1960s steady progress has been made in understanding and modelling human judgement and decision making, particularly in applied economics fields such as marketing, transport economics, environmental and resource economics. McFadden, [276] who shared the 2000 Nobel Prize in economics for this work, extended RUT to the case of discrete choices from multiple options, and further developments have followed [Louviere J, 1993 #641]; [277] Recent work in discrete choice modelling has demonstrated the power and predictive accuracy of discrete choice models in a range of complex choice contexts such as transport, business travel choices, environmental and eco-tourism and occupational choices; [278-280]

Conventionally, economic modelling has worked with actual market data (i.e. revealed preferences). However, in health care, market data, particularly regarding prices, are limited. Contingent valuation (CV) methods such as willingness to pay or willingness to accept; [281, 282] have been used to ask people directly about their preferences and their willingness to pay in order to generate estimates of benefits for the purposes of cost-benefit analysis. However, in the context of health care, CV has been criticised on a number of grounds. The choices are hypothetical and respondents may answer strategically (i.e. they may say they are willing to pay more if they know they will not have to pay, or less if they believe that the payment will be shared by other, for example as a levy or tax). Further, people are not used to paying the full cost of health care and the question may be unrealistic.

Finally, it has been established that willingness to pay is influenced by ability to pay and, as

well as affecting responses, the use of the technique may conflict with equity objectives in health care. [281-283]

Stated preference data can also be generated in a form that allows discrete choice modelling. [277]For this, any choice alternative must be described in terms of its attributes. The levels of the attribute can be varied over a realistic range. Unlike real markets, individuals can be asked to repeat their hypothetical choices, thus generating multiple observations. There are some implications of this for statistical analysis, in that the data should be analysed as repeated measures. Describing a program or service in terms of a small number of attributes provides a large number of attributes to be tested. For example, three attributes each with four levels generate 64 alternatives. The principles of experimental design are crucial here in that they provide a means of generating from the full set of alternatives (the full factorial design) to a sample (a fractional factorial design) which has properties that allows the effect of each attribute to be estimated independently. Complex designs are needed to model choices in health care.

The use of SPDCM in health economics and health services research is relatively new, but expanding. So far, it has largely been applied to direct evaluations of different policy relevant attributes of health care interventions. In general, these have been attributes other than health or non-health outcomes, such as waiting times; [284]; [285]; [286, 287]; [288].

There have been a number of studies published in which some non-health outcomes have been included in choice experiments. Graf et al [289]used attributes derived from patient satisfaction studies in a choice experiment designed to inform hospital administrators (in the United States) about the combination of characteristics most likely to optimise patient

satisfaction. Five attributes (room switching between labour and delivery and post-natal care, nursing care for mother and baby, visitor policy, hospital type and hospital care) were varied and respondents were asked to evaluate 16 hospital profiles. Results indicated that room switching and hospital type were preferred by patients. Markham et al [290] included the attribute “who makes care decisions” in another study of the aspects of patient-physician interaction important for patient satisfaction. The results, described as how each attribute was ranked in terms of the variance it accounted for, indicated that the decision making attribute was ranked second (of five) accounting for 20% of the observed variance in patients’ preferences.

Using SPDCM provides researchers with an opportunity to enhance their understanding of the characteristics of health care that users and potential users of health care services prefer. The results of SPDCM experiments can therefore be used to inform providers, managers and funders about ways in which health care can be planned and delivered in a way that is most acceptable to patients and users of services. The SPDCM framework can be used to investigate how different attributes of health care, in particular health and/or non-health outcomes are combined in preference assessment. Thus, the application of this method has the potential to greatly improve the manner in which benefits are valued and therefore the comprehensiveness of health care evaluations. The use of SPDCM to consider non-health outcomes in this thesis represents the first (known) attempt to consider the preferences of patients for a comprehensive set of non-health outcomes.

4.3.2 The analytical approach to SPDCM

SPDCM involves the use of experimental design principles to develop stated preference surveys (choice experiments) to provide data which allow for the efficient estimation of consumers’ preferences for goods. In a SPDCM experiment, individuals are asked to choose

a good or service they prefer from a set of hypothetical interventions (the choice set). The services being evaluated are described in terms of a range of attributes which each have a defined number of levels. The approach assumes that individual's choices reveal their preferences, that is, consumers choose the alternative from which they derive the most utility.

Utility is not directly observable, but we can observe consumers' choices (here, hypothetical choices or "stated preferences"). Utility (unobservable) is estimated from consumers' choices (observable) as follows. For the i th consumer faced with J choices, suppose that the utility of choice j is U_{ij} . If the consumer makes choice j in particular, then we assume that U_{ij} is the maximum among the J utilities. Hence the statistical model is driven by the probability that choice j is made, which is

$$\text{Prob}(U_{ij} > U_{ik}) \text{ for all } j \neq k ; j, k \in J$$

RUT states that a consumer's true utility for a particular health product or program has two components, an explainable and a random component:

$$U_{ij} = V_{ij} + \gamma_{ij},$$

where U_{ij} is utility of the health product j for consumer i ; V_{ij} is the explainable component; and γ_{ij} is the random, or unexplained, component.

Let Y_i be a random variable that indicates the choice made. Given the choice between health products j and k , the probability that person i chooses health product j is given by:

$$\text{Prob}(Y_i = j | j, k) = \text{Prob}[(V_{ij} + \gamma_{ij}) > (V_{ik} + \gamma_{ik})], \text{ for all } j \neq k ; j, k \in J$$

The utility U_{ij} depends on aspects of the health product and aspects of the consumer. Thus if \mathbf{x} is a vector of attributes of the health product and \mathbf{z} is a vector of attributes of the consumers, $V_{ij} = \mathbf{S}'\mathbf{x}_{ij} + \mathbf{z}'_{ij}$ where \mathbf{S} and \mathbf{z} are vectors of parameters that represent the influence of attributes of the health products and/or characteristics of individuals. If the γ_{ij} are independently and identically distributed extreme value random type 1 variates, the conditional multinomial logit model results. [276] However, when consumers makes a series of choices (as in choice experiments), it may not be reasonable to assume that the γ_{ij} are independent, i.e. the γ_{ij} may be correlated for an individual i . This can be modelled by decomposing the random component into a part that is specific to and constant for an individual across choices, and a part representing the remainder which results in a random parameters mixed logit (RPML) model. This specification of the random component leads to the mixed logit model. [291]

4.3.3 Designing and undertaking an SPDCM experiment

There are seven stages in an SPDCM experiment, each of which will be described briefly below: [280]

- Define study objectives: This step is necessary for every research project, including ones involving SPDCM. Difficulties may arise if the researcher is unsure of the question he or she wishes to have answered by SPDCM or whether SPDCM is a suitable tool to use for a particular research question. In the context of health care, the issues to be considered revolve around the purpose of the evaluation. For example, the purpose may vary from understanding what provider or service characteristics would cause users to evaluate the person or program positively to what would increase the chance that people would use a product or service.

- Conduct supporting qualitative study: The underlying validity of the model depends on the analyst's ability to specify correctly the program/product attributes that are relevant, which requires detailed understanding of the consumer's experience and point of view. While there may be considerable information available from the policy context or from literature about the set of attributes that influence choice, researchers and policy makers will rarely understand the attributes of interest in the way consumers do. Thus, qualitative research is regarded by many exponents of SPDCM as an important and necessary preliminary phase of a choice experiment. For the purposes of the research described in the Chapter Six, the results of the qualitative research into non-health outcomes described in the previous chapters served to identify the set of attributes used in the SPDCM experiment. In combining the results of qualitative research with SPDCM, a question also arises about the translation of relatively complex concepts such as having trust in a health care provider, being treated with dignity, legitimation and being provided with reassurance into one-line statements which people would be able to understand and respond to. This was dealt with in two ways: by providing a description of each concept in the information given to participants and by using words and phrases in the statements about GPs which had been used by respondents about their doctor in the in-depth interviews reported on in Chapter Six. For the purposes of the survey, the non-health outcomes were described as in terms of how GPs behaved. This meant that a specific description of each non-health outcome was chosen and transformed into a simple statement. For some, this was relatively straightforward. For example, the outcome "reassurance" was rendered as the statement "the doctor encourages and reassures you". However, others were not transformed so simply. The outcome "legitimation" was transformed into "the doctor takes notice of what you say about your health". Transformations from outcome label or item to statement were effected using definitions and descriptions from the literature and from the empirical work described in

Chapter Six. Thus, although it is not possible to observe exactly how participants understood the statements, confidence in the results is increased by the fact that they had no difficulty in completing the survey and that they responded in the expected ways. However, because the definitions and interpretations were not explored specifically with the respondents to the SPDCM survey, there is no guarantee that they and the candidate would have the same interpretation of the statements.

- Develop and pilot the data collection instrument: Traditionally, SPDCM tasks are presented to individuals in the form of a questionnaire, in a tabular form. [277]Attributes are arranged in rows and alternatives in columns. However, there are many ways in which this layout can be modified in order to enhance respondents' use and interpretation of the questionnaire. This is one of the main objectives of conducting pilot testing of the questionnaires.
- Define sample characteristics: The sampling frame defines the population of respondents from which a sample is drawn to administer the data collection instrument. As in all research, the objectives of a study dictate the sampling frame, that is, the sampling frame must be defined so the research questions can be answered using the estimations of preferences developed from the sample. Given the sampling frame, a sample size must also be defined. That is, it is necessary to calculate a minimum sized sample which will enable the results of the study to be both valid and generalisable to the population of interest.
- Perform data collection: in undertaking this aspect of a SPDCM experiment, consideration must be given to how to recruit respondents, what type of survey instrument to use and the level of assistance to be given to respondents. Recruitment methods depend on the sample required; patients may need to be recruited with the assistance of health care providers or services, while random samples of the general population may be recruited using the telephone directory or purchased lists of potential

respondents. Choices about survey type and respondent assistance include the use of mailed surveys, interviewer assisted one-to-one or group surveys, telephone or computer assisted surveys.

- Conduct model estimation: In this step, details about how the model will be specified and estimated are set out. Depending on how the choice experiment is presented to individuals, different aspects of the general RUT model given in Section 4.3.2 will be specified to determine the appropriate statistical model for a particular survey. For example, in the survey to be undertaken in connection with this research, two aspects of the general RUT model were specified. First, each respondent was presented with one scenario at a time and asked to indicate what they would do if they needed to consult a GP for a specified condition (i.e. how they would choose among three alternatives), $j = 1$ to 3. Second, it is usually assumed that the random or unexplained component (ϵ_{ij}) is distributed independently and identically with a logistic distribution (i.e. that an individual's probability of choosing is a function of the specified factors, in this case the attributes and other personal factors such as age, education level and income). In this case, the correct model to be specified is a multinomial logit model (MNL) which is a linear model for the logit (natural log of the odds) of the probability of choosing as a function of specified quantitative factors. The logit and logistic models are mathematically equivalent. [292]Models can be estimated as main effects models only, include interaction terms and/or be aggregated to include covariates such as the demographic characteristics of respondents.
- Interpret the results: Results of an SPDCM experiment are reported in a similar fashion to many quantitative surveys. The general characteristics of the sample such as response rate, demographic and personal factors and the ease with which the surveys were completed are commonly reported followed by detailed results such as the distribution of choices and the findings from the estimated model/s.

4.4 Combining qualitative and quantitative research methods

Qualitative and quantitative research methods differ in the ways in which data are collected, the nature of the data itself, the methods used to analyse these data and the way in which results are interpreted. Qualitative methods often require the personal interaction of the researcher and those people whose experiences are the subject of the research and involve the use of interviews, observation or analysis of documents. It has been said that, in qualitative research, the researcher is the research instrument. [53] In contrast, a quantitative researcher may never see his or her subjects or respondents as quantitative methods require the use of standardised measures in which responses are assigned to pre-determined categories to which numbers are assigned.

Thus, qualitative research produces a wealth of detailed information about people's experiences, feelings, opinions, knowledge, actions, interactions and responses to personal and organisational changes. Such detailed information is usually able to be collected from a small number of people and is not usually regarded as representing the views of the entire population or group within the population. On the other hand, quantitative research, by counting and measuring, is able to produce information about the reactions of many people, albeit to a limited set of queries, thus enabling the results to be generalised to much larger groups, including the population as a whole.

Philosophers of science, methodologists and researchers themselves have engaged in a long running debate about the relative value of quantitative and qualitative research. Patton [53] describes the debate as involving two competing paradigms or worldviews – logical-positivism which uses quantitative and experimental methods and phenomenological inquiry which uses qualitative and naturalistic methods. The importance of the debate is that it has examined and clarified the impact of paradigms on the way research is conducted and the

extent to which results from research have been accepted as legitimate. Thus, the tenets of each paradigm may be so firmly established in the minds of followers and practitioners that they are unable to question the assumptions that lie behind each method.

However, exponents of applied research, including evaluation research have been able to show that, although each method has its strengths and weaknesses, they may constitute alternative, but not mutually exclusive, research methods. Qualitative research can be conducted as a preliminary to quantitative research, as a supplement to it or on its own where quantitative research is not appropriate. [272]It has been recommended as a pre-requisite for high quality quantitative research especially in areas that have been the subject of little or no research. [272]Qualitative methods can be used to identify the appropriate variables to measure as well as provide an explanation for unusual or unexpected results or act as a source of hypotheses. [293]Thus, for pragmatic as well as philosophical reasons, combining qualitative and quantitative research methods is becoming more popular and acceptable in health services research as researchers learn to appreciate the strengths and weaknesses of both methods and to discover ways in which the results from one method can be used to strengthen, complement or provide input to the other.

Evaluation has been defined as any effort to increase human effectiveness through systematic data-based enquiry [53]or as a process that attempts to determine as systematically and objectively as possible the relevance, effectiveness and impact of activities in the light of their objectives.. [292]That is, evaluation attempts to judge whether attempts made by people to improve things (e.g. programs, services) have been successful. Evaluation *research* occurs when judgements about effectiveness are arrived at following systematic and empirical examination and analysis of data. Evaluation research is applied

research or action research because it generates findings that can be used to inform action,

enhance decision making, improve services and programs and solve human and societal problems. [53] Depending on the reasons for an evaluation, when it is being conducted and what type of information is required, different types of data may be useful and therefore, either or both qualitative and quantitative research methods may be appropriate.

The aim of this thesis is to answer questions about the relevance and importance of non-health outcomes and about the preferences people have for these outcomes. The extent to which qualitative or quantitative methods should be used can be gauged by the way in which each question is defined in relation to non-health outcomes. Thus, relevance refers to whether an idea or concept has a bearing on the question or is pertinent to it. A non-health outcome could be considered relevant if people considered it to be germane to their experience of health care. An idea or concept is considered important if it is seen to be of great consequence or significance or to carry great weight. A non-health outcome could be considered important if it is mentioned or discussed by a substantial number of people or if its presence is considered meaningful or given weight by some people. Preferences represent a liking for one thing better than another. Preferences for non-health outcomes can be indicated by the way in which they are ranked relative to each other, that is, the order of priority they are given by respondents.

These definitions and explanations suggest that relevance would be best examined using qualitative methods, as whether a concept is relevant depends on how people describe their experiences and feelings and on their opinions. The importance of non-health outcomes, however, could be assessed by either qualitative or quantitative methods. The number of people who mention and/or discuss each concept and, to some extent, the emphasis placed on each one could be assessed using qualitative methods. Quantitative methods can also be used to count and estimate the weight or significance (statistically speaking) of individual

non-health outcomes. In this context, preferences are best measured quantitatively as the objective is to determine how people rank each non-health outcome relative to the others.

In this thesis, in-depth interviews were chosen as an appropriate method to use in assessing whether non-health outcomes were relevant and, to some extent how important they were to patients. In contrast, a quantitative technique, Stated Preference Discrete Choice Modelling was chosen to assess the preferences of people for non-health outcomes. The SPDCM experiment also allowed an estimate to be made of the relative importance placed by respondents on each non-health outcome, thus providing a method of verifying the results of the in-depth interviews. A description of the specific application of each method, the results and a discussion of the findings is presented in Chapters Five and Six.

Chapter Five

The importance of non-health aspects of health care to patients: an empirical exploration

Chapter 5 The importance of non-health aspects of health care to patients – an empirical exploration

5.1 Introduction

So far, there has been little or no empirical assessment of the extent to which the factors reviewed in Chapter Three are considered to be relevant, important and/or influential from a patients' or users' perspective. The studies described in this chapter were designed to explore these issues with two groups of patients or potential recipients of care – people with chronic renal failure and women in the age range recommended for cervical screening (Pap smears).

The aim of the research reported here was to investigate if non-health outcomes were relevant and/or important to members of the two groups. One way of assessing relevance and importance in individuals' own terms is to ask them to describe one or more experiences (in this case, decisions about health care), to observe which aspects of care they describe and (to a limited extent) examine the relative emphasis they place on each of the concepts of interest (in this case, non-health outcomes). This research was approved by the Ethics Review Committee of Central Sydney Area Health Service.

5.2 Methods

Potential participants from both groups were asked to take part in a semi-structured, tape-recorded interview. All interviews were undertaken by MH. The topics covered in the interview were generated from a review of the peer-reviewed and popular literature covering the broad topic “experience of illness”, described in Chapter Three and from the detailed review of each concept presented in Chapter Four. The topics are listed in Table 9.

Table 9. Topics covered in the research interviews

Chronic renal failure	Pap smears
<ul style="list-style-type: none"> • Decision making processes related to dialysis or transplant • Influences of health professionals/families/other • Assistance with making decisions • Trust • Relative importance of health care decisions to other decisions in life • Emotional support • Legitimation 	<ul style="list-style-type: none"> • Regularity of Pap smears • Decision about next Pap smear • Decision about initial Pap smear • Positive/negative experiences of Pap smears • Encouragement/discouragement to have Pap smears • Any “worrying” results from Pap smear? • Pap smear provider history • Trust • Personal manner of provider • Other influences on decisions to have Pap smears

In general, the interviews were designed to: elicit the critical aspects or attributes of the patient-provider relationship (in particular to understand the degree of importance patients attach to the concepts outlined above), to understand the importance and use of information exchange in developing and consolidating such relationships and in making decisions about health and health care and to elucidate how and in what way patients consider their input to decision making contributes to their well-being. Copies of the information sheets, consent forms and list of questions for both studies can be found in Appendices One and Two.

5.3 Analysis

- In both studies, an iterative thematic analysis of the information obtained in the interviews was undertaken. The steps in the analysis were as follows: [53]
- The candidate listened to and read the tapes and transcripts to acquire an overall sense of each participant’s story. The supervisor also read the transcripts. Both researchers independently wrote a summary of the story being told, listing important issues and possible explanations which emerged from each interview. These issues and explanations, as well as the framework provided by the interview questions and the

concepts discussed in the previous section, form the basis of the main categories under which the analysis has taken place.

- Both researchers compared and discussed the issues and explanations raised by the participants. Any differences were discussed and debated until a final solution regarding the issue and its meaning was reached.
- The candidate re-read the transcripts and extracted statements directly relevant to each issue listed in Step One above.
- The candidate attempted to interpret each statement. This can be described as moving from what was said to what was meant.
- The meanings were organised into themes which are recurring opinions, preferences, assumptions or perceptions.
- Using these themes and the categories of non-health outcomes, the “results” were described in detail, using direct quotes from the interviews to illustrate the points being made. In this context, “results” mean the answers to the research questions outlined in the broad description of the interviews.

Permission was requested to send each participant a copy of the transcription of his/her interview. Fifteen participants from the group with chronic renal failure and all women eligible for Pap smears gave their permission and received a copy of the transcription. Participants were invited to comment on the contents and/or verify the details. No comments were received from respondents with chronic renal failure. Two women who participated in the Pap smear interviews made minor “editing” changes to the transcripts of their interviews and the changes were incorporated into the final copies of the transcript used by both coders.

5.4 Results

In the results sections, the findings from each study are discussed in terms of the concepts

described and discussed in Chapters Two and Three. The results are illustrated by direct quotes from the interview transcriptions. After each quote, the participant is identified: in the case of people with the chronic renal failure, as either female (F) or male (M) and by whether s/he was the recipient of renal dialysis (D) or of a kidney transplant (T); in the case of women eligible for Pap smears, by the age range to which they belonged. An explanation of the presentation of participant quotations is given in detail in the footnote.¹

5.5 Study of people with chronic renal failure

5.5.1 Introduction

People with a chronic disease such as diabetes or renal failure can expect to become familiar with many health care providers, many different programs and services and many aspects of the health care system within which they are treated. People with chronic renal failure typically experience some years of episodic ill-health during which it becomes clear that they will require dialysis in the future. It is often at this stage that they are given information about the options for dialysis and the opportunities for kidney transplantation. Eventually, decisions are made about dialysis and/or transplantation and a different stage of living with a chronic disease is experienced by individuals. Thus, a group of people with potentially both long and broad experiences of disease and health care could be expected to have a wide range of perspectives on both health and non-health outcomes.

5.5.2 Methods

Purposive sampling, which involves deliberately choosing respondents based on their possession of characteristics of interest, was used to recruit participants. [272]Patients attending the hospital for dialysis or transplant follow-up were recruited by the candidate with the help of staff of the dialysis and transplant units at the Royal Prince Alfred Hospital,

¹ All quotations from participants are presented in italics. The quotations are drawn directly from the transcription, and the punctuation has been inserted by the transcriber. Words in square brackets are words inserted by the candidate into the participants' quotations to provide continuity in the printed quotation. Words in round brackets in normal print are information inserted by the candidate to clarify for the reader what the participant has said. Dots (...) in the text represent a break or pause in the respondent's speech.

Sydney. Other patients were invited to participate via a mailed letter. The initial criteria for participation were that respondents spoke English proficiently and were willing to be interviewed. The aims of the study were explained to all potential participants and an appointment for an interview was made with those people who agreed to take part in the research. In this way, 20 people were interviewed. Ten participants were interviewed in a hospital setting (including one staying in a hospital-run hostel), nine in their homes and one in a café. Eleven women and nine men were interviewed. Participant recruitment ceased when the point of saturation was reached, that is when no additional data was being gathered that would add to the themes being developed. [271]

5.5.3 Results

The distribution of age and sex characteristics of the 20 participants is illustrated in Table 10. Of these, nine were receiving renal dialysis (including one person whose cadaveric transplant had failed a number of years previously). Of the 11 people with transplants, eight had received a kidney from a living person and 3 from cadavers (including one person who had previously received a transplant from a living person).

Table 10. Age and sex of participants

Age	Female	Male
20-29	-	1
30-39	3	2
40-49	4	3
50-59	4	3

Information

A wide variety of experiences and opinions were voiced about how much information was required, how and when it should be delivered and the extent to which it assisted decision making. There were no marked differences in the experiences of dialysis and transplant patients. A few participants indicated that they needed as much information as possible

while others were content with what they were offered by health professionals at a particular time. One woman said:

“What I do is I try and get as much information as I can and I try and process it myself. If I can’t process it then I go back to the medico and I just push him for the information until we sort it out”. (F, T)

However, another person offered a different opinion. He said:

“No, I didn’t worry about it (getting information). I thought what I didn’t know wouldn’t hurt me. ...it’s (renal transplant) not something I really am going to study or look up or look into”. (M, D)

Most people relied on the information they were given by health professionals, facilities or support groups (e.g. the Kidney Foundation). The information consisted of booklets, newsletters and information sessions (during the day or evening) about specific aspects of renal failure and/or transplant. Most participants found this information sufficient and helpful, although a few voiced dissatisfaction with the amount of information they were able to access and/or frustration with obtaining information from doctors. One woman said:

“first of all [renal specialist] doesn’t really tell you a great deal...and if you don’t know what is ahead of you and you don’t know what to ask, well then you don’t get the answers”. (F, D)

Two people mentioned access to computers and the Internet as also being valuable for accessing information.

“because I was in the computer industry, so from the internet I got down everything about side effects and like cyclosporine and all those things, and so I had a lot of information”. (M, T)

“now I can jump on the web and type in a name and up come a few references.”. (F, D)

Most dialysis patients who had been on the transplant list for a number of years no longer felt any need for information about transplants; others believed that additional information for people on dialysis was needed rather than more information about transplants. Two participants responded in this way:

“I received bits and pieces in the mail...about information days and what was going on and I looked at them and threw them out. I thought, ‘they’ll tell me what I need to know when I get there’ (for a transplant)”. (M, T)

“We have been to a workshop and stuff like that (regarding transplant), that is irrelevant to me. I think they really need something to be set up for dialysis people and I’ve sent a survey form back to the Kidney Foundation” (F, D)

Seven participants indicated that they were interested in information specifically related to their problems and what they felt was most important to them. For example, approximately half the people on dialysis said that detailed, specific information about diet and the dietary restrictions associated with renal failure and dialysis were most useful. A few of the participants had unusual diagnoses associated with their renal failure and were interested in information about their disease and its causes.

A few participants distinguished between access to information (and, by implication, gaining knowledge) and using this information and knowledge to enhance their input to the decision making process (or be involved in decision making). While this topic will be discussed further in the section on decision making, it is worthwhile to note how one woman described the difference:

“Whether I’d call it decision making or my questioning, in the past I probably would have sat back much more and taken the advice of the doctors. Now I’m more questioning...me wanting to know what I could do all the time to keep myself as well as possible”. (F, T)

Five people had family experience of renal failure (some inherited). These people had more long-standing knowledge of the disease process and possible treatments than others; that is, their decisions were backed up by more information and understanding than might have been obvious from the time they had spent considering their options. In addition, a few participants had experienced renal problems (though not necessarily dialysis) since childhood and so were more familiar with the problem and the treatment than others who developed renal failure as adults.

Dignity

Dignity in specific health care situations was not mentioned by the participants of this research. However, in line with the definition of dignity which asserts that it is associated with wholeness and controlling one’s own fate, [198]many people described a strong sense of having detailed knowledge of their body and responsibility for taking notice of bodily signs and symptoms which they associated with decisions about their health and health care.

One woman described this in a way which was representative of the participants:

“It is OK to take blood tests, they do prove what is going on, but it is my body. I am listening to my body, my body is telling me this, telling me that. I have got to act on it – otherwise...you have to take responsibility of your own body. That is what I did”. (F, T)

Most participants had spent many years in close contact with the health care system and had experienced many procedures. As they had developed long-standing relationships with

health care professionals, they may have felt that, unless it was seriously violated, dignity was a minor issue compared with others in the decision making process.

However, a few participants did mention being treated with respect which they associated with acknowledging their worth as a human being. In speaking about how she reacted during a dispute with a health professional, one woman said:

“I believe if you want respect you have it but only if you respect the person you want it from” (F,D).

Another woman expressed it differently:

“I think some doctors need to recognise that we are people. I think that, because some of them are just – we are either experiments or they don’t see the human side of it”.

(F, D)

Reassurance

Most people interviewed for this research were experienced users of the health care system. Moreover, most of them had been seeing the same doctor or doctors (and other health professionals) regarding their renal failure and/or transplant for months or years. It was obvious from their remarks about and their knowledge of the system that their attitudes to and their relationships with health care professionals were well developed. Although a few participants spontaneously mentioned needing reassurance from the providers of care, others may have felt it was not necessary to specifically mention or discuss this concept during the interview.

People who were newer users of the health system and those who had recently experienced a different type of care were more likely to mention the need for reassurance. For example, a woman who had been on dialysis for a few months said:

“I’ve never known nurses like them...it really does, of course, reassure you” (F, D)

A man who had recently had a transplant operation described how he looked for and found reassurance prior to the operation:

“I didn’t have any worries. ...talking to the [renal specialist] and talking to the doctor and talking to [nurse]..you would say this happened today [nurse], she would say, probably this, probably that” (M, T)

One participant, in explaining how she made a decision to accept the offer of a kidney transplant described how her specialist reassured her thus:

“I wasn’t quite sure whether to take it or not, but once I spoke to my [specialist], he said look considering you are on dialysis, if you had a transplant you would feel a whole lot better” (F, T)

Other participants believed that they had missed out on receiving reassurance which they needed. A woman who had received a transplant said:

“...they [health professionals] don’t get emotionally involved and they don’t say to you, look this is the information, but it’s going to be alright, this is the way we think it’s going to go and it’s going to be fine – give you a little bit of encouragement or a little bit of a push along, but they don’t do that”. (F, T).

The same participant contrasted her recent experience of transplantation with her previous experience of dialysis and the attitude of nurses and doctors involved in dialysis:

“Because in haemodialysis, the nurses were so encouraging and so wonderful and that kept you going...But they were the emotional side and the medicos were the technical side”. (F, T).

Another participant explained that she needed reassurance while waiting to find out if a potential donor was compatible. While she understood the health care professionals' desire to be cautious, she found it upsetting that they did not reassure her that things would go well. She contrasted their attitude before the compatibility was known with that after she had the transplant:

“I know [the nurses didn't] want to see me get my hopes up too high and all that kind of thing, but at [that] moment I need[ed] to see some light at the end of the tunnel”.

“...they all came to see me before the surgery and popped in after the surgery...they were great” (F, T)

Almost all participants also described how members of their family and others who had experienced renal failure or a kidney transplant offered reassurance about the process they might (or would) experience and that the outcome was worth all the negative events that might happen along the way. One woman said:

“I met two people who had transplants and they said to me regardless of all the drugs you take and what you have to go through at the end it is all worthwhile, definitely”. (F, T)

Recognition of and support for emotional distress

All participants recognised that emotional distress was (to a greater or lesser extent) part and parcel of ill-health and decisions about health care. Support during periods of illness and particularly the process of decision making were seen as very important. Participants described this support as coming from their family in the first instance, but many were also

able to describe the support they had received at crucial times from health care professionals.

As well as giving support at particular times (e.g. when the patient was in hospital), families were described as providing sounding boards for decisions and as monitoring decisions.

The statement by one participant who said:

“I talk it over of course with my husband...” (F, D)

was typical of the sounding board type of support offered by families, particularly spouses or partners. The monitoring type of support was described by one participant thus:

“...because I’m sure that if I make the wrong decision, someone is going to come and nudge me and say ‘hey look, you are being stupid, think about it’. I know my father is always doing that. Mum is always there to support me, to support my decision, but you can always tell the concern in a mother’s face”. (M, T)

Not surprisingly, participants who were on dialysis (especially those dialysing at home) were more conscious of family support, while those who dialysed at a health care facility or who were transplant recipients were more aware of the support (or lack of support) of health care professionals. One woman, dialysing at a hospital, said:

“Here, they’re marvellous. I’ve never known nurses like them. They have so much patience, never raise their voices, unbelievable. It makes a big difference and they are friendly too”. (F, D)

Another woman, who had received a transplant, contrasted the attitudes of doctors and nurses and that of dialysis and transplant staff. She said:

“The nurses are better than the doctors. Because in haemodialysis the nurses there were so encouraging and so wonderful, they kept you going every day and helped

you through every session of dialysis. But they were the emotional side and the medicos were the technical side”. (F, T).

A third participant had found that, at times, her relatives provided better support than health professionals. In speaking of her relatives, she said:

“...they all came together at the time of the transplant, they were fantastic and they came from everywhere...”

In describing the attitudes of the staff she came into contact with, she said:

“...my doctor was very positive about transplants. I felt that the associated nursing staff, initially, were very...I found it a very negative thing. One resident said ‘you have got to face the fact that you are going to be a renal patient for the rest of your life’. And I just found that so negative”. (F, T)

Some specific examples of support were mentioned. For example, two transplant recipients noted that health professionals had organised family “conferences” where information about the transplant could be exchanged. Such experiences were seen as providing the recipient and family with practical support from health professionals and the medium through which family members could express their support for the transplant recipient (and donor if it was intended that the kidney be provided by a living donor). One man said:

“The doctor in [city] said if we did want to go ahead with it, he’d like to have a family meeting and we could ask whoever we wanted along...They explained everything and he said if anyone has anything to say about it, they can say it now, ask questions and everyone was agreeable with it.” (M, T)

As well as offering practical support, participants mentioned health professionals' personal manner as providing evidence that they were supportive. One participant described the manner of a number of health professionals:

“One night we rang him (the specialist) when one of my early grafts packed up on a Saturday evening and he saw me straight away. I found they were really good in that sort of way. People like the anaesthetist went out of his way to be really nice...they (specialists) were always particularly pleasant”. (F,T).

Another participant described the non-supportive manner of one of her doctors:

“...my specialist is very arrogant, he is like what I say goes and I don't want to hear what you have to say. I find that really intimidating and difficult to cope with sometimes”. (F,T).

Three participants also mentioned the use of Internet support groups. Others described receiving support from people with experience in the area (both patients and health professionals) and from knowing that there were people available to talk to.

A few people referred to the need for support for carers of people on dialysis and for donors of organs. Two participants were involved in offering support to others on dialysis or receiving transplants, both formally (being a member of a support group) and informally (by keeping in touch with people they met in hospital).

Transplant recipients were more likely than people on dialysis to describe the emotional issues associated with their decisions about health care. In part this was due to the fact that most people had not had their transplants very long and so were still experiencing the uncertainty and emotional highs and lows associated with the early days of a transplant. But

it may also have been due to the fact that transplantation is in itself a very emotional issue, involving either the death of someone (where the donor is a cadaver) or (where the donor is living) an operation on an otherwise healthy person who is likely to be very closely connected emotionally to the recipient. Participants described the emotion associated with the idea of a transplant and also with the early days after the procedure was completed. One participant said:

“...the whole process was very emotional, because my mother died four years ago (from renal failure) my father strangely enough was on dialysis just before he died too, which was two years ago”. (F, T)

Another said:

“...one of the renal physicians that I was under felt there were a lot of issues involved and it [living donor transplants] was not a particularly easy thing to do”. (F,T).

The majority of participants described how being able to talk to health professionals and other patients was a source of support during emotionally trying times. One woman described her time on dialysis as:

“just like a big family. And not just the nursing staff, but also the other patients. Because we knew each other so well, we talked a lot between each other. [One of the doctors] was a woman around her mid-30s but she was a different sort of personality and very easy to talk to. I guess we talked to her in a much freer way at times and I suppose there were some times when I made a decision to talk to her about some problems because she was a woman”. (F, T)

A few participants related their experiences of professional support in assisting them to deal with the emotional issues surrounding living donor transplants. One woman was

particularly concerned about talking things through with her donor with the help of a professional counsellor. In particular recipients were aware of the guilt they anticipated if the transplant failed. Two participants described the issue in these words:

“I particularly wanted to work through the issue of how I would feel – the guilt if things went wrong. I had a few issues like that which I felt needed to be resolved and I didn’t find it easy to talk to her about and I thought we would have some sort of counselling here”. (F,T)

“I had to go and see a psychiatrist three times. T (donor) didn’t, he didn’t have a problem with it. I had a problem with taking his kidney. I had a problem with first ‘what if it failed’...that was my biggest fear...”. (F,T)

Legitimation

Although it was not a major theme of the interviews, a few participants mentioned the importance of having their opinions, ideas or perceptions about their illness or treatment acknowledged. However, most were cautious about challenging the experts. Four participants described how they monitored their condition, read and thought about what the problem might be prior to confronting a doctor, disputing an opinion or attempting to have their point of view accepted. Two people described specific situations which ended positively when they succeeded in having their ideas regarding treatment or side-effects taken into account.

A few participants referred to being labelled, but (understandably), this was not a common theme. Two participants described past experiences which they believed had led to their being labelled difficult or not suitable for transplant. Both experiences involved questioning what was happening to them; one participant believed that more could have been done to treat her symptoms and prevent her feeling unwell for much of the time while the second

person believed that her demonstrations of anger about her disease and the failure of treatment were interpreted by staff as signs of an aggressive personality.

Trust

Six participants explicitly discussed the issue of trust, while four others referred to it indirectly. All of the former believed that trust was a necessary component of the doctor-patient relationship. Asked to elaborate on what made a person trustworthy or how they would know that someone was trustworthy, participants described a sense of discovering over time that the doctor (or health professional) was proved right in what s/he said, was able to answer questions and provided information which turned out to be useful. Participants differed in whether they considered a health professional's personal manner to contribute or detract from their ability to trust them. Three people described how a friendly, open manner contributed positively, while others denied that personal manner had any impact on their ability to perceive a person as trustworthy.

One participant described the need to trust health professionals because she did not have the same expertise:

“Oh you have to trust them (doctors and health professionals) because you just don't have the knowledge yourself”. (F,T)

The same person believed that a combination of knowing health professionals were qualified, seeking information about their reputation and personal experience combined to convince her that such a person was trustworthy. She said:

“I think that people just trust them because they have ‘doctor’ in front of their name, really. He (her doctor) seems to know his stuff...and he's been there for years...I have never been let down by them (health professionals) in that everything flowed, everything worked, that kind of thing”. (F,T)

A woman on dialysis succinctly described her understanding of the combination she relied on:

“I suppose over time you get a feeling. Through their advice and what seems to be true and what they say is going to happen generally does, so you come to rely on that and what they are doing. I suppose the fact their qualifications, where they are now, they’ve done the research, and they know more than I do, they have seen 60, 70 other people the same as me and they have a reasonable reputation”. (F,D)

Another participant felt that, after an initial positive experience with a doctor concerning a serious illness, he could trust all doctors:

“Well the first experience I had was at about 40 years of age, that was when I had the (first serious illness). [Doctor] there at [Hospital] he is a friend of my brother and wife, and he looked after me through the (illness). From that time on I just had all the faith in the world in them. As far as I am concerned, they are all the same as him”. (M,T)

A fourth person described knowing that someone is trustworthy as:

“...well, it’s your gut feeling”. (M,T)

A few participants also believed that personal manner and the way a health professional interacted with them contributed to the development of trust:

“...they have got be warm and friendly” (F,D)

Participation in decision making

Most participants perceived that they make their own decisions about their health and health care because they believed that no-one else was able to make decisions about their body and

that individuals have the responsibility to make these decisions. A common theme was that a person's body and its state of health was her/his own responsibility. A number of quotes are reproduced below as examples of how participants described this feeling:

“Well, I’m an adult now, if I don’t look after myself and I don’t make the decisions, nobody else is going to”. (M,T)

“[You make your own decisions] because you are in charge of your own body” (F,T)

“Yes, there is nobody else to do it for you, you have to make your own decisions regarding your health”. (F,D)

“...I believe my body is my body and it should be my decision what happens to it”. (F,D)

However, one individual perceived that all the decisions regarding dialysis (i.e. when to start, how and where to do it) were made by others and she went along with these decisions:

“I don’t think I really made any decisions, I think they were all made for me and I just went along with it. I didn’t have to make any decisions on it at all”. (F,D)

It is worth noting that this patient had not been seriously affected by kidney disease until just before she began having dialysis a few months previously. Her experience contrasted with many others for whom dialysis was a long-term experience.

A widespread perception among participants was that they made all or many decisions about their health and health care. However, such opinions should be understood within a framework of common assumptions about how kidney failure would be best treated. All the participants assumed that, for some aspects of care, no choice was available and therefore, that some decisions were inevitable and did not need to be consciously made by either the patient or the health care professional. For example, a common assumption among

participants was that renal failure meant that, initially, dialysis was the only possibility. However, dialysis is not inevitable: two participants had made a decision not to have dialysis (or to put it off as long as possible); both received a living donor organ without ever receiving dialysis.

It may be that most people would choose to avoid dialysis (e.g. by having a transplant as soon as possible) if they had the opportunity, but this is not true in every case – three participants had received an offer of a kidney from one or more family members, but waited up to three years before accepting an offer. One participant waited until he began to suffer from a side-effect of dialysis before accepting the offer of a kidney from a relative, whilst another was gradually talked into accepting the offer by the donor and other relatives over a number of years. After describing how she had rejected the initial offer she said:

“I thought maybe in a few years time, down the track, if things are not going well, we would have to think about it, but I didn’t ever ask her again. [Last Christmas] I became aware that they (family) were talking about this (the possibility of an offer of a transplant) and [the donor] had obviously made the decision that she was going to give it to me”. (F,T)

Another common assumption was that transplantation was a better treatment option than dialysis (for quality of life, lifestyle and family and social reasons). Most people viewed dialysis as a “stopgap” option while they waited for a suitable kidney to be donated. One woman said:

“Well, you just can’t be on dialysis for the rest of your life”. (F,T)

Another equated having a transplant with normality:

“I thought to live a normal life you need a transplant so that was what I intended to do”. (F,T)

Being placed on the transplant list was also regarded as inevitable by most participants. Nearly all participants had been or were on the list, and only two participants mentioned that the patient or the doctor might decide not to put a name on a list. Thus, inclusion on a transplant list was an automatic event which happened as they began dialysis. It was described thus:

“That (being placed on the transplant list) was an automatic thing they did for me”.

(F,T)

“To me it (going on the transplant list) was awfully obvious. I hadn’t planned to spend the rest of my life on dialysis, so I thought I have to have at least a go of getting off it. I’m never going to be cured so it’s (a transplant) the next best thing”.

(F,D)

However, the literature reveals that institutions and health care professionals restrict access to transplant lists for reasons including age, health status and co-morbidities. [294]One participant had (in the past) taken herself off the transplant list. She explained why she did this:

“I think I had got sick of waiting, sick of pagers going off that were false alarms, just stress stuff really, so I decided to go off, have a break...”. (F,D)

Another woman referred indirectly to the age restriction:

“I thought I might as well go on it (transplant list) and see – I might run out of time”

(pass the age limit). (F,D)

The longer a person had had to prepare for dialysis, the more likely they were to have thought about a transplant and the issues of either living or cadaver donation. Whilst it was regarded as a good option by most participants, the idea of a living donation was not viewed as wholly positive by a few participants. Others reported some ambivalence on the part of health professionals and the fact that there are differences of opinion about the ethical and moral aspects of living donations. [294]

All participants indicated some reliance on significant others for support in making decisions. However, the extent to which this happened varied widely across the group.

A few people indicated that their family listened to their experiences and offered advice, but that the major decisions were made by them alone. This was expressed as follows:

“My husband likes to have his say, but really it’s (making the decisions) up to me”.

(F,T)

“I talk it over of course with my husband, but no I make my own decisions”. (F,D)

Other participants indicated that there had been more input from family - for example, they were seen as offering another viewpoint, opinions or monitoring the decisions being made as well as offering support once the decision had been made:

“It’s been a load off my mind, having another side and opinion, so I might not be in the right frame of mind to make a decision and [partner] can give me another view of it and that can help me weigh things up”. (F,D)

“I’m sure that if I made the wrong decision, somebody is going to come and nudge me and say ‘hey, look, you are being stupid, think about it’”. (M,T)

“...I bring something up and she (relative) says ‘well why don’t you tell them?’ and I say ‘oh yes, I will next time’. So I suppose I just float along and I mention something and she picks it up and says ‘tell them, tell them’”. (M,D)

A substantial minority mentioned that being an independent decision maker had been one of their goals in life and that their attitude to decision making regarding dialysis was an extension of this personal characteristic (i.e they always looked after themselves). These people were likely to make judgements about who they would rely on for advice (i.e. whom they trusted) and have mechanisms developed to assist them to decide on what basis professionals= advice would be trusted (how much knowledge and experience they were seen to have, how well their past advice had turned out and how well they communicated their reasons with participants). They described their attitude in the same way as this woman who said:

“I really have had to make decisions for myself since I started dialysis...I’ve always been such an independent person”. (F,D)

Another man said:

“I think I [make decisions independently] because I’ve been looking after myself since I was fifteen...to prove myself to my parents and the rest of the world that I can do it (make decisions) myself”. (M,D)

However, approximately half of the participants claimed that their attitude to and/or method of decision making had changed over time. This was supported by examples which centred around being more aware of their body and state of health, being more assertive in asking for information and asking health professionals to listen to them and act when requested (even if the added information would not change the treatment plan):

“...in the past I probably would have sat back much more and taken the advice of the doctors. Now I’m much more questioning”. (F,T)

While the majority denied that their illness limited their ability to make decisions, one person mentioned that chronic renal failure had affected her ability to make decisions. A few people mentioned the relief of going on dialysis and how much better it made them feel. One woman, who had since received a transplant, said:

“(when you have chronic renal failure) physically you cannot cope with anything, mentally or physically, something happens to your brain.” (F,T)

While not a common topic, one or two participants revealed that, occasionally, they would have liked to hand over the responsibility for decision making to someone else, but they also believed that this was not generally possible:

“Sometimes I would like to wash my hands of the whole lot, but you know you turn around and think about something else and it’s gone” (M,T)

“Yes, [I would like someone else to make the decisions for me] but there is no-one to hand it to.” (F,D)

Some aspects of decision making applied only to those participants who had received a transplant. People looked forward to transplants, sometimes for a long time. Two participants had experienced transplant failure. The only course of action for them was to go back on dialysis. However, both immediately went back on the transplant list (one has since had a cadaveric transplant and the other is awaiting results of compatibility procedures for a potential living donor). Describing the decision making process he undertook after being offered a cadaveric kidney, one person said:

“...they (the doctors) laid the stats (statistics) on the table...well, I thought, if I do take the kidney and it doesn't work, then at least I've tried...so I did ask what the chances were of rejection and they said the same as always 'there is always a good chance of rejection and there is always a chance it will work' and it wasn't really a decision I had to ponder on”. (M,T)

Participants who had received transplants from living donors had all been offered the chance of receiving a kidney in this way and many stressed that they could not have actually asked anyone to donate a kidney to them. Almost all people described their donor as the instigator of the procedure, implying that the initial decision was not theirs to make:

“It was a one-off thing. My wife said I'll donate a kidney you know. We were always pretty certain that it (the decision) was right...she (donor) more than me.” (M,T)

“ I never said anything to my (donor). (Donor) had obviously made the decision that she was going to give it (kidney) to me.” (F,T)

As discussed above, a number of participants were so hesitant about depriving a healthy person (usually a relative) of a kidney that they had originally turned down the donor's offer. They gave reasons such as they were doing well on dialysis or could not contemplate taking a kidney from a close family member or did not believe they had reached a point where a transplant was the only option. However, all described deciding to take up the offer when they experienced problems with dialysis or changed their minds about receiving a live donation.

While four people expressed difficulty in bringing up the subject with their potential donor and gave the impressions that they had been talked into it@ by the donor and other

members of the family, the majority were able to discuss the issues more freely or to suggest the idea and leave it up to the potential donors to make the next moves:

“I said [to the specialist] I have [a number of potential donors] and he said...let’s get all [the potential donors] tested...they [potential donors] said they were happy to be tissue tested and it turned out that [a number of potential donors] were compatible. I hadn’t made any commitment to anybody or got anybody to make a commitment to me. I didn’t want to be seen to be pressuring the [potential donors] or anything like that. Anyway, the [potential donors] got together one day and they decided one of them should donate. How they did it I have never inquired, I don’t want to inquire, that is their business.” (M,T)

“I actually had no hesitation in asking my [donor] because we are a very nuts and bolts kind of family and one of us has a problem then you fix it kind of thing. But essentially, it was he and I did it together, it was a joint decision”. (F,T)

One person, while describing her doctor as very positive about living donations, described how she had seen other people hampered in their quest for a kidney by their doctor=s neutral or anti-living donation attitudes.

All participants described the reasons that they would be (and in some cases were) better off having a kidney transplant. These were that they would not be tied to dialysis (and its side effects), they (and their family) would experience a better quality of life and the transplant would result in savings in terms of work time, travel costs etc:

“...[Our] main motivation was to get some sort of lifestyle back and for (child’s) sake, give her back her [parent] basically”. (F,T)

“My [donor] said it will be a better quality of life for the both of us. To go to [dialysis centre] three times a week costs a lot of money for a start and it’s three days out of your week, so I don’t know how I’d have been able to work”. (M,T)

“I thought it (dialysis) didn’t really appeal to me because I am still pretty active...it didn’t really suit my lifestyle...the only way you could do it would be to virtually sell my business, move to [town] and live in [town].” (M,T)

For a few recipients, the bond between themselves and the donor and the emotion they felt about someone giving up a kidney for them were beyond words or too private an issue to be discussed in the interview. Becoming a little emotional as he spoke, one participant said:

“When [donor] and I met the first time after the operation, that was something for only [donor] and me. It belongs to us”. (M,T)

5.5.4 Discussion

People who were on dialysis generally perceived themselves as independent decision makers. However, they also perceived that some decisions about having dialysis and being on a transplant list were inevitable and therefore relatively easy. Some people were more interested than others in having detailed information on topics about which decisions would be made (either by them or health care professionals). These participants were more likely to describe a system of monitoring their own health, believing that they knew their body and its reaction to ill-health and treatment better than any health professional could. Further, these participants were also likely to question doctors and nurses about their treatment and its effects and feel that they should be included in communication and decision making processes.

Participants who had received a cadaveric transplant described how they made decisions by weighing up the risks of accepting a kidney that was not a perfect match and therefore might

be rejected by their body against the benefits of a) doing everything they could to become healthy and b) the potential to have a healthier body, better quality of life and enjoying a more normal routine with their family. They were also reliant on the advice and recommendation of experts in this situation.

Many people who had received a kidney from a living person described their donor as being more in favour of the live donation than they themselves were, at least initially. They listed reasons for this which were connected to worries they had (before and after transplantation) about the possible waste if the kidney was rejected by their body and how they would face the donor if this happened. In the beginning, because of these concerns, participants handed the decision over to the donor. However, as they then had to make a decision to accept the donation, overall, the decision could be described as a joint one. Four people described themselves as being won over by the positive attitude of the donor. In making their decision to accept a living donation, a few participants had considered issues such as how much they would be blamed if the kidney failed and how much the donor would want to watch or check up on them after the transplant to make sure they were doing the right thing.

Thus, the possibility of the kidney failing and the resultant feeling of guilt were very real to the participants and were issues many felt the need to discuss with a professional. However, while recipients of live transplants were clear that there were difficult psychological issues to be dealt with and that the risks and uncertainty were difficult to live with, overall, they had been convinced that the eventual outcomes (see above) would make it all worthwhile.

In many ways, health professionals did not participate in this decision making process, although two or three people described being assisted through this process by talking to counsellors or psychiatrists. One person described her doctors as being wary of becoming

involved in the decision about a living donor (although once the decision was made the doctors became fully involved in the process of matching, preparation for surgery and the surgery itself). However, a few participants described how the doctor had talked about the success of live transplants and encouraged potential donors to begin the process of establishing compatibility prior to the ultimate decision being made (i.e. who, if any, of the potential donors would offer their kidney). It must also be noted that although health professionals were not perceived by participants as being actively involved in many of the decisions discussed during the interviews, they would, over years of treatment, have influenced participants' attitudes to dialysis and transplant.

Almost all participants were content to try dialysis when their kidney failure was advanced enough and to put their name on the transplant waiting list as soon as they began dialysis. However, three recipients of living organs had received their new kidneys prior to their needing dialysis or had attempted to do without dialysis for as long as possible (hoping for a cadaveric kidney or waiting for their potential donor to complete the pre-surgical work-up and be passed (or not) for donation). In describing how they made their decision to bypass dialysis, these people emphasised the difficulties dialysis would have imposed on their lifestyle (e.g. disrupted work, many hours of travelling and the costs of moving permanently to or staying in a city or town for three days per week). They also described the impact dialysis had or would have had on their health (e.g. complications such as infections, many people feel unwell for a number of hours after dialysis). However, apart from the fact that their transplant had preceded any need for dialysis (or an extended period of dialysis), the decision making processes for these participants were not different from those of other recipients of live organs. Like people who were transplanted with cadaveric kidneys, they usually had some advance warning (often a number of years) about the likelihood of their

kidneys failing and the need for treatment, that is, dialysis and/or transplantation. Hence, they had time in which to consider whether the option of live donation was viable.

As indicated in the Results section, there was a wide variation in the level of interest among study participants in either general or specific information about dialysis and/or transplantation. Most people on dialysis felt that they knew as much as they needed to know about each subject and would gather or be given more if it was needed (e.g. if they were offered a kidney). Apart from its lack of immediate relevance, another reason for participants' lack of interest in gathering information can be found in a theme about personal knowledge and responsibility which ran through many interviews. This theme encompassed participants' beliefs that although health professionals might know about renal failure in theory and be able to provide information about it and interpret signs and symptoms according to their expert knowledge, only the patient her/himself felt and therefore truly understood the effects of the disease and treatment on her/his body. This belief provided a powerful incentive for participants to be actively involved in decision making about their health and health care.

Dignity in specific situations was discussed in terms of being seen as a human being who deserved respect, rather than as an illness or a body to be treated. The concept was also linked with the notion of the only true understanding of the body's reaction to renal failure and treatment being available to the patient her/himself.

The experiences discussed by participants generally indicated that for much of the time while their renal failure was under control or their condition was stable (i.e. they were on dialysis or their transplant was successful), they were not in need of reassurance. However, if their condition changed or they underwent a procedure, they were more likely to describe

a need for reassurance. In particular, if they were in the process of making a decision, they considered reassurance very helpful. In this instance, reassurance seemed to mean the provision of information or an opinion coupled with personal encouragement and support aimed at minimising the distress associated with the uncertainty surrounding the change and subsequent decisions.

Participants were aware that having a chronic illness like renal failure and, in particular, having to make decisions about subjects such as transplants were potential sources of emotional distress. This was indicated during interviews when participants used words such as “emotional”, “upset” and “distress” to describe their feelings about particular experiences. All were acutely aware of the need for support during periods of emotional upheaval. Most turned first to their families for this support, but those who experienced long periods of time in a health care facility (either as an inpatient or while undergoing dialysis) were also aware of the need for such support from health care professionals. Most participants were able to describe instances of support from health care professionals and one or two differentiated the type of support provided by nurses and doctors during dialysis and transplant procedures. A few participants were also able to describe a perceived lack of support at different times during their health care experiences.

Legitimation was mentioned infrequently and labelling even less frequently by participants during the interviews. This may be because renal disease is “obvious” and common (i.e. its symptoms are well known and it is an accepted medical condition compared with conditions such as chronic fatigue syndrome, repetitive strain injury or premenstrual tension). However, almost all participants mentioned the care they took to monitor their condition and keep up with the latest developments in treatment, asking their doctors about their treatment etc. A few participants referred to specific incidents where they had disputed test findings

or questioned symptoms to the extent that, eventually, their (the patients') ideas were accepted and the management of their condition changed accordingly.

Regarding labelling, although it was not discussed directly, a few participants referred obliquely to a perception that they were viewed in a less than positive light by a health professional/s, usually because they asked questions, expressed their opinions and were generally "difficult". Thus, they perceived themselves as being labelled due to their behaviour, rather than their illness.

The attributes of trust which seemed to fit best with the perceptions and experiences of participants included the perception of expertise, which, over time, had resulted in consistent, predictable actions and ultimately led to the development of confidence in the health care professional and their recommendations for management. There was no mention of loss of trust. A substantial minority believed that the personal manner displayed by a health professional also contributed to the development of trust and named a caring attitude, empathy and respect as behaviour which enhanced trust.

The major limitations of this research are that it involved a relatively small number of participants who were treated by a renal service based in one Area Health Service which receives a large number of tertiary referrals. As such, their experiences may not be representative of all people receiving renal dialysis or of all transplant recipients. In addition, there was an over-representation of recipients of transplants from living donors. However, this was a deliberate recruitment strategy to explore specific issues regarding decision making with this group. Finally, as involvement in the research was voluntary, participants were largely self-selected and thus, their views may not be representative of the population from which they were drawn. However, the variety of experiences described and

the ease with which participants expressed their opinions (both positive and negative) allow the results to be interpreted with some confidence.

In summary, the results of this research indicate that participants, by and large, perceived themselves as independent decision makers, their rationale being the belief that only the person experiencing the problem could understand its effects and therefore know how to proceed regarding treatment. To fully appreciate this result, it is necessary to take into account the fact that participants regarded some decisions (i.e. having dialysis for kidney failure, going on the transplant list) as inevitable, therefore automatic and easy to make. Decision making was perceived by patients as being influenced by the provision and exchange of information, the recognition of support for emotional distress and the development of a trusting relationship with health professionals. It was less influenced by being treated with dignity, being reassured, having their ideas legitimated or being labelled.

The particular emphasis participants placed on the contribution various attributes made to decision making may be influenced by the fact that nearly all the participants had long standing renal failure, were experienced users of the health care system and were in relatively good, stable health. People with acute or unstable illnesses, or those who were inexperienced users of the health system may have emphasised different attributes. Similarly, participants who were not ill at all (e.g. users of a screening service) may have recounted different experiences and emphasised different attributes.

In conclusion, the significance of this research is that it has provided some empirically-based evidence for the extent to which patients with a chronic illness perceived they made decisions about their health and health care. It also elucidates which attributes of the patient-professional relationship enhance or detract from patient input to decision making. In

describing patients' experiences and perceptions, and in clarifying the importance they attach to them, the results add to our understanding of what patients want from health care providers and services in relation to decision making.

5.6 Study of women eligible for Pap smears

5.6.1 Introduction

The previous study examined the factors people with chronic renal failure perceived as being relevant and important in terms of their health and health care. People with chronic renal failure have a chronic disease and typically experience many years of exposure to health care services, both in-hospital and ambulatory care services. Thus, they are likely to have a different perspective on non-health outcomes than people who experience health care in the context of acute illness, minor illness or when undertaking preventive health care (e.g. screening). To explore the relevance and importance of non-health outcomes with another group of people, a second qualitative study was undertaken with women about their experiences of Pap smears.

5.6.2 Methods

In this study, women were recruited utilising a snowball method of sampling. Snowball sampling involves identifying a small number of participants as initial contacts and asking them to put the researcher in touch with people who also fit the criteria for the research project, then asking those people to participate and so on. [271]The criteria used to choose the sample were that participants should be women aged between 18 and 70 years (the age group recommended for cervical screening in Australia), speak English proficiently and have not been diagnosed with major gynaecological disease (e.g. cervical or uterine cancer) or undergone a hysterectomy. Initially, four women were contacted through a women's health nurse at Central Sydney Health Service. As each woman was interviewed, she was

interviewed, all in their homes. After approximately 18 interviews, no new data were obtained, that is, the data categories had reached saturation. [271]

The aim of the interviews was to examine, from the women's perspectives, how they make or have made decisions about Pap smears, their experiences of having a Pap smear and what they perceived as the personal, social and contextual influences on previous and current decision making. In particular, the following were explored:

- What or who influenced decisions by women to have both initial and subsequent Pap smears;
- How they obtained information about Pap smears, their need for and opinions of the information they received (i.e. the amount, relevance, language, inclusiveness and reliability of the information) and its use in respect of decision making; and
- If, how and why the following were important to them during the decision making process and in relation to health care in general: being reassured; being treated with dignity; having emotional distress recognised and/or supported; developing trust and/or feeling that they are trusted; and having their feelings, illness and decision legitimated.

All participants were sent copies of their transcribed interview and invited to alter it or make comments. Two participants altered their transcriptions. Alterations made by these participants were aimed at clarifying what they had said – the meaning of words used did not change. The results are presented in the following section. Following a brief discussion of the age of participants and a summary of their Pap smear history in terms of numbers of smears received, smear intervals and providers, the key results are presented in terms of the concepts listed in Chapters Two and Three. The results are illustrated by direct quotes from the interview transcriptions. After each quote, the participant cited is identified by their age group.

5.6.3 Results

As in the study of renal patients, the exact age of participants was not obtained as such information was not considered necessary for the purposes of the research. However, it was possible from the information volunteered during the interview to ascertain the approximate ages of participants (i.e. which decade of life they were in). The age distribution of the women is shown in Table 11.

Table 11. Age of participants

Age	
20-29	6
30-39	4
40-49	4
50-59	5
60-69	1

Two women had never had a Pap smear. Both were in their early twenties. Not surprisingly, the number of Pap smears participants had experienced varied across the group. Much of this variation was due to age, with younger women having fewer opportunities to have smears compared to older women. However, there was also variation in how regularly women had Pap smears. While 11 women stated that they were consistently regular in having Pap smears, six described their Pap smear history as irregular and one as mixed. However, four of the six women who said they had Pap smears irregularly actually described different periods of Pap smear regularity over the course of their life, that is, there were times when they were more or less regular in having Pap smears. In addition, women also varied in terms of their provider history, that is, in the number and type of provider used.

Of the eighteen women who had ever had a Pap smear, fifteen currently or previously had the test undertaken by a GP. Most of these women nearly always had their Pap smears done

by a GP, with the most common deviation occurring after the birth of children when it was considered routine for the obstetrician involved in their care during pregnancy and birth to do a follow-up Pap smear. However, it was rare for women to use the same GP throughout their lives. As well as being for obvious reasons such as women or GPs moving or the retirement or death of GPs, five women had deliberately changed GPs for the purposes of a Pap smear (either permanently or just for the smear). Three women stated that they wanted a woman to do their Pap smears, but were happy to continue with their male GP for all other medical services. Two women changed because they felt that their male GP did not want to do a Pap smear. Two women did not use a regular GP but attended a medical centre for their Pap smears. Both women asked for a female doctor at the centre to do their Pap smears. Three women had their Pap smears done exclusively by a gynaecologist and two had used a family planning clinic for all their Pap smears. However, three women had had a number of Pap smears undertaken by a gynaecologist (besides those after childbirth), three others had used a family planning clinic at some time and one had used a women's health centre to do Pap smears before the birth of her children. The four initial participants in the study had received their last one or two Pap smears from a women's health nurse (and all said they would continue to do this) and one other woman had used a women's health nurse for a number of pap smears.

Three women had, in the past, received a positive result from a Pap smear. All three had received treatment and follow-up Pap smears. Three other women had been asked to have a repeat smear due to the previous one being inadequate in some way. Two women had other minor gynaecological problems (i.e. small growths in the vagina) detected at the time of a Pap smear which were subsequently treated.

Information

Although some women stated that they had never received any specific information about Pap smears, most had seen advertisements as part of a media campaign and had picked up brochures or leaflets recommending Pap smears at their doctor's surgery:

"I've read about it [Pap smears], I guess I talked to other people, I see ads on TV and see brochures at the Doctor's surgery. (Participant in her 40s).

Information gained as a result of personal conversation was rare and usually centred on the detection of a problem and its treatment. Such conversations were most likely to occur among friends, but occasionally were part of family discussions. These discussions, although resulting from a negative aspect of Pap smears, were usually positive or encouraging in their outcome (i.e. women believed that the treatment worked and/or were encouraged to have a Pap smear themselves).

"I have a lot of lady friends and we sit around and discuss it. You listen and weigh it all up and you hear 'so and so went for it' [Pap smear] and you think 'I'd better have that done'." (Participant in her 50s).

In other cases, any reference within the family to Pap smears was negative. Three of the younger women in the study (including the two women who had not had a Pap smear) described how their mothers' attitudes to Pap smears had discouraged them from having one. One woman said:

"From Mum [I know] it's horrible. Mum always has to be prompted to go. The process is not painful like that; it's the indignity of it all". (Participant in her 20s)

However a number of the younger women described being encouraged by their friends to have the test. These women were more likely to have discussed with their friends how a Pap smear was undertaken, the fact that anticipating the event was likely to be worse than the actual event and that it was quick.

“I’ve been saying [to friends] ‘Oh I don’t want to go and get one it’s such a pain’. And they’re like “it’s quick, it’s not a big deal and you should go and have one’.”
(Participant in her 20s).

Four of the women also described encouraging their daughters to have Pap smears, although all made it clear that either they did not feel it necessary or their daughters had discouraged them from providing details about what it was like to have one.

“I wanted to, I tried to [discuss Pap smears with her daughter] but she just said ‘Mum, we know all about that’.” (Participant in her 50s).

Although a number of women described being encouraged by their doctor to have a Pap smear, little information appears to have been given by doctors to the women at this time. No woman could recall ever being given specific information about Pap smears by a doctor. Doctors provided information to women if they received a positive result from a Pap test. All the women to whom this applied expressed satisfaction with the amount of information they had received, how it was given and how well they were able to understand and relate to it:

“She [doctor] drew me an illustration, she showed me what would happen when she did a cone biopsy. She explained to me the levels of changes (CIN 1-3) and she

impressed on me that if I didn't do anything then my number (CIN level) would change and get worse." (Participant in her 40s).

Dignity

The women mentioned dignity in both general and specific ways. It was chiefly discussed in relation to the indignity of the test itself. Many women described being always embarrassed as they had or even contemplated a Pap smear, but there were some who were not concerned by this aspect. Contrasting attitudes are expressed by the following two quotes:

"I mean it is very uncomfortable, it is a horrible experience, even with a female it's really horrible." (Participant in her 20s).

"But it really doesn't bother me, I think of it as a procedure and I have never had any painful experiences with it." (Participant in her 30s).

While it was clear that many women regarded the test as innately undignified, it was also apparent that women were aware of ways in which their embarrassment could be minimised by the attitude and/or behaviour of the provider:

"I like a person who speaks nicely to you and make you feel as if this is something they really want to do." (Participant in her 50s).

"I suppose it is lack of hesitancy. Matter-of-factness, not being unnecessarily modest about the whole procedure." (Participant in her 30s)

A few women mentioned being treated well by all staff connected with the provision of Pap smears (and health care in general) as contributing to their dignity in the face of a Pap test.

However, it was more common for women to mention the attitude and/or actions of individual providers as contributing to or detracting from the potential indignity of the test:

“This doctor [local GP] has one of those rough manners, he is a good doctor and just has that manner and anything personal I couldn’t go to him.” (Participant in her 50s).

“There always seems to be lots of information [given by the provider] and a pretty relaxed atmosphere.” (Participant in her 20s).

Four women who attended a family planning clinic or had received a Pap test from a women’s health nurse mentioned the fact that having the test done in the context of monitoring specific female-related aspects of their health (e.g. having a breast examination, discussing menstrual or menopausal issues) was conducive in minimising embarrassment or indignity:

“It was nice to feel that you could be female and vulnerable [and discuss] how I felt about getting older. And I also asked to have my breasts examined and that was fine.” (Participant in her 40s).

Trust

All women considered it important that they trust the providers of Pap smears. In respect of individual providers, a few women mentioned aspects such as being given information, previous experience with the doctor and knowledge of their expertise as being among the reasons they trusted their doctor:

“She [doctor] seemed to me to be quite thorough – competent and provide continuity in my treatment.” (participant in her 20s).

“She [doctor] is really easy to talk to, always straight to the point, she is just always ready to give information if you ask.” (Participant in her 20s).

However, it was far more common for women to mention the personal attitude or manner of their doctor as providing signs that they were trustworthy:

“She is calm and quietly confident and makes you feel safe and happy.” (Participant in her 20s).

“It’s the way they address you when you come into the surgery and the way they talk to you, they tell you to relax...and they won’t rush you.” (Participant in her 50s)

Some women discussed both personal attitude and signs of professional competence as ways of knowing whether a provider was trustworthy. One woman described in detail how trustworthiness was evident in:

“Their [provider’s] attitude to you, just the way they treat you like a person rather than a patient. The amount of information they give you. How honest they are in giving you another alternative and recognising that they don’t have all the answers to everything and that the world of medicine isn’t perfect. How much empathy they show towards you. How much interest they show in you as a person, in your personal life, your family and what you are doing in your life, and how that affects your health and how they see you as a whole person. I guess just how reliable their diagnosis and treatment is.” (Participant in her 40s)

The women who attended a family planning clinic or women’s health centre were more likely to discuss the trustworthiness of the service or centre. This was seen to be largely related to the specialisation of the centre and therefore to the expertise of the staff, rather than to characteristics of individual providers, although all the women who described a service or centre as being trustworthy could also back this up with examples of individual staff member’s expertise and trustworthiness:

“I think I like going to the clinic because I know that is what they do pretty often as opposed to a GP who might do it less regularly.” (Participant in her 20s).

“Things like how good they are about following up. Whether they are discreet if you ring up for results over the phone. Just organisation, I want to make sure every year the results are on file.” (Participant in her 20s).

Reassurance

Reassurance was not discussed frequently by the participants. This may be because this group of women was reassured by actually having a Pap smear and, as they took responsibility for their smears, they, and not a provider were the source of reassurance. However, the concept of reassurance was mentioned in connection with two aspects of Pap smears. Women who attended family planning clinics or had their Pap smears done by a women’s health nurse mentioned being reassured by the expertise available:

“I go now to the Family Planning clinic because they seem to know what they are doing. They don’t seem concerned by it – they treat it like an ordinary procedure.”
(Participant in her 30s).

“It’s [having a Pap smear from a women’s health nurse] coupled with knowledge. It’s having it done by an expert [in] interacting with people.” (Participant in her 40s).

Women who had experienced a positive result from a Pap smear also mentioned being reassured by how the issue was dealt with by their doctor:

“I think she explained it [positive smear] well. I just thought, she’s the expert”.
(Participant in her 40s).

“He explained what he was doing [regarding the positive smear] and he appears to know what he is doing.” (Participant in her 50s).

A few women had continued to have more frequent smears (i.e. annual) after a positive test result. They described this as part of being reassured:

“About 5 years ago I had some abnormal cells detected and that is when they emphasised that it was important for me to have them [Pap smears] annually. Some of them [doctors] will say that 2 years is enough but I think most women I am around tend to feel much more secure in themselves that they have them every year regardless of the doctor’s advice.” (Participant in her 30s).

This latter issue was closely associated with the extent to which women perceived that having any real or potential distress recognised and supported was dealt with.

Recognition of and support for emotional distress

This concept was discussed in relation to two aspects of Pap smears: the physical and emotional discomfort of the test itself; and the receiving of a positive test result. Women dealt with the former by choosing a female provider, being stoic, receiving encouragement from their friends (and occasionally from family members) and, to a lesser extent by being assisted by the attitude and behaviour of the provider. Two women discussed the embarrassment aspect in the following way:

“I was worried initially [about being embarrassed] but I dealt with this by making a decision to only see a female doctor.” (Participant in her 40s).

“No [I have not been embarrassed] but I choose to go to a different GP than my family one because I want to see a lady doctor.” (Participant in her 30s).

Stoicism was mentioned by 5 women as being one way to deal with the idea of a Pap smear:

“It’s just one of those things, you know, you just have to have it done.” (Participant in her 50s)

Regarding friends, one woman said:

“With close personal friends, it might come up in conversation, someone might say “I had a Pap smear” and that reminds me I am due for one, I must make an appointment, that sort of thing.” (Participant in her 40s).

Providers were much more prominent in assisting women to deal with the emotional distress associated with a positive smear. However, family and friends also played a part here too:

“I think it’s nice for them [providers] to have a friendly approach to you and put you at ease when you go have these things [Pap smears] done.” (Participant in her 50s)

“The important thing to me is someone you can relate to that isn’t being condescending or being really patronising because you are a patient and they are a doctor.” (Participant in her 40s)

Legitimation

Legitimation was mentioned by two groups of participants, those who had not had a Pap smear and a number of older women whose history of having Pap smears had been irregular. The two women who had not had a Pap smear discussed their age and lack of sexual activity as legitimate reasons for not yet having a Pap smear. One of them also described not being targeted by the media campaigns she had seen as legitimating her stance:

“I’m not sexually active, so that is the main thing [reason for not having Pap smears]. With those ads [on TV], they are not really targeting 15 to 20ish year olds, that is my personal point of view.” (Participant in her 20s).

Three older women described a lack of knowledge (both on their and on the medical or public health experts’ part) as legitimate reasons for their not having Pap smears as younger women. They believed that this ignorance had led to a lack of encouragement or advice to women to have Pap smears and cited their daughters’ improved knowledge as evidence of how expert and lay knowledge had improved over time:

“I don’t think it was anything that occurred to me before I got married, just old fashioned girls, never thought of anything like that. I don’t think there was a lot of knowledge around when I was young.” (Participant in her 60s)

“The younger ones now are more in tune. And it’s out there now [knowledge]. All these things you get on TV now [information].” (Participant in her 50s).

One woman actively labelled her lack of regularity in having Pap smears even though she could rationalise her actions:

“No [I don’t have regular Pap smears], I’ve been very naughty.” (Participant in her 60s).

Because all the women supported the idea of Pap smears, labeling was discussed in relation to past attitudes by a few of the older participants. Among the labels referred to were ones relating to life stage and genetic inheritance:

“I don’t think it was anything that occurred to me before I got married – just old-fashioned girls. If there was something in the family that someone had problems with you would tend to be a little more vigilant.” (Participant in her 60s)

“When I went through the change of life I never went back [for a Pap smear].”
(Participant in her 50s).

Participation in decision making

All the participants had made conscious decisions about having a Pap smear. However, the factors they perceived as influencing these decisions varied. Three women had received reminders, two others discussed having a Pap smear as part of their responsibility to stay healthy, while two others discussed the obverse of this issue – the need to know if there was any possibility that they were unhealthy:

“I got a reminder this time and I knew it was roughly about two years since I’d had the other one so I thought I better do something about it.” (Participant in her 50s).

“You have to keep doing it for yourself [organising to have Pap smears] because it’s a hidden thing.” (Participant in her 50s)

“It’s better to know sooner rather than later if there is a problem.” (Participant in her 40s)

Most participants described practical influences on their decision making regarding Pap smears: media campaigns, personal reminders, advice or offers from providers and peer pressure were the most commonly described ways in which their decisions were swayed:

“The public education campaign in the media [made her decide to have a Pap smear].” (Participant in her 40s)

“My doctor has usually said he thinks I need to have one and that’s it.” (Participant in her 50s)

“I knew that I was overdue and I promised my doctor that I would have one very soon. Perhaps I would have left it longer if she hadn’t hassled me about it.” (Participant in her 20s).

“I think with friends I have talked about it, talked to my partner about it. I don’t feel shy about discussing it [Pap smears].” (Participant in her 20s)

Four women described the reasons they were (or had been) discouraged or “put off” having a Pap smear. The reasons included embarrassment, pain, lack of time and a provider’s attitude:

“I stopped having the Pap smears [because] I was a bit embarrassed with the male doctor.” (Participant in her 50s)

“Pain [has discouraged her] and disorganisation, lack of time [has also caused her to put off a Pap smear].” (Participant in her 40s)

“I had asked my doctor before and he did not seem very comfortable with the idea of giving me a Pap smear – he is an old doctor and has since retired.” (Participant in her 40s).

Women who described changes in test provider and the frequency with which they had Pap smears usually described the reasons for change as being connected with changes in the stages of their lives. Sexual activity, childbirth, a specific birthday, previous positive Pap smear results and menopause were examples of stages in women’s lives which caused them to re-evaluate their decisions about Pap smears:

“For me, I thought that once I became sexually active I should have a smear test every 2 years or regularly.”(Participant in her 20s)

“[I had] the first one [Pap smear] because I was about to commence on the pill.”(Participant in her 20s)

“After I had the kids, the obstetrician [did a Pap smear] as part of the 6 week check-up.” (Participant in her 30s)

“Well I turned 40 and I thought, “I think I should go and have a check-up – a thorough check-up.” (Participant in her 60s)

“I have had one every year after that [positive Pap smear result] and then they’ve been right ever since.” (Participant in her 50s).

“I have them [Pap smears] every year now – the gynaecologist said that the risks increased around or after menopause.” (Participant in her 50s).

5.6.4 Discussion

All the women in this study had made independent decisions about having Pap smears. All indicated that they believed Pap smears were a necessary part of staying healthy or of preventing cancer. However, nearly half the women had made a decision either not to have a Pap smear (yet) or, at different times during their lives, to delay having a Pap smear. Active offers of or reminders about Pap smears, either by their family doctor or gynaecologist or by a specialist service (e.g. Family Planning or a women's health nurse), were the common triggers for women who had delayed Pap smears to decide to have another one.

While information, either about the nature of Pap smears or the necessity for having them regularly, was not perceived as important in assisting their decision making, most women indicated that they had read or noted specific health promotion information in the form of media campaigns or leaflets. The few women who had experienced an abnormal Pap smear result were more positive about the value of receiving written information about the changes to their cervix and the proposed action or procedure to be followed to treat or follow-up the abnormal result.

Most women accepted that the nature of the test was invasive, potentially uncomfortable and possibly embarrassing. Some women mentioned that, for them, the anticipation of the test was worse than the actual event. A few cited the use of specific techniques, either physical (i.e. related to the instruments used to carry out the test) or psychological (ie. encouraging relaxation or providing information) which providers had used to minimise the discomfort or awkwardness associated with the procedure. The most common step women themselves took to minimise potential physical and/or psychological problems was to ensure that a

woman did their smears. They did this either by having a female GP or choosing a female provider specifically for their Pap smears (i.e. another GP, the family planning service or a women's health nurse).

Trust was an important aspect of the relationship women had with their Pap smear provider. Participants discussed personal attitude and the perceived professional competence of providers as indicators of how trustworthy providers were. A combination of a warm and relaxed personal manner and evidence of professional reliability (i.e. knowledge, being proven right in their diagnosis and treatment) was the combination favoured by many participants.

While most women did not seem to require specific reassurance about any aspect of Pap smears, three or four women who chose to use family planning clinics or women's health nurses described the reassurance they gained by knowing that their providers were experts in the field as important. However, reassurance was an important aspect of dealing with an abnormal smear, especially in respect of follow-up. Three women had chosen to continue with annual Pap smears following a positive test result, even though they had been advised they did not need to do so.

While the emotional distress associated with having a Pap smear was minimised by nearly all participants, those women who had experienced an abnormal smear were more aware of experiencing distress and how it could be relieved by a provider's behaviour. Such behaviour included personal contact (i.e. a phone call about the result), reassurance that the changes were not cancer and could be treated, and specific information about the nature of the problem, the proposed treatment and follow-up.

All the women were aware of the current guidelines recommending women have a Pap smear every 2 years. Two women who were not sexually active regarded this as a legitimate reason for not having a smear and three women who had not always had regular Pap smears discussed society's lack of knowledge as legitimate reasons for previous behaviour. Although all the women who described their Pap smear history as irregular looked crestfallen when they talked about it, only one of them labelled herself; she said she was "naughty". Labels regarding sexual activity (ie promiscuity) which reflect attitudes more common in the past were only mentioned (obliquely) by one participant.

In summary, the results of this research indicate that this group of women accept that Pap smears are a necessary, if uncomfortable and potentially undignified, procedure to ensure good health. The invasive and sexually explicit nature of the test are the most likely reasons for the importance with which participants regarded personal attributes of providers (i.e. they favoured women and those with a warm, empathic personal manner). While women acknowledged that aspects of the procedure had the potential to delay their having a Pap test, most felt that a personal approach (either by an individual doctor or via a written reminder) would be successful in encouraging regular Pap smears.

Decisions to have a Pap smear (either initially or regularly) were described as being influenced to a large extent by having trust in a provider or service, being treated with dignity and being reassured, especially in the face of an abnormal result. Although the sample of participants was small, they appeared to be broadly representative of generally healthy women living in an urban area who have a good general understanding of the nature and significance of Pap smears. Thus, the results provide some empirical evidence for the extent to which women take various social and personal factors into account when they are making decisions about Pap smears. In this way, the research has added to our knowledge

of what women regard as important when choosing whether to have a Pap smear and may be indicative of their attitude towards other screening services, particularly breast cancer screening.

5.7 Conclusion

In this chapter, the relevance and importance of seven non-health outcomes of health care have been explored with two groups of people: people with a chronic disease (chronic renal failure) and people eligible for screening (women in the age range for Pap smears). This research confirms that while all are relevant to both groups, they differ in the extent to which they are important, both between and within the groups. Both groups of participants considered that individuals needed to make or have an input to decision making about their health because of an over-riding personal responsibility for their health. Variation in the extent to which decision making was considered to be the sole responsibility of an individual was related to both personal characteristics and the specific context in which decision making took place.

The need for information varied between individuals in both groups and can be seen as closely connected to personal factors such as an individual's personality and their interest in health-related ideas as well as to changes in their health (e.g. people wanted more information when they underwent transplantation or received an abnormal Pap smear result). These results indicate the close relationship between information and decision making.

Trust was important to people in both groups. Its definition was consistent with that in the literature, that is, a firm belief in the honesty, integrity, reliability and fairness of another person. Many participants described trust as developing over time and being dependent on the perception that providers were competent or had expertise and their actions and advice were predictable and consistent.

However, the need for reassurance, recognition of and support for emotional distress and dignity varied between the two groups. This was due primarily to differences in the nature of chronic diseases versus other conditions and variation in the amount and type of contact individuals had with the health care system and health care providers. People with chronic diseases are usually able to adapt to the constraints of their disease to a large extent. Often the symptoms and associated treatment become an integral part of their everyday life, and, as such, their family and friends support them with their condition, largely as they would if they did not have a chronic disease. In contrast, women having a Pap smear every two years are more likely to rely on health care professionals and health services to provide them with the requisite amount of dignity, emotional support and reassurance. However, it is important to note that people with a chronic disease are likely to need health care professionals and services to supply more of these factors at times when additional illness or need for health care causes significant change and uncertainty.

Despite the additional knowledge which this research has generated, it is still not clear whether the factors discussed by participants are equally preferred by all patients, how they are valued relative to health gain or whether preferences for them vary according to personal characteristics (of patients), patients' social and cultural circumstances or the context in which a health care consultation takes place (e.g. general practice, specialist consultation or hospital clinic). Thus, there is a need for further research to address these issues.

Some of the issues for further research will be explored in Chapter Six where a Stated Preference Discrete Choice Model (SPDCM) experiment will be used to examine the extent to which non-health outcomes are preferred by people who have visited their general practitioner (GP) recently. The strength of the SPDCM approach is that it enables more

precise estimation of how choices of health care (in this case GP services) are affected by changes to attributes (non-health outcomes).

Chapter Six

Using Stated Preference Discrete Choice Modelling to examine preferences for non-health outcomes

Chapter 6 Using Stated Preference Discrete Choice Modelling to examine preferences for non-health outcomes

6.1 Introduction

In this chapter, the results of using stated preference discrete choice modelling (SPDCM) to test the importance of and preferences for seven non-health outcomes described previously (participation in decision making, reassurance, information, being treated with dignity, legitimisation, trust in health care professionals and recognition of and support for emotional distress) are described.

In the context of receiving health care, one or more relationships are formed between a patient (and sometimes including family and other carers) and health care professionals. Both verbal and non-verbal behaviours of health care providers seem to be both relevant and important to patients and previous chapters of this thesis have examined seven in particular. However, although they are relevant and important to patients, it is not clear if they are equally preferred, how they are valued by patients in relation to health outcomes and whether patients' preferences for them vary according to personal or demographic characteristics (of patients) or the context in which a health care consultation takes place.

In Chapter Five, the relevance and importance of the non-health outcomes previously identified were examined in relation to the experiences of people with chronic renal disease and women in the target age range for Pap smears. These two groups were chosen because it was believed that non-health outcomes may be more relevant to people with a chronic condition or to those seeking screening than, for example, to people seeking health care for an acute and/or minor condition where most can expect to be treated and cured relatively quickly and smoothly. Thus, people with a chronic condition or those seeking screening may be better able to describe what non-health outcomes mean to them. However, once the

relevance and importance of non-health outcomes has been established, it is necessary to examine how important they are to the wider population while still presenting the issues within a health care setting. One context that would be applicable and familiar to many members of the general public, that of general practitioners (GPs), was chosen for the purposes of this research. To further place the survey within a familiar situation, four common reasons for visiting a GP were chosen: upper respiratory tract infection, check-up, vaccination and minor injury. A check-up was defined as screening or testing for a particular condition (e.g. Pap smear or cholesterol test). Thus, some women who were surveyed may have been to their GP for a Pap smear. Moreover, some respondents who visited their GP for any of the chosen reasons may also have a chronic condition.

6.2 Aims of the study

This study attempts to deal with two issues - preferences for non-health outcomes relative to each other and the impact of specific personal and demographic characteristics on the preferences of respondents - in the context of a general practice (GP) consultation. Specifically, the study aimed to:

- provide insights into the preferences of individuals for participation in decision making, information and five other non-health outcomes in the context of a consultation with a general practitioner;
- provide information about the relative importance of each non-health outcome; and
- provide a better understanding of whether, from a methodological standpoint, the application of choice modelling techniques to elicit non-health outcomes, is appropriate.

6.3 Methods

As outlined in Chapter Four, in an experiment using SPDCM individuals are asked to choose which good or service (in this case aspects of general practitioner services) they prefer from a set of hypothetical goods or services (the choice set). The service being

evaluated is described in terms of a range of attributes (in this case the non-health outcomes) which each have a defined number of levels. The approach assumes that individuals' choices in hypothetical situations reveal the importance they attach to individual attributes and their preference for a particular combination of attributes which make up all or part of a service.

The context chosen for the study was that of a general practitioner consultation for one of four common reasons for visiting a GP (i. check-up, ii. upper respiratory tract infection, iii. flu or travel vaccination and iv. minor injury). It was considered appropriate to specify the context in which a GP might be consulted so as to make the situation realistic for respondents and four relatively simple and common reasons for consulting a GP were chosen. [295] A random sample of 128 English speaking people aged 18 and over, living in the community, were approached and included in the study if they had visited the doctor for any one of the reasons listed above within the past 6 months, and they agreed to participate. Although each participant signed a consent form, the actual responses were anonymous, as consent forms and surveys were not attached to each other or dealt with together. Respondents completed the surveys in the presence of a trained interviewer. This method enabled respondents to feed back any problems with the survey technique or the way the questions were phrased.

The experimental design, survey design and data analysis were undertaken by the candidate. In consultation with the candidate, sample frame definition, recruitment of respondents and conduct of the interviews were carried out by an external recruitment and data collection firm, Surveys Australia. Participants were approached by Surveys Australia using a door to door method and were recruited if they had been to their GP for one of the four reasons within the last six months and agreed to participate. Respondents received an information

sheet and signed a consent form. This study was approved by the Human Ethics Committee of the University of Sydney.

In an SPDCM questionnaire individuals are presented with a number of hypothetical situations, in each of which they are asked to make a choice. In this study, a picture of respondents' preferences for non-health outcomes of health care was built up by asking participants to compare the GP described in a hypothetical scenario with their last visit to their own GP. To enable the comparison to be made between the last visit and the hypothetical GP, respondents were first asked to evaluate their last visit to their GP (for the specified reason) in terms of the seven non-health attributes. They were then shown 24 hypothetical situations created by varying these attributes and asked to compare the GP described in the scenario with the GP they last visited for the selected condition. Respondents were then asked to choose whether they would prefer being treated by their current GP, a hypothetical GP or another (unspecified) GP if they needed to consult a GP again for the specified condition. The inclusion of another GP as a possible choice was felt to mirror a realistic situation where a consumer might prefer neither their current nor the hypothetical GP but still need to visit the doctor. A description of each attribute was included in the survey instructions, which respondents read before they completed the survey. The attributes and levels as they appeared in the scenarios are shown in Table 12, together with the attribute label in brackets.

At the end of the survey, respondents were asked to supply demographic details (age, sex, marital status, educational level achieved, and personal income) and health care information (how many times they had visited the GP in the previous 12 months and how long they had been visiting the GP).

Table 12. Attributes and levels in the SPDCM experiment

Attribute	Level
Doctor treats you with dignity (dignity)	Yes No
Doctor recognises your pain/distress (support for emotional distress)	Yes No
Doctor takes notice of what you say about your health (legitimation)	Yes No
Doctor reassures you (reassurance)	Yes No
Doctor is trustworthy (trust in doctor)	Yes No
Doctor gives you information	If you ask for it Whether you ask for it or not Only about where you can get information No
Doctor accepts your decisions about your health	Yes Yes, but also gives advice/opinion No, but tells you about his/her decision No

As illustrated in Table 12, the experiment consisted of seven attributes, five with two levels and two with four levels. Thus the full factorial for the whole design was $2^5 \times 4^2$, a total of 512 possible scenarios. Although only two attributes (participation in decision making and information) have more than two levels, it is necessary to test the extent to which these represent the true upper and lower bounds of these attributes. To do this, the first eight scenarios were the same for all participants and used only the endpoints or extremes of the levels (i.e. yes or no). The next 16 scenarios seen by each respondent were chosen randomly from among the 512 versions of the full factorial. It is possible that some respondents were also presented with an “endpoint only” scenario as part of the second 16 they answered. However, this would only be a problem if they were presented with the entire eight endpoint scenarios again and this did not occur. Whilst it would have been acceptable to offer respondents a forced choice of either their own (current) GP or the hypothetical GP, it is more realistic to also offer them the choice of neither. Thus, respondents could also choose to consult neither current nor scenario GP but another, the characteristics of which were not specified. Below is the initial evaluation, which in this example is for a check-up (Table 13)

and examples of four scenarios - two from the first eight, with end-point only responses (Table 14), and two from the full factorial design (Table 15). An example of a full survey (24 scenarios), including the information and instruction sheets, is given in Appendix Three.

Table 13. Respondents' initial evaluation of the last consultation with their GP

Your last consultation with your GP for a check-up

Please circle the number most applicable to your last visit to your GP.

When you visited your GP, were you treated with dignity

Yes 1

No 2

During the consultation, did the doctor recognise any pain and/or distress you were feeling?

Yes 1

No 2

Did your doctor listen to you and take notice of what you had to say about your health?

Yes 1

No 2

Did your doctor encourage you and/or reassure you that everything would be alright?

Yes 1

No 2

Did you trust your GP's actions and advice?

Yes 1

No 2

When you visited your GP, he or she:

Offered you information if and when you asked for it 1

Gave you information whether you asked for it or not 2

Told you where you could get information 3

Did not give you information 4

During the consultation, your GP:

Gave you the opportunity to make decisions about your health 1

Told you which tests/treatment/other action he/she would advise 2

Told you which tests/treatment he/she was going to order 3

Ordered tests/wrote a prescription without explanation 4

Table 14. Example of first eight scenarios (end point responses available only)

Please read the description of each GP consultation and answer the questions at the end by comparing your last visit to the GP for a check-up with the consultation described below:

Scenario Number	<i>1</i>
The doctor treats you with dignity	<i>No</i>
The doctor recognises your pain/distress	<i>Yes</i>
The doctor takes notice of what you say about your health	<i>No</i>
The doctor reassures you	<i>Yes</i>
The doctor is trustworthy	<i>No</i>
The doctor gives you information	<i>If you ask for it</i>
The doctor accepts your decisions about your health	<i>Yes</i>

If you needed to go to the doctor again for a check-up, would you choose

Your own GP?	1
The GP described above?	2
Another GP?	3

Scenario Number	<i>2</i>
The doctor treats you with dignity	<i>Yes</i>
The doctor recognises your pain/distress	<i>Yes</i>
The doctor takes notice of what you say about your health	<i>Yes</i>
The doctor reassures you	<i>Yes</i>
The doctor is trustworthy	<i>Yes</i>
The doctor gives you information	<i>No</i>
The doctor accepts your decisions about your health	<i>No</i>

If you needed to go to the doctor again for a check-up, would you choose

Your own GP?	1
The GP described above?	2
Another GP?	3

Table 15. Example of scenarios from the full factorial design

Scenario Number	9
The doctor treats you with dignity	<i>No</i>
The doctor recognises your pain/distress	<i>Yes</i>
The doctor takes notice of what you say about your health	<i>Yes</i>
The doctor reassures you	<i>No</i>
The doctor is trustworthy	<i>No</i>
The doctor gives you information	<i>Whether you ask for it or not</i>
The doctor accepts your decisions about your health	<i>No, but tells you about his/her decision</i>

If you need to go to the doctor again for a check-up, would you choose:

Your own GP?	1
The GP described above?	2
Another GP?	3

Scenario Number	10
The doctor treats you with dignity	<i>Yes</i>
The doctor recognises your pain/distress	<i>Yes</i>
The doctor takes notice of what you say about your health	<i>No</i>
The doctor reassures you	<i>Yes</i>
The doctor is trustworthy	<i>No</i>
The doctor gives you information	<i>If you ask for it</i>
The doctor accepts your decisions about your health	<i>No, but tells you about his/her decision</i>

If you need to go to the doctor again for a check-up, would you choose:

Your own GP?	1
The GP described above?	2
Another GP?	3

6.4 Analysis

The aim of the analysis was to determine whether the preferences of respondents for non-health outcomes of health care were consistent with the model of individual health care decision making as expressed by consumer theory. [275]As previously described (Chapter Four) a multinomial logit (MNL) model was specified. An MNL model has a vector of attribute parameters β_j for each choice option. One of these vectors must be set to zero. In this case the vector for “another doctor” was set thus, meaning that the utility of choosing this option (i.e. neither current GP nor hypothetical GP) was zero. Thus, the probabilities of choosing current GP, hypothetical GP or another GP were estimated by:

$$P(Y = j|x_k) = \frac{e^{\beta_j'x_k + \gamma'z_i}}{1 + \sum_{j=1}^3 e^{\beta_j'x_k + \gamma'z_i}}$$

for $j = 1$ (current GP), 2 (hypothetical GP) and

$$P(Y = AnotherGP|x_k) = \frac{1}{1 + \sum_{j=1}^3 e^{\beta_j'x_k + \gamma'z_i}}$$

where β_j is the transposed vector of alternative-specific parameter estimates and x_k is the vector of the design variables and γ is the transposed vector of individual-specific vectors and z_i is the vector of characteristics including gender, education level obtained, marital status, number of years with current GP and number of time the respondent has consulted with the GP in the past 12 months. The software packages SAS [296] and SYSTAT [297] were used for the analysis.

6.5 Results

Completed questionnaires were obtained from 128 (100%) respondents. Characteristics of the respondents are summarised in Table 16. Equal numbers of responses were obtained for each of the 4 reasons for consultations, and an almost equal number of male and female respondents overall was recruited. Most people were married and reported a personal income of under \$40,000 per year. They averaged almost 6 visits to the GP in the past 12 months and had been with this GP for an average of 11 years. Almost all respondents reported that the outcome of the visit to the GP which they were evaluating had been positive.

Table 16. Example of scenarios from the full factorial design

Age (years)	Mean: 47.8 (range 18-80) SD: 18.2
Gender (%)	
<i>Female</i>	53.1
<i>Male</i>	46.9
Highest education level (%)	
<i>Primary/some secondary</i>	21.1
<i>Completed secondary</i>	22.7
<i>Trade certificate/diploma/some university</i>	23.4
<i>Bachelor/postgraduate degree</i>	32.8
Income (%) per year	
<i>Up to \$19,999</i>	38.3
<i>\$20,000-\$39,999</i>	29.8
<i>\$40,000-\$59,999</i>	16.4
<i>\$60,000 or over</i>	11.7
<i>Not stated</i>	3.9
Marital status (%)	
<i>Married</i>	60.9
<i>Single</i>	39.1
Number of visits to this GP in past 12 months	Mean: 5.9 (Range 1-48) SD: 6.6
Time going to this GP (years)	Mean 11 (Range 1-40) SD: 8.4
Outcome of GP consultation (%)	
<i>Positive</i>	98.4
<i>Negative</i>	1.6

Most respondents were positive about their last visit to their GP (Table 17). In Table 17 the labels for each attribute are used, although respondents evaluated the visit using the same descriptions as in the scenarios (see Appendix Three).

Table 17. Responses to the assessment of the last visit to their own GP

Attribute	Response (%)
Treated with dignity	Yes 100
Recognition of and support for pain/distress	Yes 88.3
Legitimation provided	Yes 98.4
Reassurance provided	Yes 83.6
Trust in provider	Yes 99.2
Information provided	If you ask for it 48.4
	Whether you ask for it or not 44.5
	Only about where to get it 2.3
Participation in decision making	No 4.7
	Yes 31.3
	Yes, but gives advice/opinion 47.7
	No, but tells you about decision 20.3
	No 0.8

All respondents considered that their GP treated them with dignity and nearly all indicated that their GP listened to them, took notice of what they said about their health and was

trustworthy in terms of their actions and advice. More than 80% of respondents also believed that their GP recognised the pain and distress associated with being ill and provided them with reassurance when they were ill. Nearly half of the respondents received information from their GP if they asked for it and 45% received information whether they asked for it or not. Nearly 80% of people believed that their doctor respected their decisions about their health, with more indicating that this occurred in conjunction with the GP offering his or her advice or opinion about the individual's health. Thus, twenty-one per cent of respondents indicated that they did not participate in decision making.

With 128 participants responding to 24 scenarios, a total of 3072 responses were received. Of these, 2815 (91.6%) indicated that the participant preferred his/her own GP, 173 (5.6%) preferred another GP and 84 (2.73%) preferred the hypothetical (scenario) GP. Overall, 89 of the 128 respondents (69%) chose their own general practitioner (GP) in all 24 scenarios.

The results of the multinomial logit (MNL) model are presented in Table 18. This model was estimated with all the variable effects coded and includes the entire sample. A model was also run on scenarios 1-512, that is, excluding the effect of using only the scenarios which evaluated only endpoints (the first 8 scenarios). However, because there was so little variation in the responses, the inclusion of the extreme level responses was found not to affect the estimates overall, but did add to the statistical power of the analysis.

As participants were offered three choices (current GP, hypothetical GP or another GP), there are two constants in the model (current and hypothetical GP). Thus, all results can be interpreted as the probability of an individual choosing their current GP or the hypothetical GP relative to another (unspecified) GP. The choice of another (unspecified) GP was set to zero because the probability of choosing either the current GP and the hypothetical GP were

of most interest. The positive values of both the coefficient and T-ratios (columns 2 and 3) for the current GP indicates that respondents were more likely to choose this alternative (than they were to choose another GP) while the negative values for the hypothetical (scenario) GP indicates that respondents were less likely to choose this alternative. Most attributes have a positive sign, indicating that, as would be expected, the more positive the attribute, the more likely respondents were to prefer it. However in the first model Table 18, two aspects of the decision making attribute have negative signs, indicating that the more a doctor moves away from accepting an individual's decisions about their health, the less likely this was preferred by respondents.

Table 18 illustrates the importance of the attributes (non-health outcomes) without the modifying effects which might be produced by socio-demographic variables. The T-Ratio (column 3) gives some indication of the relative importance of the attribute. Thus, in this model, the attributes in order of importance are: reassurance (T-Ratio = 7.090), recognition of and support for emotional distress (6.925), participating in decision making (5.260), being able to trust the provider (5.093), legitimation (4.406), being given information whether it is asked for or not (4.183), being treated with dignity (3.953), being given information if it is asked for (0.311) and being given information only about where to obtain information (0.045).

Table 18. Results of SPDCM estimation using attributes only

Variable	Coefficient	T-Ratio	p-Value
Intercept			
Current GP	0.505	2.101	0.356
Hypothetical GP	-1.46	-8.286	0.000
Dignity	0.512	3.953	0.0001
Recognition and support for emotional distress	0.513	6.925	0.0000
Legitimation	0.494	4.406	0.0000
Reassurance	0.460	7.090	0.0000
Trust in provider	0.637	5.093	0.0000
Information			
Only about where you can get it	0.009	0.045	0.9641
Whether you ask for it or not	0.469	4.183	0.0000
If you ask for it	0.033	0.311	0.7560
No	-0.511		
Participation in decision making			
No, but tells you about decision	-0.457	-3.651	0.0003
Yes, but gives advice/opinion	-0.286	-2.547	0.0109
Yes	0.583	5.260	0.0000
No	0.160		

Separate models were estimated by condition (reason for consultation). However, the results were not useable because within each condition there were too few respondents who indicated they would be prepared to “trade”, that is, choose either the hypothetical GP or another GP, rather than their own. However, the conditions were included in an aggregate model which also included the demographic and health information collected at the end of the SPDCM survey. The results of this model, presented in Table 19, generally support the previous findings, although the order of importance of the attributes (non-health outcomes) has been modified and some socio-demographic variables are also important as measured by the T-Ratio.

In the second model (Table 19), a negative sign indicates that respondents are less likely to choose a GP if they are only told about where to get information and if the doctor does not accept their decisions about their health. Thus, this group of respondents rated non-health outcomes in the following order of importance: trust (5.248), legitimation (5.146), recognition of and support for emotional distress (4.715), dignity (3.893), reassurance

(3.116), information whether it is asked for or not (2.724), decision making including receiving advice from the doctor (0.826), autonomous decision making (0.547) and information if it is asked for (0.535). While the final three T-Ratios are positive, their proximity to zero indicates that these levels of information and participation in decision making had little effect on respondent's preferences.

Table 19. Results of SPDCM estimation including demographic and health information

Variable	Co-efficient	T-Ratio	p-Value
Intercept			
Current GP	2.598	7.469	0.0000
Hypothetical GP	-0.022	-0.040	0.9684
Dignity	0.562	3.893	0.0001
Recognition of & support for emotional distress	0.700	4.715	0.0000
Legitimation	0.807	5.146	0.0000
Reassurance	0.429	3.116	0.0018
Trust in provider	0.855	5.248	0.0000
Information			
Only about where you can get it	-0.263	-0.978	0.3280
Whether you ask for it or not	0.597	2.724	0.0065
If you ask for it	0.113	0.535	0.5925
No	-0.447		
Decision making			
No, but tells you about decision	-0.245	-0.900	0.3679
Yes, but gives advice/opinion	0.201	0.826	0.4091
Yes	0.112	0.547	0.5842
No	-0.068		
Condition	Curr; Hypo*		
URTI	0.576; 0.742	3.330; 2.657	0.0009; 0.0079
Vaccination	-1.344; -1.477	-8.085; -4.796	0.0000; 0.0000
Minor injury	-0.102; 0.248	-0.580; 0.914	0.5620; 0.3606
Check-up	0.870; 0.487	5.062; 1.702	
Age			
	0.0098	1.601	0.1094
	0.033	-2.781	0.0054
Sex			
Male	0.062	-0.684	0.4938
Female	0.272	1.694	0.0903
Marital status			
Married	0.014	0.132	0.8952
Single	-0.104	-0.525	0.5995
Visits to GP in 12 mths			
	0.042	1.284	0.1993
	0.027	-0.559	0.5759
Years going to GP			
	0.090	6.202	0.0000
	0.093	4.316	0.0000
Education attained	Curr; Hypo*		
Did not complete secondary	-1.057; -0.684	-4.412; -2.026	0.0000; 0.0427
Completed secondary	-1.394; -1.699	-0.863; -2.523	
Trade qualification	-0.207; -0.842	4.757; 5.388	0.3881; 0.0116
Bachelor degree or higher	2.658; 3.225	-4.031; -4.015	0.0000; 0.0000
Income	Curr; Hypo*		
Up to \$19,999	0.806; 0.956	3.403; 2.571	0.0007; 0.0102
\$20,000-\$39,999	-1.212; -1.002	-7.212; -3.805	0.0000;
\$40,000-\$59,999	-0.151; 0.229	-0.781; -0.707	0.0001
\$60,000 or over	0.557; -0.183	2.796; -0.572	0.4349;
			0.4793

* Curr = Current GP; Hypo = hypothetical GP

Table 19 also illustrates the impact of the condition and various socio-demographic variables. In relation to the condition about which respondents consulted their GP, the probability of choosing either their current GP or the hypothetical GP relative to “another GP” decreases if the reason was for a vaccination (T-Ratio -8.085 for current GP and -4.796 for hypothetical GP), increases if the person went to the GP for a check-up (5.062 (current GP) 1.702 (hypothetical GP) or for an upper respiratory tract infection (3.330 , 2.657) and was not affected if they consulted the GP for a minor injury (-0.058 , 0.914).

The longer a person had been with their GP (measured in years), the more likely they were to choose either their current GP (T-Ratio = 6.202) or a hypothetical GP (T-Ratio = 4.316) rather than another GP. However, their probability of choosing either their current or the hypothetical GP over another GP was not affected by the number of visits they had made to their GP in the past 12 months (T-Ratios = 1.284 (current GP); -0.559 (hypothetical GP)).

The impact of the socio-demographic variables was mixed. The probability of respondents choosing their current GP relative to “another GP” was not affected by age, gender, marital status, completion of secondary school or having an annual income between \$40,000 and \$59,999. However, the probability of choosing the current GP was increased by having a trade qualification, an income of less than \$20,000 or more than \$60,000 per year. The probability was decreased if the respondent had not completed secondary school, had a Bachelor’s degree or had an income of between \$20,000 and \$39,999 per year.

The probability of respondents choosing the hypothetical GP relative to “another GP” was not affected by marital status, having an annual income between \$40,000 and \$59,999 or greater than \$60,000. The probability of choosing the hypothetical GP was increased if the respondent was male, had a trade qualification or an income of less than \$20,000 per year.

The probability was decreased as the age of the respondent increased, if she or he had not completed secondary school, had a Bachelor's degree or had an income of between \$20,000 and \$39,999 per year.

A series of probability plots illustrates the results. Three examples are given in Figures 1, 2 and 3 (see Appendix Four for a complete set of probability plots).

Figure 1 illustrates how the probability of respondents choosing their current or the hypothetical GP changes as the attribute levels moves from least favourable to most favourable. That is, changing from a scenario where the GP did not treat the respondent with dignity, provide recognition or support for emotional distress, legitimization or reassurance, could not be trusted and did not encourage participation in decision making to one where all these non-health outcomes were present increased the proportion of respondents who chose their own GP from about 10% to more than 80%. In other words, the more a GP is described as behaving in a way that respondents perceive produces non-health outcomes, the more likely they are to choose this option. While the same change in attributes has an effect on the proportion who chose the hypothetical GP, because the number of respondents who chose this option was small, the impact of changing the scenarios from negative to positive is also small.

Figure 1: Effect of Least and Most Favourable Attribute Levels

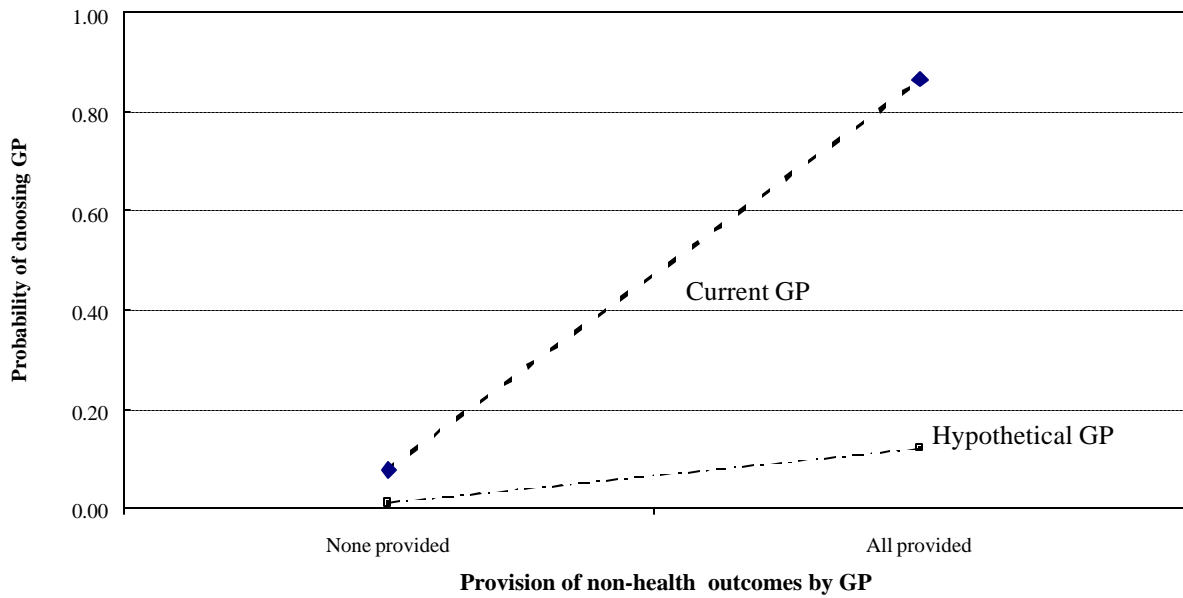


Figure 2: Effect of Perceived Trustworthiness

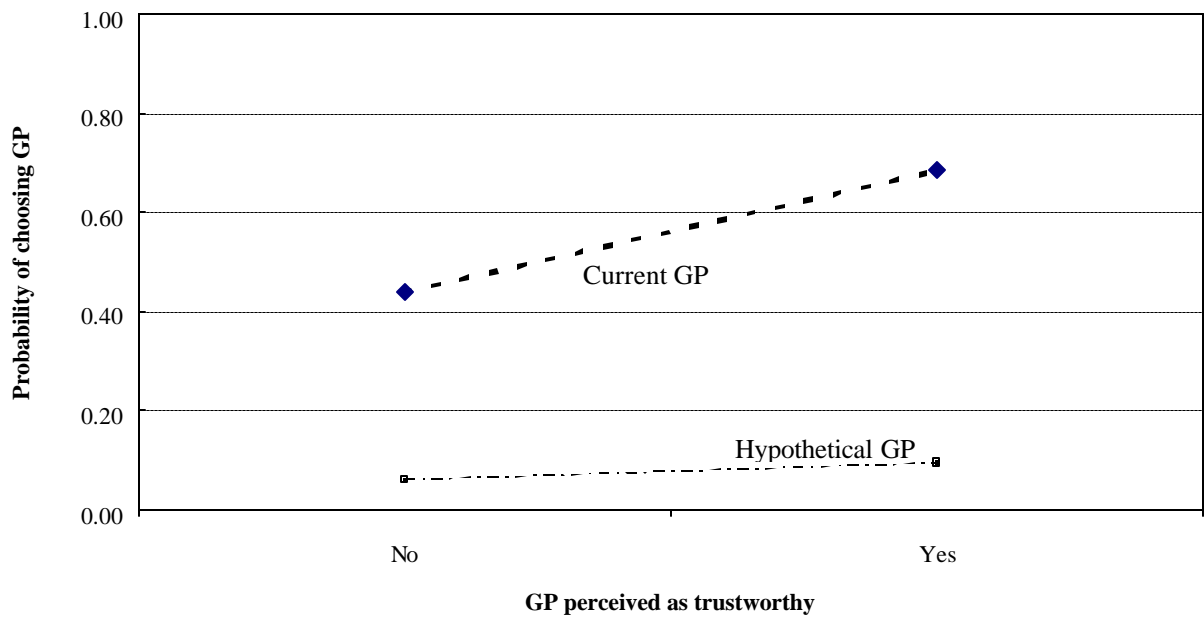
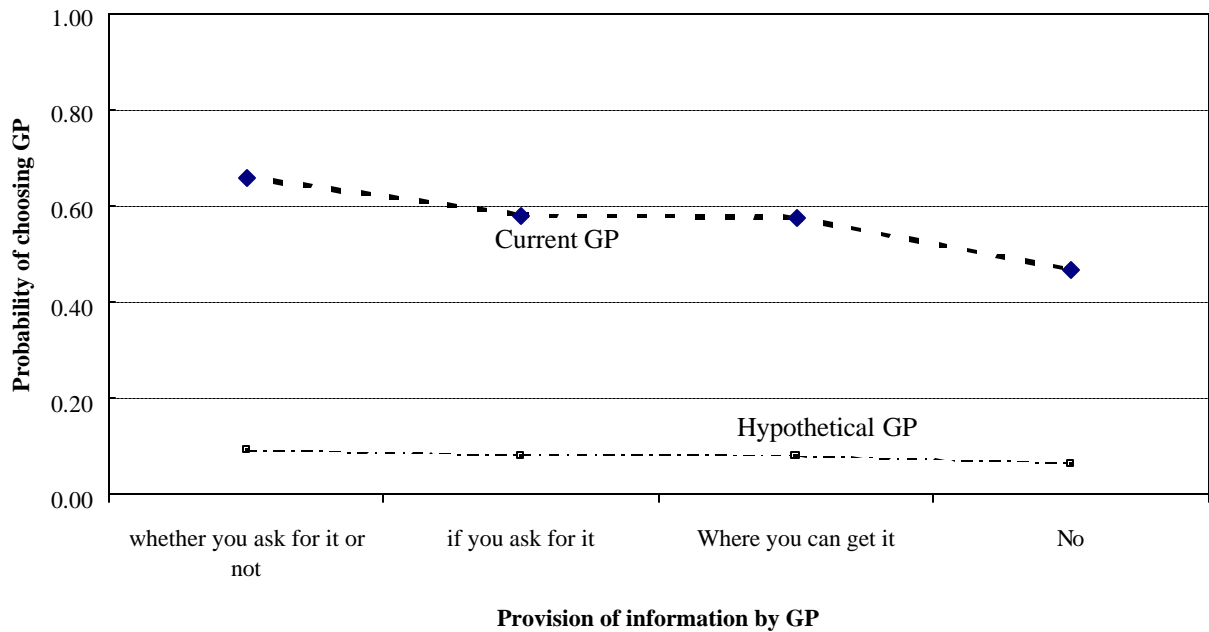


Figure 3: Effect of provision of Information



The perception that they could trust their GP increased the proportion of respondents who chose both their current GP and the hypothetical GP and again the increase was more noticeable among those who indicated they would choose their current GP (Figure 2). Figure 3 demonstrates the impact of changes in the levels of information received by respondents. While giving information, with or without a request for it, results in an increase in the proportion of respondents who chose either their current GP or the hypothetical GP, not being given information or only being told where to get it produces either a small decrease in the likelihood of respondents choosing their own GP or very little change in how they would choose (hypothetical GP).

6.6 Discussion

The sample of people who participated in this research were generally representative of the population living in metropolitan Sydney. [298] Respondents had visited their doctor an average of 5.9 times in the past 12 months, a figure very similar to the Australian average.

[299]Participants indicated that they had been visiting their current GP for an average of 11 years. Although not directly comparable, results from another Australian study show that 63% had been seeing their doctor for at least 5 years. [300]There are a number of potential explanations for the longevity of association displayed by the respondents to their current GP.

First, their current GP may fulfil all the requirements regarding providing health and non-health outcomes that participants considered necessary. That is, they may consider him or her to be the right choice. The results from the initial evaluation of their GP indicated that participants rated their own GPs highly. Most considered that their doctor treated them with dignity, recognised their pain and distress, listened to them and took account of their opinions regarding their health, reassured them and was trustworthy. Most also received information and participated in the decision making process during the consultation. These results support previous findings. In a study carried out in Sydney, [300]17% of respondents mentioned affective qualities (i.e. aspects concerning the interpersonal relationship between the patient and provider) and 27% mentioned whether the doctor had been recommended to them by other patients or doctors as being the reason they had first chosen their GP. Forty-one percent of respondents indicated that affective reasons influenced them to remain with their GP compared with 31% who mentioned instrumental reasons (i.e. technical competence). Thus, the respondents in this study may have chosen their GPs carefully, using the extent to which they were able to provide non-health outcomes as (some) of the criteria in selecting a particular doctor. Having fulfilled the criteria or at least not completely ignored them, their current GP remains their preferred choice.

Second, positive evaluations may reflect the costs of changing doctors. In the study by

Lupton et al, [300]72% of respondents reported that they had never changed GPs. Changing

doctors is not easy even when the act is made necessary by a change of residence – many people have emotional ties to their GP and there are costs associated with assisting another GP to become acquainted with the medical history and social and cultural circumstances of individuals and families. Even if an individual considers his or her GP to be less than ideal, they are likely to be averse to the risk of trying to find a better doctor when it is difficult to know before switching whether they will be better off. Further, patients may be reluctant to report that their GP does not attain the high standard implied by the questions asked or statements made in the questionnaire or survey. For example, asking respondents to indicate whether their GP treats them with dignity implies that such conduct is expected of a good doctor. An admission to the contrary may be perceived to reflect badly on the patient's decision making ability or to have the potential to cause trouble, if a patient believed that the researcher could find out who their GP was. While the first reason may have influenced the responses of participants in this study, the second is unlikely as no questions were asked about the identity of the respondents' GPs.

Third, there is some evidence that, generally, health care consumers prefer the status quo. Research has shown that within the context of maternity care, rheumatology and screening for bowel cancer, patients choose the type of care or service they have experience with; [301-303] This preference for the status quo has been termed the endowment effect [304] or the status quo bias. [305] These effects or biases refer to the fact that individuals are more likely to prefer or value more highly goods or services they own or have experienced. Changing doctors is also made less likely by the fact that most people do not visit the doctor very often and may therefore be more willing to tolerate some less than ideal characteristics or behaviours. This suggests that people with chronic or complex conditions may be more likely to switch GPs.

A labelling effect or hypothetical bias may also explain preferences for the status quo Salkeld. [303] If a labelling effect existed it would mean that despite the fact that the current GP and scenario GP were described in terms of the same attributes, respondents have interpreted the descriptions and thence evaluated the options in a different way. That is, the title “own GP” may conjure up a mental picture completely different to the one described in the survey and any positive or negative associations respondents have with their own GP may have overridden the description using non-health outcomes. The fact that the experiment also included an additional labelled choice (another GP) further complicates the interpretation of responses as participants were free to ascribe any attributes they chose to this choice. Hypothetical bias may occur if respondents do not consider the alternatives to be real choices.

This study had a number of limitations. Insufficient resources placed a constraint on the number of people who could be surveyed, thus potentially restricting the analysis. The limited “trading” undertaken by participants also suggests that a larger sample may be required to fully test the model. For example, the small numbers and lack of trading did not allow for the analysis of data from the first eight scenarios (i.e. the extreme or endpoint design) on their own. The study also considered relatively minor health conditions in the context of general practice. However, as one of the aims of the study was to evaluate the application of choice modelling techniques to elicit non-health benefits, such a straightforward approach was appropriate. Further studies are needed to evaluate complex and chronic conditions and other health care contexts such as specialist medical care, hospital care and care in the community. Finally, further research is necessary to examine the relative preferences of patients for health and non-health outcomes.

6.7 Conclusion

This chapter has described the conduct and results of a SPDCM experiment in which respondents were asked to choose among their current GP, a hypothetical GP represented by a scenario or another GP on the basis of their preferences for seven attributes representing non-health outcomes. Respondents overwhelmingly preferred their current GP, whom they evaluated as providing care in ways likely to produce positive non-health outcomes. They indicated that being able to trust their GP and having their concerns and ideas noted (legitimation) were most important, followed by having their emotional distress recognised and supported, being treated with dignity and being reassured. Although receiving information and participating in decision making about their health care was positively assessed by the respondents, these attributes were not as important as the first five.

As well as perceiving that their GP provided an excellent standard of care and, therefore, they were not in need of a change, participants may have been reluctant to choose the scenario GP or another GP because of an underlying preference for the status quo, because they had previously changed GPs so that their current GP provided them with the requisite level of non-health outcomes or because they perceived that the amount of health care they needed was not sufficient for them to need more in the way of non-health outcomes than their current GP was providing.

Chapter Seven

Discussion and Conclusions

Chapter Seven Discussion and Conclusions

7.1 Introduction

This chapter, the final section of the thesis, has a number of aims. Its overall aim is to discuss the extent to which the theoretical framework outlined in Part One of the thesis was supported by results from the empirical work undertaken in Part Two. In particular, the following will be explored:

- An assessment of the usefulness of using the specific qualitative and quantitative research tools in gauging the relevance and importance of and preferences for non-health outcomes, including the advantages and disadvantages of combining the methods.
- A comparison of the results of this research with other research about patients' preferences for non-health outcomes;
- The implications of the findings for the measurement of health care benefits including the evaluation of health care from the patient's perspective; and
- What, if any, further research would be helpful in clarifying or extending issues raised by the finding.

7.2 Using qualitative and quantitative research methods to examine the relevance, importance of and preferences for non-health outcomes

7.2.1 Qualitative research regarding relevance and importance to patients

Specific reasons for choosing a qualitative research method (in-depth interviews) to explore the relevance and importance of non-health outcomes were outlined in Chapter Four. The type of interview undertaken (the general interview guide approach) [53] required that a set of issues or topics be developed for discussion with each participant. The guide was further refined by setting the interview within the context of making decisions about health and health care. Participants responded to the invitation to describe their experiences of decision

making in different ways so that careful listening and checking was needed to make sure all topics were covered. The extent to which this choice was justified can be gauged by the fact that almost everyone approached readily agreed to be interviewed, no interviews were terminated prematurely and no-one had difficulty in understanding the topic or providing examples of their experiences. In particular, this technique, while allowing the framework of non-health outcomes to be used in the analysis of the information supplied by interviewees, was sufficiently flexible to prevent the labeling and/or framing of questions which might have influenced participants' responses. Thus, the strengths of qualitative research, such as enabling an in-depth examination of a particular topic including the meaning participants attach to particular events was evident both during the interviews and from the results. Such characteristics were crucial to the aim of using patient's perspectives to judge the relevance and importance of non-health outcomes.

Undertaking interviews, like all qualitative research, is time-consuming and a great deal of organisation and effort is necessarily expended in setting up interviews, travelling to a suitable location (often participant's homes) and introducing the topic in such a way that respondents are comfortable talking to a stranger about relatively intimate and private subjects such as their health and health care. Large amounts of data are produced and undertaking the analysis is also time-consuming, requiring painstaking coding and re-coding to ensure that all potential ideas and themes are fully explored. The major weaknesses of the qualitative research undertaken here were that only a small number of interviews were able to be undertaken and the respondents were, to some extent, self-selected. Thus, the findings are unlikely to be generalisable across all similar populations. However, overall, the interviews were undertaken successfully, met their objectives, produced results which were sensible and able to be used to gauge the relevance and importance of non-health outcomes to patients. The findings from each study are summarised below.

Forty in-depth interviews were undertaken with two groups of people: twenty men and women with chronic renal failure and 20 women in the target age range for Pap smears. These groups were chosen to test the assumption that people with chronic, complex conditions and those receiving or considering screening would emphasise non-health outcomes in narrating their experiences of health care, particularly as it related to decisions they had made about health care. This proved to be the case although the groups differed in the emphasis they gave to different non-health outcomes.

Overall, people with chronic renal failure perceived that, within a context which severely constrained choices, they were independent decision makers who, over time, came to regard themselves as experts in their own disease and, to some extent, personally responsible for their own health. Although information was important to them, its level of importance varied between patients and over time in each patient. The long period of time over which many respondents had received health care had reduced their expectations about the way health care providers would treat them. However, non-health outcomes increased in importance whenever their condition or treatment changed, that is, as uncertainty increased. In all circumstances however, patients regarded the extent to which they could trust their health care provider as important.

Women receiving Pap smears (mostly from their GPs) were influenced (positively and negatively) in their decision-making by information and attitudes expressed by the media, health workers, family and friends. Life stages are also an important influence on decision making. Although they regarded some unpleasantness and inconvenience as an inevitable part of the process of having a Pap smear, they will actively manage their care to reduce this as much as possible. Information, reassurance, recognition of and support for emotional

distress and involvement in decision making were felt to be particularly important when they or close others had an abnormal test result. Finally, women placed importance on being treated with dignity and being able to trust their doctor or other health care professional.

Although it is very useful to elicit the views of patients and consumers about what is important to them, such unstructured opinions do not indicate how patients would prioritise potential changes to health care. As the aim of the evaluation of health care is to recommend improvements that would result in a more acceptable service to patients, thus potentially enhancing its effectiveness and efficiency, it is also necessary to elicit the preferences patients have for factors which influence the acceptability of health care.

7.2.2 Quantitative assessment of the preferences of patients for non-health outcomes

The consumption of goods or the use of services reveals, in an ideal world, the preferences of consumers. However, as has been made clear in this thesis, health care consumers do not live in an ideal world. They are unlikely to have complete information, access to the full range of choices available or the time to reveal their preferences in this way. Hence, stated preferences are as close an approximation to how they might act, as it is normally possible to identify. A number of methods for eliciting stated preferences exist. The most common methods are rating or ranking. Respondents rate one or more items either by giving them a numerical score between 0 and an arbitrarily chosen highest number or by assigning each item a qualitative score (e.g. bad, good, excellent). Ranking is achieved by asking respondents to order a list of items from low to high but neglects the distance between items on the list. [292] However, the use of these methods to determine what changes should be made to health care services is problematical in terms of acting on the results. If respondents consider some or most items on a list important, they may rate all of them highly. Thus it will be difficult to judge what not to change or how much to change those rated highest. In

listing items from least to most important, respondents are not necessarily indicating that only the first or first few items should be acted on or where, if anywhere, the cut-off point for ceasing change is. Therefore, using the results from a rating or ranking exercise has limited capacity to inform health care service providers about what change in the balance of factors would produce the most acceptable service to patients or users. It will also not inform managers about what trade-offs patients are prepared to make in order to have access to their preferred type of service.

To overcome such problems, stated preference discrete choice methods have been developed. Choice experiments are used to estimate an index of utility of a good which is modelled in terms of its constituent parts or attributes. In addition, the contribution of each item (called attributes) to the overall choice respondents make can also be estimated.

SPDCM is particularly useful in estimating preferences for goods (or services) where no or limited data are available from the market (e.g. due to market failure) or for predicting the uptake of new goods or services (including those not experienced by individuals).

Lancaster's consumer theory [275] and Random Utility Theory [306] form the theoretical basis for SPDCM, and the choice experiment is operationalised using surveys in which respondents are presented with a number of descriptions of the good or service in which the attributes of interest are varied systematically. An increasing amount of work in marketing, transport, environmental and health economics attests to the power and predictive accuracy of SPDCM; [280]; [285, 286];

In the study undertaken for this thesis, people were asked to state their preferences for GP services which were described in terms of the non-health outcomes previously identified as important, both in theory and empirically. The results provided support for the findings of

the qualitative research: all the non-health outcomes were considered important by

respondents with trust most important, followed by legitimation and recognition of and support for emotional distress. Interestingly, the provision of information and acting autonomously or participating in decisions about their health care were the least important non-health outcomes for patients. This is in contrast to the emphasis placed on them in the literature, perhaps reflecting the importance they have for health care providers. It may also reflect the different contexts; information and autonomy may be much more important for an individual consulting a specialist about a serious or chronic illness than in the case of a consultation with a GP for a relatively minor ailment.

Two (related) results from the SPDCM experiment were unexpected. These were, first, the fact that so many people rated their GP highly and second, the unwillingness of most respondents to “trade”, that is to change GPs. Possible reasons for these findings include the treatment of relatively minor conditions as the context in which to set the experiment and the limited number of levels of the non-health outcomes presented in the SPDCM scenarios – five of the seven were described in terms of two levels only, while two had four levels. People consulting their GP for more serious or chronic conditions might be more critical of their doctor or more interested in obtaining non-health outcomes and thus be more willing to trade. Increasing the number of levels of some of the non-health outcomes would have increased participants’ choices but it is not possible to speculate about the extent to which this would have affected the results. Although each attribute (non-health outcome) was defined and explained briefly in the introductory literature, they are concepts about which individuals may have constructed different definitions based on past experiences. Therefore, the extent to which the respondents were choosing between the same “things” may be questionable.

Respondents were asked to complete 24 scenarios. There has been some debate in the literature about the “right” or maximum number of scenarios an individual will be able to complete before their ability or willingness to respond is affected. [277] However, some SPDCM experiments have used up to 48 or in one case 96 scenarios without any adverse effects on either respondents or results. [277] No respondent to the study presented in this thesis reported any difficulties in either understanding or completing the questionnaire. The design of the SPDCM was informed by the results of the qualitative research. Therefore, it is possible to be confident that these were the right attributes to include in the questionnaire. However, a pilot study may have revealed the non-trading issue allowing some modification of the levels of one or more attributes.

Contracting the implementation of the SPDCM questionnaire to a company experienced in undertaking all aspects of population-based surveys in general and SPDCM in particular was successful and is likely to be cost-effective. The costs and effort of training interviewers, obtaining the required sample, undertaking the survey and entering the data are beyond the experience and means of most small research units or academic departments and the expertise of specialist research staff is much better spent in undertaking and checking aspects of SPDCM such as design, analysis and interpretation. Once the data are coded appropriately, analysis using standard software is straightforward and the results are easy to understand.

The strength of SPDCM lies in its ability to produce findings which provide evidence about how individuals choose to consume a good or not using hypothetical data. In particular, the contribution of each attribute to the choice to consume the good or not can be estimated.

This capacity has been realised in this study as the results have demonstrated that, while all non-health outcomes presented to respondents were important to them, they preferred some

more than others. Therefore, the application of this method has the potential to elicit preferences and values for the outcomes of health care and thus enhance the comprehensiveness of health care evaluations. However, the issue of non-trading by respondents also raise the question of whether concepts such as the behaviour –related non-health outcomes used here are as amenable to SPDCM as more directly policy-oriented non-health attributes (for example, those concerned with access to health care such as cost, distance to travel or waiting times) might be.

The final results of the thesis benefit from the complementary use of both qualitative and quantitative research methods. Because the topic of non-health outcomes has not been extensively researched, particularly from patients’ perspectives, qualitative research was used firstly as means of exploring complex concepts related to patients’ experiences, the meanings they ascribed to these experiences and their opinions about them. In-depth interviews enabled this to be done in a non-threatening way and in a relatively naturalistic setting. Secondly, the qualitative research was an essential preliminary to the quantitative research, providing verification of the attributes to be used in the SPDCM experiment and descriptions of the non-health concepts which could be used in the scenarios. Within the context of GP services for four relatively minor conditions, the use of SPDCM has consolidated the findings from the qualitative research that all the non-health health outcomes were regarded as important by patients and resulted in a better understanding of which non-health outcomes are preferred by patients and in what combination.

Moreover, the results of the SPDCM are in contrast to those reported in the literature (see Chapter 3, Table 6, page 48). Using the amount of published research as a guide to importance, it might be inferred that participation in decision making was the most

important non-health outcome (72 articles), followed by information, then reassurance, trust

and recognition of and support for emotional distress (27-30 articles) with dignity and legitimation (8 and 6 articles respectively) being not very important. However, the SPDCM results are almost the reverse of this. Respondents indicated that they preferred trust, legitimation, recognition of and support for emotional distress, were less influenced by being able to received information whether or not they had asked for it and were relatively neutral in their preferences for participation in decision making and receiving information if it was asked for (see Chapter 6, Table 18, page 197).

In Chapter 3, Table 7 (page 102), illustrated the potential relationships between health and non- health outcomes and whether either type of outcome was related either to an individual's presenting problem or to his or her interaction with the health care system. Table 20 below updates Table 7 on the basis of the findings of this research, showing that as far as non-health outcomes are concerned, recognition of and support for emotional distress and legitimation are context-specific (i.e related to the presenting problem).

Table 20. Outcomes of seeking health care

	Health outcomes	Non-health outcomes
Related to presenting problem	Improved health status	Information and knowledge of presenting problem
	Removal of problem	
	Relief of problem	
	Prevention of problem	
Related to interaction with the health care system	Slower deterioration of presenting problem	Reassurance about any/all aspect/s of presenting problem
	Improved ability to cope with presenting problem	Emotional support from health care provider/s
		Having any/all aspects of presenting problem legitimated
		Participation in decision making about presenting problem

Trust in health care
provider/s

Being treated with dignity

7.3 Comparing the results of this research with previously published research

There have been few published studies which explored patients' preferences for non-health outcomes, although some have included one or more non-health outcomes among the study factors. Two studies compared the preferences of doctors and patients, finding that they differed in important ways. In particular, patients were more likely to include non-health aspects of health care such as humaneness, involvement in decisions, time for care, informativeness and exploring patients' needs than were doctors;. [307, 308]The results of this thesis support the evidence that non-health outcomes rank highly as aspects of care for patients. [308]

A small number of SPDCM studies have included attributes described as non-health outcomes in choice experiments. One study [289]included non-health attributes derived from patient satisfaction studies. However, the attributes included did not resemble the non-health outcomes described and assessed in this thesis, but instead described characteristics of service delivery such as ability to switch rooms, visitor policy and nursing care for mother and baby. A study of physician-patient interaction conducted by Markham et al [309]which included the attribute "who makes care decisions" as one of five attributes found that it was ranked second. However, as this was the only non-health attribute included in the study, the results are not directly comparable to those of this thesis.

The results of two studies are more directly related to those of this thesis. In a study of couples' preferences for in vitro fertilisation services Ryan [286]included three non-health attributes, described as "the attitudes of staff towards you", "continuity of contact

with the same staff” and “follow-up support”. All were statistically significant at the 1% level, with couples likely to choose services with higher levels of positive staff attitudes and continuity of contact (i.e. the coefficient signs were positive) and lower levels of follow-up support (i.e. the coefficient sign was negative). People not wanting to discuss their infertility was suggested as the reason that follow-up was not preferred. Although the non-health outcomes presented to respondents in Ryan’s study were more general than those in this thesis, the results of both studies are similar in showing that patients prefer non-health outcomes. Finally, in a study of patients’ preferences for the processes and outcomes of liver transplantation, non-health outcomes described as “continuity of contact with the same medical staff”, “amount of information received about the transplant” and “follow-up support received” were included in an experiment which involved six attributes in total. All of the attributes, including the non-health factors, were significant and preferred by patients. [310]Once again, the results generally support those found in this thesis, but differed in that the results of Ratcliffe’s study did not enable differentiation between patients’ preferences for non-health outcomes.

7.4 The need for further research

This research represents an initial step in conceptualising potentially important benefits of health care and provides some empirical evidence that they should be considered for inclusion in measures of outcome. Within the context of health services research one method used (that of semi-structured interviews) is well established while the use of SPDCM to examine preferences in health care is in its infancy. However, although interviews are well accepted as a method of research, they are less commonly used as part of the routine monitoring or evaluation of health services. Particularly in the area of patient satisfaction, there has been a tendency to use “off-the-shelf” instruments, which have the advantage of being readily accessible and having established psychometric properties, but which may not be sensitive to local cultural or organisational nuances. The results of this research reinforce

the need for preliminary qualitative exploration to provide evidence about the topics patients think are relevant within a local context, thus enabling the development of a valid survey tool for more widespread use.

As the use of SPDCM within health services research is relatively new, there is much to be learnt about its usefulness as a method in this context. The future research agenda for SPDCM should include methodological questions such as how many alternatives (choices) should be offered to respondents, what are the risks and benefits of offering a forced choice, of allowing respondents to opt out (i.e. choose none of the alternatives) or of labelling, or of not labelling the choices. There are also questions about who should be sampled, what the right sample size is for a particular size of experimental design and whether all types of attributes of health services are suitable for inclusion in an SPDCM questionnaire.

This research has shown that patients believe that non-health outcomes are an important part of health care services and they prefer GPs whom they perceive as providing them.

However, the research has also shown that the importance of preferences for such outcomes may vary with experience, type of disease and the context in which care is provided. Thus, further research is needed to explore patients' preferences for both health and non-health outcomes (i.e. if and how patients trade-off gains in health gain against non-health outcomes such as being able to trust the doctor) and the relative importance of different non-health outcomes in specific contexts.

7.5 Lessons for the evaluation of health care from the patient's perspective

Although the idea that how research or evaluation is conducted depends on the perspective adopted is not new, the findings of this research emphasise its importance. Patients' perspectives are different from those of health care providers or from those who plan and/or fund health care services. If it is considered appropriate that patients' views inform the

nature of health care services, the use of narrative-based research will enable the experiences

of patients to be used to approach issues holistically, allowing participants the opportunity to introduce their own ideas and to avoid aspects of the subject they do not consider relevant or do not wish to discuss.

However, it does not follow that all research or evaluation which is based on patients' perspectives needs to imitate exactly the methods used here. As well as perspective, the methods used depend on the objectives of the research or evaluation. If the objective is to elicit a comprehensive set of outcomes or important issues before testing consumers' or patients' preferences for them, qualitative research is a recommended first step. This can often be accomplished efficiently using focus groups rather than individual interviews, but time and resources will need to be spent on training or employing a group facilitator, ensuring that an appropriate sample of consumers or patients is recruited and analysing the results. Of course this step can be avoided if sufficient confidence can be placed in the results of prior qualitative research. If the perspective sought is that of providers or funders then the literature is likely to yield good information about the outcomes these groups consider relevant.

Once the relevant attributes or outcomes have been established, the question of whether to use SPDCM or another method to obtain information about preferences or the degree of importance placed on outcomes or issues may depend on the type of outcome being considered. If the attributes are ones directly related to the organisation of health care services (e.g. pre-admission or day of admission surgical work-up, home or hospital birthing services) or are quantifiable aspects of the delivery of care (e.g. waiting times, cost, mobile or fixed screening units, doctor- or nurse-delivered care), SPDCM is likely to be a suitable means of generating preferences. However, if the attributes are concepts or behaviours then a simple ranking exercise may be more appropriate. Examples of concepts or behaviours

include the non-health outcomes used in this thesis, or the perceptions of patients about the level of care or helpfulness demonstrated by staff.

In summary, using narrative and other qualitative tools will elucidate which benefits of health care patients think are relevant and important, thus pointing to their use as part of the evaluation of health care. SPDCM surveys have the potential to reveal patients' preferences for any combination of health and non-health outcomes, thus providing policy makers, managers and providers with information about how to organise and deliver health care. The results of this research have shown that patients want more from health care than health gain alone and will evaluate positively providers and services which deliver non-health outcomes.

Specific problems with the conceptual basis for patient satisfaction, the uncertainty that all patients consider the variables included in patient satisfaction surveys to be relevant and/or important and the inability of satisfaction surveys to measure patients' preferences (as outlined in Chapter Two), indicate that the use of patient satisfaction surveys as a means of understanding patients' views about health care should be approached with caution.

Although such surveys may represent the most straightforward means of obtaining feedback from patients, if the results are neither useful nor meaningful in terms of providing better health care, they will not be the most efficient method of eliciting patients' opinions. If both health and non-health outcomes are potential benefits of health care, acquiring information about which attributes patients or users consider relevant, important and are preferred can be conceptualised as a form of indicator development in preparation for measuring what patients actually gain from health care. Although likely to be more expensive, obtaining context-specific information from patients or users of services about the relevant outcomes, including non-health outcomes and then measuring the importance and/or preferences for

such outcomes will ensure that the perspective taken in any subsequent evaluation is truly that of the patient or service recipient.

7.6 Conclusion

The overall goal of the research undertaken for the thesis was to answer the following questions:

What non-health outcomes of health care are relevant to patients?

What non-health outcomes of health care do patients consider important?

What non-health outcomes of health care do patients prefer?

The literature indicated that there were seven pre-eminent non-health outcomes which could be considered as potentially relevant and important to patients. The frequency with which they were discussed provided a ranking of the seven thus: participation in decision-making, information, trust, reassurance, recognition of and support for emotional distress, dignity and legitimation. Qualitative research reinforced the notion that all seven were relevant to a wide range of patients but also brought ideas of health care context and individual experiences into focus. People with chronic renal failure were more likely to emphasise decision making, information and legitimation than were women in the target age range for cervical cancer screening who perceived reassurance, recognition of and support for emotional distress and dignity as significant. The disease or condition being considered as well as the context in which the research participants were receiving health care are the most likely reasons for these differences. Both groups believed that trust was an important non-health outcome. The SPDCM experiment was able to differentiate patients' preferences and the relative importance of each non-health outcome more clearly again. The results showed that although all the non-health outcomes were, to some extent, preferred by respondents, trust was most important, followed by legitimation and recognition of and support for emotional distress. Once again, these results point to the importance of context in the

evaluation of health care from the patient's perspective. While still being perceived as positive aspects of health care, the provision of information and acting autonomously or participating in decisions about their health care were the non-health outcomes considered least important by patients.

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Appendix One: Information sheet, consent form and question guide for Chronic Renal Failure interviews.

Information Sheet

Title of Research Project: **Patients' perspectives on health care decision making.**

Investigators: **Marion Haas, Peter Sainsbury**

The Research Question:

This study will be asking you to describe some experiences you have had of health care, particularly in relation to decisions that have been made about your (health problem). In undertaking this research, we are aiming to find out what patients think is important when they (and their families) are faced with decisions about their health and health care.

We will be asking you to participate in an interview. The interview can take place either in your home or at the hospital, whichever is most suitable for you. We expect that the interview will take about one hour.

We would like to tape the interviews so that we don't miss anything you tell us. The tapes will then be transcribed onto paper, so that we can read and analyse what you have said. Your name, address, telephone number, diagnosis or any other information which could be used to identify you personally will **not** be transcribed from the tape.

We will be publishing the results of the study. No personal, identifying information will be published. The person who will be organising and conducting the interviews is:

Ms Marion Haas
Senior Research Officer
Centre for Health Economics Research and Evaluation (CHERE)
Building F, Level 6
88 Mallett St
Camperdown NSW 2050
Telephone 9351 0908

Please telephone Marion if you have any questions about the study or if you wish to change any interview arrangements. If you have any questions about your rights as a research subject, please contact the Royal Prince Alfred Ethics review Committee on (02) 9515 6766.

Consent Form

Research Project: Patients' perspectives on health care decision making.

Investigators: Marion Haas, Peter Sainsbury

Iof.....

.....

have read the information about being a participant in the research project entitled **Patients' perspectives on health care decision making** 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 may be recorded in writing or on audio tape 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 interviews 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.

I understand that the research project will be carried out according to the principles in the National Health and Medical Research Council on Human Experimentation.

I understand that if I have any questions about my rights as a research subject, I may contact the Royal Prince Alfred Ethics Review Committee on (02) 9515 6766.

Name.....

Signature.....

Date.....

Name of Witness.....

Signature of Witness.....

Research Questions:

I'd like to start by asking you to recall one or more experiences you have had where decisions have been made (by you alone or by you in conjunction with others) about treatment for your (chronic renal failure). [An example of a decision may be given here to assist the participant].

Could you think back and remember the process you went through when you were making this decision?

Could you tell me about what did or did not help when you were making this decision?

[If necessary or appropriate, probes or prompts will be used to elicit information about the following:

- . what personal, social and/or contextual influences the participant perceives there to be on decision making regarding his/her health problem. For example, the following factors may be discussed by patients as being more or less important:
 - .the type of decision (choosing a course of action, adhering to treatment, changing treatment, having a diagnostic test); the seriousness of the outcome; familiarity with the decision; level of certainty; family considerations; age; marital status etc.
- . if and how the participant uses information as an aid to decision making (e.g. how much and what sort of information is needed and/or sought; the participant's opinions of the relevance, language, inclusiveness and reliability of the information);
 - .if and how important the following were to the participant during the decision making process: reassurance; dignity; recognition of emotional distress; trust; and legitimation].

Appendix Two: Information sheet, consent form and question guide for Cervical Screening interviews.

Research Study Into Women's Decisions About Cervical Screening Information For Participants

You are invited to take part in a research study into **Women's decisions about cervical screening**. In this study, we will be asking you to describe some experiences you have had of making decisions about cervical screening (having a Pap test) particularly in relation to what you think is important when patients (and their families) are faced with decisions about their health and health care. The study is being conducted by Marion Haas, Principal Research Officer at the Centre for Health Economics Research and Evaluation and Peter Sainsbury, Director of the Social Health Research Unit in Central Sydney Area Health Service.

If you agree to participate in this study, you will be asked to participate in an interview, which we expect will take about one hour. We will be audio-taping the interview and then transcribing the tapes onto paper, so that we can analyse the conversations. The interview can take place either in your home or at the hospital, whichever is most convenient for you. A copy of the interview transcription will be sent to you for verification. A postage-paid envelope will be provided for you to return the transcription to Marion Haas once you have checked the transcription and made any changes to or comments about it.

All aspects of the study, including results, will be strictly confidential and only the investigators named above will have access to information on participants. A report of the study will be submitted for publication, but individual participants will not be identified in such a report.

While we intend that this research study furthers medical knowledge and may improve the way services are delivered in the future, it may not be of direct benefit to you.

Participation in this research is entirely voluntary: you are in no way obliged to participate and - if you do participate - you can withdraw at any time. Whatever your decision, please be assured that it will not affect your medical treatment or your relationship with medical staff.

When you have read this information, Marion Haas will discuss it with you further and answer any questions you may have. If you would like to know more at any stage please feel free to contact Marion Haas on 02 9351 0908. This information sheet is for you to keep.

The research project will be carried out according to the principles in the National Health and Medical Research Council on Human Experimentation.

This study has been approved by the Ethics Review Committee (RPAH Zone) of the Central Sydney Area Health Service. Any person with concerns or complaints about the conduct of a research study can contact the Secretary on 02 9515 6766.



RESEARCH STUDY INTO WOMEN’S DECISIONS ABOUT CERVICAL SCREENING PARTICIPANT CONSENT FORM

I.....(name)

of.....(address)

have read and understood the Information for Participants on the above named research study and have discussed the study with Marion Haas.

I have been made aware of the procedures involved in the study, including any known or expected inconvenience, risk, discomfort or potential side effect and of their implications as far as they are currently known by the researchers.

I freely choose to participate in this study and I understand that I can withdraw at any time.

I also understand that the research is strictly confidential.

I hereby agree to participate in this research study.

NAME:.....

SIGNATURE:.....

DATE:.....

NAME OF WITNESS:.....

SIGNATURE OF WITNESS:.....

Questions for participants

Do you have regular Pap smears?

- How long have you been having Pap smears for?
- Who does your Pap smear?
- How/why did you start having Pap smears?
- Was anyone/anything particularly influential in this decision?

How do you decide when to have another Pap smear?

- own initiation?, reminder from doctor/Pap test register?
- some other method? (reminder from own doctor, friend, media, someone with cervical cancer)

Has anything ever discouraged you from having a Pap smear?

- ?lack of time, embarrassment, forgetting, fear of results, discomfort of the examination, indignity, fees, doctor's advice

Has anyone ever talked to you or given you specific information about having a Pap smear?

- Who?
- What?

Once you have had your Pap smear, do you think about the results of the test?

- What do the results of the Pap smear mean to you?

Have you ever had any positive results/worrying results from a Pap smear?

- how was this dealt with/handled by doctor/health professional?
- how did you handle it?
- Could/should things have been done differently?
- Did it change your attitude to having a Pap smear?

Have you had any particularly positive or negative experiences connected with having a pap smear?

- What could/should have been done differently (ie to make the experience easier or more positive for you?)
- Have you ever been embarrassed or experienced discomfort when having a Pap smear?

Have you always had your Pap smears done by the same provider?

- Why?
- Does the sex of the person doing the Pap smear make any difference to you? How?

What part does trust play in your relationship with your (Pap smear provider)?

- How do you decide/work out that someone is trustworthy?

Does your (Pap smear providers') personal manner influence your thinking about whether or not or when to have a pap smear?

- If yes, how?
- If no, why is it not influential?

Have you ever discussed Pap smears with other people who are important to you?

(e.g. partner, sister, brother, mother, father, daughter, son, close friends, workmates)

- How much do you think they are in favour of or opposed to your having Pap smears?

Is there anything else you want to tell me about Pap smears?

Thank you very much for participating in this study.

Appendix Three: Information and Consent forms and an example of the SPDCM questionnaire

Patient preferences in general practice

Information Sheet

We would like to invite you to participate in a study designed to gain an understanding of patients' preferences in the context of general practice (GP) consultations. The study is being undertaken by the Centre for Health Economics Research and Evaluation.

If you agree to participate, you will be asked to complete a survey about your preferences during a GP consultation.

The survey we will ask you to complete consists of an evaluation of your last visit to a GP followed by 32 hypothetical, but realistic situations that describe a consultation with a GP. Each situation differs in terms of a number of aspects that could affect your decision to consult the GP in the future.

In the survey, we will ask you to answer a series of questions about yourself and your willingness to attend GPs in the future. This will take approximately 20 minutes to complete.

Your participation in the survey is completely voluntary. If you decide to participate, you will be free to leave the study at any time. Your responses to this survey are strictly confidential and at no time will the answers you give be linked to your identity. Your participation in this survey will not be revealed to anyone, other than the researchers, without your written consent.

If you choose to participate in the research, an interviewer will help you to complete the survey. You can choose where you would like the interview to take place, be it your home, your office or at the CHERE offices. You will also be asked to read and sign the consent form provided by the interviewer.

If you would like to speak to someone about the study, or the survey itself, please call Marion Haas on 9351 0908.

Any person with concerns or complaints about the conduct of a research study can contact the Manager of Ethics and Biosafety Administration, University of Sydney, on (02) 9351 4811.

Consent Form

PATIENT PREFERENCES IN GENERAL PRACTICE

Approval has been given by the Human Ethics Committee of The University of Sydney to conduct this survey. The Committee requires us to obtain your written consent before proceeding.

To maintain confidentiality, this consent form will be separated from your responses, which ensures that the responses you give can not be linked back to you .

Please complete the following:

I, _____
(name)

of _____
(address optional)

have read the attached information sheet and understand the information about being a participant in the study “Patient preferences in general practice”.

Any questions I had have been answered to my satisfaction.

I understand my identity will not be revealed to anyone other than the researchers conducting the project without my written consent and that I may withdraw my consent at any time.

I agree that the research data may be published, but that my name will not be used and that I will not be identified in any way.

I understand that should I have any problems or queries about the way in which the study is being conducted and I do not feel comfortable contacting the research staff I may contact the Manager for Ethics and Biosafety Administration, The University of Sydney, on 9351 4474.

I hereby agree to take part in this survey.

Signature of participant _____ Date _____

Understanding Decisions to Participate in Genetic Screening

Survey Instructions

In the first part of the survey, we will be asking you to evaluate your last visit to your GP.

In the second section of the survey, there are 32 hypothetical situations describing different consultations with a GP. For each situation we would like you to tell us whether you prefer this situation to the last experience you had with your GP by indicating whether, in the future, you would prefer your GP, the GP in the hypothetical consultation or neither. This means that for each situation, you will be asked to tick one of the boxes in answer to the following question:

If you needed to go to the doctor again for a check-up, would you choose ?

Your own GP?

The GP described above?

Another GP?

Each situation you will see differs from the others on one or more of the following aspects:

Doctor treats you with dignity: This means that when you attend the doctor, he or she treats you as someone worthy of attention and respects your need for control of the situation, including your need for privacy.

Doctor recognises your pain and/or distress: This means that the doctor shows you that she/he cares about the pain or distress you may be suffering.

Doctor takes notice of what you say about your health: This means that the doctor pays attention to your reasons for consulting him or her and acknowledges that your reason for consulting is appropriate.

Doctor reassures you: This means that the doctor is encouraging about your health and offers you hope that everything will be alright.

Doctor is trustworthy: This means that you are confident that the doctor will give you the right advice about your health because she/he is both competent and understands your situation.

Doctor gives you information: This means that the doctor gives you appropriate information about your condition in such a way that your knowledge is improved.

Doctor accepts your decisions about your health: This means that the doctor offers you the opportunity to make the decisions you want to make about your health.

Here is an example of the type of situation you will be asked to consider:

Sample Situation

The doctor treats you with dignity	<i>Yes</i>
The doctor recognises that you are experiencing some pain or distress	<i>No</i>
The doctor takes notice of what you have to say about your health	<i>Yes</i>
The doctor reassures you	<i>No</i>
The doctor is trustworthy	<i>Yes</i>
The doctor gives you information about your condition	<i>If you ask for it</i>
The doctor accepts your decisions about your health	<i>No</i>

If you needed to go to the doctor again for the same reason, would you choose:

- | | |
|-------------------------|-------------------------------------|
| Your own GP? | <input checked="" type="checkbox"/> |
| The GP described above? | <input type="checkbox"/> |
| Another GP? | <input type="checkbox"/> |

In the situation above, a choice made was to return to the person's own GP.

We now ask that you first evaluate your last visit to a GP for a check-up and then complete the following 16 pages, comparing your last visit to your GP with the GP consultation described in each situation.

Patient preferences in general practice**Part 1: Your last consultation with your GP for a check-up**

Please circle the number most applicable to your last visit to your GP.

- 1 When you visited your GP, were you treated with dignity
- Yes 1**
No 2
- 2 During the consultation, did the doctor recognise any pain and/or distress you were feeling?
- Yes 1**
No 2
- 3 Did your doctor listen to you and take notice of what you had to say about your health?
- Yes 1**
No 2
- 4 Did your doctor encourage you and/or reassure you that everything would be alright?
- Yes 1**
No 2
- 5 Did you trust your GP's actions and advice?
- Yes 1**
No 2
- 6 When you visited your GP, he or she:
- | | |
|---|----------|
| Offered you information if and when you asked for it | 1 |
| Gave you information whether you asked for it or not | 2 |
| Told you where you could get information | 3 |
| Did not give you information | 4 |
- 7 During the consultation, your GP:
- | | |
|--|----------|
| Gave you the opportunity to make decisions about your health | 1 |
| Told you which tests/treatment/other action he/she would advise | 2 |
| Told you which tests/treatment he/she was going to order | 3 |
| Ordered tests/wrote a prescription without explanation | 4 |

Patient preferences in general practice

Part 2

Please read the description of each GP consultation and answer the questions at the end by comparing your last visit to the GP for a check-up with the consultation described below:

Scenario Number	<i>1</i>
The doctor treats you with dignity	<i>No</i>
The doctor recognises your pain/distress	<i>Yes</i>
The doctor takes notice of what you say about your health	<i>No</i>
The doctor reassures you	<i>Yes</i>
The doctor is trustworthy	<i>No</i>
The doctor gives you information	<i>If you ask for it</i>
The doctor accepts your decisions about your health	<i>Yes</i>

If you needed to go to the doctor again for a check-up, would you choose

Your own GP?	X
The GP described above?	X
Another GP?	X

Scenario Number	<i>2</i>
The doctor treats you with dignity	<i>Yes</i>
The doctor recognises your pain/distress	<i>Yes</i>
The doctor takes notice of what you say about your health	<i>Yes</i>
The doctor reassures you	<i>Yes</i>
The doctor is trustworthy	<i>Yes</i>
The doctor gives you information	<i>No</i>
The doctor accepts your decisions about your health	<i>No</i>

If you needed to go to the doctor again for a check-up, would you choose

Your own GP?	X
The GP described above?	X
Another GP?	X

Scenario Number	3
The doctor treats you with dignity	No
The doctor recognises your pain/distress	No
The doctor takes notice of what you say about your health	No
The doctor reassures you	No
The doctor is trustworthy	Yes
The doctor gives you information	If you ask for it
The doctor accepts your decisions about your health	No

If you needed to go to the doctor again for a check-up, would you choose

Your own GP?	X
The GP described above?	X
Another GP?	X

Scenario Number	4
The doctor treats you with dignity	Yes
The doctor recognises your pain/distress	No
The doctor takes notice of what you say about your health	Yes
The doctor reassures you	No
The doctor is trustworthy	No
The doctor gives you information	No
The doctor accepts your decisions about your health	Yes

If you needed to go to the doctor again for a check-up, would you choose

Your own GP?	X
The GP described above?	X
Another GP?	X

Scenario Number	5
The doctor treats you with dignity	<i>No</i>
The doctor recognises your pain/distress	<i>Yes</i>
The doctor takes notice of what you say about your health	<i>No</i>
The doctor reassures you	<i>No</i>
The doctor is trustworthy	<i>No</i>
The doctor gives you information	<i>No</i>
The doctor accepts your decisions about your health	<i>No</i>

If you needed to go to the doctor again for a check-up, would you choose

Your own GP?	X
The GP described above?	X
Another GP?	X

Scenario Number	6
The doctor treats you with dignity	<i>Yes</i>
The doctor recognises your pain/distress	<i>Yes</i>
The doctor takes notice of what you say about your health	<i>Yes</i>
The doctor reassures you	<i>No</i>
The doctor is trustworthy	<i>Yes</i>
The doctor gives you information	<i>If you ask for it</i>
The doctor accepts your decisions about your health	<i>Yes</i>

If you needed to go to the doctor again for a check-up, would you choose

Your own GP?	X
The GP described above?	X
Another GP?	X

Scenario Number	7
The doctor treats you with dignity	<i>No</i>
The doctor recognises your pain/distress	<i>No</i>
The doctor takes notice of what you say about your health	<i>No</i>
The doctor reassures you	<i>Yes</i>
The doctor is trustworthy	<i>Yes</i>
The doctor gives you information	<i>No</i>
The doctor accepts your decisions about your health	<i>Yes</i>

If you needed to go to the doctor again for a check-up, would you choose

Your own GP?	X
The GP described above?	X
Another GP?	X

Scenario Number	8
The doctor treats you with dignity	<i>Yes</i>
The doctor recognises your pain/distress	<i>No</i>
The doctor takes notice of what you say about your health	<i>Yes</i>
The doctor reassures you	<i>Yes</i>
The doctor is trustworthy	<i>No</i>
The doctor gives you information	<i>If you ask for it</i>
The doctor accepts your decisions about your health	<i>No</i>

If you needed to go to the doctor again for a check-up,
would you choose

Your own GP?	X
The GP described above?	X
Another GP?	X

103VICU

Scenario Number

9

The doctor treats you with dignity *No*

The doctor recognises your pain/distress *Yes*

The doctor takes notice of what you say
about your health *Yes*

The doctor reassures you *No*

The doctor is trustworthy *No*

The doctor gives you information *whether you ask for it or not*

The doctor accepts your decisions about
your health *No, but tells you about his/her decision*

If you need to go to the doctor again for a check-up, would you choose:

Your own GP? X

The GP described above? X

Another GP? X

259VICU

Scenario Number

10

The doctor treats you with dignity *Yes*

The doctor recognises your pain/distress *Yes*

The doctor takes notice of what you say
about your health *No*

The doctor reassures you *Yes*

The doctor is trustworthy *No*

The doctor gives you information *If you ask for it*

The doctor accepts your decisions about
your health *No, but tells you about his/her decision*

If you need to go to the doctor again for a check-up, would you choose:

Your own GP? X

The GP described above? X

Another GP? X

144VICU

Scenario Number	<i>11</i>
The doctor treats you with dignity	<i>No</i>
The doctor recognises your pain/distress	<i>No</i>
The doctor takes notice of what you say about your health	<i>No</i>
The doctor reassures you	<i>Yes</i>
The doctor is trustworthy	<i>No</i>
The doctor gives you information	<i>No</i>
The doctor accepts your decisions about your health	<i>No</i>

If you need to go to the doctor again for a check-up, would you choose:

Your own GP?	X
The GP described above?	X
Another GP?	X

335VICU

Scenario Number	<i>12</i>
The doctor treats you with dignity	<i>Yes</i>
The doctor recognises your pain/distress	<i>Yes</i>
The doctor takes notice of what you say about your health	<i>Yes</i>
The doctor reassures you	<i>Yes</i>
The doctor is trustworthy	<i>No</i>
The doctor gives you information	<i>No</i>
The doctor accepts your decisions about your health	<i>No, but tells you about his/her decision</i>

If you need to go to the doctor again for a check-up, would you choose:

Your own GP?	X
The GP described above?	X
Another GP?	X

170VICU

Scenario Number	<i>13</i>
The doctor treats you with dignity	<i>No</i>
The doctor recognises your pain/distress	<i>No</i>
The doctor takes notice of what you say about your health	<i>No</i>
The doctor reassures you	<i>No</i>
The doctor is trustworthy	<i>No</i>
The doctor gives you information	<i>Only about where you can get information</i>
The doctor accepts your decisions about your health	<i>Yes, but also gives his/her advice and opinion</i>

If you need to go to the doctor again for a check-up, would you choose:

Your own GP?	X
The GP described above?	X
Another GP?	X

136VICU

Scenario Number	<i>14</i>
The doctor treats you with dignity	<i>No</i>
The doctor recognises your pain/distress	<i>No</i>
The doctor takes notice of what you say about your health	<i>No</i>
The doctor reassures you	<i>Yes</i>
The doctor is trustworthy	<i>No</i>
The doctor gives you information	<i>Whether you ask for it or not</i>
The doctor accepts your decisions about your health	<i>No</i>

If you need to go to the doctor again for a check-up, would you choose:

Your own GP?	X
The GP described above?	X
Another GP?	X

339VICU

15

Scenario Number

The doctor treats you with dignity *Yes*

The doctor recognises your pain/distress *Yes*

The doctor takes notice of what you say *Yes*

about your health

The doctor reassures you *Yes*

The doctor is trustworthy *Yes*

The doctor gives you information *If you ask for it*

The doctor accepts your decisions about *No, but tells you about his/her decision*

your health

If you need to go to the doctor again for a check-up, would you choose:

Your own GP? X

The GP described above? X

Another GP? X

400VICU

Scenario Number

16

The doctor treats you with dignity *Yes*

The doctor recognises your pain/distress *No*

The doctor takes notice of what you say *No*

about your health

The doctor reassures you *Yes*

The doctor is trustworthy *No*

The doctor gives you information *No*

The doctor accepts your decisions about *No*

your health

If you need to go to the doctor again for a check-up, would you choose:

Your own GP? X

The GP described above? X

Another GP? X

470VICU

Scenario Number	<i>17</i>
The doctor treats you with dignity	<i>Yes</i>
The doctor recognises your pain/distress	<i>No</i>
The doctor takes notice of what you say about your health	<i>Yes</i>
The doctor reassures you	<i>Yes</i>
The doctor is trustworthy	<i>Yes</i>
The doctor gives you information	<i>Whether you ask for it or not</i>
The doctor accepts your decisions about your health	<i>Yes, but also gives his/her advice and opinion</i>

If you need to go to the doctor again for a check-up, would you choose:

Your own GP?	X
The GP described above?	X
Another GP?	X

49VICU

Scenario Number	<i>18</i>
The doctor treats you with dignity	<i>No</i>
The doctor recognises your pain/distress	<i>Yes</i>
The doctor takes notice of what you say about your health	<i>No</i>
The doctor reassures you	<i>No</i>
The doctor is trustworthy	<i>Yes</i>
The doctor gives you information	<i>if you ask for it</i>
The doctor accepts your decisions about your health	<i>Yes</i>

If you need to go to the doctor again for a check-up, would you choose:

Your own GP?	X
The GP described above?	X
Another GP?	X

230VICU

Scenario Number

19

The doctor treats you with dignity *No*

The doctor recognises your pain/distress *No*

The doctor takes notice of what you say *Yes*

about your health

The doctor reassures you *No*

The doctor is trustworthy *No*

The doctor gives you information *Whether you ask for it or not*

The doctor accepts your decisions about *Yes, but also gives his/her advice and*
your health *opinion*

If you need to go to the doctor again for a check-up, would you choose:

Your own GP?	X
The GP described above?	X
Another GP?	X

487VICU

Scenario Number

20

The doctor treats you with dignity *Yes*

The doctor recognises your pain/distress *No*

The doctor takes notice of what you say *Yes*

about your health

The doctor reassures you *No*

The doctor is trustworthy *No*

The doctor gives you information *Whether you ask for it or not*

The doctor accepts your decisions about *No, but tells you about his/her decision*
your health

If you need to go to the doctor again for a check-up, would you choose:

Your own GP?	X
The GP described above	X
Another GP?	X

306VICU

Scenario Number	21
The doctor treats you with dignity	<i>Yes</i>
The doctor recognises your pain/distress	<i>Yes</i>
The doctor takes notice of what you say about your health	<i>No</i>
The doctor reassures you	<i>No</i>
The doctor is trustworthy	<i>Yes</i>
The doctor gives you information	<i>if you ask for it</i>
The doctor accepts your decisions about your health	<i>Yes, but also gives his/her advice and opinion</i>

If you need to go to the doctor again for a check-up, would you choose:

Your own GP?	X
The GP described above?	X
Another GP?	X

274 VICU

Scenario Number	22
The doctor treats you with dignity	<i>Yes</i>
The doctor recognises your pain/distress	<i>Yes</i>
The doctor takes notice of what you say about your health	<i>No</i>
The doctor reassures you	<i>Yes</i>
The doctor is trustworthy	<i>Yes</i>
The doctor gives you information	<i>if you ask for it</i>
The doctor accepts your decisions about your health	<i>Yes, but also gives his/her advice and opinion</i>

If you need to go to the doctor again for a check-up, would you choose:

Your own GP?	X
The GP described above?	X
Another GP?	X

241VICU

Scenario Number	23
The doctor treats you with dignity	No
The doctor recognises your pain/distress	No
The doctor takes notice of what you say about your health	Yes
The doctor reassures you	No
The doctor is trustworthy	Yes
The doctor gives you information	<i>if you ask for it</i>
The doctor accepts your decisions about your health	Yes

If you need to go to the doctor again for a check-up, would you choose:

Your own GP?	X
The GP described above?	X
Another GP?	X

332VICU

Scenario Number	24
The doctor treats you with dignity	Yes
The doctor recognises your pain/distress	Yes
The doctor takes notice of what you say about your health	Yes
The doctor reassures you	Yes
The doctor is trustworthy	No
The doctor gives you information	<i>Only about where you can get information</i>
The doctor accepts your decisions about your health	No

If you need to go to the doctor again for a check-up, would you choose:

Your own GP?	X
The GP described above?	X
Another GP?	X

Patient preferences in general practice

Part 3:

About you:

1 Are you: Female? 1 Male? 2

2 How old are you (in years)?

3 What is the highest level of education you completed?

Some primary	1	Completed primary	2
Some secondary	3	Completed secondary	4
Trade certificate	5	Trade diploma	6
Some university	7	Bachelor's degree	8
Postgraduate certificate or diploma	9	Higher degree	10

4 Please indicate which of these categories best matches your income.

Under \$20,000	1	\$50,001-\$60,000	5
\$20,001-\$30,000	2	\$60,001-\$70,000	6
\$30,001-\$40,000	3	\$70,001-\$80,000	7
\$40,001-\$50,000	4	over \$80,000	8

5 What is your current marital status?

Married	1	Single	2
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6 How often have you visited this GP in the past year (i.e. the one you evaluated in Part 1)?
.....times.

7 How long have you been a patient of this GP?

.....(in weeks/months/years)

8 Did the consultation with this GP have a positive or negative outcome?

Positive	1	Negative	2
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Thank you very much for participating in this survey

Appendix Four: Figures 4 – 8 illustrating the effects of GP treating patients with dignity, recognising emotional distress, legitimating their condition, providing reassurance and accepting their decisions.

Figure 4: Effect of being treated with Dignity

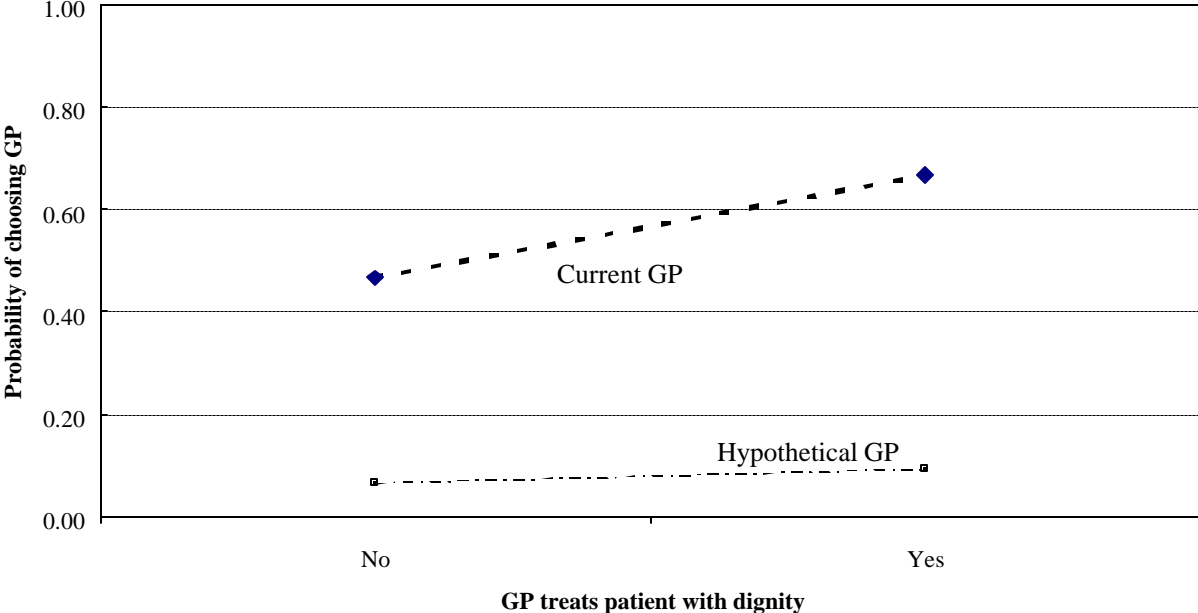


Figure 5: Effect of GP Recognising of Emotional Distress

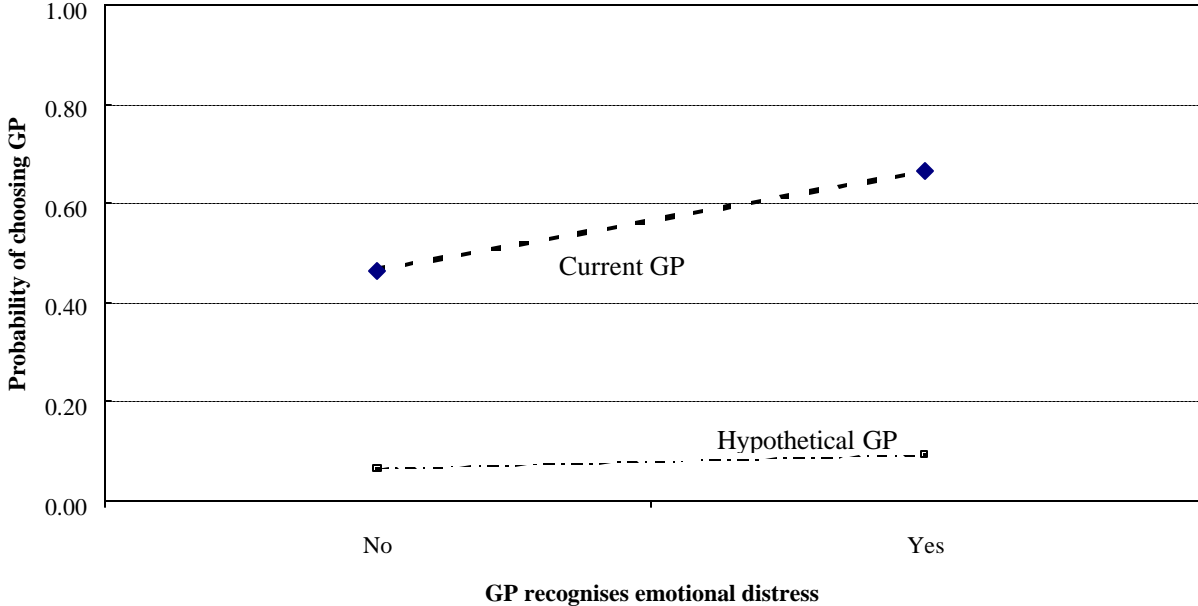


Figure 6: Effect of GP providing Legitimation

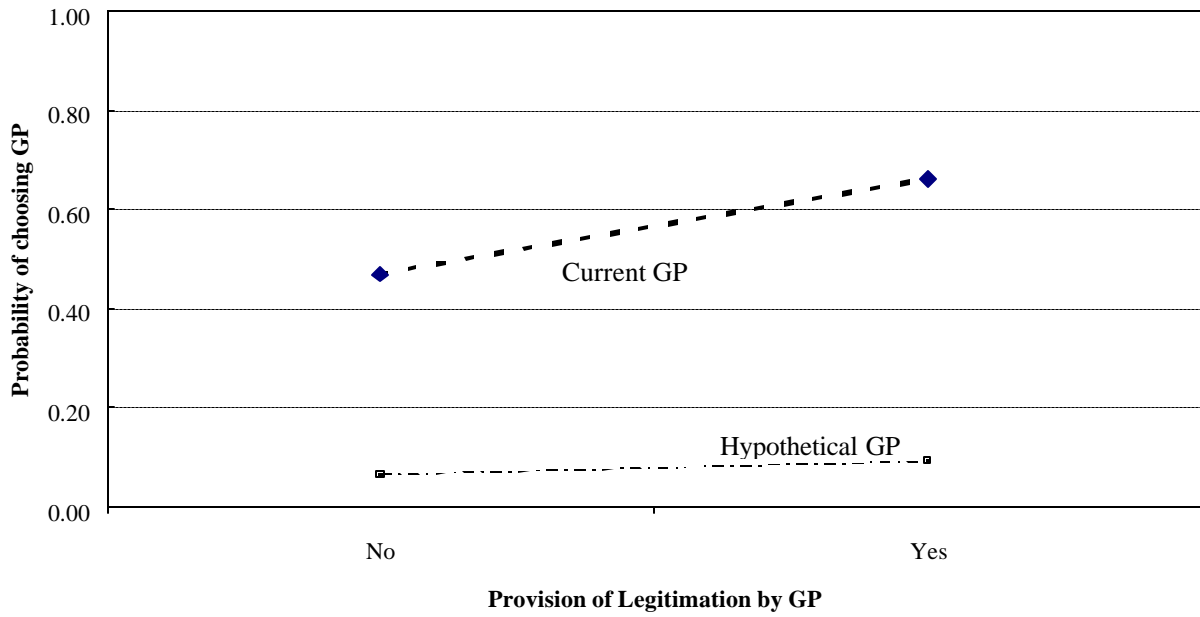


Figure 7: Effect of GP providing Reassurance

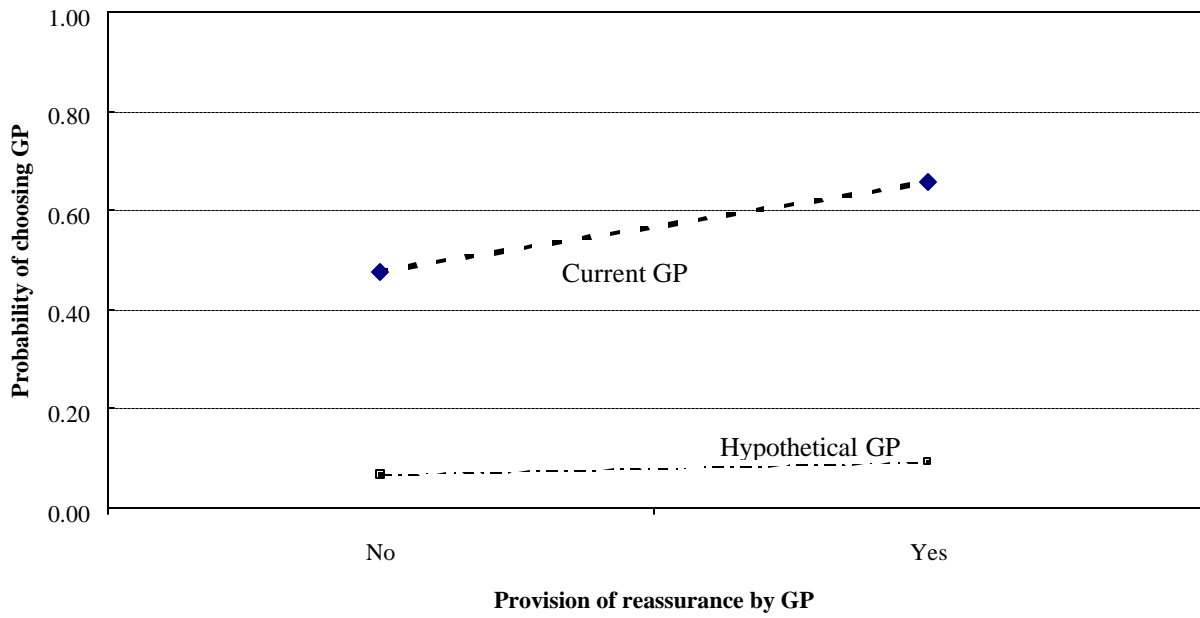


Figure 8: Effect of GP Accepting Patients' Decisions

