Ethics of the everyday: Using values transparency software to explore values based decision making in healthcare

Diane Newcombe

A dissertation submitted in part fulfillment of the requirements for the degree of Master of Health Science, Auckland University of Technology, 2007.

Contents

List of Tables

Ethics of the Everyday

List of Figures

List of Appendices

Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgement), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Acknowledgements

As expected, I have learned a lot undertaking this study; unexpectedly, I have learnt how to accept considerable amounts of help generously given, and my grateful thanks are due to many people.

Firstly I have appreciated the opportunity to have studied with Professor David Seedhouse, whose work and approach to Ethics and Health is inspiring. Secondly, I am very grateful to Valerie Wright-St Clair, whom I have come to know and admire in the course of undertaking this work, and whose supervision was instrumental in its completion.

To my daughters, Rhiannon and Bronwen; one of whom gave far more help than one would normally expect, and the other of whom asked for less help than one would normally expect. Thankyou.

Thanks to Helen Frances, for supporting this endeavour in numerous ways, not least of which with her interest, and to Nick Garrett, Denise Moffit, and Sharyn Gruzelier whose skills have contributed in various ways.

To Marion Jones, Leanne Meikle and Maureen Grant in the post-graduate office at AUT, who have been unfailingly helpful and supportive all through my course of study.

To my friends, thank you for all manner of help including expecting nothing of me for some time.

But most thanks are due to the occupational therapists who enthusiastically gave their time to participate in this study and contributed openly and thoughtfully their considered deliberations, from which I was able to draw some indicators and themes for reflection and discussion to inform this work.

Abstract

This dissertation presents discussion and analysis on values based decision making, based on a small pilot study using values transparency software, the Values Exchange, (2005). The intent is to contribute to knowledge about the essence and purpose of values based decision making and the role of values in healthcare. The literature was explored using key statements from Seedhouse (1998; 2001; 2005a), which guided exploration and discussion of the moral context of health, ethical analysis of moral issues, and the role of values and evidence in decision making. The approach, though naturalistic in philosophy, used mixed methods of data gathering, in a concurrent nested design, thus reflecting the tenet underpinning the subject of values based decision making, which is the explicit use of both values and evidence.

Occupational Therapists were used as a case group to deliberate on a scenario using the process of ethical analysis afforded by the values transparency software. Fifteen community occupational therapists participated in the study. Each participant completed a pre-participation questionnaire to ascertain their views on ethically challenging situations, their understandings of ethical practice, and their expectations of participating. Next, each participant deliberated over a challenging scenario. This involved logging onto the Values Exchange secure website which had been set up for the purpose and completing ethical deliberation of the situation using the software to guide analysis. Post-participation questionnaires were completed after participation using the Values Exchange with a view to noting change in views regarding ethical practice and also to assessing their experience of participating in the study. Participants' responses were analysed using quantitative reports, which indicated trends of value-selection, and theming of the qualitative material. Views from the pre-participation and post-participation questionnaires were analysed using frequency tables and theming. Analysis also included participants' views on using the software, information from questionnaires which they completed before and after participating, and synthesis from the literature review. The results showed disagreement among the participants regarding the course of action which the scenario proposed, and variation within the groups agreeing or disagreeing as to the case participants made to build their argument. The question of risk to the client was seen as the cause of most variation in decision making. As had been found in previous studies, for example, Barnitt and

Partridge (1997), participants described the tension between practicing in a client centred way and a way that limits perceived harm to the client.

A key finding arising from this study is that decision making by participants was values-based, and that in this study the software enabled that decision making to be transparent. This supports the view argued in the literature that values should be visible in decision making and part of the evidence in healthcare Haynes (2002). In addition the therapists' deliberations highlighted a key issue, also noted in the occupational therapy literature, of the tension experienced by therapists between wanting to be client centered and achieving it when client goals conflict with therapist's goals or recommendations.

Therapists' views on using the software are incorporated with recommendations for its future uses and other recommendations suggest strategies for practically improving the visibility of values in health care decision making. A case study methodology could well suit future exploration into the values behind decision making, and a further future study should be a philosophical analysis of therapists' and clients' perception of risk.

Chapter 1: Introduction

Chapter 1 provides a background literature review, covering four main areas. Firstly, in Section 1.1, I will examine the reasons for interest in the topic of values based decision making, and the use of values transparency software. Section 1.2 outlines the aim of the project, and in Section 1.3, I will briefly introduce the approach and methodology of the project. Finally, in Section 1.4, I will provide a brief overview of the remaining chapters 2-5.

1.1 Reasons for interest in this topic

This study explores the concept of values based decision making and uses review and discussion of the literature, and the use of values transparency software to do so. The interest to pursue this work was prompted through ethical studies and the growing awareness of the roles values could and should be playing in health care today (Fulford, 2004).

The Values Exchange, which is a values-transparency software tool to support ethical analysis, and which will be described further in Chapter 3, was developed by David Seedhouse from previous tools used to support ethical decision making (Seedhouse, 1998). My particular interest in the use of this software followed from a health care ethics project undertaken in 2005. That project used the Values Exchange to assist three groups of people to deliberate on an ethically challenging situation, and, using the software, to build a case to defend their decision making. That situation centered on ambiguity over whether or not to provide resuscitation for a person who at the time lacked the capacity to make their wishes known.

In developing the present study three issues were important. First, in the initial project conducted in 2005, the topic that was discussed was the kind of life and death scenario which often takes centre stage when health ethics are under discussion. However, as I will discuss in Chapter 2.1.2, health ethics is, or should be, present in every clinical encounter (Christiansen & Lou, 2001; Hasselkus, 1999; Hope, 2004; Hugman, 2005; Wright- St. Clair & Seedhouse, 2004). I wanted the present study to reflect this

perspective, and to consider the moral content and ethical analysis of an everyday situation.

Second, having become familiar with the term *values based decision making* through the use of the Values Exchange and studies in ethics (e.g., Wright 1987; Fulford, Dickenson & Murray, 2002; Fulford, 2004; Mills & Spencer 2005; Seedhouse 2005b;), I also wanted to look at the practical use of the term and its connection with evidence based decision making, client centred care and ethical analysis.

Finally, having recruited a multi disciplinary group in the previous project in 2005, I wanted to work with a single group of health professionals to explore its use in the kind of situation they encounter daily. One of the participants in the 2005 study who expressed considerable interest in using the tool was an occupational therapist. The therapist was at that time exploring challenging decision making in a community setting with colleagues, and I could see potential benefit in using a tool such as the Values Exchange with that health professional group.

I had used the Values Exchange on numerous occasions, and found the process to be thought provoking, and promoting of analytical thinking. Therefore, an additional purpose of the study was to test the assumption that the process of participation itself would increase health professionals' understanding of ethical deliberation.

In summary, the present project was instigated through studies in ethics and values, and from experience with using the values based decision making software, the Values Exchange. This small study presented an opportunity to work with a single group of health professionals, occupational therapists, to explore the roles values play in ethical decision making in an everyday issue.

1.2 Project Aim

The primary aim of this study was to conduct an exploration of values based decision making in a group of occupational therapists using the values transparency software, the Values Exchange.

The following questions were posed to guide discussion and analysis:

- What is values based decision making, what is its relationship with evidence based decision making, and is it a useful term?

- What situations do occupational therapists find ethically challenging, what do they use to assist decision making and what is the role of their discipline's code of ethics?

- To what extent is there convergence or divergence of decision among (community) occupational therapists when deliberating an everyday case scenario requiring decision making of an ethical nature?

Responses to these questions will be discussed in Chapter 5

1.3 Project approach; Methodology

Questions of a naturalistic nature such as those outlined above are most suited to exploration by qualitative research methodologies (Greenhalgh & Taylor, 1997), because the aim is to conduct exploration in a natural setting, exploring the meaning people bring to issues. Exploring participants' use of the Values Exchange and the meaning their participation brought to understanding values based decision making was a key purpose of the study and therefore required a qualitative approach.

The design and scope of the present study will be discussed in Chapter 3. Participants were occupational therapists with experience of working in a community setting and the data gathering was primarily through the reports generated by the Values Exchange, and information supplied by participants on questionnaires completed before and after

deliberating the case. Thematic analysis was employed (Thomas, 2003) to categorise responses where this was not done automatically by the Values Exchange software.

The dissertation was approached, as suggested by Levin (2005), by viewing the project work and the dissertation as two distinct parts. The project included all of the preparatory and exploratory work, reviewing current knowledge and understanding in the field. In addition, the project included all of the activity aimed at increasing that knowledge or understanding, which is described in Chapter 3 (the setting up of the case on the Values Exchange, the development of the questionnaires, and the enrolling of and communications with participants for the study). The dissertation involved writing up the entire activity, along with reflection, analysis and discussion.

The background for the study is reviewed in Chapter 2, and includes the literature review and is framed to focus exploration and discussion on health as moral work, ethics as analysis of the moral, and values as well as evidence being an essential component of decision making. To support and give emphasis to this framework I have used the following three quotes from the work of Seedhouse.

> "Work for health is a moral endeavour" (Seedhouse, 1998, p. x111).
>
> "Ethics should be part of every health encounter" (Seedhouse, 2001, p. 36).
>
> "Ethical analysis is thinking about human problems using both evidence and values explicitly, in order to arrive at a defensible solution (or at least one the reasoner feels able to defend)" (Seedhouse, 2005a)

These quotes will each lead a section of the background focusing respectively on moral issues, ethics and values.

Throughout the background discussion, I am aware that many terms frequently used in healthcare are done so with assumptions made that they are universally understood, when the reality is that they may be understood differently by different people.

I am aware that the same critique could be leveled against me, and many of the terms I am using would benefit from some philosophical analysis, for example healthcare; health professional and client/patient/person. Although this study is informed by the

traditions of philosophical analysis and will be questioning concepts, it does not have space to offer significant analysis, so instead I will provide explanations of my usage. It is not appropriate to attempt to succinctly define "healthcare", but, although services in New Zealand are often separated along "health" and "disability" boundaries for various philosophical, political, financial or pragmatic reasons, the use of the term healthcare in this work includes services which people seek to address what they perceive as a health or disability need. I am not attempting here to define either health or disability.

The people seeking a health service are called variously by people working in the service, the literature, and themselves; "patient", "clients" "service users", "consumers", "people", and again throwing light on what all these distinctions might mean is beyond the scope of this work. I use the terms "patient" and "client" variously, often depending on the context, or the work I am referencing, but also to reflect common usage which has developed in my own practice setting, where the term "patient" is used when a person is admitted to a hospital setting and the term "client" otherwise. Again, I do not wish to analyse this approach here, but merely to explain terminology.

1.4 Overview of the chapters

This work is structured in line with suggestions posed by Levin (2005), which is outlined further in Chapter 3. However, in summary, Chapters 2, 3 and 4 describe what Levin refers to as the project side of the work, while Chapters 5 and 6 contain the dissertation, the synthesis, analysis, conclusion and presentation of the work as a whole. Specifically, Chapter 2 explores the concepts of morals, ethics and values raised in the quotes from Seedhouse, introduced in Chapter 1.3. Section 2.2 continues by considering decision making in healthcare and the tools used to assist that decision making. The background section concludes in Section 2.3 by looking at any particular issues related to ethical decision making for the group selected for this study, occupational therapists, and the setting of community practice.

Chapter 3 describes the current project, and outlines the methodology and methods used. The results described in Chapter 4 complete the project side of the work. More specifically, Section 4.2 outlines the findings from pre-participation questionnaire which was completed by participants before using the Values Exchange to deliberate on

the case. In Section 4.3, the results from the reports which were generated by the Values Exchange are reviewed and discussed, and in Section 4.4, findings from the post-participation questionnaires which had been completed by the participants after using the Values Exchange are presented. A summary of the results and analysis of the project is presented in Section 4.5.

Chapter 5, according to Levin's model (2005) summarises the dissertation; discussion, analysis and synthesis between findings from the study and pre-existing ideas and knowledge which were described in described in the Chapter 2, in keeping with the expectations of qualitative inquiry (Shank 2006). Finally, in Chapter 6, conclusions are drawn from those patterns of meaning and recommendations for future work are discussed.

Chapter 2: Background

Chapter 2 provides background to the study. In section 2.1, the three statements from David Seedhouse which were introduced in Chapter 1 are used to explore the concepts of morals (Section 2.1.1), ethics (Section 2.1.2) and values (Section 2.1.3). Decision-making in health care, and tools to assist decision making are discussed in Section 2.2, and the background section concludes in Section 2.3, by looking at particular issues for occupational therapists relating to the topics under discussion.

2.1 Exploring of Seedhouse's statements on moral, ethics and values

Section 2.1 discusses the three concepts of moral work, ethics and values, each using a quote from David Seedhouse to frame the discussion.

2.1.1 Exploring: "Work for health is a moral endeavour" (Seedhouse, 1998, p. x111).

This section will review this statement and ask: what does moral mean, is health work moral work, do health professionals' codes require it and is moral work visible?

Defining moral

The search for a definition of moral has been underpinning the work of philosophers for centuries, with Socrates, for example, defining it as how one ought to live (Rachels, 1995). Philosophy definitions are wide ranging and complex, and analysis is beyond the scope of this work. Modern examples which support the approach I am taking include Bunge (2003) who considers the term is to do with the harm or benefit of an action, or one's responsibility to the welfare of others. Similarly Austin, Lemermeyer, Goldberg, Bermum & Johnson (2005) agree that whether or not work has moral content is related to the degree to which it can affect others. These views offer a basis for the understanding that health work is moral work, given its affect on others.

In the health literature, definitions of moral vary greatly. An example from Fry and Johnstone (2001) links moral with goals and rules which is argued differently by

Purtillo (1993), who broadly defines morals as conforming with perceived standards of right and wrong. I have included a dictionary definition from dictionary.com (2007): "moral action is based on the principle of right conduct rather than on legislation or custom". Based on the review and analysis of the literature, including the works listed above, I am defining moral as that which we believe to be right and good and has the capacity to affect others for good or harm.

Is health work moral work?

Many other writers make assertions similar to that of Seedhouse, that health work is moral work, because health work has the capacity to affect others for good or harm. For example, Austin et al (2005) and Fletcher (1964) refer to health professionals being engaged daily in decision making that has moral content because the aim of that decision making is to bring about the good. Campbell et al. (2002) suggest that morality in healthcare has to do with attitudes, behaviour and relations to others and the daily decisions that are made. Wright (1987) contends that in health care, workers do the best they can to promote the well being of the person receiving care, and it is therefore moral work.

So given the assumption that all health work has the capacity to affect those seeking it for good or ill, and in particular to assist them to achieve as much autonomy as possible, (Seedhouse, 1998) then yes, it can be argued that health work is moral work. Whether or not the work of an individual practitioner is aiming for the right and the good, every person in a healthcare organization has the capacity to affect a person seeking services in some way. This can be said to apply to the admitting clerk, the person writing policy, to the neurosurgeon and to an occupational therapist working in a community setting.

There are many other areas of work that can be similarly described as moral enterprises, (because their purpose is to bring about the good, or because workers have the capacity to affect others) but it may often be the case that people's health needs mean they are likely to be presenting to our services with a degree of vulnerability, or at least susceptibility, beyond what they might usually experience. Therefore, they may be more open to being affected by the actions of others than may be the case in other

Ethics of the Everyday

situations; therefore, this is more of a reason to be considering health work to be moral work.

Possibly, although not explored here, it is because health is a moral endeavour (that is to say, provides an opportunity for a health worker to "work for good") that people are attracted to work in health in the first place. There are other reasons for choosing to work in health such as security of income, but those working in health are likely to say that the paradigm of care should prevail and should be the basis for what individual health workers are trying to do for each person – work for the good. The more the work is intended to bring about the good, or release as much human potential or flourishing as possible in the circumstances (Seedhouse 2005b), the more it can be considered moral work.

Do health professionals' codes require moral work?

Having discussed above that health work is moral work, it should then follow that all health workers should work in a moral way. However, a further question is whether health care bodies' codes of conduct include moral work as a requirement? The codes of conduct of the professional bodies are generally referred to as Codes of Ethics. In the next section (Chapter 2.1.2), I will be making a distinction between the terms ethics and morals, but for now will say that they should indeed, more logically, be called moral codes, as they generally are a description of moral standards; what the profession considers to be right or wrong. However, codes do not appear to portray a sense of what it means to be truly moral in the sense of the relationship and "affect on other". Codes do attempt to set standards of behaviour, presumably because of how that behaviour may affect others, (Edge and Groves, 2005) and therefore it can be argued that they have moral intent, although, as an example, the term "moral" is not used in either the Occupational Therapy Board of New Zealand's (OTBNZ) "Competencies for Registration" (2007), nor its "Code of Ethics" (2004), to which the first document refers.

Is moral work visible?

To explore the issue of whether health professionals work in a moral way, it is necessary to take into account the context of time. How healthcare as moral work is understood by people working in health changes over time. For example, a health

professional giving service in a technically excellent way but unfocused on the needs of the particular person receiving the service, might have twenty years ago considered themselves, and have been viewed by others, as behaving in a morally sound way, because they considered they were doing the best thing for the client. Today it is viewed that centering that work and its impact on the person who is affected, rather than only on the skill of the practitioner, is logical and necessary, and I would argue, moral. Technical excellence alone is not a sufficient delineator of competence to practice competently in healthcare (Peloquin, 1994; Van Amburg, 1997). The notion of professional competence should be inclusive of a complex cluster of knowledge, skills and attitudes in relation to working with people and families in context (Wright-St.Clair, 2001).

To be a truly competent health worker one must not only have the technical skill which one is claiming through ones training and discipline body but also be competent in understanding and evaluating the impact one is having on the client one is working with (Wright St. Clair, 2001). These should not be seen as separate requirements but part of overall competence to practice (Seedhouse & Lovett, 1992).

Health professionals are more likely to achieve evidence of moral practice if the theory of health that underpins their work requires it, for example the Foundations Theory of Health (Seedhouse 2001). This theory can be summarised by the following statement: "work for health is a moral endeavour because work for health can release more or less human potential" (Seedhouse, 2001 p 45).

2.1.2 Exploring: "Ethics should be part of every health encounter" (Seedhouse 1998, p. 36)

Having argued in section 2.1.1 that health work is moral work, this section addresses the everyday nature of ethics as background to this study:

Ethics of the Everyday

What does ethics mean and how is the term distinct from "moral"?

Some writers use the terms ethical and moral interchangeably, for example, Foye et al (2002), Butler (2004), Seedhouse (1998), Bandman (2003), Rachels (1995), and Wells (2005), and their arguments can be philosophically complex. However, I consider it useful for practical reasons to make a distinction between the two terms (while acknowledging it is a difficult one to make). The reason for making the distinction is because I consider that if there was clarity about the meanings of the two terms separately, this would lead to clearer ideas of the importance of each separately. For example, it could be clearer what should be expected from resources such as those entitled "Codes of Ethics". In Section 2.1.1, I described the definition of moral that I am working with, which is, what is believed to be right and good, and that moral work is work that has the capacity to affect someone else.

Based on a review of the literature, I am defining ethics as the analysis of, or reflection on, that "rightness", "goodness", and "affect-on-other". Weston (2001) argues that the distinction is between moral as moral values we happen to hold and understand to be right and good, and ethics, as the deliberate process of thinking them through.
Hope (2005) argues similarly by defining ethics as "working out the right action to take through reasoning" (p14).
Many other theorists hold similar views distinguishing the between the terms morals and ethics (e.g., Bunge, 2003; Edge & Groves, 2005; Hugman, 2005; Wells, 2005). Other writers agree that the terms moral and ethical should not be used interchangeably, however, some do not have arguments that I support. For example, Van Hooft et al. (1995) claim that the distinction is between ethics as dealing with matters of a professional nature and moral as being to do with every day life. This statement reinforces the idea of ethics being something special that sits outside everyday practice, and is contrary to the essence of what I am arguing.

What are health ethics?

Next, I will explore the definition of ethics in the health context. Although health ethics have been central to medical care for at least 2500 years (English & Somerville, 2004), up until the middle of the 20th century, clinical focus was the overriding medical concern and paternalism reigned. There was a turning point after the World War II and explanations suggest that a mixture of abhorrence at the war atrocities, changing social

attitudes with less deference to authority, other values-based contributing factors such as the rights movements, and increasing understandings of the concept of informed consent (Kuczewski, 1996) all contributed to the development of what was to become known primarily as bio- ethics, which along with medical ethics, is a term which pre-dominates in the health literature. Other terms, however, are used. These include analytical ethics (English & Somerville, 2004); professional ethics (Cribb & Duncan, 2002); and healthcare ethics (Fulford et al., 2002).

Having a variety of ways of categorising ethics in health contributes to the fact that like so many other terms used in healthcare, it is one which is assumed to have a commonly accepted meaning but is understood differently by different people. For instance, when a person is said to be practicing ethically, it could be meaning one of three things. First, ethical practice could mean that a healthcare worker is practising to general (but usually undefined) moral standards. Second, it could mean that they are practicing to the specific norms and standards of their professional body. Finally, it could mean, (and I am arguing here that it should mean), that the person is using skills and knowledge of deliberation to show that they being moral agents. Is this a generally accepted way the term is viewed? If so, one would expect that a practitioner's profession have the requirement to be using skills of ethical deliberation as one of their standards, but most do not.

However, the Code of Ethics of the OTBNZ (2004), does spell out that the code is intended to reflect the first and second options described above (general and profession-specific standards of behaviour), although they do not use the term "moral'. The term "ethics" is not defined, but the code does include a statement saying that occupational therapists are expected to use a process of ethical reasoning, which covers the third option discussed above. That is, they are expected to be using skills of deliberation to show that they are being moral agents. Codes and their role in assisting ethical decision making will be discussed further in Chapter 2.3.

Ethics of the Everyday

Are ethics part of every health encounter?

If one were to base one's ideas of what constitutes ethics in health today on the cases that gain public attention via the headlines, one could be forgiven for thinking it is all about the bizarre or the extraordinary, or at the very least, life-and-death situations (Hope, 2004). While it is appropriate that these are given attention, the media pick up on the more sensational aspects of these cases and have contributed somewhat to extending the myth in health care that health care ethics are for the extreme cases as well as creating unrealistic ideas of what actually happens in health situations of this kind. For example, one study found 67% of televised events relating to cardio-pulmonary resuscitation led to successful outcomes compared with 6.5-15% reported in the medical literature (Diem et al., 1996),. So if, as argued in Chapter 2.1.1, all health work has moral content, it follows that all health work will require some sort of analysis, reflection, study or understanding of its moral nature, and this is what ethics is. Ethics cannot be separated from health practice (Foye et al., 2004; Hugman 2004, Seedhouse, 1998, Weston, 2001).

However, I argue that ethics as a term and as a process of deliberation is perceived as separated from everyday health practice. This view is based on experience of working in health settings, and from review of the health literature. Although health literature has volumes written about ethics, it does not necessarily follow that ethics are widely discussed and practiced in everyday healthcare practice.

I consider there are three main reasons why ethics are not currently viewed as part of every health encounter by all health disciplines. First, for pragmatic reasons such as time, health professional cannot do analysis on everything, which is why practice guidelines have been developed. In many situations, these will provide the necessary framework to be able to do well what is needed and show reflection on what we are doing (although even in these circumstances, we need to individually decide how to behave). Often deciding is in the moment, engaged with the client, not disengaged and viewing objectively from a distance (Gilligan, 1990).

Second, and I consider this both a cause and an effect of ethics not being seen as part of everyday work, ethics have come to be seen as something of a specialty (Seedhouse, 1998); something for which we need to call in the experts. This would be appropriate if

the purpose of these consultants was to guide decision making processes, but in some quarters people in ethics consultancy roles can be regarded as experts in value judgements. Seedhouse (1998) argues that once this idea sets in, it moves the concept out of the ordinary, by definition.

Third, the irresistible push for evidence based medicine, alternatively called evidence based practice or decision making, in health care has encompassed health ethics as it has most other aspects of healthcare. This has led to the hiding of values in our ethical decision making in an effort to be seen to be meeting the "gold standard" of evidence. In doing this we miss the point that it is values (values conflicts and values divergence) that are the r'aison d'etre for ethics (Fulford, 1996) and which sit under good decision making. I will also argue in chapter 2.2 that in addition we miss the point that the originators of evidence based decision making did not intend to exclude views other than research evidence from their definition of evidence based practice.

So I am arguing that health is a moral context, that ethics is the analysis of the moral, and that they should be seen as part of everyday work and not as a specialty, as appears to be the case now. Fulford et al. (2002) address the issue succinctly in their model of "healthcare ethics" in which they describe a general, inclusive, values based approach instead of the "quasi-legal" fact-based approach which many others adopt. Table 2.1 below summarises the comparison of the differences in approaches to ethics in healthcare outlined by Fulford et al. (italicised comment is mine).

Table 2.1: Comparison of the Healthcare Ethics model with that of "Quasi-legal ethics" (adapted from Fulford et al., 2002).

	"QUASI-LEGAL ETHICS" (Fact based medical model)	**"HEALTHCARE ETHICS"** (Fact plus values based healthcare model)
Aims	**Regulation** **Advocacy of particular values** *(Evidenced by application or theory, principles etc)*	**Partnership** **Respect for diversity of values** *(Comfort with ambiguity but also need the capacity to have the differences visible)*
Scope of application	**Treatment** *(Ethical challenges are associated with significant medical treatment decisions)*	**Whole clinical encounter** *(All work for health is ethical work and issues can be challenging or require the process of deliberation at any stage of the clinical encounter)*
	Secondary care *(As above, it is often perceived that hospitals have the greatest need for ethical decision making)*	**Primary as well as secondary care** *(Primary health decisions can be more ethically complex because the work is more value laden)*
Ethical reasoning	**Substantive ethical theory** *(Knowledge of ethical theory required)*	**Analytic ethical theory** *(Deliberative skills as well as knowledge of ethical theory required)*
Conceptual model of medicine	**Medical-scientific model (fact-based)**	**Healthcare model (fact + value-based)**
Practical applications	**Ethical rules** *(Ethical reasoning is used to decide " what is right" - This is fine if values are shared, but it is often used as a means of resolving differences)*	**Ethical process** *(Ethical reasoning is used to explore differences and work out a defendable strategy)*
Communication skills	**Communication skills executive** *(A way of communicating decisions)*	**Communication skills substantive** *(Fundamental to the deliberative process)*

There is a richness of information contained in this model which supports the argument

I am making, that because health work is moral work and ethics are the analysis of the

moral, ethics should be part of every health encounter. It gives some explanation for the reasons behind the existence of the more fact based approach to ethics in health, and summarises the role values play, which I will now discuss further.

2.1.3 Exploring: "Ethical analysis is thinking about human problems using both evidence and values explicitly" (Seedhouse 2005a).

The statement above from Seedhouse is not echoed in the health, ethics, or philosophy literature to the same extent as the previous two quotes, but there is a growing body of theorists who support this claim such as Fulford et al. (2002), but also others (e.g., Hester, 2001; Kuczewski, 1996). In Section 2.1.2, I suggested that part of the reason that ethics are not currently seen as being part of every health encounter is because values in health are somewhat hidden in the push for evidence. I used the model developed by Fulford et al. (2002) to introduce the place values should hold in health ethics. In section 2.1.3, I will explore values further, along with values based decision making and its relationship to client centered care and comparison with evidence. I will start by looking at the current situation which emphasizes evidence. I will go on to ask: what is evidence, what are values, using values as well as evidence, and what is values based decision making?

What is evidence?

For the purposes of this work, I am using the term evidence based decision making although much of the literature uses the terms evidence based medicine or evidence based practice. There is no shortage of health literature about evidence. Since publication of articles on the subject in the early 1990's (e.g. Guyett 1991) there has been an increasing call driven initially by medicine but picked up by most disciplines for healthcare practice to be evidence based (Cody, 2006).

What does the term evidence based decision making mean? It is another example of a term used in health which, although while widely used is not understood, and there is considerable discussion in the literature over the extent of its meaning. A predominant view is that it means decision making that is informed by scientific research.
Later papers on the subject (Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996) emphasised that the role of research evidence was to assist the clinician to evaluate

Ethics of the Everyday

personal experience and external evidence in the best way. Nonetheless, large numbers of health professionals have taken hold of both the term and its implied de-valuing of the subjective. However, theorists who were involved in the early publications on evidence based medicine, assert that the original goal of the evidence-based "movement" was to add rigour to the objective rather than exclude the subjective (Haynes, Deveaux & Guyatt et al., 2002). They propose a broader understanding of evidence which includes other ways of knowing, including one's own experience, and the experience and values of the person receiving the healthcare. This view is captured in the model depicted in Figure 2.1 below.
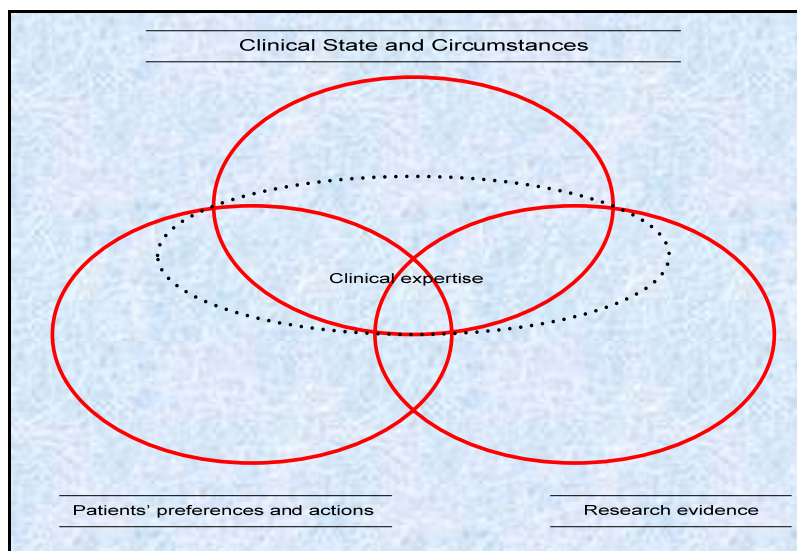
Figure 2.1: An updated model for evidence based clinical decision (Haynes et al., 2002).

Using this model, the decision maker uses much more than evidence from research and includes as evidence information from the situation for both the patient and the health professional, and what Haynes et al. (2002) refer to as their preferences, values or subjective experiences. DePoy and Gitlins (2005) view of evidence as being information to support a claim is a useful one to move from discussing evidence to values.

What are values?

Given that the concept of values is central to this current project, it is important to define them. However, this undertaking is not an easy one, with people generally, as well as theorists, finding it difficult to articulate an answer to the question (Woodbridge & Fulford, 2003). Although not restricted to health, it is another widely used term, with an elusive meaning. Rokeach (1979) alluded to the difficulty of defining values when he said "the term values has been used variously to refer to interests, pleasures, likes, preferences, duties, moral obligations, desires, wants, goals, needs, aversions and attractions, and many other kinds of selective orientation" (p.16). I will start with definitions in current use, agree to a definition myself, then later in the discussion section of this work, analyze whether that definition is adequate to assist us with this present inquiry.

Many writers talk about values and principles being overlapping ideas, for example, Cribb and Duncan (2005), state that often in the literature there is little or no difference in what is being talked about when the terms values or principles are being used. In the field of ethics this approach can be confusing, as the term principles itself is one that has assumed a centre stage role to the extent that people quote certain principles as if that means they understand ethics (Veatch, 1985).

Some writers use the term values liberally, without any definition , for example Itlis (2005), while others avoid attempting to define the term altogether by talking instead about examples of a value (e.g., courage), rather than what the term values itself means. For example, in English and Somerville (2004) core values for medical practitioners are listed as including competence, caring, commitment, integrity, compassion, responsibility, confidentiality, spirit of enquiry, and advocacy,

Although I am referencing the work of numerous writers as background to this study, I am primarily drawing on that of the following: Seedhouse (1998; 2005b), Fulford (1996; 2004), Fulford et al. (2002), Wright (1987), Haynes et al. (2002), and Weston (2001; 2002). After much analysis, all of these writers come to the understanding of values as preferences. This is echoed by others for example Kane and Caplan (1993) and Monagle and Thomasma (1998).

Ethics of the Everyday

Rokeach (1979) writes that values fundamentally involve having criteria or standards of preference.

I will therefore use values as preference as a working definition, but in the discussion section of this work (Chapter 5) will consider the term further, and its applicability in the practical context of this study.

Using values as well as (or as) evidence

Having considered the point above that values should be an equal partner in health decision making why is their role not more visible? First, although values were at the centre of the reaction against the modernist push for science-based facts, which produced both bio-ethics and the patient centred movement, that same push remains, as does the risk for undermining the role of values (Hester, 2001). A way that reinforces both the emphasis on the evidence and the underplaying of values is seen in the tendency to use the idea of a "quasi-legal" approach to ethics, to find moral "facts" to assist with decision making (Fulford et al., 2002).

A second reason for values not seeming to be at least an equal partner in decision making is that they are often not visible, being implicit if they are shared. It is often when different values are operative in a given context that they are become visible (Hare, 1952). Decision-making is less likely to be ethically challenging if there is congruence of values, though this does not necessarily mean that there is no ethical question to be answered.

Although we tend to avoid the conflictual, it is the diversity of values that makes them visible, and leads to the heart of ethically challenging situations. We need an approach to values that takes into account the existence of this diversity, rather than insists on values conformity. This can only be achieved if values are visible.

A third reason for invisibility of values could be that they are seen to be competing with evidence. Arguing for the need for values to be made visible is not at all to be suggesting that healthcare decision making should ignore evidence. Some situations call for more of one kind of evidence than others, and writers such as Culpepper and Gilbert (1999) discuss the corresponding diminishment of the role of values as the care advances through secondary to tertiary health settings. Values and evidence need to be

seen as complimentary, both being essential for good healthcare decision making. Some aspects of practice may at first glance appear substantially factual, such as diagnoses, research and national or local policy documents, but if they have an evaluative component they will contain more values than expected (Woodbridge & Fulford 2003, (Little, 1998).

Similarly, as Seedhouse explains in information on the Values Exchange website, good evaluators use as much evidence as they can. Woodbridge & Fulford (2003) add that values based decision making is not anti-fact, but requires particular skills where different (and therefore likely to be conflicting) values are in play. The benefit evidence brings us is that it shows what applies across many cases, the role of values is that they point us to what applies in *this* case: the particular values applying in *this* patients life, the particular impact of the health condition for *this* patient and the evaluative nature of the selection of evidence as facts in *this* case.

Values based decision making as a concept

This study uses the term values based decision making and therefore some discussion of the meaning of the term is necessary. As noted above, given both the current lack of a shared definition of evidence based decision making, and the uncertainty around the definition of values, care should be taken to not introduce the concept of values based decision making and expect everyone to know what it means.

Much of the existing literature on values based decision making refers to organisational decision making and tends to emphasise the values of the organisation (Mills & Spencer, 2005). The term is starting to be used in healthcare where here also the emphasis is on describing particular values (e.g., Itlis, 2005), although other writers are beginning to use it as a term alongside evidence based decision making (Teutsch,2005). Seedhouse (2005) presents extensive discussion on the term as it applies to the healthcare environment and decision-making.

Is the term values based decision making necessary? How does it relate to an existing term, client or patient centred? (once again, a term with a range of understandings). Do we already have a framework for understanding values-based decision making by

considering what client centred cares means? This will be discussed further in Chapter 2.3.

Fulford's earlier work (1996), includes a model depicted in Figure 2.2, which sets out to explain the essence of the difference between patient and professional centred care and outlines his view of the relationship between values and facts.
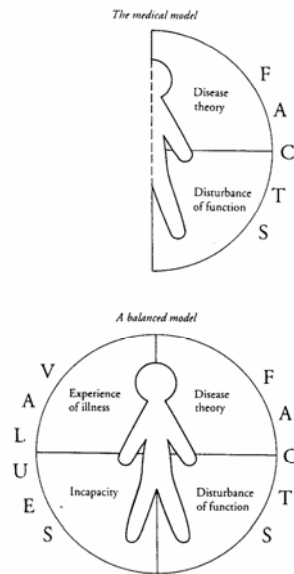
Figure 2.2: The definition of patient centred care (taken from Fulford, 1996).

This model effectively introduces the notion of the presence of values being the distinguisher of the concept of patient centred care and the importance of values in all clinical encounters. It also is helpful to see that while the physician may be the expert on the medical "facts" it is the patient who has insight into their private sphere of values (Kuczewski, 1996). I am using it as a model on which to base understandings of what is meant by values-based decision making, given that at the basis of both of the terms of client centred care and values based decision making is the notion of giving due regard to the subjective (Fulford, 2004).

Having discussed the centrality that values have in healthcare, and introduced the concept of values based decision making and its relationship to evidence, in section, 2.2, I will look at how health professionals make decisions and the tools that they use in assisting these decisions.

2.2 Decision making and tools to assist

In the preceding sections of Chapter 2, I have built a picture of morals, ethics, and values, to provide background to this study and to their role in healthcare decision making, a founding purpose of ethics (Weston 2001). In this Section, I will discuss decision making itself, along with describing some of the tools health professionals use to assist with the decision making process.

Most actions in healthcare involve a decision of some sort. A question central to decision making in health care is, of all the things that could be done with or for this person, what should be done?

It is not practical or necessary to require complex processes of analysis for all these situations, and health professionals have developed ways of streamlining activities using standard approaches, as discussed in Section 2.1.2. What is different about ethical decision making is that it is required when values or evidence or principles are conflicting. When there is uncertainty about which is the right course of action because of that conflict, there is an ethical problem. Often these problems are not distinct and well defined (Weston, 2002), but can present to the decision maker as vague areas of tension. The term ethical dilemma is used in a situation where not only is it not known what is the preferred course of action, but that both options presenting seem to have undesirable outcomes (Edge & Groves, 2005). Ethical problems or dilemmas require ethical decision making to which ethical analysis is central. Avoiding or postponing a decision may be a valid option. But typically the reason there is an ethical dilemma is that a decision has to be made.

What are the means of achieving a considered decision? Wright (1987) states that all problems need to be addressed by considering five categories (see Figure 2.3 below). To frame further exploration and discussion about decision making, I am using Wright's model of decision categories, and I will discuss these categories in turn.

Ethics of the Everyday
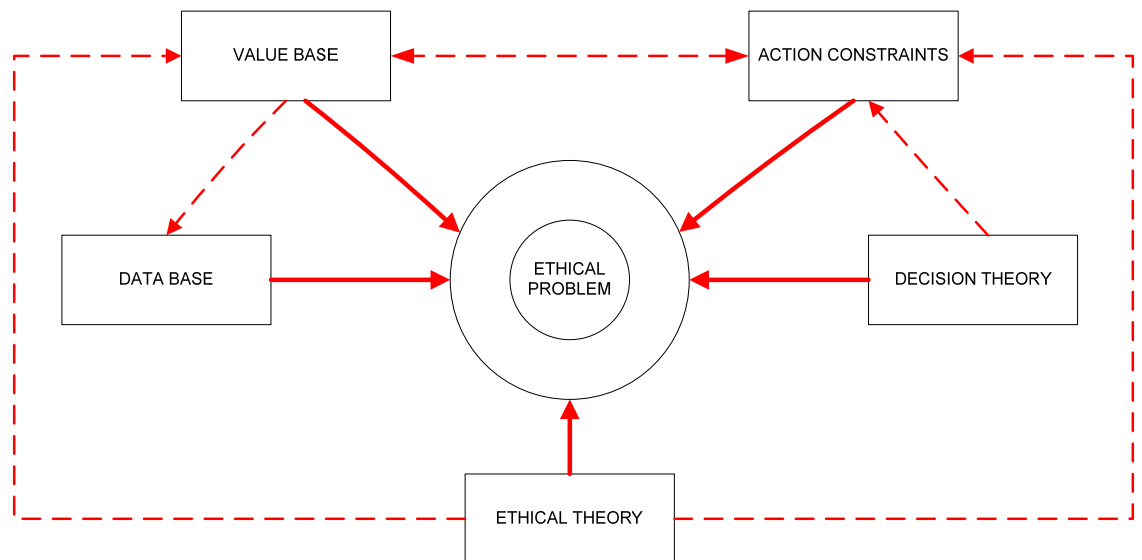
Figure 2.3: Categories of decision information (Wright, 1987).

The model describes aspects and components of decision-making, and the relationship of the components to each other. In so doing, Wright emphasises points covered in Section 2.1.3, of the centrality of values as well as evidence to the decision making process and the relationship between the two (evidence being depicted in this model as "data"). Significantly, he considers values to be part of the data (or evidence), but regards them as important enough and complex enough to have their own category in this model. Wright considers data gathering as crucial to both adequate identification of the problem, and to developing options for resolution. In addition, while ethical decisions are not factual decisions, they cannot be made without a solid basis in factual evidence, and values frame the problem, supply alternatives and direct judgement.

Having already covered discussion of evidence and values in the preceding section 2.1.3, I will now discuss the remaining categories from his model: action constraints, ethical theory, and decision theory. In addition, I want to discuss codes of conduct as a separate category, because I am interested in the role they play in decision making and because there may be a case to argue for their inclusion in any or all of the above three categories.

Action constraints

By action constraints, Wright (1987) means that health workers cannot always do what they want to do, and requirements of their society, their organisation, or their own

situation may impose restrictions on the options that are open to a decision maker in health. These constraints impose a barrier to the response that a health professional wishes to make, can lead to a phenomenon described by Austin et al. (2005) as moral distress, and can create the moral problem, or magnify an existing one.

Examples of constraints imposed by society are laws of the organisation, specific regulations to be followed, or lack of resources, skills or available time. In addition, as shown by the model above, values can contribute to action constraints.

Ethical Theory

Ethical theories are a further key category of decision making according to Wright (1987), and the subject of much controversy as to the extent of their usefulness. These theories assist decision making by giving a framework from which to begin moral reasoning (Weston,2002) but although ethical theories are widely taught to healthcare students, they do not necessarily help practitioners to solve ethical problems in practice (Allmark, 2005).

Ethical theories have been grouped in many ways by different theorists (Campbell et al, 2002), but according to Seedhouse (1998) the major division is between consequentialism and deontology. I will include in this background exploration a brief explanation of these two major theory groups, along with additional comment on virtue ethics, as well as on rights-based approaches (because of their predominance in the current health context in New Zealand today). In Chapter 5, the discussion section of this work I will consider if the use of theories contributed to the deliberations compiled by participants in my study.

Consequentialists argue that an act is right if it produces consequences at least as good as the consequences of any alternative act. Alternatively, deontologists (from the Greek *deon* meaning duty), deny that results alone are the basis for judging the rightness of acts, and argue that factors such as individual rights and codes of practice must be taken into account in the moral assessment of acts (Kenyon, 1999). Deontologists consider certain actions are right and good in themselves regardless of consequences (Austin et al, 2001).

Ethics of the Everyday

Rights-based theory, although often considered under deontology, has a complex relationship with duties (Wright, 1987), and is worth mentioning separately because of the emphasis in New Zealand of the Code of Rights for people receiving health and disability sector services (Health and Disability Commission, 1996).

Virtue ethics is another ethical theory which stems from Aristotle's writings on virtues, and has received some attention in the health literature (e.g., Fry & Johnstone, 2002). Virtue ethics focus on the character traits of the decision maker, such traits considered to be stemming from the motivation to do what is right and good, and do not require reliance on rules, codes or principles (Turner, 2003).

Principles of ethics stem from ethical theories and are widely discussed in the health literature. In spite of disagreement as to their usefulness, most health ethics theorists argue that principles should be fundamental at least as guides (Thomasma, 1984), but it is an area of considerable controversy not least of which is agreeing which principles should be the ones considered to be at the heart of health ethics.

The "four principles approach" of Beauchamp and Childress (1989), seems from my experience to be often quoted in health practice situations in response to the question: "what are health ethics" as if they are set in concrete, and this is also reflected in the health literature. Little (1998) attributes this to a drift from principles into precepts and suggests that if people can quote the four principles like a mantra they "know ethics and can stay out of trouble" (p. 70). For example, under a heading of "the four ethical principles" (p.245) in one publication (Atwai & Caldwell, 2003) the authors list the four principles which Beauchamp and Childress (1989) propose, as if they were the definitive list of ethical principles to be addressed in health ethics (respect for autonomy, non-maleficence, beneficence and justice). However, as they stand principles are too blunt an instrument to be useful in a particular case (Cribb & Duncan, 2002) and other ethical principles could equally be proposed. In fact, other writers have proposed different things. For example, Edge and Grove (2005) add role fidelity, veracity and confidentiality to the usual list of four. In any case, to assist with decision making in a dilemma, which principles should one choose? Indeed it is often bearing principles in mind and trying to balance the tension between them that creates the

dilemma. Therefore, whilst useful to define the dilemma, principles cannot be relied upon to solve it.

Thus, whilst neither theories nor principles can solve a problem (Weston, 2002), they can frame a response and enable the decision maker to understand the position the case is being argued from (both one's own position and that of others). Additional guidelines or tools for applying these theories or principles to practice are, however, needed (Thomasma, 1984).

Decision Theory

In this section I will discuss the use of tools such as decision trees and algorithms which health professionals use to assist them in a practical sense and find a way into a problem which theories and principles cannot provide (Parker & Dickenson, 2001).

Numerous writers in the field of health ethics propose a tool or structure that, although based on theories and or principles, can go further by assisting the user to gain hold of a problem and begin to deliberate it, thus combining elements of both practical and philosophical approaches (English & Somerville, 2004).
Many writers point out limitations of such tools, for example, Allmark (2005), but their strength is that they can provide sensitivity to a particular situation rather than the "holding sway" of principles which are intended to be helpful in a general way (Hester, 2001). Generally tools outline a step by step approach and Table 2.2 summarises key components of some described in the health literature.

Table 2.2: Key components of tools for ethical analysis

Author	Name of tool	Key components
Thomasma (1984)	Contextual grid	Establishing the degree of values and rights present in a case (individual to community; primary to tertiary)
Van Hooft et al.(1995)	10 step Decision making strategy	Define the problem; gather information; identify constraints; generate possible solutions; identify criteria for judging best solution; evaluate possible solutions according to criteria; implement solution; check /modify.
Jonsen et al. (1998)	Case analysis	Four areas to consider: medical indications; patient preferences; quality of life; contextual features
Purtillo (1999)	Six step approach	Data gathering; problem identification; problem analysis using theory & principles; exploration of practical options; selecting a course of action; evaluation of the process and outcome
Weston (2001)	What is the goal of analysis?	Check if the goal is to: explore an issue; to get unstuck; to make a case; to decide for yourself.
Corey et al. (2003)	Seven step process	Recognizing a problem; defining a problem; developing solutions; choosing a solution; reviewing the process with the client and choosing; implementing and evaluating with the client; continuing reflection
Swisher et al. (2005)	RIPS model use Realm, Individual, Process-Situation at each step	Recognise and define the ethical issue; reflect on facts, stakeholders, consequences, relevant laws and duties, professional guidance, "right vs. wrong test"; Decide the right thing to do
Ethics Resource Centre (2006)	Six Steps model (P.L.U.S.)	Define the problem; identify available solutions; evaluate the alternatives; make the decision; implement the decision; evaluate the decision. At each step check consistency with **P**olicies, **L**aw, **U**niversal principles or values of organisation, **S**elf – own standards of right, good, fair
The Center for Health Ethics and law (2006)	7 step process	What are the ethical questions? What are the clinically relevant facts? What are the values at stake? What could you do? (List options) What should you do? (Choose best) Can you justify your choice? How could this issue have been prevented?
Seedhouse (1998)	Ethical Grid Rings of perception	Consider: create autonomy; respect autonomy; respect persons equally; serve needs first; duties; outcomes; practical considerations

With numerous and various tools such as these recommended by their authors as being

useful to assist the process of ethical deliberation it is clear that there is no right way. A

criticism I have of some of these approaches is that they tend to look for solutions before values conflicts are identified.

The Ethical Grid developed by Seedhouse (1998) draws on health theory, ethical theory and pragmatic or practical considerations, and has at its heart Seedhouse's Foundations Theory of Health (2001), which in brief regards the fundamental purpose of health is to create as much autonomy as possible. The values transparency software (The Values Exchange) being used for this study has developed from this concept.

Codes of ethics/ conduct

Although the codes of conduct of the different professions could be considered under any of Wright's (1987) three categories discussed above, I want to explore them separately because of the emphasis they are given by health professions, (Veatch, 1985) and because I want to see, given that they are mostly termed codes of ethics, what practical bearing they could bring to ethical decision making. There is a potential for codes to be either ignored because they are too broad and vague (Edge & Groves, 2005), or regarded as law in that typically they are written in a way that implies they are binding (Seedhouse, 1998).

Because I am arguing that ethics is the analysis of the moral, and most of these codes do not address the need for the skills of ethical deliberation, my preference would be to refer to them as codes of conduct, although moral codes would also be a useful term. English and Somerville (2004) pick up on this need for distinction and attempt to explain it by highlighting two views of ethics, analytical and professional; analytical covering the definition of ethics in healthcare, which I am proposing, and professional, relating to standards of conduct. I argue that the codes would more usefully be called just that; standards of conduct, being explicit about what the discipline understands about morality as it relates to healthcare, and which refers separately, although most usefully in the same document, to an expectation of the skills of ethical analysis to help professionals achieve that morality.

I will be exploring in more detail in Chapter 2.3, the code of ethics used by occupational therapists in New Zealand, but first will discuss a similar document for another

Ethics of the Everyday

discipline with whom occupational therapists frequently work, and am choosing as an example the New Zealand Society of Physiotherapy's code (NZSP, 2003), entitled "Guidelines for the Code of Ethical Principles".

As a discussion point, the title alone begs analysis, and the words: guidelines, code, ethical and principles may well be understood differently by different physiotherapists, given the absence of definition. The code includes sections on principles, responsibilities to the patient, standards of care, rights of patients, responsibilities to the profession, research, advertising, endorsement and responsibilities to the community. Many of these are headed "responsibilities", so read like standards, rather than things to consider when making ethically challenging decisions.

Some of the statements are straightforward ones about expected behaviours such as record keeping, but other statements are less clear. For example number 56 from the code of ethical principles section: "Physiotherapists act in the best interests of their patients, and Section 2.1 of the guideline for the code: "Physiotherapists shall practice only in those areas in which they are competent". It is possible that there is another document which outlines how best interest should be interpreted for this professional group and what is meant by the term competent, but this is not stated in the code. These statements are similar to those from other professional codes and do not address the understanding of ethics that I have put forward so far, which is that ethics is the analysis of, and the reflection on the moral. There are some exceptions. For example, the Code of Ethics of the OTBNZ (2004), which I will discuss below, and the International Council of Nurses (2000), which includes a requirements that a nurse must apply their reasoning abilities and ethics knowledge to a patient care situation to determine what action ought to be taken. This indicates a clear expectation that the nurse is expected to practice ethically in the way I am using the term ethics.

In general, however, codes tend to describe or prescribe standards, rules of behaviour or principles to be adhered to as expected from someone of that discipline, but fail to deliver on their promise to promote or guide moral conduct and moral judgements in the professional context (Wright-St-Clair & Seedhouse, 2004). In addition, although codes imply specificity to a profession most are so general that the standards could apply across the board to various disciplines. This in my view is a good thing because acting

in a moral way and using skills of ethical analysis should be universal health aims, and suggests that one code for all health professionals would merit exploration. Berwick, Davidoff, Hiatt and Smith (1997) made an attempt to produce a universal code for health professionals, referred to in the health literature as the Tavistock Principles. However, once again the principles that they have outlined were so broad they may not offer much assistance in an ethical dilemma.

Turning to a review of the case professional group of occupational therapists, the revised Code of Ethics produced by the OTBNZ (2004) begins well by being explicit about the purpose of the code, which is to "inform and protect current and potential consumers of occupational therapy services, and to protect the integrity of the occupational therapy profession" (p.1). Whilst I think there would be a good opportunity here for some analysis of what is meant by some of the terms (integrity and profession), the code is clear that its purpose is: to give information to others and to occupational therapists about the standards of behaviour or conduct that they can expect (so, again, should perhaps be more appropriately titled code of conduct). The statement about protecting the integrity of the profession is very up-front as although Edge and Grove (2005) state in a critique of codes that this is indeed often a primary goal of them, it is not spelt out from the outset in this way, in other codes that I have reviewed.

The Code of Ethics of the (OTBNZ) (2004) is also unusual, but I consider positively so, in that it makes it clear from the outset that occupational therapists are expected to "use a process of ethical reasoning" (p. 1). The code instructs users to access an example from the website of the OTBNZ, which would be an excellent way to give therapists a good understanding of sound ethical reasoning intended to create as much autonomy for the person in question as possible, but in fact there is not an example there at the time of writing.

However, lack of example notwithstanding, this health professional code does make two things very clear:
- a)   its own limitations as to its ability to address ethical issues; and,
- b)   the expectations that users will use a process of ethical reasoning to address challenging ethical matters.

If all health work is moral work, and ethics are about that analysis of that morality, it should then follow that knowledge in how to practice ethically, should be a requirement for all health professionals and not just specialist experts, as has become the trend (Butler, 2004).

Thus, all health workers should be equipped with the theoretical knowledge and the practical tools to incorporate ethical practice or decision making into their daily work, in the same way and at the same time that they use theory and tools to inform their clinical work, and their professional codes could reasonably be expected to describe or advise on those tools.

2.3 Occupational Therapy, contextual factors to consider for this study

The preceding discussion relates to heath professionals in general, and therefore, to complete the background section for this study, I include some exploration into relevant contextual factors relating to occupational therapists, the group selected for this study. This exploration starts with a brief overall description and definition of occupational therapy then will follow the outline I have used for the background discussion and review of the literature, through the sections which have been covered in general terms in Chapter 2. The topics then, for this section, will be: occupational therapy; moral work; ethics; evidence; values and decision making, (all as they relate to occupational therapy). Before concluding this chapter I will introduce some discussion on specific issues relating to working in a community, as distinct from working in a hospital setting, as the scenario to be debated using the Values Exchange was to be situated in the community.

Occupational Therapy

According to the website of the OTBNZ (2007), "Occupational therapists are registered health professionals, who use processes of enabling occupation to optimise human activity and participation in all life domains across the lifespan, and thus promote the health and well-being of individuals, groups, and communities". These life domains include: learning and applying knowledge; general tasks and demands; communication; mobility; self-care; domestic life; interpersonal interaction and relationships; major life

areas; and community, social and civic life. Enabling occupation incorporates the application of knowledge, principles, methods and procedures related to understanding, predicting, ameliorating, or influencing peoples' participation in occupations within these life domains. Such practice is to be evidence-based, undertaken in accordance with the OTBNZ's prescribed Competencies and Code of Ethics and within the individual therapist's area and level of expertise (this Board's definition of evidence follows on p. 44).

The epistemology of occupational therapy differs from medicine which was founded in the physical sciences, whereas occupational therapy was founded on humanistic values (Yerxa, 1991). Since the 1980s a paradigm of client centred care has been very evident in the occupational therapy literature (Russell, Fitzgerald, Williamson, Manor & Whybrow, 2002). The research base which informs occupational therapy is increasingly acknowledging the validity of naturalist inquiry as congruent with the need to understand outcomes from the perspective of the person receiving a service however, while qualitative research holds the potential to be client centred it is not necessarily so (Hammell, 2001).

There are various theories underpinning occupational therapy, such as the importance to health of human engagement in significant occupations (Wright-St.Clair & Seedhouse, 2004), and that of client/patient/person centred care (Sumison, 2000) both of which are reflected in the definitions given above and from which various models have been developed, for example The Canadian Model of Occupational Performance Measure (Law et.al.,1998) and The Model of Human Occupation (Kielhofner & Burke, 1980.

Is there a theory of health to which occupational therapists subscribe and that reflects this centrality of the person? The literature does not point to a consistent view of an overarching theory of health subscribed to be the profession as a whole, but Yerxa (1991) states that occupational therapists do not consider health to mean the absence of disease or disability, but rather the capacity to participate in life through occupation. This is consistent with Creek's (2003) view of occupational therapy as being concerned with the meaning and purpose that people place on occupations and activities and with the impact of illness, disability, social deprivation or economic deprivation on their ability to carry out those occupations and activities. There is support in the

Ethics of the Everyday

occupational therapy literature, for example, Imms (2006) for the World Health Organisations' International Classification of Functioning Disability and Health (Imms, 2006). Whilst not a theory, and whilst it has limitations (Christiansen & Lou, 2001), it is a model which attempts to measure not just the impairment component of a health or disability issue for a person, but also what the person can do, how this affects their capacity to participate in their preferred aspects of life, and takes into account contextual factors relevant to them.

A framework used in some health settings, whilst not specific to or grounded in occupational therapy practice is Care Aims (Malcomess, 2001, 2005). It is not described by the author as a theory, but it draws on participatory values-based models of care and can support a client centred agenda by asking not "what is wrong?", but "what do you need?"; and not "this is what I can do", but "how can I help?" As a concept this is very congruent with the Foundations Theory of Health (Seedhouse, 1998), which Wright St Clair and Seedhouse (2004) suggest could well provide a framework to inform and guide moral practice for occupational therapists. The Foundations Theory has at its heart the goal of creating as much autonomy as possible with a view to achieving more human flourishing, and is congruent with occupational therapy epistemological underpinnings, stated philosophies, and theories and models of practice stated above.

Occupational therapy as moral work

A way in which moral work can be described in the current environment is by being client centred. Many disciplines appear from their literature to describe themselves as leading the way with being client centred, and occupational therapy is no exception. For example, Yerxa (2001) argues that where comparisons with medicine are drawn, the clear intent is to demonstrate that occupational therapy's epistemological underpinnings position the discipline to be more client centred than others, or at least more than medicine. Since the 1980s there has been discussion in the occupational therapy literature suggesting that client centred care is or should be underpinning the profession (Duggan, 2005; Hammell 2001; Hasslekus, 1991; Lane, 2000).

Whatever version of the term client, patient, person or family centred care is used, and they are being challenged by other terms such as *relationship* centred care (Kyler, 2005)

the notion of person centred care speaks to a universal standard of substantive inclusion of the person in decision making, and emphasises the health professional as an agent of that person, assisting them to be as autonomous as possible.

Sumison (2000) provides a definition of client centred care for occupational therapists: "a partnership between the client and the therapists that empowers the client to engage in functional performance and fulfil his or her occupational roles in a variety of environments. The client participates actively in negotiating goals which are given priority and are at the centre of the assessment, intervention and evaluation. Throughout the process the therapist listens to and respects the client's values, adapts interventions to meet the client's needs and enables the client to make informed decisions" (p. 308). I have retained this quote as a reference point in the interests of shared understanding as although client centred care terminology is widely used in the health literature with various definitions. Sumison's appears in much of the occupational therapy literature.

Although working in a truly client centred way, as defined above by Sumison (2000) could contribute to truly moral work, there is no mention of moral work per se, or what it might mean to work in a moral way, in the description of competencies to practice produced by the OTBNZ, or that body's Code of Ethics. However, both these documents do give clear expectations that therapists should use the process of ethical reasoning, which I will now discuss further.

Ethics in Occupational Therapy

I argued in this chapter that ethics is the analysis of the moral, and while there is some discussion in the occupational therapy literature about ethics, the skills of analysis are not frequently discussed. So while there is some agreement in the literature for example, with the notion that ethics should be part of all health care (Early, 2001), there is not a lot of discussion as to how ethical analysis to inform moral practice is achieved.

As stated above the OTBNZ Code of Ethics (2004) specifies that occupational therapists engage in a process of ethical reasoning, but I have not been able to source examples or further references. There are many examples in the occupational therapy literature of

Ethics of the Everyday

the need to develop and show the skills of clinical reasoning, (e.g., Fondiller et al., 1990; Mitchell & Unsworth, 2005; Rogers, 1983; but much less on ethical reasoning (Hasslekus, 1991).

With regard to ethical theory which might underpin approaches to ethical reasoning, the occupational therapy literature reflects both deontological and utilitarian view points (discussed in Section 2.1.2) and principles are widely but inconsistently used, though there are numerous references to those proposed by Beauchamp and Childress (1998) (e.g. Atwai & Caldwell, 2003). Neither ethical theory nor ethical principles are mentioned in the Code of Ethics or competency requirements from the OTBNZ.

I have been discussing occupational therapy context regarding moral and ethical issues as background to decision making, and want now to explore how values- or evidence-based decision making are viewed by that discipline.

Evidence and Occupational Therapy

Occupational Therapists like other professionals in the 1990s were eager to respond to the call put forward by medicine to be evidence-based (Ilott, Taylor & Bolanos 2006).However, without the more recent broad definitions of what it means to be evidence based, it is argued by some that the profession may have turned during that period from its humanistic value base in an attempt to be seen as more scientific (Blair & Robertson, 2005; Duncan, 2006).

Expectations that the term evidence based practice or decision making include values are numerous in occupational therapy literature but also in regulation. The OTBNZ (2007) cites on its website that evidence based practice "utilises clients' knowledge of their occupational concerns and circumstances, insights drawn from experience and reflection, and critical appraisal of best available evidence drawn from research, experts and theory, to inform practice decisions".

Generally occupational therapy literature describes definitions of evidence based practice that demands that both client knowledge and the knowledge of the occupational therapist are used in decision making. These inclusive definitions reflect that proposed by Haynes et al. (2002) described in Section 2.1, and link with Hammell's work (2001)

using a five-step approach showing that evidence based practice can be congruent with client centred care and makes visible the values component of evidence.

Values and Occupational Therapy

There is considerable mention of values in the occupational therapy literature, much of it referring to what therapists value. For example, Yerxa (1991) declares that occupational therapists value the individual, human life and occupation, a somewhat sweeping statement and there is not the scope here to explore if it means anything, but one would expect that it would translate into having clients' values as central to occupational therapy.

Regarding the term values-based decision making, I have not found specific reference to it in the occupational therapy literature, but evidence of values-based approaches to theory is widespread (for example, in the definitions of client-centred care and evidence-based practice discussed above). However, Boutin-Lester and Gibson (2002), and Duggan (2005), describe the determination of clients' values to be far from standard practice, with the rhetorical theory of client centred care not being met in practice.

Fondiller, Roage, and Neuhaus (1990) in discussion on values use the term: "non quantifiable influences on performance" (p. 42), which if transposing decision-making for performance could usefully add to the discussion of meaning of the term values-based decision making.

Decision making in Occupational Therapy

Before discussing issues with particular impact for occupational therapists, Table 2.3 shows a summary of several studies from the international literature in which the researchers have identified key issues which therapists described as ethically challenging.

Table 2.3: Ethical issues identified in studies of occupational therapy practice.

Author	Main issues identified
Kyler (1998)	21% of therapists face dilemmas daily Resource restrictions that jeopardise patient care Inaccurate documentation Inadequate supervision Providing unnecessary treatment Colleague violating confidentiality
Barnitt (1993)	1.Ineffective treatment 2.Unethical/incompetent colleagues 3.Priorities in treatment 4.Causing pain and discomfort 5.Treating patients despite refusal 6.Misleading the patient 7.Confidentiality
Barnitt & Partridge (1997)	Client's wishes conflicting with therapist's judgement about their safety, or when therapist's judgements were questioned
Russell et al. (2002)	Mismatch between client and therapist goal (issues of safety, duty of care) "invoking the safety clause"
Foye et al. (2002)	1. Health care reimbursement issues 2. Conflicts re goal setting including client disagreement 3. Patient refusal (e.g., rehabilitation)

As shown in Table 2.3, many past studies have highlighted the tension between the goal or theory of client centred care and delivering it in practice. Another area of conflict is resourcing. In Section 2.2, I referred to Wright's (1987) model of decision categories, which included action constraints, factors which limit or complicate decision-making options. Such factors mentioned in the occupational therapy literature are frequently those connected with resources and there is evidence of considerable tension for therapists when clinical decisions need to factor in restrictions imposed by third party funders.

Constraints such as funding restrictions are a practice reality, and provide even more of an imperative for therapists to be equipped with skills of ethical reasoning in order to be able to make and defend the best possible decisions within those constraints, and with reference to a meaningful theory of health or practice. For example, the Foundations

Theory of Health (Seedhouse, 2001) aims to provide a guide to practice where a therapist would act to create as much autonomy as possible.

Given the need for the skills in the area, one might expect assistance to be coming from the occupational therapy registration body (OTBNZ). However, although the OTBNZ goes someway towards this by creating the clear expectation in both the Code of Ethics (2004) and the document outlining competencies for registration that therapists use skills of ethical reasoning, I could find no further reference to a recommended standard or process for such skills.

The context of community practice

To conclude the background section of this work, I will make general comments about ethical issues in community practice. For occupational therapists working in the community, ethical issues can be made more challenging because they may be working in isolation. In addition many theorists comment on the fact that contrary to widely held views, far from being less ethically challenging than hospital-based-care, community care should be considered more challenging. Fulford et al. (2002) argue that the further one gets from tertiary or secondary health care into primary care, the greater not less becomes the need for skills in ethical analysis, because there are more choices, more values in play and more potential for value diversity/ conflict. Similarly this is how Culpeper and Gilbert (1999) view the difference between specialist and generalist practice.

Finally, occupational therapists in the community are general practitioners and are thus working in a values-rich context, from three perspectives. Firstly from the perspective of the community as a setting, as argued by Fulford et al. (2002). Secondly from their generalist role with numerous decision options open to them as argued by Culpeper and Gilbert (1999). Finally, from the underpinnings of their profession of humanistic paradigms and client centred care, as discussed in this chapter.

Ethics of the Everyday

Chapter 3: Methodology

This chapter outlines the methodological approach of this study under the following headings: methodology, study design, context, and scope.

3.1 Methodology

This small study used a qualitative scientific methodology (Shank, 2006), so described because although it uses mixed methods to gather data to explore the subject matter, it is fundamentally naturalistic in its underpinnings. In approaching the inquiry in this way I selected the methodology to reflect the topic (values based decision making), the basic tenet of which is the explicit use of evidence and values. Having reference to both qualitative and quantitative approaches is congruent with that philosophy of complimentary ways of knowing (DePoy & Gitlin, 2005)

The primary aim of qualitative research is to explore, interpret and obtain a deeper understanding of a particular clinical issue (Greenhalgh & Taylor, 1987) and to provide an empirical search for meaning, the method must be systematic (Shank, 2006). The issue for which I sought a deeper understanding, and which I set out to address systematically in this study, was that of values-based decision making. In order to do that, the realms of moral practice, ethics and values in health were explored along with evidence and decision making, to provide background for studying the use of the values transparency software (the Values Exchange), with the aim of:

a)   exploring the role values plays in decision making with a view to generating "patterns of meaning" (Shank, 2006); and

b)   testing the assumption, that using the Values Exchange, as well as being useful to deliberate a specific case, enhances the user's understandings of ethical analysis.

3.2 Design including assumptions, sources, documentation

Study design

The design is best described as concurrent nested design (Cresswell, 2003; Hammell, 2004). A concurrent design explores not only what happens but why, and this is the demonstrated by both the reports produced by the Values Exchange, and the use of the pre- and post-participation questionnaires. Creswell (2003) describes the approach of concurrent nested strategy, which uses both qualitative and quantitative methods, but one is nested in the other. This study's overall methodology is qualitative but aspects of quantitative components have been included to assist with looking for trends or additional background information. The use of the Values Exchange was both a primary reason for the study, and also the primary method for gathering data. In addition questionnaires were also used to gain further perspectives from the participants. Themes discussed from the health and philosophy theorists provided context for discussion and synthesis.

Separate to the study methodology, as discussed in Chapter 1.3, the approach to the study as a whole used the model suggested by Levin (2005). This model makes a distinction between the project work, which includes the background review work, the data gathering, and the presenting of the results from that project work, while the dissertation itself, is the analysis, synthesis and developing patterns of meaning presented in the Discussion Chapter.

Table 3.1: Model showing project and dissertation components (Levin, 2005).

	Project	**Dissertation**
Focus	Subject/topic The phenomenon, situation, theory, event or what is being studied – for this study, the role of values in ethical decision making.	Title Ethics of the everyday: using values transparency software to enhance values-based decision making in health care.
Activity	Background; literature review; designing the study, enrolling participants	Analysis, synthesis and presentation of the work
Structure	The plan of work and time table	Chapter and section headings

Context of the study

There are a number of reasons behind the decision to include only occupational therapists in the study. First, which was outlined in Chapter 1, there was interest expressed by an occupational therapist who had been a participant in a previous project using the values transparency software. A second reason was that, as discussed in Chapter 2.1.2, I wanted to explore the view that ethics are part of *every* health care encounter (Seedhouse, 1998), rather than bought into play at the extreme ends of the healthcare spectrum where, for example, health and law intersect. Working with a group of community occupational therapists would give an opportunity to illustrate that point as their practice setting is not of the extreme life and death situation that is often conceptualised as ethical decision making in healthcare (Hare, 1963).

When designing the project, I was also interested in locating the situation for deliberation in the community, for reasons discussed in the previous section; that community practice involves decisions not necessarily affecting whether someone lives or dies, but how their life is affected.

Use of values-transparency software

There are many ways to begin deliberating an ethical issue, and numerous tools to do so. These are discussed in Chapter 2.3, but in summary, having used the Values Exchange in the previous project and having seen its potential to assist with ethical analysis, exploration of its use was the basis for this present inquiry. Although it is not primarily intended as a research tool, the previous project showed that using the Values Exchange to explore the values that are operating in a particular case can give an insight to a larger picture, such as factors to consider in policy or to highlight issues of values divergence or convergence which a process of values transparency brings to the light.

Sampling

The sampling method used was convenience sampling, one of four non-probability sampling methods used in qualitative and quantitative studies (DePoy & Gitlin, 2005). Convenience sampling is also known as volunteer sampling, and for this study, people who met the criteria (occupational therapists with experience of working in the community) were able to volunteer.

I had aimed for a minimum of 20 participants; however, I also predetermined that satisfactory numbers for participation would be between five and 30. I considered that a minimum of five participants would provide sufficient information to be able to uncover and interpret convergence or divergence of values in decision making. Although the Values Exchange itself could easily collate information from an unlimited number of participants, I had considered that 30 would be the maximum number appropriate to include for a small study of this nature, because of the time involved with each one on background work.

The final sample size of 15 was determined by the number of volunteers who not only enrolled with the study and registered to use the Values Exchange, but also completed the questionnaires and the analysis using the software. Fifteen participants provided sufficient data for reflection and analysis, and proved a manageable number to administrate.

Recruitment process

In May 2006 an announcement was placed of the upcoming project in the New Zealand Occupational Therapy Association's newsletter, calling for expressions of interest. I also met with three groups of local community occupational therapists to outline the project and invite interested people to contact me. These meetings were arranged by consulting with the occupational therapy professional leaders of two local district health boards and scheduled in regular meeting times for therapists. The meetings involved discussion with approximately 20 therapists.

In addition I made contact where possible with professional leaders of community and other occupational therapists in all of New Zealand's District Health Boards (n=21) by phone, and asked for them to forward the Participant Information Sheet outlining the project to therapists in their service (see Appendix A for the information sheet).

Therapists who expressed interest were sent the Participation Information Sheet if they had not already received a copy from their professional leader (see Appendix A). A consent form was also forwarded to the participant (see Appendix B), along with a pre-participation questionnaire (see Appendix C) and a return envelope. The consent form contained standard Auckland University of Technology requirements for agreement to participate and the questionnaire will be explained under data gathering. Consent forms and pre-participation questionnaires were sent to 32 therapists.

Data gathering

1. The Values Exchange

The main source of data and a primary reason for the study was the values-transparency software itself (the Values Exchange). The software guides participants through a process of analysis and records their selection of options, justifications, and verbatim comment supporting their position. This information is then re-produced in the form of verbatim reporting and figures, viewable only to other participants, the researcher and the site administrator. Examples of how this data are produced are shown in Chapter 4. Quantitative and qualitative data were also produced by the pre-participation and post-participation questionnaires. Figure 3.1 summarises the data sources.

SOURCES OF DATA

VALUES EXCHANGE
(Primary source and purpose of the study)

Pre-Participation Questionnaire

Post participation Questionnaire

Qualitative and quantitative reports showing values-based decision making with an ethical issue

Examples of ethically challenging situations

Understanding of aspects of ethics, pre and post use of the Values Exchange

Expectations of using the Values Exchange

Experience of using the Values Exchange

Additional Communication from participants

Figure 3.1: Sources of data

2. Pre-participation questionnaire (see Appendix C)

The purpose of the pre-participation questionnaire was to provide some background information as to participants' understandings of health ethics in their work before they engaged in the study. This would be compared with information sought after their individual engagement in web-based ethical reasoning of an everyday moral challenge through logging into the Values Exchange website. It was understood that the number of people being surveyed was small and so the quantitative information would not achieve statistical significance, but none the less the views expressed were gathered for

Ethics of the Everyday

two main reasons. Firstly they would inform the development of the scenario for the project, a key component, and secondly, it was envisaged that they would give some information about the use of the tool itself.

Brief demographic information was included to give an understanding of the experience and ethnicity information of participants. The first question asked for examples of situations from practice which were considered to be ethically challenging and why. This information later proved helpful in constructing an everyday scenario to use for the project. Participants then answered three questions designed to glean current understandings of participants' perceptions of aspects of ethical decision making.

Whilst space was provided for open narrative responses by each participant, following consultation with the university's biostatistician, it was deemed more appropriate when using a questionnaire to have some statements which participants can rank as to their validity. This can avoid a common pitfall, that of having no data at all in a section. It also gave the opportunity to use some of the same questions in the post-participation questionnaire aimed at seeing if the act of participation itself had made any difference. I selected statements for ranking based on themes which arise in recent occupational therapy literature on ethics and practice morality (e.g., Butler, 2004; Seedhouse, 1998; Weston, 2001), and from my discussions with occupational therapists. First, participants were asked to record what they understood ethical practice to mean. The aim of the second question was finding out what occupational therapists use to assist them when faced with challenging decisions. Third, participants were invited to describe personal or organisational factors which influence decision making, and the final section was the one that was included to test the assumption that participation would in itself promote learning, and asked for participants to give expectations of participating in this study.

Developing the scenario for deliberation

The process of using the software to deliberate on a situation required a scenario, and it was important to create one that would have meaning for the participant group by reflecting their everyday work, but which would also have sufficient challenge to

warrant the time involved in deliberation. The process of developing the scenario involved four approaches.

First, during the meetings with groups of therapists to discuss the project, I also invited them to discuss with me situations they considered were challenging and would make suitable scenarios for the project. This produced a number of ideas. Many of these issues reflected concerns about the difficulties meeting client centred goals because of funding restrictions. The tension between the sense of obligation or duty to follow guidelines, and a utilitarian wish to facilitate meaningful gain for the client was clear. Second, I also discussed the issue with three individual occupational therapists who are known to me and who have experience of community practice, and we together considered situations which would merit analysis. Next, a key component of the pre-participation questionnaire was to elicit from therapists who were interested in participating in the study, their views on what constituted a situation that was ethically challenging. Finally, I gained additional insights from several studies described in the occupational therapy literature (see Table 2.3).

The scenario I selected was chosen for a number of reasons. First, because of its ordinariness, so that it would reflect the idea proposed in Section 2.1.2, that ethics should be part of every health encounter. Second, because it had components of both resourcing and client versus therapist preference, both of which had been suggested by therapists during the focus group discussions, and in the pre-participation questionnaire as presenting particularly difficult challenges. These tensions are also discussed in occupational therapy literature (e.g., Russell, Fitzgerald, Williamson, Manor & Whybrow, 2002). These writers highlight the tension for occupational therapists where the paradigm of client centred care, which is considered to underpin the profession, seems at odds with professional recommendations. The scenario is outlined below.

3. Using the values-transparency software

Of the original 35 inquirers who were sent information, 27 therapists returned the questionnaire and the consent form, reminders having been sent to nine therapists.

Ethics of the Everyday

Once the consent forms were returned, participants were then sent instructions for registering with the Values Exchange (www.uscm.Values Exchange.com) (see Appendix D). Images from the web-site are included as an illustration of how the participants were guided through the process of analysis by the software.

After registering on the website, participants were invited to deliberate on "open cases" on that site for practice purposes, as using the Values Exchange advises on its website that it becomes easier after using it for one or two cases. Participants then went to the practice scenario that had been set up for this specific project (see Figure 3.2), which could be accessed via a secure tab, and began their deliberation.
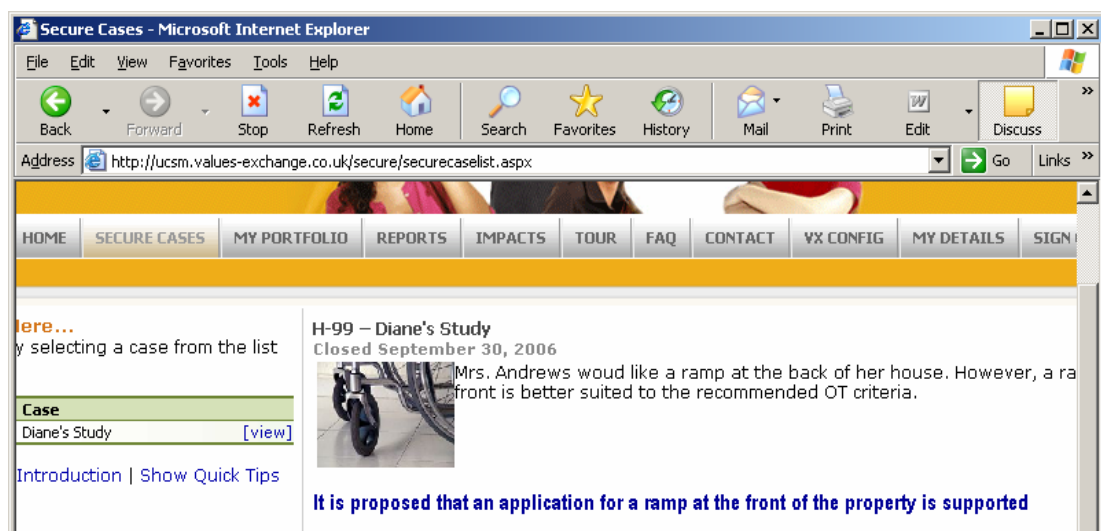
Figure 3.2: Participants view of the case on the Values Exchange

Participants then accessed the case notes back-grounding the scenario.

> *Mrs. Andrews (83) is struggling to adjust to a recent below knee amputation, necessitated by diabetes. You have been asked to assess her needs for modifications to her home to facilitate wheelchair access.*
>
> *The logical place for a ramp seems to be the front entrance, which has a wide doorway into a spacious hall, and good access to car and letter box. There is sufficient room for a ramp with very good gradients at the front.*
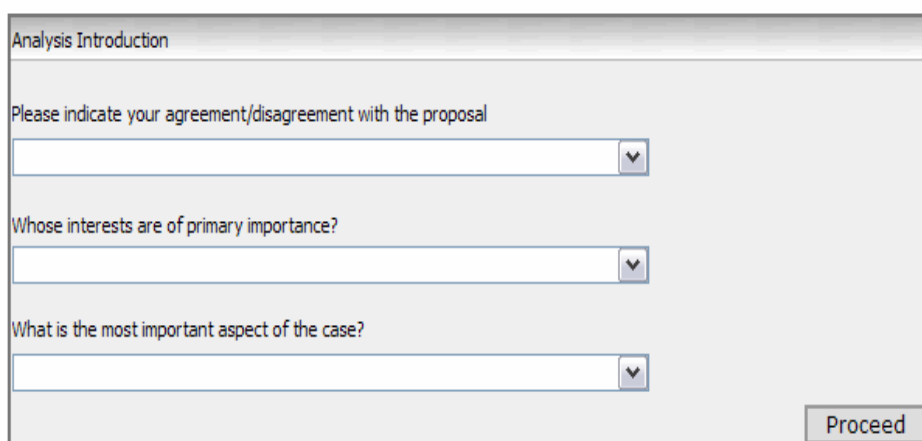
The client (and her daughter, a nurse who is putting pressure on all the team) is adamant that the ramp should be at the back entrance, as that way it will not mark her out as 'disabled'. Mrs. Andrews lives alone and says that she feels vulnerable by having her disabled status advertised to the world in this way. She also is unhappy that a ramp will change the look of the front of her property and require the removal of a rose garden which she has tended lovingly for 10 years since living here.

The back has a narrower entrance, and is higher off the ground, meaning that the gradient, while still within the 1:12 guidelines, is steeper than the ideal for those days that she will walk on the ramp. The back is also in a shadier part of the house and so more likely to be slippery. It will also need to be longer, adding some cost. You decide to use the Values Exchange to assist your own process of deliberation and to ascertain the view of a range of colleagues.

It is proposed that an application for a ramp at the front of the property is supported.

Having read the outline of the scenario participants were asked to record their first thoughts, understandings and their "position" on the case in the "initial response" section of the Values Exchange (see Figure 3.3).

Figure 3.3: Initial response section of the Values Exchange

Ethics of the Everyday

Each participant then recorded their agreement or disagreement with the proposed course of action, whose interests participants considered to be primary in this case and the issue that they regarded as key to this case, using drop down options. They then moved through the deliberative process using the software and the prompts it provides to build a case to defend their argument.

For example, the Perception Rings (Figure 3.4) assist the participant to describe their perceptions and explain their beliefs and feelings and why they have responded in a particular way. This is done by manipulating a graphic image and responding to questions to demonstrate the importance one places on each construct (e.g., dignity; human rights; primary risk; own emotion; own role; the law).
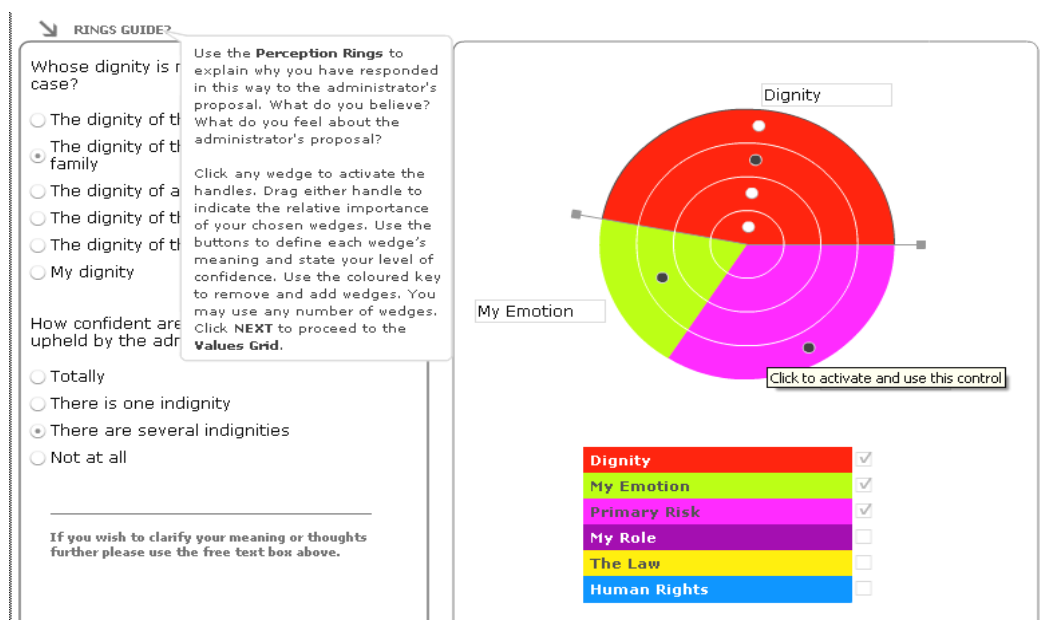
Figure 3.4: Example of the Perception Rings

Participants responses then enabled automatic generation of the Values Grid (Figure 3.5) enabling them to select tiles which would support a case for what they thought should happen, by exploring such aspects of ethics as issues of duty or utility, healthcare purpose, whose interests are primary along with practical considerations.
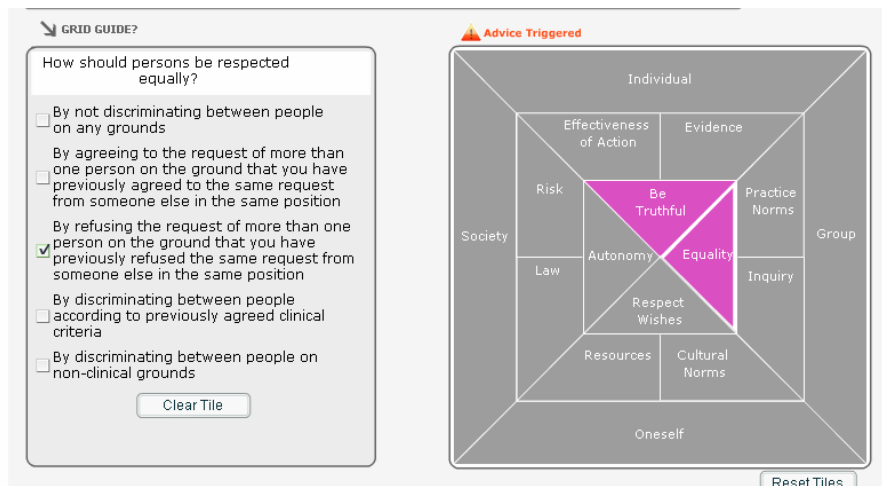
Figure 3.5: The Values Grid example

Participants were not able to submit their analysis until they had responded to any requests for further information which the software generates, for example if there were obvious inconsistencies between factors the participant presented to support their position in the Rings section and the Grid section. Before submitting they also had the opportunity to register any concluding thoughts or ideas for alternatives.

Having submitted their own analysis of the case, participants were immediately able to view their own and others' analyses and comments; therefore a particular value of using this software is that all participants can access the reports and reflect on their own and others' deliberations (and is a form of member checking, a reliability measure in qualitative research). Anonymous participation was an option for participants, which one person chose; this resulted in a number showing in the reports instead of their name.

4. Post-participation questionnaire

As the researcher I had arranged to have administration rights to the site, so I was also able to see when participants had completed their analysis. At this point I emailed them a post-participation questionnaire (attached as Appendix E), for either printing or returning in which case I provided a return envelope, or for returning electronically. This questionnaire repeated some of the questions from the first questionnaire, the purpose of which was to record if there was any difference in the way participants viewed ethical issues after they had used the process of ethical analysis offered by the

59

software. This is explored in the findings in Chapter 4. A further purpose of the post-participation questionnaire was to ascertain participants' views on using the software and to record whether or not their expectations of participating using the software had been met.

Data analysis

Findings from the data are presented in Chapter 4 and analysis of the data, with discussion, in Chapter 5. Chapter 4 describes the process where data from the qualitative responses resulting from the questionnaires and the software were categorised in several ways including topic coding and analytic coding Morse and Richards (2002), categorising being an initial form of analysis.

In Chapter 4, tables are used to present the quantitative data from the questionnaires. Differences and frequencies were calculated and primary descriptions are given of averages of responses, and of changes between responses in the pre-participation post-participation questionnaires. This was not intended to produce statistical significance, but rather to assist categorisation and the search for patterns of meaning, and points of interest to focus the discussion.

Chapter 5 will combine analysis of the data produced in the project component of this study, and compare and contrast this with the theoretical and philosophical position statements I made at the outset of this work. Synthesis of existing knowledge discussed in the background chapter, with ideas generated from the data analysis, are intended to highlight patterns of meaning and point to conclusions and recommendations for future work (Chapter 6).

Chapter 4: Findings

4.1 Introduction

Chapter 4 reports on the findings from the project work, which included the pre-participation and post-participation questionnaires and the participants' use of the Values Exchange. The primary focus of this study (explained in Chapter 3) was to explore values based decision making using the Values Exchange, and to use the reports it generates as the main data source. The decision to include a simple questionnaire to be completed by the participants before and after using the Values Exchange will be explained in Chapter 4.2. The questionnaire included a small quantitative survey and an opportunity to give qualitative comment.

The information generated by the Values Exchange is in the form of quantitative summary tables, or verbatim qualitative reports. Some of the reports are useful to give overall views of areas of convergence or divergence, with the system being designed to reveal the values behind the views. Moreover, verbatim qualitative reporting further shows the values a participant has used to support their argument, or decision-making process. This study is therefore, a mixed-method approach, a concurrent nested design, involving both quantitative and qualitative information from both the questionnaires and the Values Exchange, and data collection is summarised in Figure 3.1.

Chapter 4.2 is a descriptive report of the results from the pre-participation questionnaires, with explanations as to the reason for their inclusion in the study, and summarising the responses to the questions. In Chapter 4.3, I will present and discuss the findings based on the reports produced by the Values Exchange. Chapter 4.4 covers the information obtained from the post-participation questionnaires. This will include any change to the responses to the questions about understanding of ethics that were repeated from the pre-participation questionnaires, as well as perceptions of the value of having used the Values Exchange software to deliberate ethical issues. This results chapter will then be summarised in 4.5.

Ethics of the Everyday

4.2 Pre-participation questionnaires (see Appendix D)

The reasons for including the pre-participation questionnaire have been discussed in
Chapter 3.1, but in summary the purpose was threefold:

1. Glean further information regarding situations therapists in this professional
   group consider to be challenging;
2. Obtain an understanding of the group's knowledge of ethics and use of tools of
   analysis ; and
3. Ascertain if using the Values Exchange promoted learning in the area of ethical
   deliberation, among the group of participants.

All of the 26 people registered with the Values Exchange site completed a pre-
participation questionnaire, as it was a requirement for inclusion in the study. Fifteen of
these went on to complete the study, and therefore, for most of the questions in the pre-
questionnaire, the results and analysis will be limited to those 15 questionnaires.

However, as noted above, one of the primary reasons for the questionnaire was to
ascertain what situations therapists considered to be ethically challenging. The primary
reason for wanting that information was to inform the development of the scenario to be
deliberated using the Values Exchange. I, therefore, used all 26 responses to the first
question, "Please list some examples of situation in your practice which you consider to
be ethically challenging", to give the widest consideration of ideas from the professional
group. Even though 11 of the 26 people did not go on to complete the study for various
reasons (the main one given was time constraints), all of those people who had
participated to the extent of completing consent and the first questionnaire were people
who had expressed an interest in ethics, and, therefore I was interested in their
responses.

Of the 26 participants who completed the pre-participation questionnaire, 19 had been
practicing more than eight years, four between four and eight years; two for one to three
years, and one for less than one year. All identified their culture as being European,
with the exception of one participant, who identified as "other" (New Zealander). I
included these questions because they may have offered insights to particular trends

from the data, for example where there different trends shown related to length of experience as an occupational therapist.

I now turn to a discussion of the results, using the three purposes of the pre-participation questionnaire as headings.

1. Gleaning further information regarding situations therapists in this professional group consider to be challenging

Participants were asked to list situations and the reasons they found them to be challenging. The question was unstructured, resulting in open responses, which I then interpreted and grouped around central issues. Thematic analysis such as described by Thomas (2003) and Cook (2001) was utilised, and situations were collapsed into key themes which enabled me to look at the frequencies with which they occurred.

Table 4.1: Categories of situations considered ethically challenging by participants.

Categories	Frequency
Funding restrictions/gate keeping	16
Waiting list/resources	13
Client disagreeing with therapist recommendations	9
Client/ family/support situation	6
Client personal factors– behaviour, culture, actions	5
Organisation – e.g. management accountability	3
Client rights not met – e.g. informed consent	3
Team issues – e.g. racist comments from others	2
Therapists issues – e.g. competence	1
Total	58

There were 58 responses to this question received from the 25 therapists (one did not complete this question), and of those, 29 related to situations made ethically challenging for the therapist because of either Ministry of Health funding or gate keeping restrictions, or waiting lists or some other resourcing issue (see the first two categories in Table 4.2.1). Outside of these issues, the next most challenging issue identified was that of client and therapist disagreement, and the tensions that sets up in the context of client centred care.

Ethics of the Everyday

The information obtained from question 1 above was useful in developing the scenario for deliberation. Ultimately, the one I developed included aspects of the need to meet New Zealand Ministry of Health funding guidelines, as well as client/therapist disagreement.

2. Obtain an understanding of the group's knowledge of ethics and use of tools of analysis

The second objective of the questionnaire, and the focus of the next three questions, was to obtain an understanding of the group's knowledge of ethics and use of tools of analysis. The tables below show the results from those questions. First, Question 1: "I understand ethical practice to mean":

Table 4.2: Knowing the right thing to do

Category	No	Frequency	Percent
Strongly disagree	1	0	0.0
Disagree	2	1	6.7
Neutral	3	3	20.0
Agree	4	7	46.7
Strongly Agree	5	4	26.7
	Total	15	100.0

From Table 4.2, we can see that 73.4% of participants agreed or strongly agreed that ethical practice involved knowing the right thing to do. Interestingly, no participants strongly disagreed with this proposition.

Table 4.3: Doing what is best for the patient

Category	No	Frequency	Percent
Strongly disagree	1	0	0.0
Disagree	2	1	6.7
Neutral	3	4	26.7
Agree	4	6	40.0
Strongly agree	5	3	20.0
	Total	14	93.3
	Missing	1	6.7
	Total	15	100.0

As seen in Table 4.3, 60.0% of participants agreed or strongly agreed that doing what is best for the patient was ethical practice. Again, no participants strongly disagreed with this statement.

Table 4.4: Doing what is best for the community

Category	No	Frequency	Percent
Strongly disagree	1	0	0.0
Disagree	2	2	13.3
Neutral	3	7	46.7
Agree	4	5	33.3
Strongly agree	5	0	0.0
	Total	14	93.3
	Missing	1	6.7
	Total	15	100.0

Table 4.4 shows that 33.3% of participants agreed with the assertion that ethical practice involved doing what is best for the community, although a similar number were neutral (46.7%) or disagreed (13.3%).

Next, we examine participants' answers to Question 2.When I have to make an ethically challenging decision I think about:

Table 4.5: Following the code of ethics

Category	No	Frequency	Percent
Strongly disagree	1	0	0.0
Disagree	2	0	0.0
Neutral	3	2	13.3
Agree	4	10	66.7
Strongly agree	5	2	13.3
	Total	14	93.3
	Missing	1	6.7
	Total	15	100.0

Table 4.5 indicated that 80.0% of participants agreed or strongly agreed with the statement that following the code of ethics was something that they thought about when making an ethically challenging decision, and although some were neutral, none disagreed.

Ethics of the Everyday

Table 4.6: The preferences of everyone involved

Category	No	Frequency	Percent
Strongly disagree	1	0	0.0
Disagree	2	2	13.3
Neutral	3	4	26.7
Agree	4	6	40.0
Strongly agree	5	2	13.3
	Total	14	93.3
	Missing	1	6.7
	Total	15	100.0

Table 4.6 shows that 53.3% of participants reported that they agreed or strongly agreed with the statement that they thought about the preferences of everyone involved when making an ethically challenging decision.

Table 4.7: Following guidelines

Category	No	Frequency	Percent
Strongly disagree	1	0	0.0
Disagree	2	0	0.0
Neutral	3	1	6.7
Agree	4	12	80.0
Strongly agree	5	1	6.7
	Total	14	93.3
	Missing	1	6.7
	Total	15	100.0

Finally, as outlined in Table 4.7, in response to question 2, 86.7% of participants endorsed that they agreed or strongly agreed with following guidelines when thinking about an ethically challenging decision.

The next set of tables relates to Question 3: Personal or organisational factors which influence my decision making are:

Table 4.8: Fear of making the wrong decision

Category	No	Frequency	Percent
Strongly disagree	1	1	6.7
Disagree	2	4	26.7
Neutral	3	4	26.7
Agree	4	6	40.0
Strongly agree	5	0	0.0
	Total	15	100.0

Table 4.8 indicates that 40.0% of participants agreed with the assertion that fear of making the wrong decision was a factor that included their personal decision-making. However, almost as many participants (33.4%) disagreed or strongly disagreed.

Table 4.9: Lack of training in ethical theory

Category	No	Frequency	Percent
Strongly disagree	1	0	0.0
Disagree	2	6	40.0
Neutral	3	4	26.7
Agree	4	5	33.3
Strongly agree	5	0	0.0
	Total	15	100.0

Table 4.9 shows that 33.3% of participants agreed with the statement that a lack of training in ethical theory influenced their decision making. Interestingly, the largest group disagreed with the issue (40.0%), and 26.7% were neutral on the issue.

Table 4.10: Other people's opinion

Category	No	Frequency	Percent
Strongly disagree	1	0	0.0
Disagree	2	3	20.0
Neutral	3	6	40.0
Agree	4	6	40.0
Strongly agree	5	0	0.0
	Total	15	100.0

In relation to question 4.10, 40.0% of participants agreed with the statement that other people's opinion was a factor that influenced their decision making. Conversely, 20.0% of participants disagreed with this statement, and again, a large proportion of participants were neutral.

Table 4.11: Having enough facts to make a decision

Category	No	Frequency	Percent
Strongly disagree	1	0	0.0
Disagree	2	0	0.0
Neutral	3	2	13.3
Agree	4	6	40.0
Strongly agree	5	6	40.0
	Total	14	93.3
	Missing	1	6.7
	Total	15	100.0

Table 4.11 highlights that 80.0% of participants agreed or strongly agreed with the statement that having enough facts to make a decision was a factor that influenced their decision making. No participants disagreed or strongly disagreed with this statement.

As discussed in Chapter 3, the number of people surveyed was too small for the results to have any statistical significance however, for this small study they are useful to suggest possible indicators, to use as concurrent data along with that from the Values exchange and the literature. There is a general consistency of responses, although less so for those to categories in Question 3 regarding the factors that influence decision making, where often as many agreed as disagreed. Question 3d, however, produced interesting results in that it was one of the questions with the most consistent results overall, showing 80% (12 of the 15 participants) agreed with the statement "factors which influence my decision making are having enough facts to make a decision". The other three statements that produced high degrees of agreement were: 1a (73.4% agreed with the statement "ethical practice means knowing the right thing to do"); 2a (80% agreed with the statement "when I have to make an ethically challenging decision I think about following the code of ethics"); and 2c (when I have to make an ethically challenging decision I think about following guidelines"). Collectively these statements show a tendency towards using an evidence-based, rather than a values-based, approach to decision making for this group.

3. Ascertain if using the Values Exchange promoted learning in the area of ethical deliberation, among the group of participants.

The third purpose of the questionnaires was intended to explore the participant's interest in using the software, to be later compared with similar questions in the post-

participation questionnaire. Results from these responses in the pre-questionnaire will be summarised with the findings from the post-participation questionnaire in Chapter 4.4.

4.3 Results from the Values Exchange

As discussed in the methodology section (Chapter 3.2), participants who had completed the consent form and the pre-participation questionnaire were then sent instructions for logging on to the Values Exchange site that was designed for the study. Twenty six participants were sent the information, and were registered on the site.

Eleven of the 26 who registered did not complete the case before it closed on September 30th 2006 (after two extensions), leaving a total of 15 participants for inclusion in the study. Most of those who did not complete communicated their reasons with me, although this was not a requirement. Time pressures were given as the main reason, and I will be discussing this further in Chapter 5.

A benefit of the Values Exchange lies in the reports it generates. These enable a participant to reflect on their own argument, but also those of others who have submitted an analysis of a case. The reports make visible not only the levels of agreement or disagreement with a proposal, but also the value judgements behind those positions. In addition the system notes "alerts" if responses show an area that needs further exploration.

Six weeks after the case closed data from nine of the 15 participants had been deleted from the Values Exchange due to an error by the site administrator, and with those deletions all of the data entered by those people into the system. However, printed copies of all of the quantitative reports had been retained thus providing most data from the original 15 participants, as well as that of the six participants' data which remain in the system. Qualitative comment from six of the participants who disagreed with the scenario's proposal was lost. The majority of the results are based on data from all 15 participants that was saved and printed, and this is supplemented where appropriate with "live" examples from the six participants whose deliberations remain on the Values-

Ethics of the Everyday

Exchange. The effect of the loss of qualitative data on analysis will be discussed in Chapter 5.

I will now turn to the results and analysis of the reports, for each step of the system. First, I will explore the results for the first section which recorded participants' initial response to what was proposed in the case. The reports from the next section, which the system refers to as the Perception Rings, gives reports on the reasoning behind the position which the participants took. The third section, the Grid Tiles further shows the argument each participant uses to support their view as to what should be done, see Chapter 3.

4.3.1 Reports from the first section of the Values Exchange: Initial response

Having opened the case and read the case notes (see page 56), participants then recorded their initial thoughts on the case in response to three questions:

1. Did they agree/disagree with what was proposed?
2. Whose interests were primary?
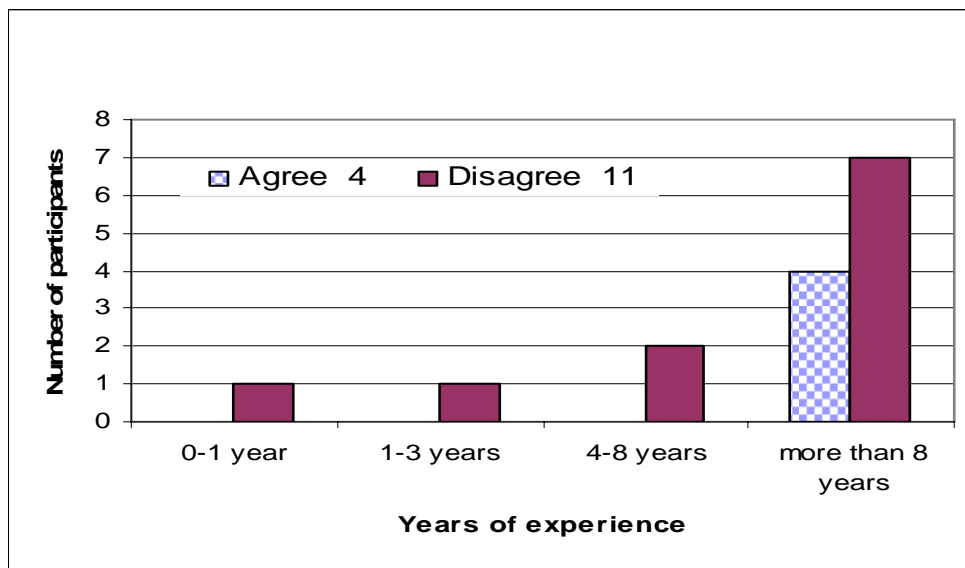3. What did they consider the most important aspect of the case?

Figure 4.1: Participants agreement/disagreement with proposal, showing years of participant experience

The first question asked whether the participant agreed or disagreed with the proposal that the application for the ramp is supported. Of the fifteen, 11 disagreed with the proposal (73%) and 4 agreed (27%). Demographic information obtained from the questionnaires regarding the years of experience of participants was included to see if there was any divergence of view, might it be related to experience.

From the outset, the first result shows that the case of Mrs. Andrews selected for its ordinariness and because it included features which occupational therapists find ethically challenging, produced divergence of opinion among a group of experienced occupational therapists, and therefore, warrants further exploration. The Values Exchange "alerts" function was triggered, which indicates that further analysis was necessary, because more than 50% of the participants were not willing, or willing to a limited extent to carry out what was proposed. I consider the alert to relate more to the fact that in a group of therapists working in the community, approximately 25% have a different view from the majority.

A second reason for following up the alert is that, on the face of it, 25% of the group would support an application for an intervention that the person did not want, which would lead to the question, how does this sit alongside the occupational therapy profession's stated paradigm of client centred care? Comment from the pre-questionnaires, and reports from the occupational therapy literature record that this tension is source of ethical challenge for occupational therapists (Barnitt & Partridge, 1997; Foye et al., 2000; Russell et al., 2002). Therefore, most of the subsequent analysis was conducted with the group who agreed with the proposal. The simple quantitative report showed the divergence of agreement/disagreement, but it is the further qualitative information provided by participants that showed the values informing those views.

In response to the second question for the participant's initial response, "whose interests are primary?" all participants entered either the patient or patient and family, regardless of whether they agreed or disagreed with the proposal.

The third initial response questions asked participants to state the most important aspect to consider in the case, selecting between dignity, human rights, law, risk, my role and my emotion. Their responses are noted in the figures below.
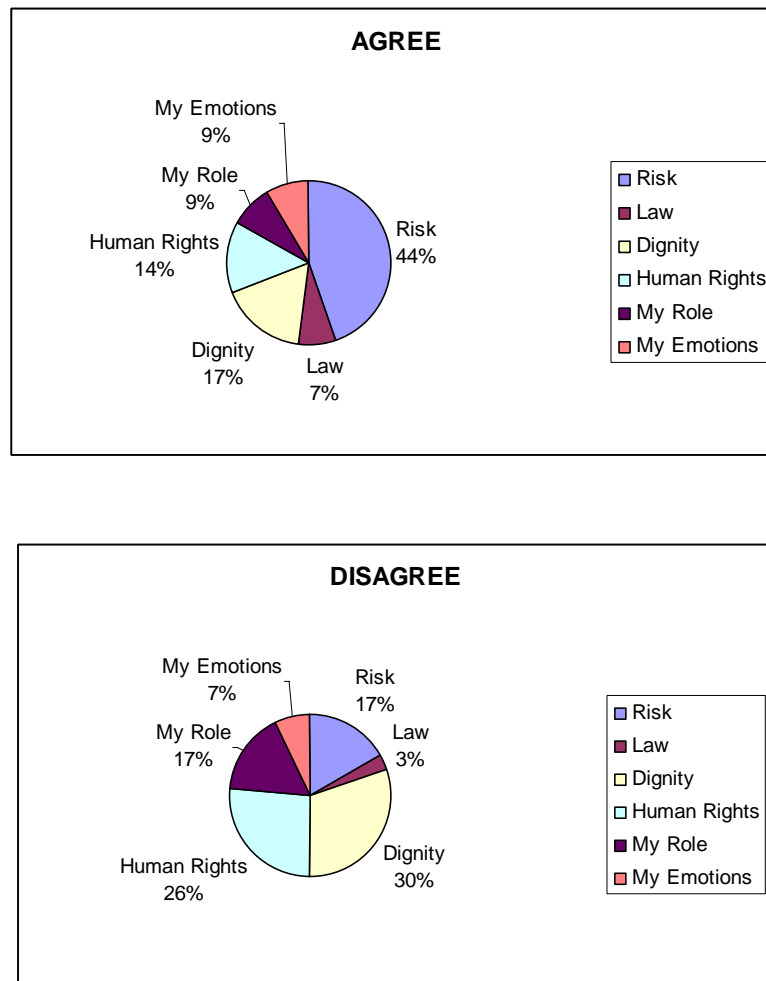
Figure 4.2: Most important aspect of the case selected by participants, reported by whether they agreed or disagreed with the proposal.

Once again, Figure 4.2 provides a simple early quantitative picture of issues which would merit further qualitative exploration. Of most interest was the emphasis placed on risk by the agree group, compared the disagree group, given that the literature describes concerns regarding safety for clients can be a factor which overrides considerations such as client preference for occupational therapists (Russell et al, 2002) This will be discussed in Chapter 5. Further analysis of the reports of individuals who agreed with the proposal, show that not only as a group, but that as individuals, they all considered primary risk to be the most important factor, three of them by some

considerable margin. Issues of most importance for those who disagreed were human rights and dignity.

4.3.2 Reports from the second section of the Values Exchange: Participants' perceptions of the case

The results from the next section, which the values exchange system refers to as the Perception Rings, provide reports on the reasoning and values behind the position the participants took. These results are displayed in the Figures below, showing the numbers of responses to different qualifiers of importance or verbatim comment from the participants.

The first report gives a view of participants' willingness to carry out the proposal.
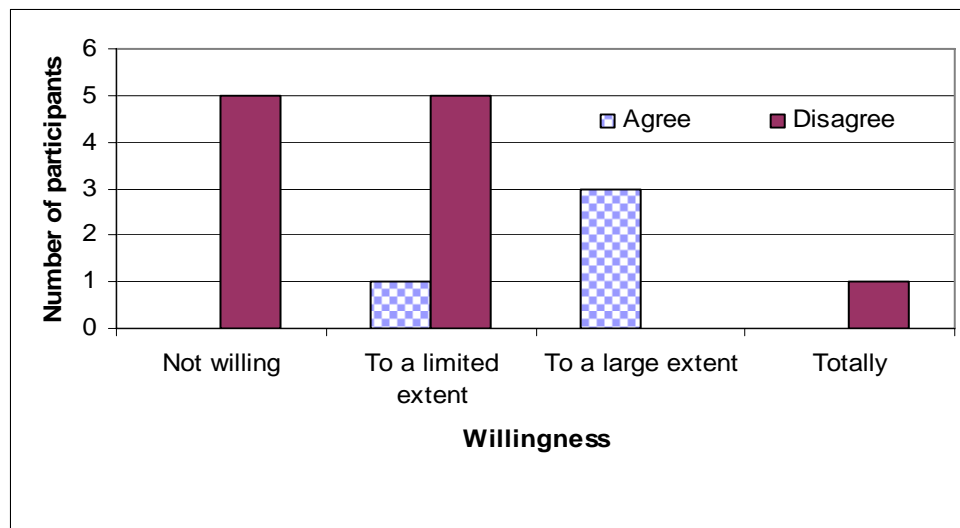
Figure 4.3: Participants' willingness to carry out the proposal

Figure 4.3 provides a more in depth picture of the values behind decision making, and shows that while four people agreed with the proposal, none of those were totally willing to carry it out. (There was an incongruence showing in the graph in that one person who disagreed with the proposal was shown to be totally willing to carry out the proposal). The next figures start to show some how risk was perceived.

Ethics of the Everyday
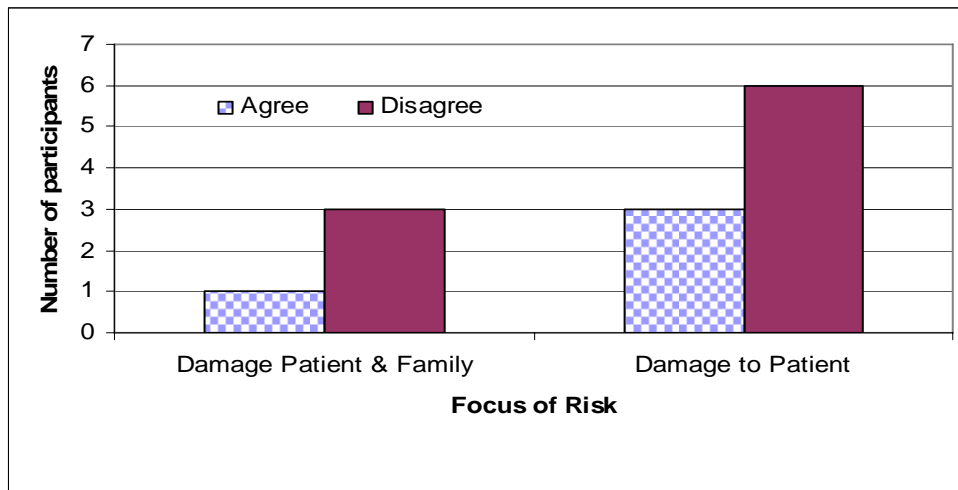
Figure 4.4: Participants' perception of risk
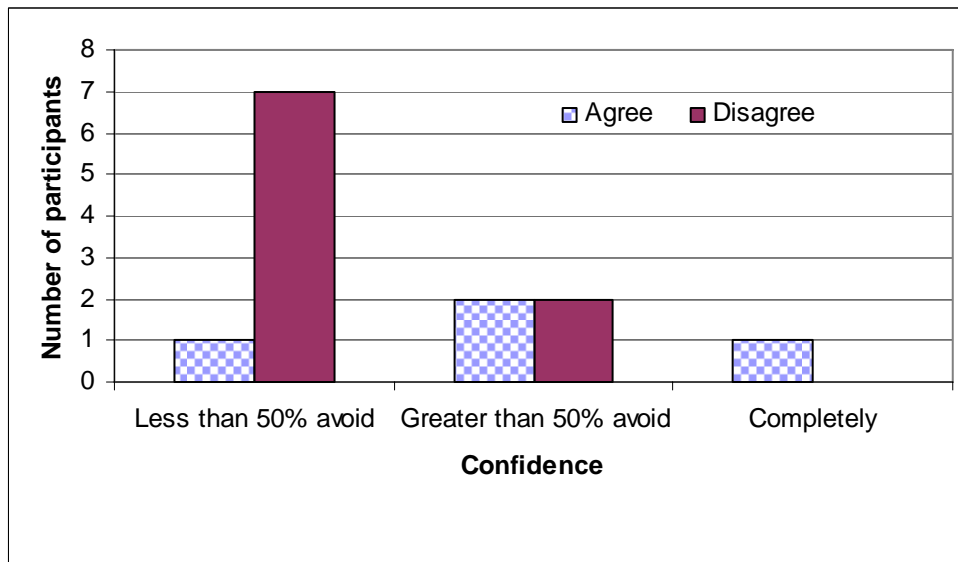
Figure 4.5: Participants' confidence that risk can be avoided

Having a significant minority (just over 25%), with a different view from the majority, and because the indication from the first reports show that this difference is their perception of risk, I further analysed the participants' perception of risk.

Figure 4.4 above shows that most participants considered that risk relates to the patient, or the patient and their family (rather than for example to themselves or the community). Further, Figure 4.5 shows that the disagree group are not confident that this risk to the patient can be avoided if the proposal goes ahead. Although it is the agree group who cite risk as the most important aspect of the case, all participants

thought it to have some importance, and for this reason it is useful to explore verbatim comments behind their analyses.

Below are examples of comments relating to risk from participants who agreed with the proposal:

1. "Although I recognise this client's wishes as significant what I see as the risks to her override her preference".

This is a view also reflected in the occupational therapy literature, and indeed in health literature generally (Russell et al 2002).

2. "The administrator's proposal is supported on the grounds of the O.T. criteria and what we are bound to. The client's rights and dignity are important but must be enhanced with participation and balance with the client's safety"

This participant considers that the Ministry of Health guidelines require the most optimal placement for the ramp, and is viewing safety and risk in the sense of physical harm.

3. "Balance must be weighed between the client's safety and the client's dignity"

Tension inherent in ethical decision making is demonstrated here as the participant highlights the issue of the client's dignity, but as they went on to argue for the proposal, came down on the side of safety from physical harm to build the argument to support their decision.

The following are a selection of statements about risk from participants who *disagreed* with the proposal:

1. Patient dignity must be upheld, but simultaneously, primary risk must be investigated. I believe it is a team decision which should include both patient and her family, and all options should be considered prior to a decision being made.

Ethics of the Everyday

While disagreeing with the proposal, this participant reflects the same tensions as were expressed by many of those agreeing with the proposal but does not consider there are sufficient grounds for agreeing with the proposal. However, neither did they propose going ahead with the client's preference for a ramp at the back, without further exploration of the options

2. I think that the back access should be considered as an option for access, because of client's reasons for privacy and her rose garden, and because I think there may be a better option to consider. My feelings are that the ramp needs to be client-centred and address client's needs /wishes. My instinct is that I don't believe she will use the ramp if it is at the front of the house and waste of public funding monies.

This participant interestingly combines a client centred approach with a utilitarian perspective, viewing an unwanted (and, it is therefore assumed, unused) ramp as a waste of public money.

3. I am uneasy with this proposal. I do not feel an application for a ramp at the front is warranted. My reasons are, 1 the client is not in agreement with this proposal, and will probably not sign the application papers, 2 the client is still coming to terms with the lose of her leg and the changes this has made in her life. This may be clouding her judgement and her families. The clients view may change in time.

The concerns here are clear, the approach has aspects of pragmatism (the client probably will not sign the papers) and this participant also considers delay would be advantageous, giving reasons for proposing this.

4. While the front door proposal appears a more expedient and possibly more cost-effective option the opinion and feelings of the family are important. The client has raised valid issues in firstly her own safety and her perception of how this will be changed with a ramp in full public view and secondly her concern of the loss of her garden. This is also part of her 'home' and her feelings about the loss of this in addition to the loss of a limb are understandable and deserve respect

and catering to if possible.

Explicit mention of the client's perspective on safety supports this participant's argument to disagree with the proposal.

Another aspect of note from the participants' perceptions of important aspects of this case was that of human rights.
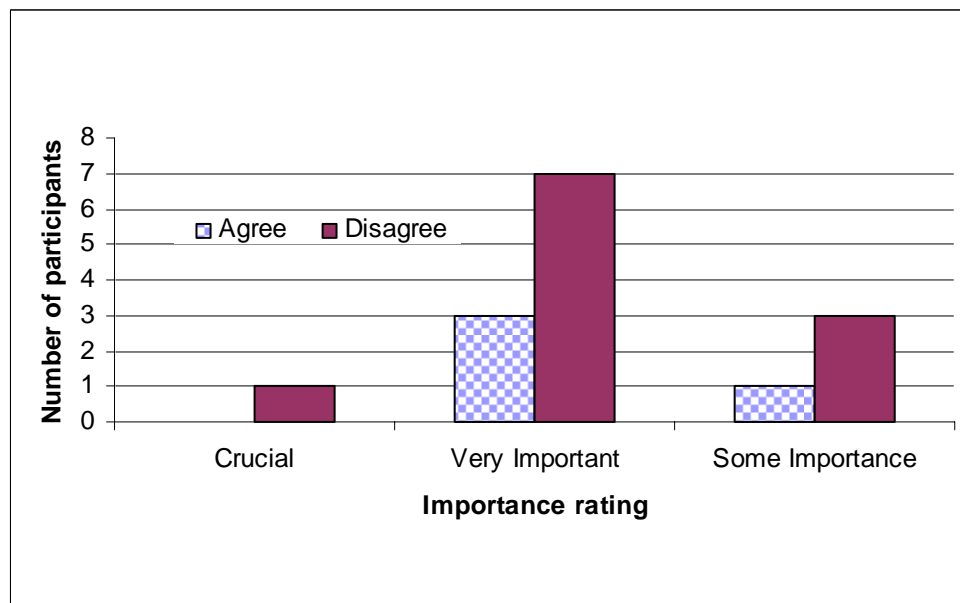
Figure 4.6. Participants' rating of importance of rights.

As seen in Figure 4.6, there is unanimity that rights have at least some importance in this case, regardless of whether participants were agreeing or disagreeing with the proposal.

Ethics of the Everyday
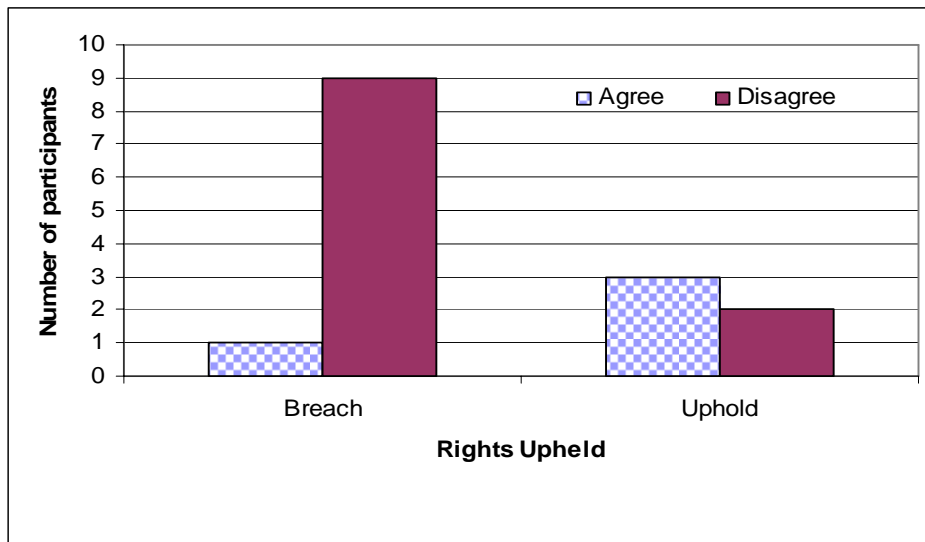
Figure 4.7: Whether rights are upheld by the proposal

However, Figure 4.7 shows there is disagreement as to whether the proposal breaches those rights.

4.3.3 Reports from the third section of the Values Exchange: Participants' further argument as to what should be done

In this section, the Grid Tiles (based on the Ethical Grid, Seedhouse, 1998) further show the argument each participant uses to support their view as to what should be done, and the views of participants who agreed or disagreed with the proposal can be compared.

The grid tiles represent aspects of ethical theory or moral principles that can be put forward to support a participant's argument. These tiles are represented in the Figures below, which suggest trends. Figure 4.8 shows the number of times each tile was highlighted by a participant, and Figure 4.9 shows this by agreement/ disagreement with the proposal.
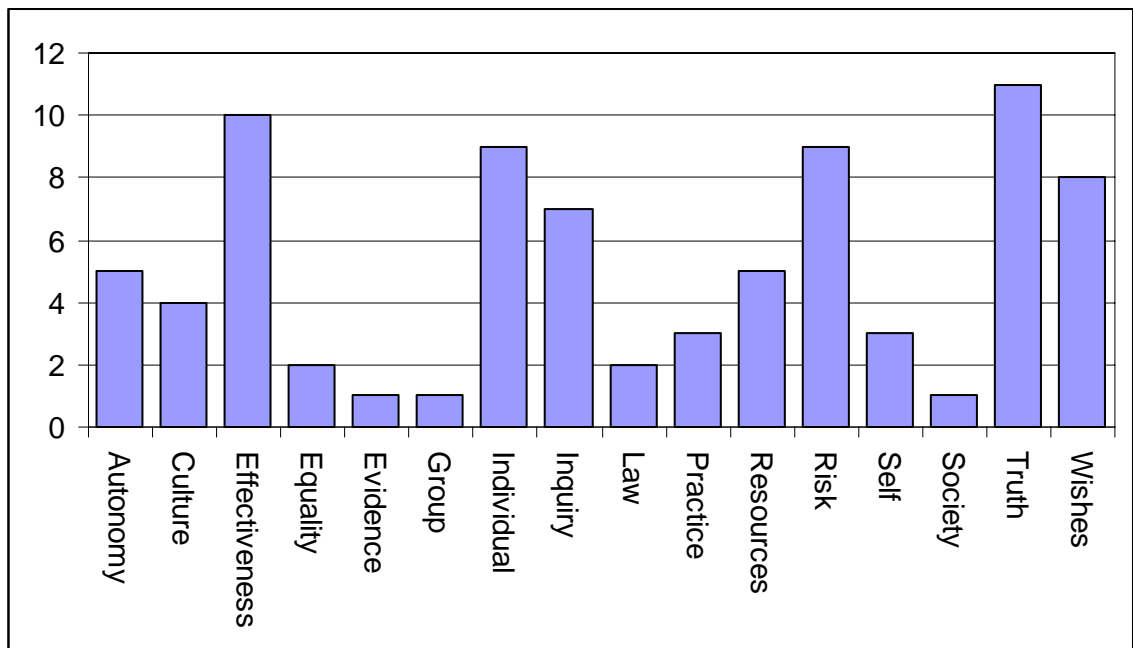
Figure 4.8: Number of times items grid tile items was selected.
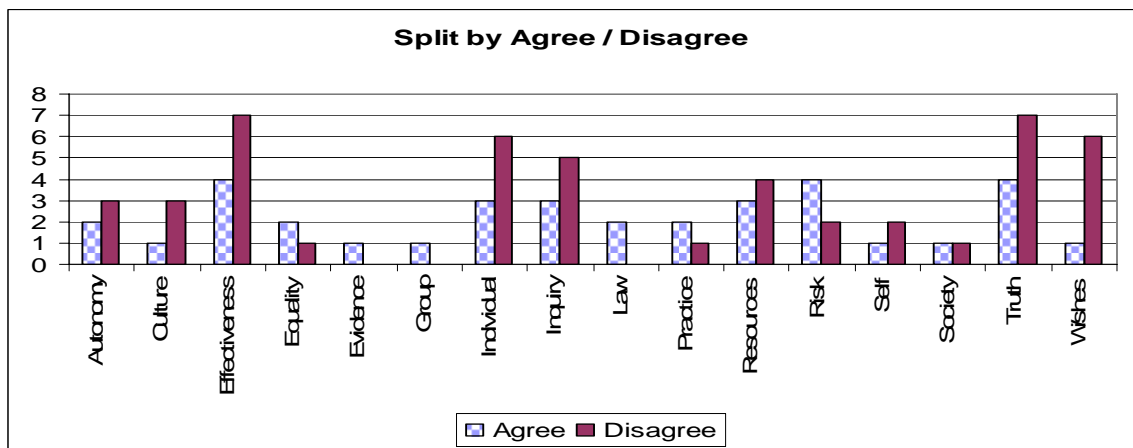
Figure 4.9: Tiles selected showing agree/ disagree status

Overall the tiles most selected were truth, effectiveness, individual and risk, with the two most often selected by the agree group being effectiveness and risk, and the two most selected for the disagree group being effectiveness and truth. Once again, these results highlight a point of difference and I will be exploring this further.

Interestingly, while there is divergence of agreement/ disagreement with the proposal for some of the group, this shows that there is convergence of values supporting the arguments, although they are interpreted differently. Merely looking at outcomes of

Ethics of the Everyday

argument did not give the full picture, and I will be exploring this further in the discussion section (see Chapter 5).

I further examined the reports for the tiles selected most frequently by the participants whose data remains on the system, starting with effectiveness, being most often selected for both groups, followed by risk and truth. Data from individual analyses of the grid tiles were among that missing both from the system and from the copies taken of reports. Therefore, to explore the statements being given to support their argument I used an example comment from the six participants who remained on the system (one of whom agreed with the proposal and the other five disagreed).

Effectiveness
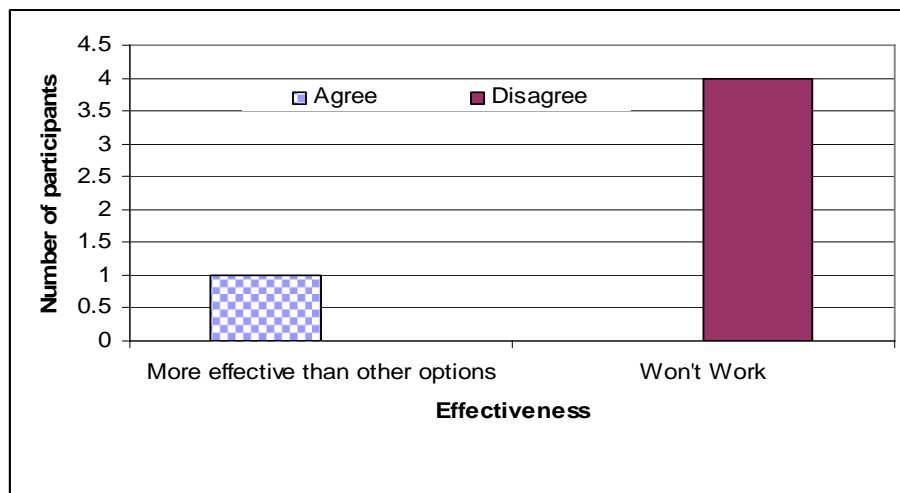
Figure 4.10: Reasoning behind the selection of "effectiveness" tile, showing agree/disagree status

The participant from the remaining sample who agreed with the proposal did so with some reluctance, as can be seen by the tentative estimation of the effectiveness of the proposal being better than other options. However, those who disagree are emphatic: this will not work.

Risk
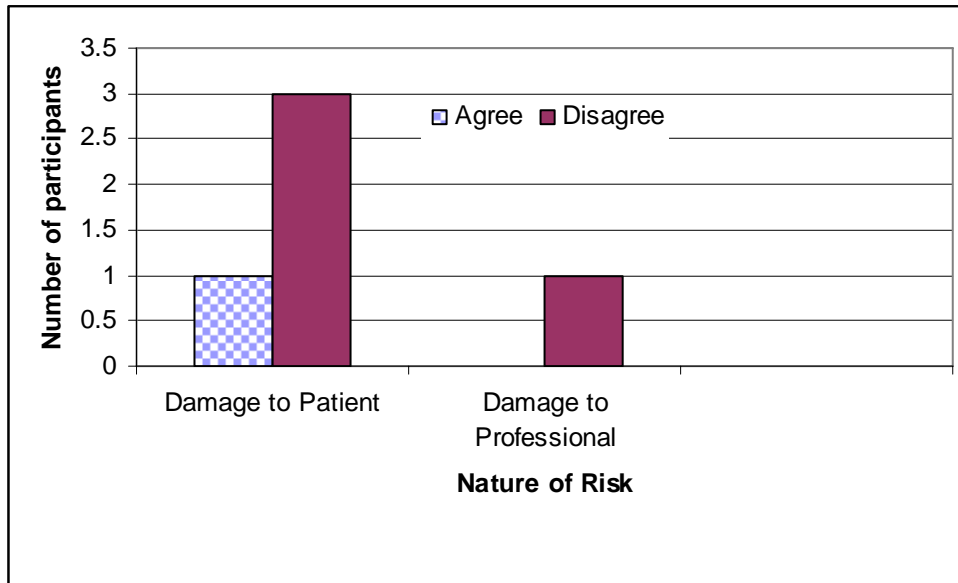
Figure 4.11: Reasoning behind the participants' understanding of risk, shown by agree/ disagree status

Risk is the area of most interest because it features strongly in both the Rings and Grid analysis for the agree group, and indicates the primary point of difference. It is also of interest because, as stated above, it is known from the occupational therapy literature to be an area of challenge.

Here is overall comment from the system from a person who agrees with the proposal:

> Grid comment   Although I consider it of primary importance to consider the client (and family) and to work in partnership with them, in this case I consider that having a ramp in an unsuitable position puts the client at considerable physical risk and therefore believe this is not a good use of the available resources.

This argument of a participant who agrees with the proposal is that the risk to be avoided is that of physical harm from falling on the ramp.

Below is an example of comment behind the selection of the grid tile "risk" by a person who disagrees:

> Grid comment   Should ramp is installed at front of house, there is risk patient won't use ramp, and/or patient's dignity will be offended which will affect self esteem and self efficacy. As patient is already struggling to accept new health status, this is a real issue which needs investigation. Should ramp be installed at back of house, several safety issues need consideration, e.g. safety of access, risk of

Ethics of the Everyday

> patient falling at back of house and not being seen by passers by. Query have all options for ramping at front of house been considered, has patient been informed of all options or considered primary risk, has administrator considered client centred approach??? Damage to patient is potential risk of access to patient safety if back entrance is ramped. Alternatively damage to self esteem and self efficacy if ramp is put at front entrance.

This participant sees risk as both physical and emotional. However, although agreeing that there is greater risk of falls if the client's preference is followed:

What do you mean by 'damage to the patient'?	the client is at greater risk of falls if the housing alteration she wants goes ahead

The participant sees more risk in going ahead with the proposal.

What do you mean by 'damage to the patient'?	Decreasing her self image in the destruction of something she has worked for - her garden. Increasing her feelings of loss of dignity and choice

This participant's response to the request from the values exchange system to clarify risk produced this response; harm to the client's self image.

Summary from the Values exchange reports

These findings will be interpreted in depth in Chapter 5, but I will end this section with a comment from a participant who disagreed with the proposal.

Are you certain your decision is in line with clinical protocol?	My perspective is that I believe that many Occupational Therapists would install the ramp at the front as it is a practise norm

The mix of qualitative narrative data and quantitative reports from the Values Exchange gives a richness of results. Here, there is evident tension recorded by this participant, believing their views may be at odds with colleagues.

This scenario reflected an everyday situation for occupational therapists who work in the community, and yet the results showed not only divergence of agreement or disagreement with what was proposed, but also the values behind those views, which are usually hidden.

4.4 Post-participation questionnaire

Questions from the pre-participation questionnaire were repeated in the post-participation questionnaire, with a view to noting any shift in perspective following participants' use of the values exchange system. A comparison of data for all questions from questionnaires, calculating differences and frequencies, did not show significant changes. The questions where the most movement was observed are noted below.

Table 4.12: Difference in responses between pre- and post-questionnaires.

Question	Pre/Post difference	Frequency	Percent
Question 1a: "I understand ethical practice to mean": **Knowing the right thing to do**			
	-2	2	13.3
	-1	3	20.0
	0	8	53.3
	1	0	0.0
	2	1	6.7
Total		14	93.3
Missing		1	13
Total		15	100

Averaging the numbers of participants who registered more agreement compared with those who agreed less, there was overall .35 less agreement with the statement that ethical practice means knowing the right thing to do

Question 1b: "I understand ethical practice mean": **Doing what is best for the patient**	Pre/Post difference	Frequency	Percent
	-2	1	6.7
	-1	2	13.3
	0	10	66.7
Total		13	86.7
Missing		2	13.3
Total		15	100

Ethics of the Everyday

There was little change in agreement/disagreement for most

participants but overall .3 less agreement.

Question 3d: personal or organisational factors which influence my decision making are: **Having enough facts to make a decision**	Pre/Post difference	Frequency	Percent
	-3	1	6.7
	-2	0	0
	-1	5	33.3
	0	5	33.3
	1	2	13.3
	2	1	6.7
Total		14	93.3
Missing		1	6.7
Total		15	100

Overall, there was .28 less agreement with the statement that having

enough facts affects decision making.

Question 3a: personal or organisational factors which influence my decision making are: **Fear of making the wrong decision**	Pre/Post difference	Frequency	Percent
	-2	0	0
	-1	2	13.3
	0	6	40
	1	5	33.3
	2	1	6.7
Total		14	93.3
Missing		1	6.7
Total		15	100

Overall, there was .3 less agreement with the statement that fear of

making the wrong decision affects decision making.

Question 3c: personal or organisational factors which influence my decision making are: **Other people's opinion**	Pre/Post difference	Frequency	Percent
	-2	0	0
	-1	2	13.5
	0	7	46.7
	1	4	26.7
	2	2	13.3
Total			100

Overall there was .4 increase in agreement with the statement.

These five responses are the ones that showed the most differences between the pre-participation questionnaire and the post-participation questionnaire. There was overall less agreement with the following statements: ethics is knowing the right thing to do; and ethics is about doing the best thing for the patient and needing enough facts to make a decision. This could suggest a possible inference that using software decreased the participants' reliance on facts, and increased the understanding that the important thing with ethical analysis is presenting a case to support the best decision one can make, not achieving the right decision per se.

The two post-questionnaire statements which recorded a small increase in agreement were: fear of making a wrong decision being a factor which influences decision making, and other peoples' opinion being a factor which influences decision making. A possible inference from this is that some participants were affected by the experience of having their decision-making transparent. However, additional inquiry would be needed to substantiate this.

The following section considers the participants' pre-participation and post-participation responses to the questions which targeted their expectations from participating study. The expectations from participation are listed below in Table 4.13, as expectation of participation compared with experience of participation. Note that the final four questions were only asked in the post-participation questionnaire.

Ethics of the Everyday

Table 4.13: Expectation and experience of participation

Number of Participants out of 15	Expectation of participation	Number of Participants out of 15	Experience of participating
14	Wanted to learn more in the field of ethics	15	Extended their knowledge of ethics
6	Had used the ethical grid	12	Found the software was helpful
12	Wanted to improve skills of ethical deliberation	13	Improved skills of ethical deliberation
11	Wanted to see if the tool would provide useful forum for professional discussion	14	Thought it would provide a useful forum for professional discussion
11	Wanted to discover what values based decision making was about	14	Increased their understanding about values based decision making
13	Thought they would value seeing the deliberations of others	12	Benefited from seeing the deliberations of others
10	Hoped that participation would contribute to updating competency	12	Believed participation had contributed to updating competency
		5	Thought the process was too complex for everyday use
		9	Valued the transparency of the use of full names
		12	Found the experience challenged how they thought about client centred care
		14	Would like to use the method to deliberate a specific case from practice with colleagues

Table 4.13 highlights that overall expectations of the participants were at least met, and in most cases, passed. This was a self-selected group, whose comments on the pre-participation questionnaire indicated that they were motivated individuals and reflected their interest in the topics of ethics, professional development and occupational therapy research, who had been prepared to commit some time and effort to this project. Therefore, I consider that the fact that the expectations of this group were exceeded to be important, given that their initial expectations were high. The only area where there was less experienced than expected, was that of benefiting from seeing the deliberations of others, and one less person experienced this as useful compared with those expecting it would be useful. However, the quantitative view of expectations met needs to be read

with the qualitative comment about the experience which I have categorised in Table 4.14 and will discuss in Chapter 5.

Table 4.14: Feedback from participants after using the Values Exchange

Overall comments, positive	Overall comments, negative
Thoroughly enjoyed it	Extremely rigid and did not allow me to make my own statements
Kinaesthetically, visually satisfactory	Too black and white for me
Interactive	Not sure the outcome was what I intended as I had trouble understanding from which point of view the statement was being made
Already use grid - values overlay even more useful	VERY frustrating
OK experience but may have rushed reading instructions	Seemed very American -
Otherwise very enjoyable and retrospective	Didn't understand the legal issues
Prompts stimulated further response	I had a query about who is the administrator
Reflection on practice/insights, positive	**Reflection on practice/insights, negative**
Good to review different perspectives as not my practice area	Now see it as a bit muddled and opened to mood on the day!
Good for people returning to work	
Good for challenging acculturation of "norms"	
I had a change of mind of my assessment outcome	
It has made me question my decision making process	
As I progressed found myself wanting to re-evaluate the decisions I had already made	
It has helped me be creative and to consider situations in a larger framework	
Problem is we OTs focus a lot on service delivery, are busy and don't stop to deliberate as much as we probably should	
Doing this has helped me with one particular situation	
Using the VX will facilitate this and ensure my thinking is flexible	
Prompts stimulated further response	
Value has been to question myself and slow down	
If I could put my own case in that would be interesting and helpful	

Ease of use/ time taken; positive	Ease of use/ time taken; negative
Although process lengthy can see with training this would not be a factor	Practice took 2 hours - learning software, and lost info
	Good idea but disaster navigating website
	Despite spending so much time on the case only fraction of reports showed up
	Put off by the complexities of navigating the site
	Need an education session first
	It is a pity it is quite difficult to complete However it would probably get easier and quicker
Transparency/anonymity ; positive	**Transparency/anonymity ; negative**
Really liked transparency	Not happy about the lack of anonymity
Names not an issue but first names would suffice	

The qualitative comments comprise an interesting mix of positive reflection on what the tool offered with frustration at using the tool. This will be discussed in Chapter 5.

Time taken to complete the deliberation on the case using the Values exchange

A small additional feature of the post-participation questionnaire was the request to record the time the participant had taken to complete their analysis of the case on the Values Exchange. I had included this question because I had observed during the project work done in 2005, that some people found it to be a very lengthy process, and I was interested to see if this would be a factor for this group. Time taken to complete the questionnaire is presented in Table 4.8.

Table 4.15: Time taken to complete the case analysis using the Values Exchange

Number of minutes cited	Frequency	Percent
30	4	26.7
40	2	13.3
45	3	20.0
60	3	20.0
75	1	6.7
180	2	13.3
Total	15	100.0

As can be seen from Table 4.15, the time taken to complete the analysis using the Values Exchange was variable. Whilst time was a problem for the two participants who took two hours to complete their deliberation, most participants (60%) finished in less than an hour. One who completed in 45 minutes reported taking 2 hours on the practice case, and it is hypothesised that people taking longer than an hour had not done a practice case, although this was recommended. The other participant who took three hours to complete the case commented that it was a pity it was difficult to complete, but expected that it would get easier with continued use. The same participant reflected that doing the case had helped with a situation in which they were currently experiencing difficulty in practice.

4.5 Summary of Findings

In keeping with the concurrent design of this study, findings were taken from several sources (Cresswell, 2003; Hammell, 2004). Firstly, findings from the Values Exchange were based on both quantitative reports and qualitative narrative data, the quantitative graphs being indicative only, and showed in trends for both the decision making and the reason for that decision making. Findings from the Values Exchange showed that there was more than 25% disagreement among the group. Further, the primary factor underlying the reason for the variation was perception of risk. Additionally, within the groups agreeing or disagreeing with the proposal put forward by the scenario, there was further variation in decision making as to both what should be done and why, and explanation could be seen both from the trend reports and from the qualitative comment from participants. Finally, the particular issue that the Values Exchange reports made transparent was that 25% agreed with a proposal that was contrary to the client's wish, based on their assessment of risk for that client. These and other issues arising from the findings will be discussed further in Chapter 5.

Results from the pre-participation questionnaires showed that there was homogeneity of the group with regard to demographic information, both from an ethnicity perspective (all identified as European or New Zealand European) and from that of experience (nine of the 15 had been practicing for more than eight years). The questionnaires included a request for information regarding examples of situations which participants considered

Ethics of the Everyday

to be ethically challenging, and in summary the main concerns were shown to be issues to do with funding restrictions or gate keeping, resourcing and wait list issues and situations where client and therapist disagree. This information was used in part to inform the development of the scenario for the deliberation using the Values Exchange.

The pre-participation questionnaire provided quantitative data regarding participants' views on ethical process. The results showed that there was most agreement from the group with the statements: "Factors which influence my decision making are having enough facts to make a decision"; "When I have to think about an ethically challenging situation I think about following the code of ethics"; "When I have to make an ethically challenging situation I think about following guidelines"; and "Ethical practice means knowing the right thing to do". This statistical information cannot be treated as conclusive, but it can be used to suggest a trend by the group towards a preference for a fact-based approach to decision making.

The main purpose of the post-participation questionnaire findings was to a) record if participation had made a difference to participants' perception of what ethical practice means and, b) to see how their experience of participating and using the values transparency software compared with their expectations. Findings from the post-participation questionnaire, although not significant, suggested that overall the group showed a slight tendency to select fewer fact-based aspects of ethics as being important after participation. A question about time taken to complete the task was also included, because I was aware from communications from some participants it was an issue. The average of 63 minutes may have been skewed by the two participants who took 180 minutes each; 12 of the 15 completed in one hour or less. Time will be discussed further in Chapter 5. The final data from the post-participation questionnaire was to ascertain experience of using the software and to measure any differences between expectation of participation and experience. There was an overall impression that expectations were at least met in terms of learning about ethical analysis and decision making, but the qualitative comment noted several frustrations participants had had using the site, which will also be discussed further in Chapter 5. This chapter has described findings from the data. However, the goal of qualitative inquiry is not to reproduce reality descriptively, but to add insight and understanding (Morse & Richards, 2002), and Chapter 5 sets out to do that.

Chapter 5: Synthesis

This present study set out to explore values based decision making using values transparency software, the Values Exchange, to guide and record the ethical deliberations of a group of occupational therapists debating a scenario with ethically challenging content. Chapter 5 presents discussion and analysis of key findings from the participants' analyses of the scenario using the Values Exchange, as well as the data from questionnaires which the participants completed before and after participation.

I will use the key issues which emerged from the Values Exchange findings to frame the initial discussion, and will then draw on the data from the questionnaires and the background discussion from the literature which has informed this study.

Participants engaged in the reasoning process in a deep and thoughtful way, giving time and thought to their considered responses to the practice scenario. In so doing they demonstrated, through their engagement in thinking about what was the most right thing to do for Mrs Andrews in the case example, that values transparency was enabled.

From the outset four key areas of interest emerged from the review of data provided by the participants' analyses. First of note was the degree of divergence among participants in agreeing or disagreeing with the scenario's proposal. Second, there was further variation showing in the reasons which participants' gave to support their arguments, whether they agreed or not. The third area highlighted was that the factor which contributed most to the variation was risk, and how it was perceived. This in turn led into the fourth main finding which was that concerns about risk were sufficient for some participants to argue for a point of view which was contrary to the client's wishes. Narrative data in the findings showed the tensions between wanting to be client centred on the one hand and avoid what was perceived as risk for the client on the other. All of these themes have been discussed in the background section of this study, and will be used to frame the synthesis of data emerging from the study with the previously discussed issues, referencing also to additional findings from the questionnaires, following some discussion on those questionnaires.

Ethics of the Everyday

Findings from the pre-participation questionnaires showed that issues most often cited by participants as ethically challenging were decisions and policy to do with funding constraints, and therapists' apparent discomfort in being in a gate keeping role. Other resourcing issues such as waiting lists were also reported to create challenging situations, as did the issue of client and therapist disagreeing (this last being a main feature of this study scenario itself).

Additional data from the pre-participation questionnaires showed a pattern of participant responses to questions about ethics that suggested that primacy is given to fact-based considerations within their ethical deliberations, which I will refer back to in the course of this discussion. Findings also showed that reasons for wanting to participate focused on the desire to learn more about ethics and improve knowledge regarding ethical practice.

The post-participation questionnaires showed possible indicators of less selection of fact based considerations when considering ethical matters than they had shown in the pre-participation questionnaire, although this can only be viewed as a trend. Responses from participants regarding using the Values Exchange software showed strong indication that expectations were met from a learning and knowledge point of view, but that some participants experienced frustrations associated with navigating the system. This will be discussed in Chapter 6.1, under limitations. The next section of the discussion follows the themes from the key findings discussed above.

Differing decisions

The first theme to be noticed was that there was disagreement among the group as to what should be done, as well as further variation as to the reasons given to support individual arguments.

I want to make the point that the reason for exploring the analyses the participants completed, is not to comment on the rightness of decisions (whether there was agreement or disagreement with the proposal that was outlined in the scenario), as that is not the purpose of ethical analysis. The purpose is to consider issues rising from the arguments made to defend those decisions, and to explore ethical reasoning and values divergence or convergence in those arguments. Although data from the pre-

participation questionnaire showed that a majority of participants agreed with the statement "I understand ethical practice to mean knowing the right thing to do", I am arguing instead that the point of deliberative ethics is to make a case to support one's carefully thought out decision making, having used values and evidence explicitly to build that argument (see also Seedhouse, 2004). The purpose of this discussion is therefore not to decide what was the "right answer", but to analyse aspects of rightness about each position (see Weston, 2002).

On viewing the reports which the Values Exchange produces from the participants' analyses, the thoughtful deliberations which participants had used to justify their decision making was apparent. The issue of immediate interest was that, among this group of mainly experienced therapists all working from the same "facts", there would be a range of agreement and disagreement with what was proposed in a scenario selected for its everyday features. The software posted an alert because four participants had a different view from the majority (11 participants), but it did not require the electronic flag to mark it as noteworthy.

Further analysis showed that not only was there divergence of views regarding the overall decision making, but there was variation in the considered analyses presented and cases made to support the arguments or positions. However, in general those who agreed with the proposal tended to have similar reasons to support their argument. This was their concern for the client's physical safety, and the therapist's wish to not place them at risk. Those who disagreed did so for a variety of reasons which will be explored later in this discussion. Here was a situation where all of the participants were given the same "facts", and yet produced a range of decisions or arguments. The participants were all informed by the same professional standards, competencies, and code of ethics, and the findings from the pre-participation questionnaires suggested that the group gave some priority to these factors being important for decision making, and yet they produced this different a range of responses. What more then can be said to be guiding decision making if it is not just facts, codes or guidelines?

It is clear from these findings that in selecting aspects of the case that were most right to them, participants were demonstrating values-based decision making in action.

Ethics of the Everyday

Fondiller, Roage, and Neuhaus (1990) describe values as non-quantifiable influencers on performance; the study shows the influence they have, and the literature indicates that this should be so, given the values-rich context in which the participants are working. The way this can be seen is via decision making, and particularly decision making of an ethical nature because that is where values compete (Weston, 2001).

So although participants were using values based decision making in their selection of aspects of the case to support their agreement or disagreement with the proposal, it seems from responses to the questionnaires, that the term is not used nor described, and this is borne out by both the occupational therapy literature and general health literature. Further, even though evidence based decision making is described by occupational therapy writers in such a way as to be inclusive of values, the lack of specific reference to values based approaches may contribute to the gap that some writers describe between theory and practice in the area of client centred care (Carpenter, 2004).

Values Divergence

In this next section I will discuss other aspects of values as influencers of decision making (Fondiller et al., 1990) which the software highlights and this study has explored.

In addition to whether participants were agreeing or disagreeing with the proposal, there was further variations in decision making as to what should be done and why. Interestingly the professional literature points to the notion of occupational therapists holding the same humanistic values; this study has shown that whilst professional bodies may have overarching ideas about values which are informing the discipline, in an individual situation, individual values will be in play.

Although the first impression from the analysis of the Values Exchange reports showed in a simple figure that four participants agreed and 11 who disagreed with the proposal, further analysis showed that this was not clear cut. The qualitative narrative data from the Values Exchange made the values based decision making transparent, and showed much more complexity than just whether there was agreement or not. For example, one of the participants who disagreed with the proposal indicated that the disagreement did not mean she would support an application for Ministry of Health funding for the

client's preference of a ramp at the back of the property. Instead, the participant proposed giving the client information on how to proceed with privately funding her preferred option of installing a ramp at the rear entrance to her home. Another participant who disagreed thought she might be at odds with colleagues, because it seemed like going against guidelines to support a ramp at the back of the property in this situation. Other participants disagreed for pragmatic reasons, such as knowing the client would not sign the application, and others supported making an application for a ramp at the back, but taking care to mitigate risk factors, such as dampness. Still others proposed postponement to give the client opportunities to work through matters of grief and loss, with a view to better decision making, and may have pointed to humanistic values influencing their reasoning (or may have been postponing decision making). These are not research-evidence based factors. The process of selecting factors to justify argument, whilst using as many facts as possible, was an evaluative one. It is not divergence of facts which is making the difference; it is divergence of values.

This is to be expected. I argued in Chapter 2, that for three reasons this is a values-rich area in which decision-making is occurring. These reasons were that it is in the context of primary health (Fulford et al., 2002); in a general practice area (Culpepper & Gilbert, 1999) and the discipline involved, occupational therapy, is one which has values-based concepts of occupation, participation and client-centred care as central paradigms (Sumison, 2000; Wright-St.Clair, 2001).

The values transparency reports revealed the considered analyses of all participants showing a rich level of problem solving and weighing-up of options, and highlighted the variation in a seemingly straightforward situation. It is not clear from the responses the participants made on the questionnaires, or from the occupational therapy literature, that referring to this diversity of values and making them evident in decision making is understood and emphasised.

Principles clashing

In this section I am referring to another key finding being that of some participants agreeing with a proposal that was contrary to the client's wish.

Ethics of the Everyday

Once again this was immediately obvious in the reports which the Values exchange produces. In my analysis and interpretation I am linking this to a fundamental clash of principles, which is at the heart of why the matter was challenging. Further, the findings showed that the primary factor underlying the reason for variation was perception of risk, and this was the primary reason for some participants agreeing with a proposal that was contrary to the client's wish.

People who propose that following ethical principles is sufficient to solve ethical dilemmas may do well to consider how principles would help in this case, when it is the clash of the principles themselves which is causing the dilemma. To take as an example the four principles proposed by Beauchamp and Childress (1989), the tensions described by participants who agreed with the proposal are clear, as they realised what they were proposing was against the express wishes of the client. The analyses of all participants refer to client centred practice and showed that they wanted to adhere to the principle of autonomy (to remove obstacles to the achievement of human potential; Seedhouse, 1998), but the key principle in arguing this case for those who agreed with the proposal was that of non-maleficence; they are of the view that supporting the ramp at the back will be of harm to the client. This is not a simple matter, and the potential for Mrs. Andrew to fall and be harmed in a way that creates a further obstacle to her achieving her potential is a real one. It highlights the issue of the diversity of values at play in this community setting; one can envisage the surgeon who was faced with the decision of whether or not to amputate Mrs. Andrews' leg having far fewer choices available.

I included the issue of safety considerations over-riding client preference in the scenario because it is known from the occupational therapy literature to be challenging for therapists Russell et al. (2002) In addition participants had cited this issue in their responses to the request for examples of situations they find challenging. Previous studies I reviewed in the occupational therapy literature (Barnitt & Partridge, 1997; Foye et al., 2002; Russell et al., 2002) recorded as one of the issues of conflict in challenging situations, if not the main issue, that of conflict between client and therapist goal, and this was also the issue described third most frequently in this study. This issue is not just challenging for occupational therapists (Fry & Johnstone, 2002), and it sits at the heart of what we mean by client centred care, and what we mean by values

based decision making; it is easier to be client centred when there is no divergence of values.

The findings from this study show that none of the participants who agreed with the proposal were entirely comfortable doing so, but as could be seen in one of the reports, the primary aspect of the case for that group centred on risk to the client. Conversely, the group who disagreed with the proposal to override Mrs Andrews's preference and recommend installation of the access ramp to the front entrance of her home judged the primary aspects of the case to be dignity and rights.

A further aspect which I included in this scenario because it was clear from the pre-participation questionnaire that participants found it the most challenging issue, was that of applying for environmental supports on behalf of a client from a third party funder. The issue which creates tension being that of client need compared with available resources. This was a less emphasised aspect of the study scenario, both from the way the scenario was written and from the reference to funding in the participants' deliberations. However, it was clearly a factor and some of the arguments given by participants reflected the need to be careful with public money. This demonstrated conflict between ethical theories of duties (deontology), and best outcomes (utilitarianism), and within both of those are further tensions (duties to whom?, best outcomes for whom?).

Perception of risk

This section discusses the primary factor underlying the reason for variation in decision making, which was the perception of risk. The results indicate from the outset where the key issue of divergence for the group of participants lay, that being perception of risk. Reports also highlighted how it was perceived by both groups. I have discussed above that it was this factor and the conflict between the principles of creating autonomy and preventing harm that were evident in the arguments of many of the participants. However, those who ended up agreeing with the proposal, considered the physical risk from an unsafe ramp to be the overriding factor. This reflects findings from other studies and Russell et al. (2002) called the phenomenon "the safety clause" (p. 369) where a therapist's view of safety trumps autonomy expressed by the client.

Ethics of the Everyday

If participants had referred to the code of ethics of the OTBNZ (2004) for assistance in deliberating this case they would have seen this information:

> "situations where consumer choice is over-ridden e.g. for reasons of safety should be clearly documented including a transparent reasoning process" (p. 2)

I have referred to this challenging question of therapist view of client safety versus client view of client autonomy being well documented in the occupational therapy literature, (Russell et al 2002 for example) which may explain why the issue is specifically addressed in this code. However in a document which should have as its primary purpose the goal of setting the moral context of practice for members of the profession (Wright-St.Clair & Seedhouse, 2004) this statement seems to stop very short of meeting that aim. In fact, although it is good that the code affirms the need for the reasoning process to be transparent and documented, it seems to give an "out" for invoking the "safety clause" (Russell et al., 2002). The opportunity to address the issue of fundamental moral principles, and the help which a process of ethical analysis could offer, is missed.

A further interesting feature about risk in this scenario was that it was not just that some participants considered risk to outweigh client preference, but that they considered their perception of risk to outweigh the client's perception of risk. Unpicking this somewhat from the qualitative comments, it is possible to make an assumption that participants viewed the physical risk of falls to be high, and the patient's perceived risk from intruders, and to their peace of mind, to be low. Alternatively, they may have agreed with the client, but judged the chance of supporting a successful application to a funding organisation using non-physical health factors to be low.

It would be worth exploring how risk as a concept is understood in the health professional community in general and from the point of view of this study, in occupational therapy in particular.

Summary of themes emerging from participants' analyses

To summarise the first section of the discussion which focused on the themes emerging from the analysis of the findings from using the Values Exchange, values are clearly underpinning decision making by participants in this study. I have argued that this is a good thing, particularly in this values-rich area in which the scenario was set. If values were evident in this scenario, they are likely to be present in other decision making of this nature. The goal is not to have conformity of decision making, because ultimately each health professional makes decisions according to the best research evidence, the goals and preferences of the person and their own experience of the context and practical considerations. However, it is important that the values influencing decision making can be seen, to satisfy client need for information, professional standards and public and funder expectations. The diversity of values operating in this context affirms the argument raised earlier regarding the morally rich nature of community practice, where the work is more value laden because the values are highly diverse, and they cannot be ignored for practical purposes (Parker, 2002). Occupational therapists focus of care on meaningful occupation depends for its success upon a client centred care approach.

Combining the value-rich practice area of community with the value-rich discipline of occupational therapy, suggests that while it is understood that there is likely to be variation in decision making, it is also essential that the values informing decisions are made visible so they can be understood. Do occupational therapists own and acknowledge this values rich area of work? Do they perceive that evidence-based decision making can include values?

I am continuing the discussion on values based decision making by considering how the findings are situated within the literature. I am once again using the decision categories developed by Wright (1987) to frame this section (see Figure 2.3).

Ethics of the Everyday

Decision information categories (Wright, 1987)

Action constraints: The first decision information category to be discussed is what Wright refers to as action constraints. The majority of responses from participants in my study, however, were to do with the challenge of making decisions when there are what Wright (1987) refers to as action constraints. Participants in the study highlighted in their responses to the pre-participation questionnaires the tensions when organisational issues such as waiting lists and funding restrictions appear to impact on client centred care and cast therapists as gate keepers. Aspects of this were present in the scenario debated in this study, and revealed some of the tensions.

Foye et al.'s (2002) study included similar concerns. However, they were not done in the New Zealand context, and because of the level of concern expressed by participants I suggest there is opportunity to explore this further, within the profession and with funding organisations. When clinical decision making involves meeting the criteria of third party funders, this adds complexity and further aspects to be considered. It may have influenced the decision making of participants in this study's scenario, depending on the experience they had had with one of the funding organisations.

One of the discourses underpinning eligibility for supporting applications on behalf of clients for environmental support services, such as housing alterations, has been to ask if the item is essential or desirable. Although the decision maker needs as many facts as are available to inform that question, the line to be drawn as to which of the two categories apply in a particular situation will be an evaluative one, not a matter of fact.

A question to be explored is how much scope is there for values-based decision making to transparently inform an application to a funding organisation to support an application for environmental support? Do application forms, criteria documents and system processes support demonstrating values transparency? It is a reality that there are serious resourcing constraints, as more options become available, demand grows and costs rise. That means more and more values will be in play with the potential for conflict and challenging decision making. Having them invisible is not the answer.

Ethical theory: The next of Wright's (1987) categories to revisit is that of ethical theory. I have discussed some aspects of this above under the heading principles

clashing, and in the Chapter 5 I argued that while theories are useful to frame a situation and give the decision maker an understanding of the position one is arguing from, they cannot be imposed onto a situation as they stand. Ethical theory could be seen informing some of the arguments from the participants, with some giving emphasis to the concept of duty, and others to that of best outcome, whereas the arguments of others covered aspects of more than one theory. There was one elegant example of a person who combined duties, utility, virtue and pragmatics into her response. However, there was also an example of the same theory (utility) being used to argue different viewpoints. One participant's view was that it would not be a good use of resources if the client would not use the ramp, and another view was that it would not be a good use of resources if the client fell on it and harmed herself. Clearly more than ethical theory is needed.

Under this section I include some discussion as to what theory or framework underpins health professional practice which they can use to support them to work with the highest moral content. In Chapter 2.3, several models were described in the occupational therapy literature, as well as some examples from the general literature, client centred care one specifically mentioned by participants. Although previous studies (e.g., Duggan, 2005) have pointed out that that there can be a mismatch between theory and practice, and certainly participants described these tensions, a true client centred model would certainly help decision makers in this case.

What other theories or frameworks might help? I had an indication that a particular approach could be useful when I read the comment of a few participants, who, whilst not agreeing with the proposal, did not necessarily think going ahead with the ramp at the back immediately was the best option either. The cases they built using the ethical grid to describe what should be done indicated that more work was needed before the decision should be made. This suggested to me that having a philosophy such as the Care Aims Model (Malcomess, 2001; 2005) underpinning practice decisions might assist. Whilst not a tool for ethical decision making, it can assist health professionals to be clearer about the primary reason for intervention at any particular phase of care. For example, it may have been that the first assessment with the client showed that the primary reason for intervention at that time, was not to determine the placement of a

Ethics of the Everyday

ramp, which could be categorised according to Malcomess (2005) by the care aim *enabling*, but rather to support the client to cope with their present condition, for which the aim of care is defined by Malcomess as *supportive*. Realistically, in the busy world of community health there can be pressure to respond quickly to "assess for a ramp". A framework such as that which Care Aims offers can offer clarity as to the key purpose of the work; it suggests that the questions to be asked are not "what is wrong?", and "can I change the problem?", but "can I help change the impact of this problem?". There are similarities between this and another framework, the Foundations Theory of Health referred to by Wright St Clair and Seedhouse (2004) as a model congruent with occupational therapy underpinnings of client centred care.

Decision theory: A further category described by Wright (1987) was discussed in Chapter 2.2, in which I explored resources to assist with decision information, is decision theory. One would expect that documents such as codes of ethics or professional standards documents would be first among the resources used to support decision making of an ethical nature and indeed most (80%) of the participants in my study responded that following the code of ethics helped with ethically challenging situations. However, perspectives from the health literature show that while health professionals do turn to codes and rules to help, their utility is questioned (Veatch, 1985). Wright and Seedhouse (2005) give examples where referring to codes of ethics is not helpful, and describe them as generally inadequate for decision making.

Similarly in this study, how much practical assistance could the code of ethics (OTBNZ 2004) offer in such a situation? In Chapter 2.2, I suggest that in general codes are not practically useful in offering: a) true understanding of what health work as moral work entails, and b) understanding about ethical analysis. However, the Code of Ethics for occupational therapists (OTBNZ, 2004) does go some way to addressing this in categorising the document under relationship sections and could well elaborate by embedding the moral nature of the work into those relationship headings, and by following up on the requirement for therapists to have the skills of ethical analysis. The OTBNZ code did refer to their website for an example of ethical analysis, but I was advised by a staff member that it was not available (email correspondence), and I could find no evidence of examples or standards of what those skills might be. Similarly, the competency document (OTBNZ website) makes an explicit requirement under the

competency which sets the standard for safe ethical legal practice, that therapists use "skills of ethical reasoning and comply with the code of ethics". This started to feel like a circular argument, and one which should be addressed. Wright-St. Clair and Seedhouse (2004) argue for codes of ethics to focus on supporting members to gain enriched understandings about the moral world and to build competence in decision making in that moral world.

As I have argued that codes of ethics as they currently stand are generally descriptions of expected moral conduct, there is a case to be made that the code of ethics for the OTBNZ be called a moral code, that it should be explicit about what moral work in health means for occupational therapists, and it should include information or reference material as to how therapists can engage in skills of ethical analysis in situations which challenge moral practice.

Decision theory (Wright, 1987) includes tools to assist decision making and were discussed in Chapter 2.2 (see Figure 2.3) In that section I argued that tools can be useful as they can allow the decision maker to find a way in to a problem and be able to consider the particular issues of a situation. As Parker and Dickenson (2001) point out, to use a tool is to engage at some level in moral reasoning. It is preferable that tools start from the perspective of identifying the facts and values in the situation, rather than starting from the perspective of solutions.

The Values Exchange which was used in this study is an example of such a tool and I will now discuss some aspects of its use which the study highlighted. Although in this section I am working through Wright's (1987) decision information categories to frame the discuss of the synthesis of the study with the literature, I am also going to use those same categories to evaluate the utility of the Values Exchange in providing decision making for the purpose of this study.

Commencing with the category *decision theory,* this is the fundamental purpose of the Values Exchange as it provides an opportunity to work with others using deliberative ethics with a view to making values transparent and therefore enhancing ethical decision making. The findings from the study showed that some participants benefited from the way the software is structured and enables the user to work through a process

Ethics of the Everyday

of ethical reasoning in the first place. From a researcher's point of view, the transparency the software provided made certain findings immediately obvious as trends, which could be further analysed through the qualitative data.

Values as a decision information category, is again a fundamental point of the Values Exchange. One of the most important findings the study produced was the opportunity to see values behind the decision making being illustrated so clearly.

The next decision category to be explored as a discussion of the Values Exchange is *data base.* Ethical decisions are not factual decisions but they need a solid basis in fact The Values Exchange is able to give users the opportunity to show as much research and other evidence as possible to add to their argument, although this was not an aspect of the present study scenario which participants emphasised strongly to support their analyses. A worthwhile additional feature which was not used for the present study was that when the case is set up on the Values Exchange, links to current research or other evidence can be posted to information for users to view as background to a case. Which evidence to select as background to a case is an evaluative decision.

Action constraints, as described by Wright (1987) were shown to be a feature of the case in the arguments which participants proposed. Participants clearly took into account the realities of the practice world, but where their deliberations showed different assumptions about what would be funded; having these assumptions visible could form the basis of an ongoing exploration to acquire more facts to inform that aspect of the decision. Findings from the study suggested that the Values Exchange would be useful for advisors in the funding organisation, who deal frequently with decision making and competing priorities.

The last of Wright's (1987) categories with which I am reviewing the use of the Values Exchange is that of *ethical theory.* Participants did not refer to theories specifically but some demonstrated by their argument that they were favouring a rules-based or a best outcomes approach. However, although the Values Exchange draws on many ethical theory and principles, it guides the user to frame their analysis from the perspective of the specific situation and person, and not from the perspective of an abstract principle or

theory. Because of this, some participants demonstrated using parts of various theories, leaving open the possibility of many ways of defining values (Hugman, 2005).

In summary, information is primary for decision making, and the Values Exchange meets all of Wright's decision information categories. In particular it assists us to "avoid locking ourselves into unpromising problems and to constructively engage with the problem" (Weston, 2002, p. 48).

Values and evidence: I will conclude the use of Wright's decision information categories by re-visiting *values and evidence* (evidence being depicted as "data" in the model), and explore how changing the way these are viewed may be helpful for the type of decision making such as was the subject in this study. In doing so, I will be addressing one of the study questions: what is values-based decision making, what is its relationship with evidence based decision making and is it a useful term?

Anyone exploring values based decision making in a healthcare arena does so with the awareness that the current paradigm is that of evidence based decision making and this was discussed in Chapter 2. In that chapter, I also considered the meaning of the term values based decision making, and values. Using the works of numerous writers and theorists, I chose the definition of values as preferences for the purpose of this study. I have not in the course of my study and analysis come up with another, except that of Fondiller et al. (1990) who describe values as being non–quantifiable influencers on performance. Whilst not saying what values are, this description does have a practical appeal that may be useful to use in this practical scientific world of health, as a sub-definition, a category, or explanation, to sit underneath the meaning as preferences. So, values are about preferences and for ethical analysis that means that values are the decision-influencers that we cannot measure. This reflects Fulford's (2005) idea of values as an appreciation of the subjective.

I have argued that values are, or should be, central to health work. As this study has developed I have observed in the participant's reasoning processes, and established through review of the health and occupational therapy literature the growing sense that not only is it essential that values are underpinning health but that they are seen to be so

doing. The way this can be seen is via decision making. It was clear from my review of the general health literature that values based decision making is not currently widely used. I found little reference to it in the literature of the study group occupational therapists, and the small amount of information given from participants in the questionnaires did not contradict my impression that the term is not used. In the recommendation section of Chapter 6 I will present ideas based on this discussion.

Summary of synthesis of findings with discussion on literature

In this section I have discussed the categories of decision information as described by Wright (1987), and included in that discussion I have assessed the utility of the Values Exchange for this study, using those same categories. Synthesis of ideas generated by the findings of this study, and combined with the work of theorists from the literature, have highlighted some areas where changes could be made, and these will be discussed in the concluding chapter, Chapter 6.

Chapter 6: Conclusion

6.1 Overview

This chapter will provide give an overview summary in section 6.1 which will include a discussion on the limitations and strengths of the study. Recommendations for future studies along with proposals for practical action and philosophical considerations suggested by the study will be covered in 6.2.then in 6.3 concluding remarks focus on the key issues highlighted by the study in the context of the literature.

Limitations of the study

As this study was for the purpose of a master's level dissertation, it was necessary to limit the scope of the work. However, this was difficult to do in an area as richly connected with numerous concepts of health as values is and I am aware that there are some concepts raised in the discussion which would merit further analysis. Elements of philosophical analysis were used throughout to inform the background discussion and to question concepts through the process of raising issues and looking for meaning, but there is much scope for more work in this area. For example, the concept of risk which rose as a key area of variation among the participant group would have benefited from further philosophical analysis which this study could not accommodate.

A particular limitation was the loss of data from the Values Exchange site which I was using for the study, due to human error on the part of the site administrator. This error was not one that could have been anticipated, and since this study, a change in the system has meant that the error cannot re-occur. The loss of data meant that many of the options of viewing and comparing the reports were not available, and it necessitated the reproducing by hand reports that are usually easily downloaded from the system. Fortunately, print copies taken of many of the reports before the data was deleted, meant I was able to reproduce all of the quantitative reports in graph form, which showed trends and highlighted areas of values divergence. I had also retained copies of the qualitative narrative data for some of the participants, with the result that enough data was retained to provide good insights into the considered responses given. The loss of

Ethics of the Everyday

data did not impact on the participants as it occurred six weeks after the case closed on the Values Exchange.

Some of the participants, and several therapists who didn't complete their analysis using the soft ware, experienced difficulty accessing the website or navigating the software. Most participants received their information on how to log onto the programme via email or post, and from experience I have found that it is easier and clearer if information is given in a live situation. In addition, the programme developers point out that use of the software is much easier to use after a practice session, and a future similar study could include a requirement that all participants submit a practice analysis before participating, to aid usability of the software. The Values Exchange information line was used during the study as necessary, to assist with sorting out any particular issues for participants. Most issues were locally based, but anonymised general feedback will be given to the developers of the Values Exchange to inform future development. Time taken was an issue for some participants, and again the Values Exchange developers' advice, and my experience, suggests that use becomes quicker with practice; this would need to be the case in a busy health environment.

Reflections on the study as I was engaged in analysis and discussion, suggested to me that a case study design (see Hammell & Carpenter, 2004) could be an improved option to be considered for future work using the Values Exchange. Although participants in my study were able to access reports after they had submitted their own analysis, they did so as individuals. A case study design would enable the engagement of the study participants in the study's analysis, discussions and conclusions, increasing the opportunity for reflection and learning.

I will conclude with a comment about anonymity. The option to participate anonymously was offered to participants, which one followed up on. One other noted in the post-participation questionnaire that they weren't happy with the lack of anonymity, and although one also stated they liked the transparency and for most it wasn't an issue, it is worth noting, and further discussion on the topic may be useful. Certainly, it is unlikely that occupational therapists are accustomed to having their deliberations visible in this manner; however this could also be seen as a strength of the use of software.

Ethics of the Everyday

The small quantitative numbers from the study were intended to add concurrency of information to the study, and not replicability. The intent was to explore the issue of values based decision making using the values transparency software in a small pilot; further studies will be needed to gain more knowledge about the issues raised.

Strengths of the study

Health literature points to the fact that having values transparency in ethical decision making is a good thing. This study was able to illustrate clearly the way in which participants drew on values as a significant part of their ethical analysis. Further, whilst values should be present in decision making, it is important that they are transparent. Again, this study was able to show through using the values transparency software that not only could the divergence of decision making be seen, but also the divergence of values underpinning the different positions. The concurrent nested design added useful data from the questionnaires and proved a worthwhile design.

The values transparency software, the Values Exchange, which was used by the study, is very innovative and offers numerous opportunities for health professionals to enhance moral practice; although not primarily intended as a research tool, I believe that this small study has shown that the software is well suited to research.

Whilst the findings showed that there were problems for some participants with navigating the software, there were very positive comments recorded regarding the experience of deliberating using the tool. For all participants, expectations of participation had included wanting to learn more about ethics, and for most that expectation had been at least met, and in most cases superceded.

Co-incidentally, since I commenced on this study, the New Zealand Association of Occupational Therapists has contracted with the developers of the Values Exchange to set up a site for occupational therapists. A further strength of the study may be that this work with occupational therapists as participants informs future development of that profession's use of the Values Exchange.

Ethics of the Everyday

6.2 Recommendations

My recommendations are a mixture of philosophical and practical considerations and are offered for consideration. I am presenting recommendations on: work by the OTBNZ Code of Ethics; addressing the issue of the concept of risk in the profession; highlighting some theories of health for consideration; developing opportunities for further use of the Values Exchange, and, primarily, coming to an inclusive understanding and use of values in decision making

Firstly, whilst I consider that the Occupational Therapy Board of New Zealand has produced a code of ethics which I considered the best among those I reviewed, I would recommend some changes which I believe would add practical and philosophical assistance. From a philosophical perspective I would recommend that the title and purpose be debated, with a view to changing it to that of a moral code. This would provide the framework to pick up on themes proposed by Wright-St. Clair and Seedhouse (2004) to further embed into the code ideas of what it means to work in a moral way. I would also recommend that this document give clearer information about ethical analysis; both on the imperative for doing it and on the skills to achieve it. A first, and necessary step, would be to attend to the anomaly where readers of the code are invited to view an example of ethical analysis on the website, and it is not available.

I would further recommend that members of the occupational therapy profession engage a philosopher to debate with them, and ideally with clients, the concepts of safety and risk, which could include analysis of the statement regarding the over-riding of client choice for safety reasons on page two of their code of ethics (OTBNZ 2004).

Secondly, two philosophies or theories which I have referenced in this dissertation I consider worth exploring by all health professionals and the concepts underpinning them are certainly congruent with occupational therapy, being those of creating as much autonomy as possible, and human flourishing. These are Care Aims (2001, 2005) and the Foundations Theory of Health (Seedhouse, 1998), and I would commend those interested in values-based decision making to explore them further.

Thirdly, given that occupational therapists in New Zealand now have access to the Values Exchange via the New Zealand Association of Occupational Therapists, I would

recommend that take up the real opportunities this offers to debate ethical issues of general interest with which the entire membership could engage. In addition practice groups or teams could engage together (in any size groups) to deliberate a particular clinical case, in the same way the scenario for Mrs Andrews was debated for this study, in the process of making moral sense of a situation (Parker 2002). I could envisage for example that in hard situations a therapist could attach a copy of their own deliberation to support an application to a funding organisation for equipment where the outcome is uncertain, or with which they are uneasy. This would help the next level of decision makers and the client see the level of analysis behind the therapist's stated position. There is potential to also have clients and therapists involved in analysing a case; of course the decision to include clients would be in itself values based one.

Finally, I argue for increased discussion, knowledge, and confidence amongst health professionals to be using the term evidence based decision making with a full and inclusive understanding of the term; one which allows and acknowledges the role of values in that decision making. I recommend that practice areas debate and discuss how their area encourages values based decision making and values transparency, in practical terms such as a review of documentation, but also in theoretical terms, reviewing what informs policy.

I believe from the exploration described in Chapter 3, that the case for values to be explicit in informing health care decision making has already been well made by health writers, theorists and philosophers. I do not believe that the work to promote or describe it in a way that be easily adapted by health professionals, has been done. I consider that there are three ways this could be done:

1. *Values based decision making* could be profiled as a term; one that is intended to be inclusive of evidence, as good evaluation includes as many facts as possible, and would also include client and health worker values based on their experiences and preferences. This is in essence defined by Seedhouse (2004) in his statement regarding the explicit use of values and evidence to build a case that one can defend which I used to frame exploration of the topic in Chapter 2.1.3.

Ethics of the Everyday

However, although many see the logic in the definition of values as preferences, I am aware from discussion in the literature, and from this study, that understandings of the term are very wide ranging.   Therefore, simply incorporating values, into another term (values based decision making) has the potential to produce the same confusion that has resulted in the introduction of the term evidence based decision making.

2. A new term, for example, *healthcare decision making* could be explored, in the same way that Fulford et al. (2002) recommend the use of the new term *healthcare ethics* to distinguish a more holistic understanding of ethics than is currently understood. Throughout this work, however, I have alluded to problems inherent in health care where terms are introduced and adopted without the necessary full and continuous discussion as to what the healthcare community collectively, or separately, understands those terms to mean. Therefore, I do not recommend this option.

3. The term *evidence based decision making*, could have its full holistic meaning promoted. It is already considered by many writers to incorporate the inclusion of client and health worker's values and experiences, plus evidence from research. These writers include those involved in the promulgation of the term *evidence-based practice* in the 1990s, with Haynes (2002), for example, noting that the term had become "less pretentious and more practical" (p. 6), and must continue to evolve if it is to be of use. Depoy and Gitlin (2001) explain that the word evidence itself means everything that is presented as explanation and this allows for an inclusive understanding. There is certainly no point in defining any term so broadly as to be meaningless, but in this case the broad definition already exists and is well understood in some areas, including judging from their literature, occupational therapy (Hammell, 2001).

I am therefore arguing that the term evidence based decision making which is already in wide spread use, be discussed in a way that allows the inclusion of values as well as research evidence, and experience knowledge of the health professional and the client (Haynes et al., 2002). Problems have arisen because the term evidence based practice came into disseminated usage without accompanying analysis and discussion, which has contributed to the sense of two camps of definition; those who already espouse the inclusive definition and those who understand the term to mean exclusively research evidence-based. Meanwhile, further discussion and analysis can inform the wider use

of the inclusive term, and argument that values are part of its meaning. This needs to be done not by describing values as an equal partner with research evidence, as I am against the notion of setting values up against evidence in a decision making contest, as both are fundamental. What is required is to regard values *as* evidence (Wright, 1987). The discourse to be aimed for is not "are you basing your decision on values or evidence?", but "what is the values component of the evidence supporting your argument?" This removes an either or option and can support the idea that all evidence has an element of evaluation, and values can be viewed as evidence, or can be supported by evidence. Occupational therapy literature shows that there has been strong foundation work done to support this approach (for example Sumison, 2000; Ballinger & Wiles, 2001).

Participants in this study, clearly used values-based decision making, but responses on the questionnaires suggested that the term was not well known. In addition although findings from the study questionnaires were indicative only, they suggested that among this group there was a tendency towards using more a more facts-based approach than a values based approach to ethical decision making. This is somewhat at odds with the values-based milieu in which the decisions have to be made.

Central to a discussion on values, in Chapter 2.1.3, I raised the use of another existing term in health care, widely used and variously understood, that of client (or patient) centred care. It has been discussed in the health literature for three decades and if the core of its meaning (as illustrated in Fulford's, 1996 model in Figure, see page 30) were adapted as a fundamental tenet for health, it would follow that any decision making would automatically be values based. Therefore, I am arguing, that rather than introduce and develop the relatively new term of values based decision making, or an entirely new one, such as healthcare decision making, that work is done to promote discussion and shared understanding of two existing widely used terms, client centred care and evidence based practice.

The term client centred care in its broadest sense is fundamental to moral work, and the term evidence based decision making should continue to be discussed and explained in its holistic sense which includes values as part of the evidence data base along with

research evidence. Research based evidence should be the term used if that is the specific form of evidence under discussion.

To summarise these ideas and to answer to the question, "what is values- based decision making, and what is its relationship with evidence based decision making?" I have created a model (see Figure 6.1) to assist with the conceptualising of the terms.
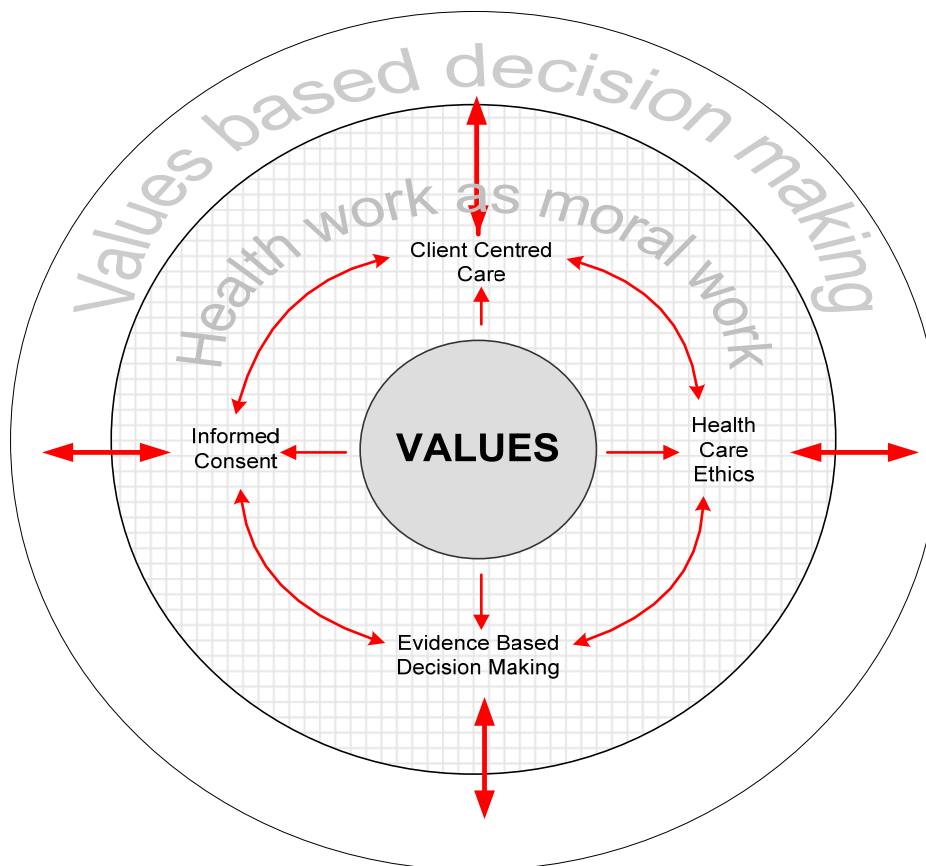
Figure 6.1: What is values-based decision making; what is its relationship with evidence based decision making?

There are several ideas this model seeks to convey. One, that values are central to health care, as was argued through Chapter 2. Second, that moral work is the main paradigm of health. Third, that there are four practical frameworks, supported by the centrality of values and an overarching understanding that decision making should be values-based, which can be made more visible and can help achieve that moral work. The terms for these four frameworks are already widely known but differently understood, as I have discussed in this work, and they are: evidence based decision

making; informed consent (or more appropriately, informed choice, not explored in this work); healthcare ethics; and client centred care.

These terms are not mutually exclusive and are not ends in themselves, but could provide a practical framework to understand and achieve the end of moral work, which is the aim of values based decision making. Expectations as to what exactly good moral practice would look like in each of those frameworks could be debated in each of the disciplines, spelled out in their moral codes and ideally discussed across the disciplines. As an example, the model proposed by Haynes et al. (2002) could be debated as an inclusive definition for evidence based decision making. Healthcare ethics, as proposed by Fulford et al. (2002) could be discussed as the way to approach ethical analysis, and Hammell's (2001) view of client centred care could inform debate on that topic. I have included informed consent in the model. I have not raised the issue in the background chapter, and nor did it emerge as a theme from the study, but it is as similarly fundamental to moral practice and a values-based decision making culture as the other three frameworks I have illustrated. I would argue that it should more properly be called informed choice, and is a reason for having the values in decision making transparent, so that clients can be truly informed.

I have throughout this dissertation argued for values to be made visible not just in decision making with individual clients, but also to be visible in healthcare models and documents which support that individual care. I am proposing that while the concepts behind it are discussed, the term itself is not promoted to be used in practice. Instead other terms that are already in widespread practical use be broadened to include and be informed by values. These are evidence-based practice, client-centred care, informed choice and healthcare ethics.

6.3 Conclusion

This study set out to explore values based decision making and answer the following questions:

1. What is values- based decision making, what is its relationship with evidence based decision making and is it a useful term?

Ethics of the Everyday

2. To what extent is there convergence or divergence of views among occupational therapists when deliberating an everyday case scenario requiring decision making of an ethical nature?

3. What situations do occupational therapists find ethically challenging and what do they use to assist decision making including code of ethics?

I have answered these questions in the course of analysis and discussion, and in this conclusion will summarise the key points arising from the study. Firstly, the study showed both from the literature and the findings that the practice area of community occupational therapy is one where values as evidence will be informing decision making at least as much as research as evidence. Therefore, divergence of values exist and I am arguing that it is essential that the decisions and the analyses behind the decisions can be seen. The study showed that using the values transparency software, the Values Exchange, is a way to have the decision making and the values behind the decision transparent. This will then give possibility to good discussion on that variation

At odds with the findings that values are informing decision making, and also highlighted in other studies, is a possible tendency that participants seek facts, rules and codes to guide ethical decision making. Basing my views on the literature, I am arguing that good skills of ethical analysis are needed, to help people deal with the complexities imposed by diverging values. I argued that the code of ethics and the competency requirements of the OTBNZ, whilst referencing the need for therapists to have these skills of ethical analysis, could go further with practical support in this area.

The theme of selecting facts when working in a values-rich area is not surprising because of the discourse surrounding evidence based practice, and I recommend that there be considerable debate and discussion as to what the term means, for all disciplines. I have argued, as have numerous writers, philosophers and theorists have, that the term already should be taken to include values, and a model such as is depicted in Figure 2.1 (Haynes et al.2002) could help inform such discussion. I believe there is some imperative about this, as there are competing discourses in the health practice area; on the one hand, client centred care is being promoted in the literature, health strategy and policy, and on the other hand a view of evidence based decision making is in place which for many does not yet include values.

The phenomenon named by Russell et al. (2002) as the "safety cause" (p. 369) was highlighted by this study, as it has been in many others, and is a source of tension and challenge for therapists. As such, I believe it would be useful for the profession to undertake some analysis and debate the issues surrounding risk. Debating the issue in the context of moral theories to support practice could offer understandings, assistance for therapists when faced with difficult competing priorities of client autonomy versus non-maleficence.

In conclusion, in emphasising the main finding, I believe that the study has contributed to the view that values can be evidence, and that health professionals should be supported to have the confidence to use them as such. However, in the same way that we expect rigour from our research evidence, so we should from the values which are informing our decision making, and for health professionals that means that they must engage in a robust process of ethical analysis with values transparency evident.

Ethics of the Everyday

References

Allmark, P. (2005). Can the study of ethics enhance nursing practice? *Journal of Advanced Nursing, 51,*618-624.

Austin, W., Lemermeyer, G., Goldberg, L., Bergum, V., & Johnson, M. (2005). Moral distress in healthcare practice: The situation of nurses. *HEC Forum, 17,* 33-48.

Atwai,A., & Caldwell,K.(2003). Ethics: occupational therapy and discharge planning: four broken principles. *Australian Journal of Occupational Therapy, 50,* 244-251.

Ballinger,C., & Wiles,R. (2001). A critical look at evidence-based practice. *British Journal of Occupational Therapy. 64,*253-255.

Bandman, B. (2003). *Moral development of healthcare professionals; rational decision making in healthcare ethics.* Praegar: Westport, Connecticut.

Barnitt, R. (1993). What gives you sleepless nights? Ethical practices in Occupational Therapy. *British Journal of Occupational Therapy, 56,* 207-212

Barnitt, R., & Partidge, C. (1997). Ethical reasoning in physical therapy and occupational therapy. *Physiotherapy Research International, 2,* 178-192.

Beauchamp, T. L., & Childress, J. F. (1989). *The principles of biomedical ethics (4th ed).* Oxford: Oxford University Press.

Berwick, D., Davidoff, F., Hiatt, H., & Smith, R. (2001). Refining and implementing the Tavistock principles for everybody in healthcare. *British Medical Journal, 323,* 616-620.

Blair, S. E. E., & Robertson, L. J. (2005). Hard complexities-soft complexities: An exploration of philosophical positions related to evidence in Occupational Therapy. *British Journal of Occupational Therapy, 68,* 269-276.

Boutin-Lester, P. & Gibson, R. W. (2002). Patients' perceptions of home health occupational therapy. *Australian occupational Therapy Journal, 49,*146-154.

Bunge, M. (2003). *Philosophical dictionary.* Prometheus Books: New York.

Butler, J. (2004). The fascination of the difficult. *The British Journal of Occupational Therapy, 67,* 286-292.

Campbell, A., Gillett, G., & Jones, G. (2002). *Medical Ethics (3rd ed).* Oxford University Press: Melbourne.

Carpenter, C. (2004). The contribution of qualitative research to evidence-based

practice. In K. W. Hammell & C. Carpenter (Eds.), *Qualitative research in evidence-based rehabilitation (pp. 1-13).* Churchill Livingston: Edinburgh.

Cassidy, J. (1988). Access to health care: A clinician's opinion about an ethical issue. *The American Journal of Occupational Therapy, 42,* 295-299.

Christiansen, C., & Lou, J. Q. (2001). Evidence-based practice forum. Ethical considerations related to evidence-based practice. *American Journal of Occupational Therapy, 55,* 345-349.

Cody,W.K. (2006).Values-based practice and evidence-based care: pursing fundamental questions in nursing philosophy and theory. In W.K.Cody (Ed) *Philosophical and theoretical perspectives for advanced nursing practice (pp5-12).* Jones & Bartlett:Boston.

Cook, J.V. (2001). Qualitative research in Occupational Therapy. Delmar: Albany, New York.

Corey, G., Corey, M., & Callanan P. (2003). *Issues and ethics in the helping professions. (6thEd).* Brooks/Cole: Canberra.

Creek, J. (2003). Occupational Therapy defined as a complex intervention. College of Occupational Therapists: London.

Cresswell, J.W.(2003).*Research design. Qualitative and quantitative mixed method approaches. (2nd ed).* Sage: Thousand Oaks.

Cribb, A., & Duncan, P. (2002). *Health promotion and professional ethics.* Blackwell: Oxford.

Culpepper, L, & Gilbert, T. T. (1999). Evidence and Ethics. *The Lancet, 353,* 829-831.

Depoy, E.,& Gitlin,L.N. (2001). In L. W. Pedretti & M. B.Early (Eds.), *Occupational Therapy. Practice skills for physical dysfunction (pp.58-68).* Mosby: St Louis.

DePoy, E., & Gitlin, L. N. (2005). Introduction to research. *Understanding and applying multiple strategies.* Elsevier Mosby: St.Louis.

Dictionary.com Retrieved September 15th 2006 from *http://dictionary.reference.com/*

Diem, S. J., Lantos, J. D., & Tulsky, J. A. (1996). Cardiopulmonary resuscitation on television: Miracles and misinformation. *New England Journal of Medicine, 334,* 1578-1582.

Duggan, R. (2005). Reflection as means to foster client-centred practice. *The Canadian Journal of Occupational Therapy, 72,* 103-112.

Ethics of the Everyday

Duncan, E. A. S. (2006). Theoretical foundations for Occupational Therapy. External influences. In E. A. S Duncan (Ed) *Foundations for practice in Occupational Therapy (pp.11-23).* Elsevier Churchill Livingstone: Edinburgh.

Duncan, M. (1998). Interpretation and Application. In J. Hinojosa & P. Kramer (Eds.), *Occupational Therapy Evaluation: Obtaining and interpreting data (pp.145-164).* The American Occupational Therapy Association: Bethesda, Maryland.

Early, M. B. (2001). The Occupational Therapy Process: an overview In L. W. Pedretti & M. B.Early (Eds.), *Occupational Therapy: Practice skills for physical dysfunction* (pp.21-28.). Mosby: St. Louis.

Edge, R. S. & Groves, J. R. (2005). *Ethics of healthcare: A guide for clinical practice (3rded).* Thomson: Australia.

English, V., & Somerville, A. (2004). *Medical Ethics Today. The BMA's handbook of ethics and law (2nd ed).* British Medical Association: London.

Ethics Resource Centre (2006). Retrieved October 23 2000 from *www.ethics.org/printable_plus_model.html*

Fondiller, E. D., Roage, L. J., Neuhaus, B. E. (1990). Values influencing clinical reasoning in Occupational Therapy: An exploratory study. *The Occuaptional Therapy Journal of Research, 10,* 41-55.

Foye, S. J., Kirschner, K. L., Brady Wagner, L.C, & Siegler, M. (2002). Ethical issues in rehabilitation: A qualitative analysis of dilemmas identified by Occupational Therapists. *Topics in Stroke Rehabilitation, 9,* 89-101.

Fletcher, J. (1964). *The ethics of genetic control.* Anchor Books: Garden City, NY.

Fry, S., & Johnstone, M. (2002). *Ethics in nursing practice: A guide to ethical decision making (2nd ed).* Blackwell: Oxford.

Fulford, K. W. M. (1996). The definition of patient-centred care. In K. W. M Fulford, S. Ersser, & T. Hope (Eds*.), Essential practice in patient-centred care* (pp.1-16). Oxford: Blackwell.

Fulford, K. W. M. (2004). Facts/Values. Ten principles of values-based medicine. In J. Radden (Ed.), *The philosophy of psychiatry. A companion (pp. 205-234).* Oxford: Oxford University Press.

Fulford, K. W. M., Dickenson, D. L., & Murray, T.H. (2002). Many Voices: Human values in healthcare ethics. In K.W.M. Fulford, D.L.Dickenson, & T.H.Murray (Eds.), *Healthcare ethics and human values. An introductory text with readings and case studies.(pp 1-19)* Oxford: Blackwell.

Gilligan, C. (1990). *In a different voice. Psychological theory and women's development.* Harvard University Press: Cambridge, Mass.

Greenhalgh, T, & Taylor, R. (1997). Papers that go beyond numbers - qualitative research. *British Medical Journal, 315,* 740-743.

Guyett, G. H. (1991). Evidence-based medicine (editorial). *ACP Journal Club,* 114.

Hammell, K.W. (2001). Using qualitative research to inform the client centred evidence based practice of occupational therapy. *British Journal of Occupational Therapy*, *64,* 228-234

Hare, R. H. (1952). *The language of morals.* Oxford: Oxford University Press.

Hasselkus, B. R. (1991). Ethical dilemmas in family care-giving for the elderly: Implications for occupational therapy. *The American Journal of Occupational Therapy, 45,* 206-212.

Haynes, R. B. (2002). What kind of evidence is it that evidence-based medicine advocates want health care providers and consumers to pay attention to? *BMC Health Services Research 2,* 1-7.

Haynes, R. B., Deveaux, P. J., & Guyatt, G. (2002). Physicians and patients choices in evidence based practice. *British Medical Journal, 324,* 1350.

Health and Disability Commissioner(1996) Retrieved February 20th 2007, from
    http://www.hdc.org.nz-Health   .

Hester, D. M. (2001). *Community as healing: Pragmatist ethics in medical encounters.* Rowman & Littlefield: Lanham, MD.

Hope, T. (2005). *Medical Ethics: A very short introduction.* Oxford University Press: Oxford.

Hugman, R. (2005). *New approaches to ethics for the caring professions.* Palgrave McMillan: New York.

Illot, I., Taylor, M.C. & Bolanos. (2006). Evidence-based Occupational Therapy: its time to take a global approach. *British Journal of Occupational Therapy 69,* 38-41.

Imms, C. (2006). The International Classification of Functioning, Disability and Health: They're talking our language. *Australian Occupational Therapy Journal, 53,* 65-66.

International Council of Nurses (2002). *Code of ethics for nurses.* I.C.N: Geneva

Itlis, A. (2005). Values based decision making: Organizational mission and integrity. *HEC Forum, 17*, 6-17.

Jensen, J. (2005). Do you practice ethically? Using the updated college of Occupational Therapists' code of ethics and professional conduct. *British Journal of Occupational Therapy, 68*, 485.

Jonsen, A. R., Siegler, M. & Winslade, M. (1998). Clinical Ethics: A practical approach to ethical decision making in clinical medicine (4th ed.). McGraw-Hill: New York.

Kane, R. A., & Caplan, A. L. (1993). *Ethical conflicts in the management of home care: The case manager's dilemma.* Springer: New York.

Kenyon, P. (1999). *What would you do? An ethical case workbook for human service professionals.* Brooks/Cole: Pacific Grove, CA.

Kielhofner,G., & Burke,J.P. (1980). A model of human occupation. 1. Conceptual framework and content. *American Journal of Occupational Therapy, 34,* 572-581.

Kuczewski, M. G. (1996). Reconceiving the family: The process of consent in medical decision making. *The Hastings Center Report, 26,* 30-38.

Kvanvig, J. (1999).The RESOLVEDD Method. Retrieved November 4,2006, from http://kvanig.tamu.edu/resolvedd.htm

Kyler, P. L. (1998). Issues in ethics for Occupational Therapy. *O. T. Practice, 3,* 37-40.

Kyler, P. L. (2005). The ethics of client –centred care models.   In R. Purtillo, G. Jensen & C. B. Royen (Eds.), *Educating for moral action. A source book in health and rehabilitation ethics (pp.159-167).* Davis: Philadelphia.

Lane, L. (2000). Client centred practice: is it compatible with early discharge Hospital-at-Home policies? *British Journal of Occupational Therapy, 63,* 310-315.

Law,M.,Baptiste,S.,Carswell,A.,McColl,M.A.,Polataijako,H., & Pollock,N. (1998). *Canadian Occupational Performance Measure (3rd ed.).* CAOT Publications: Toronto.

Levin, P. (2005). *Excellent Dissertations!* Open University Press: Maidenhead.

Little, M. (1998). Values, ethics and the law: Issues for practice and education. *Education for Health, 11,* 65-72.

Malcomess, K. (2001). The reason for care. *RCSLT Bulletin, November 595,*12-14.

Malcomess, K. (2005). The Care Aims model. In C. Anderson & A.van der Gaag,(Eds). *Speech and Language Therapy: issues in professional practice (pp 43-71).* Wiley:Chichester

Masow, M. (1999). Sure we believe in ethics and values, but whose? *Community Mental Health Journal, 35,* 489-493.

Meyer, A. (1922). The philosophy of occupational therapy. *Archives of Occupational Therapy, 1*, 1-10.

Mills, A. E., & Spencer, E. M. (2005). Values based decision making: A tool for achieving the goals of healthcare. *HEC Forum, 17*, 18-32.

Mitchell, R. & Unsworth, C. (2005). Clinical reasoning during community health home visits: Expert and novice differences. *British Journal of Occupational Therapy, 68,* 215-233.

Mirvis, D., & Bailey, J. E. (2001). Justice in healthcare: A response to Tavistock. *British Medical Journal, 323*, 619-620.

Monagle,J.F., & Thomasma,D.C. (1998). *Health care ethics. Critical issues for the 21st century.* Aspen: Maryland

Morse, J. M. & Richards, L. (2002). *Read me first for a user's guide to qualitative research methods.* Sage: Thousand Oaks, CA.

New Zealand Association of Social Workers Incorporated (1993). *Code of Ethics.* NZASW: Dunedin.

New Zealand Society of Physiotherapists. (2003). Retrieved July 15th, 2006, from http://www.physiotherapy.org.nz/index02/publications/code_of_ethics.html

Occupational Therapy Board of New Zealand (2004) *Code of ethics for occupational therapists.* Retrieved February 27, 2007, from http://www.regboards.co.nz/occtherapists/pdfs/CodeofEthics.pdf

Occupational Therapy Board of New Zealand (2004). Continuing Competence Framework for Recertification. Retrieved February 27, 2007, from http://www.regboards.co.nz/occtherapists/pdfs/CodeofEthics.pdf

Parker, D. (2006). The client-centred frame of reference. In E. A. S. Duncan (Ed). *Foundations for practice in Occupational Therapy (pp.29-35)* Elsevier: Edinburgh.

Parker, M.(2002) A deliberative approach to ethics. In KW.M. Fulford, D.L. Dickenson, T.H. Murray, (Eds). *Healthcare ethics and human values. An introductory text with readings and case studies (pp29-* Oxford: Blackwell.

Parker, M., & Dickenson, D. (2001). *The Cambridge medical ethics workbook: Care*

studies, commentaries and activities. Cambridge University Press: Cambridge

Peloquin, S. (1994). Moral treatment: How a caring practice lost its rationale. *American Journal of Occupational Therapy, 48,* 167-173.

Purtillo, R. B. (2005). *Ethical dimensions in the health professions* (4th ed.). Saunders: Philadelphia.

Putnam, H. (2002). *The collapse of the fact/value dichotomy.* Harvard University Press: Cambridge, MA.

Putnam, H. (2004). *Ethics without ontology.* Harvard University Press: Cambridge, MA.

Rachels, J. (1995). *The elements of moral philosophy (2nd ed).* McGraw-Hill: New York.

Richards, L. (2005). *Handling qualitative data: A practical guide.* Sage: London

Rokeach, M. (1979*). Understanding human values: Individual and societal.* Free Press: New York.

Rogers, R.C. (1983). Clinical reasoning: the ethics science and art. *The American Journal of Occupational Therapy, 37,* 601-616.

Russell, C., Fitzgerald, M. H., Williamson, P., Manor, D., & Whybrow, S. (2002). Independence as a practice issues in occupational therapy: The safety clause. *The American Journal of Occupational Therapy, 56,* 369-370.

Sackett, D., Rosenberg, W., Gray, J. A. M., Haynes, B., & Richardson, W. S. (1996). Evidence-based medicine: What it is and what it isn't. *British Medical Journal, 312,* 71-72.

Seedhouse, D. (1998). *Ethics the heart of healthcare (2nd ed).* Wiley: Chichester.

Seedhouse, D. (2001). *Health: The foundations for achievement.* Wiley: Chichester

Seedhouse, D. (2005a). *Applied Healthcare Ethics.* Unpublished lecture notes, Auckland University of Technology: New Zealand

Seedhouse, D. (2005b). *Values based decision making for the caring professions.* Wiley: Chichester.

Seedhouse, D., & Cribb, A. (1989). *Changing ideas in healthcare.* Wiley: Chichester.

Seedhouse, D., & Lovett, L. (1992). *Practical medical ethics.* Wiley: Chichester.

Shank, G. D. (2006). *Qualitative research. A personal skills approach. 2nd ed.* Pearson: New Jersey.

Sumison, T. (2000). A revised Occupational Therapy definition of client centered

practice. *British Journal of Occupational Therapy, 63,* 304-309.

Swisher, L. L., Arslanian, L. E., & Davis, C. M. (2005). The Realm-Individual

Process-Situation (RIPS) model of ethical decision making. *HPA Resource, 5,* 3

Tadd, G. V. (1998). *Ethics and values for care workers.* Blackwell: Oxford.

Teutsch, D. (2005). A chaplin's guide to values-based decision making. Retrieved

October 23, 2006, from, http://www.rrc.edu/site/c.iq.

The Centre for Health Ethics and Law, (2006). Retrieved October 23, 2006 from,

http://hsc.wvu.edu/

Thomas, D. (2003). *A general inductive approach for qualitative data analysis.* School

of Population Health, University of Auckland: Auckland.

Thomasma, D. C. (1984). The context as a moral rule in medical ethics. *The Journal

of Bioethics, 2,* 63-78.

Turner, M. H. (2003). A toolbox for healthcare ethics program development. *Journal

of Nursing Staff Development, 19,* 9-15.

Values Exchange, (2005). Retrieved July 23, 2006, from, http://Values-Exchange.com

Van Amburg, R. (1997). A Copernican revolution in clinical ethics: Engagement

versus disengagement. *American Journal of Occupational Therapy, 51,* 186-

190.

Van Hooft, S., Gillam, L. & Byrnes, M. (1995). *Facts and values. An introduction to

critical thinking for nurses.* Maclaren and Petty: Sydney.

Veatch, R. (1985). Value systems: Their roles in shaping policy decision. In Z.

Bankowski & J. Bryant (Eds.), *Health policy, ethics and human values* (pp.84-

91). Proceedings of the XV111th CIOMS round table conference, Athens,

Greece, 1984.

Wells, S. A. (2005). An ethic of diversity. In R. B. Purtillo, G. M. Jensen, & C. B.

Royen (Eds.), *Educating for moral action; a source book in health and

rehabilitation ethics* (pp.31-41). Davis: Philadelphia.

Weston, A. (2001). *A 21st century ethical toolbox.* Oxford University Press: New

York.

Weston, A. (2002). *A practical companion to ethics (2nd ed).* Oxford University Press:

Oxford.

Woodbridge, K., & Fulford, B. (2003). Good practice? Values-based practice in mental

health. *Mental Health Practice, 7,* 2.

Ethics of the Everyday

Wright, R. A. (1987). *Human values in healthcare: The practice of ethics.* McGraw-Hill: New York.

Wright-St Clair, V. (2001), Caring: the moral motivation for good occupational therapy practice. *Australian Occupational Therapy journal, 48,*187-199

Wright-St Clair, V., & Seedhouse, D. (2004). The moral context of practice and professional relationships. In G. Whiteford and V. Wright-St.Clair (Eds,) *Occupation & practice in context (pp.16-33).* Elsevier Churchill Livingstone: Sydney.

Yerxa, E. J. (1991). Seeking a relevant, ethical and realistic way of knowing for Occupational Therapy. *The American Journal of Occupational Therapy, 45*, 199-204.

Yerxa, E. J. (2001).The social and psychological experience of having a disability: practical implications for occupational therapists. In L. W. Pedretti & M. B. Early (Eds.), *Occupational Therapy: Practice skills for physical dysfunction (pp. 470).* Mosby: St Louis.

Appendices

Appendix A

Participant Information Sheet

Participant Information Sheet

AUT UNIVERSITY
TE WĀNANGA ARONUI O TĀMAKI MAKAU RAU

Study title: Values-Based Decision Making: The use of values transparency software to enhance ethical practice for community occupational therapists.

Invitation

You are invited to participate in this research project and I will value your contribution.

Researcher's name and background

My name is Diane Newcombe. I am a registered Occupational Therapist with several years' previous experience working in the community, and more recently in generic Allied Health leadership roles in two District Health Boards. I am currently enrolled in the Masters of Health Science programme at Auckland University of Technology, and this project forms the basis for my dissertation. My areas of interest include health ethics, and the role values contribute to clinical decision making. I have been working with the values based decision making software tool, Vid-e, developed by Professor David Seedhouse, and I wish to include the use of this software in my current study.

What is the purpose of this research?

Community Occupational Therapists are daily engaged in decision making which calls on skills of clinical reflection for which they have increasingly and appropriately looked to evidence to support their practice. However, health is a complex field and as we aim for more person- centred health work, therapists report the need for increased knowledge and skills in ethics - (or values -) based decision making. I have found the use of the Vid-e software to be thought provoking and to provide excellent learning in the area of ethics and am interested in exploring its use with a group of interested community occupational therapists My aim is:

a) to analyse and discuss the degree to which there is convergence or divergence of views among therapists regarding issues which are challenging because of the complexity of ethical content, and

b) to see if participating provides therapists with enhanced deliberative skills.

How are people chosen to be asked to be part of this research?

The study is open to any occupational therapist who is working, or who has worked, in community practice, and who is interested in exploring the skills of ethical reasoning, moral reasoning or values based decision making.

What happens in this research?

Having accepted the invitation to participate, occupational therapists will first be asked to complete a "pre-participation" questionnaire which is returned to me. They will then be invited

to register with the public website developed by David Seedhouse, the Values Exchange, (www.Values Exchange.com) where they can have the opportunity to practice deliberation, using the tools of ethical reasoning, in response to some questions which are posed for general web-site users to consider. It is not necessary to be familiar with those tools.

For the study itself, participants will register with a project-specific site where a scenario considered ethically challenging and relevant to the practice of community occupational therapists is described. (This scenario will have been selected after consultation with community occupational therapists.)

Participants will then be asked to agree or disagree with the course of action which has been proposed in the scenario, and, guided by the software, use tools of ethical reasoning to defend their decision making.

Having submitted their ethical analysis, they are then able to view the analyses of others, along with reports which the software produces, and they will be asked to complete a "post participation" questionnaire and return it to me.

What are the discomforts and risks?
No risks are identified for this study, but initially participants may feel some discomfort sharing decisions and the reasoning behind those decisions with other participants in the study. However, the gain in confidence that comes from developing understandings of ethical reasoning in this supportive environment is likely to outweigh any initial discomfort.

How will these discomforts and risks be alleviated?
Participants' responses are only available to other participants in the study, the researcher and the researcher's primary supervisor. Feedback and supportive guidance will be provided. Participants can choose to use a pseudonym if they wish to remain anonymous. They can discuss concerns directly with the researcher at any time and may withdraw at any time without giving a reason.

What are the benefits?
For participants, I am of the view that the act of participating itself will be of benefit, which is one of my reasons for selecting this approach. I have an assumption that participants will find the experience worthwhile and thought provoking, and that participation will enhance learnings in the competency area described by the NZ Occupational Therapy Board as "safe, ethical and legal practice"

The benefits for me as the study designer are being given an opportunity to see if a) using the Vid-e tool increases occupational therapists' use and understanding of the skills of ethical deliberation and b) if they see that that enhances their overall clinical decision making.

How will my privacy be protected?
As above, people may choose to participate anonymously and the consent form requires people to assure confidentiality of other participants

What are the costs of participating in this research?
There will be small amount of time required to complete the 2 questionnaires, up to ½ an hour. Using the Vid-e software to deliberate an ethical question may take up to an hour for the first time, and it would be best to allow the same for the second, although users become much quicker with practice. An overall time commitment of approximately 1 ½ to 2 ½ hours is anticipated.

What is the time frame for me to consider this invitation?
In order for me to have completed my analyses and study time frames, I need to have had responses from interested participants returned to me by July 8th 2006

129

Ethics of the Everyday

How do I agree to participate in this research?

I am enclosing a consent form with this information sheet. If after considering the information you would like to participate, please return the consent form in the envelope provided. I will then contact you regarding what happens next.

Will I receive feedback on the results of this research?

One of the benefits of participating is that you can immediately see reports based on the analyses submitted by you and other participants. In addition I will provide participants with a summary report

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor: *David.Seedhouse@aut.ac.nz*. Phone 09 9219679 (David is out of the country until September 2006 but can be contacted by email)

Concerns regarding the conduct of the research should be notified to the Executive Secretary, AUTEC, Madeline Banda, *madeline.banda@aut.ac.nz* , 09 9219679

Who do I contact for further information about this research?
Researcher Contact Details:

> *dianenewcombe@hotmail.com* phone 021483849

Project Supervisor Contact Details:

> *David.Seedhouse@aut.ac.nz*. *phone 09 9219679 or*

> *Valerie.Wrightstclair@aut.ac.nz* *phone 09 9219679*

Approved by the Auckland University of Technology Ethics Committee on *April 3rd 2006*.
AUTEC Reference number 06/13

Appendix B

Participant Consent Form

CONSENT TO PARTICIPATION IN RESEARCH

AUT
UNIVERSITY
TE WĀNANGA ARONUI O TAMAKI MAKAU RAU

Title of Project: **Values-based decision making: the use of values transparency software to enhance ethical practice for community occupational therapists**

Project Supervisor: Professor David Seedhouse

Researcher: Diane Newcombe

- I have read and understood the information provided about this research project (Information Sheet dated 24th May/28th June 2006.)

- I have had an opportunity to ask questions and to have them answered.

- I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.

- If I withdraw, I understand that all relevant information will be destroyed or deleted.

- I agree to maintain confidentiality of other participants

- I agree to take part in this research.

- I wish to receive a copy of the report from the research: tick one: Yes   O   No   O

Participant signature: ....

Participant name: ………………………….

Participant email address: ………………………

Participant postal address………………………

Date:…………………………………………………

Approved by the Auckland University of Technology Ethics Committee on April 3rd 2006
AUTEC Reference number 06/13

Note: The Participant should retain a copy of this form.
Please return to Diane Newcombe, Box 52 Waiwera, Auckland by July 14th 2006 at the latest.
Thank you.

Appendix C

Pre-participation Questionnaire

PRE-PARTICIPATION QUESTIONNAIRE

June 15 2006

Questionnaire number……….

Title of Project:

Values-based decision making: the use of values transparency software to enhance ethical practice for community occupational therapists

Project Supervisor: Professor David Seedhouse

Researcher: Diane Newcombe

INTRODUCTION

- Your responses to this questionnaire will be used for evaluating the impact of using the values based decision making software

- Please be candid in all responses.

- Please return this questionnaire to **Diane Newcombe, Box 52, Waiwera by** July 14th 2006 using the enclosed stamped address envelope, or complete on line and email to: dianenewcombe@hotmail.com; or email or phone me (021483849) regarding answering the survey questions by phone

- Questionnaires will be viewed only by Diane, and respondents will not be able to be identified in the study

GENERAL QUESTIONS

1. I am currently working in a community setting: Yes ❑   No ❑
2. I have been qualified for:
up to 1year ❑   1 to 3 years ❑   4 to 8 years ❑   more than 8 years ❑
3. My ethnicity is:
   European ❑   Maori ❑   Pacific Island ❑ Indian❑   Chinese ❑

   Other (please specify) _____

SELF-EVALUATIVE QUESTIONS

4. Please list in the table below some examples of situations in your practice which you consider to be ethically challenging

Ethically challenging situation:	Challenging because:

Please circle your level of agreement with the following statements.
Please add your own statements.

5. I understand ethical practice to mean:

	Strongly Disagree	Disagree		Agree	Strongly Agree
Knowing the right thing to do…………............	1	2	3	4	5
Doing what is best for the patient…………….	1	2	3	4	5
Doing what is best for the health of the community.	1	2	3	4	5

Other: _____

Other: _____

Other: _____

6. When I have to make an ethically challenging decision I think about:

	Strongly Disagree	Disagree		Agree	Strongly Agree
Following the OT code of ethics……………...	1	2	3	4	5
The preferences of everyone involved………...	1	2	3	4	5
Following DHB/MoH guidelines………………	1	2	3	4	5

Other: _____

Other: _____

Other: _____

7. Personal or organisational factors which influence my decision making are:

	Strongly Disagree	Disagree		Agree	Strongly Agree
Fear of making the wrong decision…………...	1	2	3	4	5

135

Ethics of the Everyday

Lack of training in ethical theory……………...	1	2	3	4	5
Other people's opinion………………………..	1	2	3	4	5
Having enough facts to make a decision……..	1	2	3	4	5

Other: _____

Other: _____

Other:

_____

9. Expectations of participating in this study:
Please tick all statements which are true for you.

☐ I haven't studied ethics and want to learn more

☐ I have some knowledge in the field of ethics and want to extend this

☐ I have previously used the "ethical grid" and want to explore using the software version

☐ I want to see if this tool will provide a useful forum for professional discussion

☐ I want to improve my skills of ethical deliberation in everyday practice

☐ I would like to discover what values based decision making is about

☐ I would value learning from the deliberations of others

☐ I am hoping that participating will contribute to updating me in the NZ Occupational Therapy Board's competency of "safe, ethical, legal practice"

Other: _____

_____

_____

General Comments: _____

Thank you for taking the time to complete this questionnaire.
Diane Newcombe

Ethics of the Everyday

Appendix D

Instructions for using the Values Exchange

INSTRUCTIONS FOR USING THE VALUES EXCHANGE WEBSITE

To begin
Go to http://ucsm.Values Exchange.com/secure .
You are already registered, so sign in by clicking **CLICK HERE TO SIGN IN** (located in the top left hand menu). Your login is your email address I am using to send you this. The password is "Values".

Demographics
Before you can begin either a practice case on the **HOMEPAGE**, or the case for this study under **SECURE,** you will be asked to complete details for the site.
Your deliberations on the study case will be viewable by me and other study participants. Once you have completed and submitted your analysis, you are able to view the reports of your own and others' deliberations. This is a very interesting part of the exercise. There are also general cases currently open on this website which you are able to access, and I recommend you try one of these for practice.
One of the underlying goals of the software is values transparency, so participants are encouraged to keep their details on the report. However, if you wish to use a pseudonym simply click on **MY DETAILS** once you have signed in, and change your First Name and Last Name.

Practice case
Although it's not essential, you will find it helpful to do at least one practice case on the **HOMEPAGE** before you proceed to the case which has been set up for this project. Start the practice case by clicking on **CONSIDERED RESPONSE** for the case you choose, and then enter your details.
Read the notes for the case (it can be helpful to minimise or print these for reference).

Click **NEXT**, after which you will be guided through your analysis, starting with whether or not you agree with what has been proposed by the system's "administrator". Do use the Video help which is available on each page.

If you wish to keep working on a case without submitting it, as long as you click on a **NEXT** button prior to logging out of the Values Exchange, your not-yet complete analysis will be saved for you to continue working on next time you log in to this site.
You can make changes to any part of your analysis prior to submitting it, but not after.

The case for this study
Once you have completed a practice case, click on the **SECURE** tab. This will take you through to the case for this study. The title "**Diane's study**" will appear at the top of the case description. Here you will follow the same process, starting by reading the case notes.

The case will close on September 3rd 2006

Reports
Once you have completed and submitted a case you can then see how others have responded.

Simply click on Show Report » and then explore each of the Single Case reports in turn.

Assistance

Ethics of the Everyday

If you need assistance at any time regarding the Values Exchange, contact enquiries@Values Exchange.com , or diane.newcombe@hotmail.com, or by phone (021483849) regarding anything to do with the study.

During the week August 20th to 26th I will be out of the country. If you need phone assistance during that time it can be arranged via enquiries@Values Exchange.com

Many thanks again for your participation

Diane Newcombe   021483849   August 7th 2006

Appendix E

Post-participation Questionnaire

POST PARTICIPATION QUESTIONNAIRE

August 5th 2006
Questionnaire number……….

Title of Project:

Values-based decision making: the use of values transparency software to enhance ethical practice for community occupational therapists

Project Supervisor: Professor David Seedhouse

Researcher: Diane Newcombe

Introduction

- Your responses to this questionnaire will be used for evaluating the impact of using the values based decision making software

- Please be candid in all responses.

- Please return this questionnaire to **Diane Newcombe, Box 52, Waiwera by** July 14th 2006 using the enclosed stamped address envelope, or email to: dianenewcombe@hotmail.com; or email or phone me (021483849) regarding answering the survey questions by phone

- Questionnaires will be viewed only by me, and respondents will not be able to be identified in the study
- The purpose of this post –participation questionnaire is to ask you to comment on your experience of participating in the exercise using Vid-e software to deliberate on an ethically challenging issue.

Questionnaire

Please circle or indicate your level of agreement with the following statements.
Please add your own statements.

1. I understand ethical practice to mean:	Strongly Disagree	Disagree		Agree	Strongly Agree
Knowing the right thing to do………..............	1	2	3	4	5
Doing what is best for the patient…………….	1	2	3	4	5
Doing what is best for the health of the community.	1	2	3	4	5

Other:

2. When I next have to make an ethically challenging decision I will think about:	Strongly Disagree	Disagree		Agree	Strongly Agree
Following the OT code of ethics……………...	1	2	3	4	5
The preferences of everyone involved………...	1	2	3	4	5
Following DHB/MoH guidelines……..………	1	2	3	4	5

Other:

3. When you completed the pre-participation questionnaire, you listed some examples of situations in your practice which you consider to be ethically challenging. If you can think of further examples now please list them below:

Ethically challenging situation:	Challenging because:

4. Experience of participating in this study:
Please tick all statements which are true for you.

☐ I have extended my knowledge about ethics

☐ I found it helpful using the software version of the ethical grid

☐ I have improved my skills of ethical deliberation in everyday practice

☐ I found the process too complex to use in everyday practice

☐ I think this tool will provide a useful forum for professional discussion

☐ I have increased my understanding of what values based decision making is about

☐ I benefited from seeing the deliberations of others

☐ I believe that deliberating a case on the Values Exchange contributes to updating my competency in "safe, ethical, legal practice", as required by the Occupational Therapy Board of New Zealand

☐ I value the transparency of me and others using full names

☐ I found the experience challenged how I think about client centred practice

☐ I would like to use this method to deliberate a case from my practice with colleagues

5. Other Comments:

Thank you
Diane Newcombe