RESOURCE ALLOCATION FOR SOLID ORGAN TRANSPLANTATION:
TOWARD PUBLIC AND HEALTH CARE PROVIDER DIALOGUE

by

ROSALIE CATHERINE STARZOMSKI

BN, Dalhousie University, 1978
MN, University of Calgary, 1984

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Department of Nursing
The University of British Columbia
Vancouver, Canada
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ABSTRACT

In examining methods to facilitate debate about resource allocation for health care, this qualitative study, using constructivist methods, was designed to: 1) describe attitudes, beliefs, values and moral reasoning processes used by stakeholder groups when discussing ethical issues related to resource allocation for solid organ transplantation; and 2) describe how these groups envisioned their role, and roles of other groups, in allocation of resources. Thirty-four consumer and health care provider groups (188 participants), were purposively selected from those with a major, moderate and minor stake in the development of transplantation. Data were collected through focus group interviews, with stimulus material (a case about transplantation) used in the discussion. Three moral reasoning processes emerged as participants reasoned about ethical concerns related to resource allocation. These included “deliberative,” “examined emotion,” and “emotional” reasoning processes. The processes were used by all groups at different times. The process used was dependent on the context of the problem, and influenced by the participant’s views about transplantation. Integrated justice and care based approaches emerged when reasoning about the ethical problems. Participants differed in applying the values and principles identified during the discussion. In particular, different theoretical perspectives of justice were used. Moral reasoning ability did not appear to be associated with education, gender or membership in a group. Three patterns of viewing transplantation were identified: “through a glass brightly” (positively), “through a glass translucently” (ambivalently), and “through a glass darkly” (negatively). These were constructed from a synthesis of values, beliefs and attitudes held about transplantation, and were dependent on factors such as personal experience, culture, ethnicity, religion, family upbringing, relationships, work context, and actual experience with transplantation. Participants supported the idea of including multiple voices in the debate about resource allocation at the macro level of the system. Consumers expressed this as an opportunity to have input into decisions, but not necessarily make them. There was support to have consumers involved in meso level decision making, including being part of boards and selection committees. Collecting data using focus groups was a way of opening up moral space for discussions about resource allocation.
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CHAPTER ONE

Background Context to the Research Problem

Major changes are occurring in society as manifested by the massive political, socio-economic, and technological upheaval occurring around the globe. The move from an industrial to a technologically based society, where knowledge and education are becoming increasingly important, has lead to a number of crises and challenges as the world continues to develop and advance (Capra, 1982; Touraine, 1988). Nowhere are these crises and challenges more apparent than in the provision of health care, where Western countries are facing significant changes as a result of increasing demands for health care services, and the rising costs for care (Evans, R.G., 1993).

The new challenges within the health care system have been attributed to an aging population with multiple health problems (Callahan, 1988), a focus on curing disease versus prevention of illness (Callahan, 1988; Hall, 1980), and an increased demand for expensive, high technologic treatments, sometimes developed with little regard for cost, outcome, or impact of treatment on the patient (Boyle & Callahan, 1992; Rachlis & Kushner, 1989; Rettig, 1989).

Recently, nations have begun to address these issues, many of which have arisen as a result of the “spare no expense” philosophy in health care (Crichton & Hsu, 1990; Lomas, 1996; Thorne, 1993). Hence, determining the best methods for allocation of health care resources has become one of the most critical issues facing society today.

Amid the chaos, confusion and change that have become part of contemporary health care, a broad range of complex ethical questions about allocation of resources has emerged (Kluge, 1992; Fox & Swazey, 1992b; Rettig, 1989; Thorne, 1993). These are fundamentally questions of distributive justice, leading to some of the most widely debated questions at all political levels in Canada. For example, there is increasing discussion about the need to determine what Canadians wish to spend on health care, how resources should be allocated within federal and provincial health care budgets to meet the health care needs of citizens, how priorities should be determined
within these budgets, and who will make the decisions about how resources will be allocated (Cull, 1992; Emson, 1991; Hadorn, 1993; Kluge, 1992, National Forum on Health, 1997).

Important challenges confront decision makers responsible for distributing health care resources in a fair and equitable manner. It is believed that the resolution of these allocation dilemmas, at all levels of the health care system, requires consideration from many sources of information by a variety of societal groups (Roy, Williams & Dickens, 1994). Furthermore, there is growing support for the idea that to identify societal needs, and to solve resource allocation dilemmas, a partnership of consumers\(^1\) and providers is required (B.C. Ministry of Health, 1993; Charles & DeMaio, 1992; 1993; Crichton & Hsu, 1990; Eyles, 1993; Gordon, 1990; National Forum on Health, 1997; Roy, Williams & Dickens, 1994).

**Solid Organ Transplantation - A Resource Allocation Microcosm**

Since the first successful kidney transplant, performed by Dr. Joseph Murray in Boston in 1954 between identical twins, transplantation\(^2\) has been considered an extremely controversial area, generating significant discussion in the health care arena (Luquire & Houston, 1992; Murray, 1992; Sells, 1992; Hauptman & O'Connor, 1997). The issues emerging from this debate reflect many of the major concerns embodied in resource allocation discussions (Balk, 1990; Bowden & Hull, 1993; Pichimayr, Kohlhaw & Frei, 1992). Furthermore, transplantation can be viewed as a microcosm within which some of the most difficult ethical issues related to the evolution of technology and allocation of scarce resources is occurring (Bailey, 1990; Fox & Swazey, 1992a; 1992b; Kjellstrand & Dossetor, 1992). Although some of the resource requirements, such as the need for donor organs, are unique to transplantation, the field can provide a prototype to focus the examination of ethical concerns related to resource allocation (Lumsdon, 1992; Wiseman, Vanderkop & Nef, 1991).

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1 The terms lay person, citizen, consumer, community and public are used interchangeably in this research.

2 For purposes of this study, the term transplantation will signify solid organ transplantation unless otherwise indicated. See Appendix 1 for the glossary of terms used in this study.
Transplantation has been heralded by some as one of the greatest achievements of the twentieth century, moving from the impossible to the commonplace, offering people with end stage organ failure "the gift of life" (Fradet & Keown, 1993; Murray, 1992). For many, a successful transplant can offer virtually complete physical rehabilitation and improvement in overall quality of life (Evans, Manninen, Maier, Garrison, & Hart, 1985; Hicks, Larson, & Ferrans, 1992; Laupacis et al., 1996; Molzahn, 1991). However, others are not so fortunate. Some people die while on transplant waiting lists, others reject their organs after transplantation and/or succumb to the many complications of the treatment (Fox & Swazey, 1992a; 1992b; Murray, 1992).

Although success rates are improving, they are still low for transplantation of some organs (for example, single lungs, pancreas, bowel, and multiple organs). Some authors have raised serious concerns about transplantation, particularly where the success rates are low or the procedures are considered experimental, pointing out that transplantation consumes a large proportion of health care resources and benefits only a few (Fox & Swazey, 1992a; 1992b; Kutner, 1987; Metcalf, 1993; Teo, 1992). Furthermore, they raise the issue of whether these resources might be used more effectively elsewhere in the health care system. They caution that society should be wary of the "technological imperative," meaning that the ability to develop extraordinary interventions should not necessarily justify their use (Ferreira, 1994).

A brief history of the development of transplantation illustrates some of the perplexing resource allocation controversies that have emerged. In the early years, because of poor immunosuppression techniques, transplantation was restricted to those with kidney failure who had genetically identical siblings, thereby excluding the vast majority of people suffering from end stage renal disease (ESRD). Moreover, there was no method to keep people with ESRD alive until transplantation was possible. Although experiments with hemodialysis were occurring as a result of Kolff’s dialysis research in the 1940’s, difficulties accessing the circulatory system for repeated treatments limited dialysis to acute situations. With no form of ongoing treatment, the majority of people suffering from chronic kidney failure died (Kutner, 1987; Murray, 1992; Starzomski, 1994). Two significant developments in the 1960’s changed this dismal situation.
The first development occurred when Belding Scribner and his colleagues developed a Teflon arteriovenous shunt for the continuous dialysis of Clyde Shields in Seattle on March 9, 1960 (Alexander, 1962; Jonsen, 1990). Following this major development, dialysis units, like the Northwest Kidney Center in Seattle, formed committees to decide which medically qualified patients would be chosen to receive dialysis in the few treatment slots available (Alexander, 1962; Fox & Swazey, 1992b). In Seattle, this committee, called the “God Squad” by its critics, generated worldwide controversy, since, up to that time, selection of patients for treatment with scarce resources was accomplished using an emergency triage system, (developed in war-time and during natural disasters) where the sickest, treatable patients were given first priority for treatment (Jonsen, 1990). However, the Seattle committee, composed of middle and upper class members of the community, moved away from this method and, in the absence of any formal principles for selection, chose patients for treatment using criteria such as the likely success of the person on dialysis, as well as criteria that rated the social worth and merit of each potential candidate (Alexander, 1962; Fox & Swazey, 1992b). This selection process was described by Jonsen (1990) as using “some common sense maxims; younger rather than older patients, those with dependents rather than those without, the emotionally mature and stable, those with a record of public service and so on” (p. 46).

Interestingly, in addition to being the catalyst for the development of chronic dialysis, the story of the Seattle group illustrated one of the problems that brought bioethics into being. Because of a lack of resources, such as dialysis machines, trained personnel and financial resources, the issue of who should be treated, when all could not be treated, became a major concern. The public attention given to the dialysis dilemma, coupled with discussion about concerns arising out of unethical experimentation with human subjects (Beecher, 1966), stimulated scholarly reflection on these issues, thus contributing to the evolution of the field of bioethics (Jonsen, 1990).

The moral dilemmas surrounding dialysis led to the discussion of ethical principles such as autonomy, beneficence and justice, as well as issues such as informed consent and resource allocation. As the number of people on dialysis increased dramatically, major policy decisions were
required to determine how much of the health care budget would be used for the treatment of ESRD (Engelhardt, 1984; Jonsen, 1986; Moskop, 1987; Simmons & Marine, 1984).

Furthermore, the dialogue that resulted did much to highlight the need for members of the public to be more actively involved in decisions about their health care and their health care system (Arras & Rhoden, 1989).

Following the development of chronic dialysis, it became possible to maintain people on life supporting treatment while waiting for a transplant. Living donors, however, were available for only a limited number of patients, thus many had no hope of ever receiving a kidney transplant. This situation was rectified after the second major development in transplantation. The development of immunosuppressive medications in the 1960's made it possible for kidneys to be removed from “brain dead” (cadaveric) donors, as well as from non-identical living donors, to be transplanted into the recipients waiting on dialysis (Fradet & Keown, 1993; Landsberg, Shackelton, Keown, Cameron, & Manson, 1993). Once again, determining who would receive the donor kidneys was a widely debated topic. Selection committees were developed, and decisions were made using similar criteria to those described previously for dialysis.

By 1968, developments in the transplant field had progressed to a point where Dr. Christiaan Barnard performed the first heart transplant in South Africa (Gudas, Ricci, & Fradet, 1993). Because of poor immunosuppression techniques and graft rejection, success rates were poor in the early years of heart transplantation. Attempts to transplant other extrarenal organs (livers, heart/lungs, lungs, pancreas) were limited by the need for more effective immunosuppression (Murray, 1992). It was not until the 1980's, with the advent of the immunosuppressive agent Cyclosporine, that extrarenal organ transplantation became a major reality (Keown & Fradet, 1993; Murray, 1992). As other transplant possibilities were added to the list of treatments for end stage organ failure, the ethical questions became increasingly difficult as more and more health care resources were required to treat very few patients (Mendez, Aswad, Dessouki, Cicciarelli, & Mendez, 1992; Rettig, 1989; Stiller, 1990). Moreover, there continued to be many more people requiring treatment than there were resources available, thus creating a need
to continue to develop methods for candidate selection (Kilner, 1988, 1990; Kluge, 1993; Seib, MacLeod & Stiller, 1990). Furthermore, since there was no bridging treatment, such as dialysis, available for extrarenal recipients, an increasing supply of donor organs was required.

Rettig (1989) proposes that the dramatization of life and death situations, especially in children, had much to do with the success of obtaining and maintaining funds for transplantation. He describes the development of transplantation during this period as highly politicized, with many individuals and hospitals becoming captivated with the idea of being part of these exciting developments. Transplant programs proliferated, and as success rates improved, candidate selection criteria became more generous, more transplants were performed, waiting lists for transplants grew and waiting time increased dramatically (Canadian Organ Replacement Register, 1996; United Network for Organ Sharing, 1996) (see Appendix 2 for Transplant Statistics).

Today, because of the shortage of donor organs, and the human and financial resources required for transplantation, distributive justice questions analogous to those posed in the early years of transplantation, are resurfacing – who will make the decisions about the resource commitment for transplantation and who should be treated when all cannot be treated? (Fox & Swazey, 1992a; 1992b). Fox and Swazey (1992b) describe transplantation as epitomizing many of the issues that are part of the debate in relation to health care reform. They note, however, that with few exceptions (Leaf, 1980; Welch & Larson, 1988), there has been an avoidance of dealing with the distributive justice question of how the financial and human resources, invested in organ transplantation, affect the ability and willingness of society to meet other needs in the area of health care. Most of the debate about resource allocation in transplantation has been related more narrowly to the methods required to procure more organs to meet the demand, rather than on discussions about the level of resource allocation for transplantation (Fox & Swazey, 1992b; Rettig, 1989). Moreover, there has been a paucity of research examining the views of the public and health care providers about how they envision resources ought to be allocated (Storch & Dossetor, 1993).

The important issues and questions arising in the transplant arena are manifested at three levels of responsibility for health care. The first of these levels is the macro level, or the level of
societal responsibilities for the health of the total population. The second is the meso level, that is the level of institutional responsibilities for programs of care. Finally, the third is the micro level, that is the level of individual professional responsibilities for patients and families receiving health care (Kluge, 1992; McDonald, 1993; Yeo & Donner, 1991).

The issues in the three levels are illustrated by a closer examination of the transplant domain. The community at large is faced with fundamental questions, at the macro or societal level of the health care system, about the level of resources to be allocated to life saving technology such as organ transplantation (Benjamin, 1992; Brooks, 1993; Evans, 1992; Turcotte, 1992). Also at the macro level, a major worldwide organ shortage (Bowden & Hull, 1993; Youngner, 1992) has raised questions about changing consent for human tissue, by examining strategies for presumed consent (Andrews, 1992; Childress, 1992; Cohen, 1992; Menzel, 1992c; Sadler, 1992; Veatch, 1991d; Youngner & Arnold, 1993), using fetal tissue for transplantation (Martin, 1992; Nelson, 1990), offering financial incentives for organ donation (Dickens, 1991; Evans, R. W., 1993; Warren, 1993), engaging in buying and selling organs (Guttmann & Guttmann, 1992; Kazim, Al-Rukaimi, Fernandez, Raizada, Mustafa, & Huda, 1992), using anencephalic infant donors (Dickens, 1988; Roy, Williams & Dickens, 1994), and considering the use of xenografts (transplanting from one species to another), as ways to solve the shortage of organs for human transplantation (Caplan, 1992; Nicholson, 1996; Rapaport, 1993; Reemtsma, 1992; Singer, 1992).

At the meso or institutional level of the health care system questions are raised about who should be the recipients of organ transplantation, and how selection criteria should be developed (Kilner, 1988; 1990; Kluge, 1993). In addition, as transplant waiting lists grow, a question arises about the number of waiting lists on which a recipient should be listed. For example, some Canadians are listed on provincial waiting lists and are also added to an American transplant center list if they are willing to pay for the procedure in the United States (U.S). Another difficult question at the meso level arises when determining how decisions should be made about the proportion of an institutional budget devoted to transplantation compared to other programs (Balk, 1990).
Decisions at the micro level of the health care system are evident around issues about how health care providers decide whether a transplant is in a given patient's best interest. For example, health care providers make decisions about removing kidneys and, more recently, parts of livers and lungs from individual living donors to be transplanted into specific recipients (Sieglar, 1992). In addition, organs from unrelated donors are being considered more frequently in transplant centers around the world (Spital, 1992; 1993). Finally, there is the question of how many re-transplants one individual is entitled to receive (Evans, Manninen, Dong, & McLynne, 1993). Although this list is not exhaustive, it provides an overview of some of the most perplexing problems evident in transplantation today.

Concerns about the principles of autonomy and informed consent arise from the issues explicated above. Moreover, the critical principle of justice is embedded in many of these ethical issues about organ transplantation, exposing deep tensions about the societal sense of what is true or just (Fox & Swazey, 1992a; 1992b; Jonsen, 1985; 1989; Kjellstrand & Dossetor, 1992). These situations raise a need for a collaborative approach among health care providers and the public to define and determine legitimate and just applications of organ transplantation technology (Fox & Swazey, 1992a; 1992b; Lumsdon, 1992; Rettig, 1989; Storch & Dossetor, 1993). How this collaboration might occur requires closer examination of the current health care system, the context in which organ transplantation is occurring.

Health Care Reform - Context for Resource Allocation in Transplantation

It is important to examine the North American health care context in which the debate about organ transplantation is occurring, in order to develop an understanding of the issues influencing the discussion. Examining what is happening in both Canada and the U.S. is useful as both countries have had major influences on one another, particularly in the development of transplantation.

In the past several years, virtually every member of the Organization for Economic Cooperation and Development (OECD), composed of countries in Europe, North America, and the South Pacific, has either proposed or launched major reform of its health care system (Evans,
R.G., 1993, p. 35; National Forum on Health, 1997). In Canada, there has been widespread support for an egalitarian approach to health care, compared to the U.S., where preservation of the autonomy of individuals in the health care marketplace has tended to mitigate against universal health care coverage (Storch, 1988). It appears, through the "natural" experiment on health care financing conducted in North America, that the Canadian single payer system has contained costs more effectively than the U.S. multi payer system (Barer, Welch & Antioch, 1991; Evans, R.G., 1993, National Forum on Health, 1997) This is illustrated by the fact that expenditures for health care in Canada have increased from 5.4% of the national income or Gross Domestic Product (GDP) in 1960, to 9.9% in 1991, with the largest increase occurring in the 1960’s and 1970’s when the country moved to a universal health care system (Evans, R.G., 1993). In the United States (U.S.), the country that has the largest, most richly supported health industry in the OECD (Getzen & Poullier, 1991), and where between 35-40 million Americans lack adequate health insurance (Evans, R.G., 1993), health care expenditures were 13.2% of the GDP in 1991 (Azvedo, 1993), up from 5.9% in 1965 (Morganthau & Hager, 1993). Moreover, Americans report the least satisfaction with their system in a poll of OECD countries, with Canadians reporting the most satisfaction (Evans, R.G., 1993).

In a very recent report from the National Forum on Health (1997) it is noted that health care costs in Canada have decreased from 10.3% of the GDP in 1992 to 9.5% in 1995. In the United States, the costs have increased from 14% of the GDP in 1992 to 14.5% in 1995. In addition, the percentage distribution of health expenditures in Canada has changed over the past 20 years, with hospital costs totaling 45% in 1975 and 37% in 1994. Costs for physicians decreased slightly from 15% in 1975 to 14% in 1994, while drug costs rose from 9% in 1975 to 13% in 1994.

Although there are differences in the health care systems of Canada and the U.S., there are parallels. Both countries are focusing on effective methods to maximize the use of resources in order to develop more efficient health care delivery systems. In the U.S., major health care reform and restructuring is being considered by politicians, consumers, and health care providers (Bonuck & Arno, 1992; Curtin, 1993; Davies, 1992; Donley, 1993; Joel, 1992; Levine, 1992; Muyskens,
1992; Stevens, 1992a; 1992b). In Canada, the federal government, and all ten provincial
governments, are examining various options to maximize resource utilization by focusing on
restructuring, re-engineering and/or decentralization of health care delivery systems and more
effective use of health care services and personnel (Barer & Stoddart, 1992; Barer, Welch &
Evans, 1984; Hurley, Birch, & Eyles, 1992; Lefort, 1993; National Forum on Health, 1997; N.S.
Government, 1989; 1994; Woodward & Stoddart, 1989). In addition, in both Canada and the
U.S., it has become clear that greater amounts of health care do not necessarily mean better health
for the population. There is a growing interest in moving to a health care model where the broader
determinants of health are considered in the development of “healthy public policy” that is
distinguished from traditional health care policy by being ecological in perspective, multi­
dimensional in scope and participatory in strategy (Milio, 1985; Pederson, Edwards, Kelner,

Furthermore, all activities within the health care system (including transplantation) are
undergoing considerable scrutiny, with emphasis on the need for all citizens to use resources in a
responsible manner. Since an estimated 80% of medical treatments, along with surgical
procedures, have never been scientifically evaluated to determine whether they are effective
(Rachlis & Kushner, 1989, p. 10), there is an increasing emphasis on the development of research
that focuses on the outcomes of health care and the impact of new technology on the health care
system (Boyle & Callahan, 1992; Deber, 1992; Goodman, 1992; Hadorn, 1993; Ingersoll, Hoffart
Reiser, 1992a; 1992b). Some authors have gone so far as to say that the use of outcome
information might postpone the need for rationing health care services by determining which
medical treatments are actually effective (Wennberg, 1990). Others contend that, even if all the
waste was eliminated within the health care system, and the system organized in the most efficient
manner, there would still be a gap between supply and demand (Roy, Williams, & Dickens,
1994). This notion is illustrated in the case of transplantation where, although elimination of waste
in the system might provide an increase in financial resources, the number of transplants to be performed would still be limited by the number of donor organs available.

For Canadians, this is a time of unrest in the delivery of health care -- a time that is characterized by reform, cost containment and major restructuring of the health care system. Although the tenets of Medicare (universality, comprehensiveness, accessibility, portability and a publicly administered health care system) are seen by many Canadians as sacred, the times are changing. Reorganization of the health care system, rooted in the social ideology of each individual province, is occurring (Crichton & Hsu, 1990, National Forum on Health, 1997). There is much discussion about the fact that rationing will be needed at the macro level of the system. Presently, decisions about allocation have been made primarily by governments, often in the form of cuts to programs, forcing rationing to occur at the meso level of health care agencies and institutions (Emson, 1991; Manga & Weller, 1991; Wilson, 1994; 1995). Moreover, some governments are examining methods, such as user fees, definitions of basic levels of care and privatization of some health care services, that may change the foundation upon which the Canadian health care system is built (Emson, 1991; National Forum on Health, 1997; Moorhouse, 1993). These changes point to a need for public discussion about resource allocation in health care to assure that the best decisions are made, that all societal voices are heard in the debate, and that the decisions are made in a democratic fashion.

Involvement of Consumer and Health Care Provider Stakeholders in Resource Allocation

Choices about resource allocation for transplantation are among those decisions that will be made over the next number of years in health care. In order to make decisions that reflect the common good, there must be mechanisms in place to allow discussion to occur among key stakeholders in the public and the health care provider domains (Cull, 1992). Restructuring of health care services in Canada is leading to proposals where, in many provinces, including British Columbia, there is potential for public and provider dialogue about resource allocation for health care (Hurley, Lomas, & Bhatia, 1993).
A review by policy analysts of more than 35 major commissions and task forces conducted in Canada over the past several years, revealed three common goals, namely: a greater emphasis on disease prevention and health promotion, a move to community-based care alternatives, and the need to increase the importance of accountability among the stakeholders (Canadian Nurses Association, 1992). The importance of the concept of accountability and community involvement was reinforced in the report of the B.C. Royal Commission on Health Care and Costs and more recently in the Prime Minister's National Forum on Health. In these reports, recommendations were made suggesting that decisions about health care delivery and resource allocation ought to be made as close to the community level as possible, allowing local people to shape their own system of delivery (B.C. Ministry of Health, 1991, 1993; National Forum on Health, 1997). This participatory direction included a desire on the part of many stakeholders to include citizens, and the values they hold about health and health care, in health policy development. In addition, decentralization and devolution of health care services was seen as a key component of efforts to empower both individuals and communities, restoring the balance in a system perceived by many to have been co-opted by experts (Hurley, Birch & Eyles, 1992, p.2).

Interest in citizen participation in health care stems from two major ethical factors: 1) a growing recognition that patient preferences ought to be incorporated into decision making involving individual treatment choices, and 2) the desire to increase public accountability for health care resource allocation decisions in order to make providers more accountable to the communities they serve (Charles & DeMaio, 1992, p.19; 1993). Consumer involvement in health care decision making is urged on by the public’s perception that governments are now less competent, trustworthy and useful than in the past (Eyles, 1993). As a result, consumers are demanding involvement in decisions related to their own health care as well as in decisions about how health care will be delivered in their communities (CHEPA, 1991; Garland & Hasnain, 1990a; Garovitz, 1985; Hill, 1990).

Although the idea of citizen participation in health care decision making is thought to be a good thing, congruent with the basic tenet of democracy -- government by the people -- for the
people (Kymlicka, 1990), it is not clear what the goals of citizen participation are or ought to be. The question of whether citizen participation is a means to an end, an end itself, or both, has been raised by several authors (Charles & DeMaio, 1992; 1993; CHEPA, 1991; Hurley et al., 1992). Why should citizens be more involved in health care decision making today as compared to their involvement in the past? Is citizen involvement required in order to capitalize on the expertise of the lay public to provide information that health care providers lack? Do citizens have a right to be involved in allocation decisions since they are the ones who pay for health care? Do citizens believe they have a duty to be involved in the discussions about the fair allocation of resources as part of their obligation as members of society? Or is citizen participation merely a “politically correct” way to attempt to reform the system? These are questions that have only begun to be addressed in the current discourse about citizen involvement in health care decision making.

Most reports dealing with public participation propose that it is a good thing and leads to better decision making, however, there is virtually no research evidence to support this claim (Charles & DeMaio, 1992; 1993; Lomas & Veenstra, 1995). Charles & DeMaio propose that one reason for the lack of research in this area is the conceptual confusion around the issues. There is little consensus and a lack of conceptual clarity about what the terms lay, consumer, community, public or citizen participation actually mean. This lack of clarity, and the absence of a common framework for describing the dimensions of citizen participation, has led to the development of analytic frameworks outlining various levels of citizen participation and involvement (Arnstein, 1969; Charles & DeMaio, 1992; 1993; Eyles, 1993; Feingold, 1977). These authors also acknowledge the need for more research in the area of consumer participation in decision making. Furthermore, although there is widespread support for the move to a decentralized decision making approach with increased citizen involvement in health care (B.C. Ministry of Health, 1991; 1993; Bruce, 1992; CHEPA, 1991; Nova Scotia Government, 1989), there is little evidence that the models of devolution and decentralization, where health care decision making by citizens is encouraged, actually work (Hurley et al., 1992; Lomas & Veenstra, 1995).
There are a few examples in the literature where attempts have been made to involve consumers in health policy decision making. In the U.S., particularly in Oregon, discussions at the "grassroots" level have been occurring about how health care resources should be allocated (Colbert, 1990; Crawshaw, 1990; Crawshaw, Garland, Hines & Lobitz, 1985; Dougherty, 1991; Hadorn, 1991b; 1991c; Hines, 1986; Jennings, 1988; 1990a; 1990b; Sipes-Metzler, 1991; Wallace-Brodeur, 1990).

In Canada, some "grassroots" discussions have taken place during Royal Commissions, during the recent National Forum on Health, and in most provinces, such as Quebec, Saskatchewan, Nova Scotia and British Columbia, there have been efforts to include citizens in a consultation process as those provinces reform their health care systems (B.C. Ministry of Health, 1991; 1993; CHEPA, 1991; Hurley, Lomas, & Bhatia, 1993; National Forum on Health, 1997; Nova Scotia Government, 1989; 1994). For instance, in February of 1993, the British Columbia Ministry of Health announced an innovative plan for health care that included a number of methods to involve consumers in the development of the new health care system being proposed in that province (B.C. Ministry of Health, 1993). Recent changes and experiences in British Columbia, following a review and subsequent modifications to the previous New Directions plan, have lead to a reconceptualization of how citizens will be involved in the regional health board and community health council structure of that province (Vancouver/Richmond Health Board, 1997). There have also been several attempts in countries outside of North America, such as Great Britain and New Zealand to include more citizen involvement in health care (Bowling, 1996; Klein, 1993; Ham, 1993).

Some authors are critical about what they call "rhetoric" in regard to the public being included in decision making about resource allocation issues in Canada. In many situations they believe public involvement in health care to be token, with providers still occupying the major roles in the system and making the important decisions (Emson, 1991; Manga & Weller, 1991). Moreover, because of the vertical, hierarchical decision making systems prevalent in society it is not readily apparent how citizen voices will be heard or how they will receive the information they
need to be involved (Checkoway, 1981; Gordon, 1990; Reiser, 1992a; Riddick, Cordes, Eisele & Montgomery, 1984). For example, Woodward & Stoddart (1989) point out that the general public need to be more aware of the expected costs and benefits of various types of investigations and procedures in order to become more involved in the debate about who should be offered various types or intensities of care. Moreover, they posit that one of the challenges facing the health care system is to achieve an informed social consensus regarding the level of health care spending, a project that requires a cooperative effort on the part of all members of society. Crawshaw et al. (1989) support this claim stating:

The role of the expert is clear and necessary in describing what is possible, but the expert cannot and should not be expected to present the limiting, broad policy values that inform a just democracy. Only legislators, supported by a courageous constituency, can establish the moral yardstick that must decide which “life and death” health benefits should be pursued under existing conditions (p.363).

The level of resource commitment to common goods, such as health care, is considered to be ultimately a matter of societal choice, with some authors proposing that members of the public ought to be involved in developing policies about the use of technology and the allocation of finite resources that are reflective of ethical principles and societal values (Davis & Aroskar, 1991; Pellegrino, Sieglar & Singer, 1991). Winner (1993) further develops this idea and points out that there is no moral community or public space in which technological issues are topics for deliberation and common action. He states:

As we ponder issues of this kind [technological issues which require social choices], it is not always clear which principles, policies, or forms of moral reasoning are suited to the choices at hand. The vacuum is a social as well as an intellectual one. Often there are no persons or organizations with clear authority to make the decisions that matter. In fact, there may be no clearly defined social channels in which important moral issues can be addressed at all. Typically, what happens in such cases is that, as time passes, a mixture of corporate plans, market choices, interest group activities, lawsuits, government legislation takes shape to produce jerrybuilt policies. But given the number of points at which technologies generate significant stress and conflict, this familiar pattern is increasingly unsatisfactory (p.47 ).

Although Winner’s comments do not refer directly to transplantation, nonetheless they can be applied to transplant technology. For example, Fox and Swazey, (1992b) and Rettig (1989), in their descriptions of the development of public policy in the transplant area, suggest that many of
the policies governing transplantation were developed in the piecemeal fashion described above. Technology development and the decisions about how to use technology have been largely under the control of experts and highly politicized (Rettig, 1989; Fox & Swazey, 1992b; Winner, 1993), hence, the need for more public involvement in future discussions about allocation of resources.

Winner (1993) goes on to support the involvement of the public in discussions about allocation of resources suggesting that further work is required, examining how the public can be involved. He states:

Rather than continue the technocratic pattern in which philosophers advise a narrowly defined set of decision makers about ethical subtleties, today's thinkers would do better to re-examine the role of the public at this time. Unfortunately, the Western tradition of moral and political philosophy has little to recommend on this score, almost nothing to say about the way in which persons in their roles as citizens might be involved in making choices about the development, deployment, and use of new technology (p. 49).

Compounding the problem of the lack of consumer voice in decision making in health care, is the additional concern that not all voices of health care providers are being heard in the debate. It has been demonstrated that collaboration among health care team members leads to better decision making and positive patient outcomes (Baggs, Ryan, Phelps, Richeson, & Johnson, 1992; Knaus, Draper, Wagner, & Zimmerman, 1986; Koerner, Cohen, Armstrong, 1985; Mitchell, Armstrong, Simpson & Lentz, 1989). Yet, communication, collaboration and effective ethical decision making among health care providers are fraught with concerns about: asymmetrical relationships, "turf wars", who has power in the system, vertical versus shared decision making models, lack of respect for contributions of some health professionals, the physician in the traditional "captain of the ship" role not encouraging team functioning, and institutional constraints that block the ability of teams to function in a manner to facilitate positive outcomes (Mariano, 1989; Rodney & Starzomski, 1993; Schattschneider, 1990). Some authors believe that the reasons these issues have not been resolved may be related to the differences in values, moral reasoning and philosophical perspectives of different health care provider groups (Campbell-Heider & Pollock, 1987; Canadian Medical Association, 1996; Gramelspacher, Howell & Young, 1986; Grundstein-Amado, 1992; Stein, Watts, & Howell, 1990), although this has not been studied extensively.
A premise upon which the involvement of consumers in health care is based, is that consumers hold different values and ideas about resource allocation than providers and so-called experts (Crawshaw, Garland, Hines, & Anderson, 1990); although, there have been few studies that support this claim. The studies that have been done tend to focus generally on attitudes of health care providers and consumers, without exploring these attitudes in more depth (Lee, Penner, Cox, 1991; Todres, Guillemin, Grodin, & Batten, 1988). Furthermore, there is little research examining whether the public (as well as the various groups that comprise “the public”) and health care providers are disparate in their reasoning and choices about resource allocation for health care. However, there is an acknowledgment that this information is required in order to develop the best mechanisms and structures for allocation decision making in groups that will determine local plans for health care resource allocation.

When discussing health care reform, then Minister of Health, Elizabeth Cull emphasized that those involved in health care provision in B.C. needed to move from a “turf mentality” to a “team mentality”, stressing that a change was required in how decisions were made with more emphasis on collaboration among health care providers and citizens (Cull, 1992). It has been suggested, however, that in order for this debate between consumers and health care providers to occur, traditional, hierarchical, vertical decision making systems will require change in order to allow consumers and indeed health care providers to have an active voice in resource allocation decision making (Knaus, Draper, Wagner & Zimmerman, 1986; Mitchell, Armstrong, Simpson, & Letz, 1989).

The Research Problem

In summary, there are a variety of ethical issues that have emerged in the field of transplantation. Many of these issues relate to the allocation of scarce resources and are overlaid with questions of distributive justice. There appears to be a need to discuss these issues in the public domain with the ultimate objective of developing public policy about the fair and just allocation of resources for transplantation.
At the same time, a new collaborative model in health care is being proposed in which it is suggested that consumers and providers have a role, in conjunction with government, in proposing how resources ought to be allocated for health care services. Several Canadian provinces are planning health care reform where consumers are, or will be, more involved with the development of some form of empowered partnership, and with planning how resources will be allocated. Although there is much discussion about involving health care provider and consumer stakeholders in decisions about how resources are distributed, there are few examples in Canada to show how to do this. Health care providers, as well as consumers, are unclear about their roles around resource allocation issues at various levels within the system, and there is evidence that, because of an asymmetrical power structure in the health care system, not all voices are being heard.

Furthermore, although there is a stated preference for effective communication among stakeholder groups, and team work to solve ethical dilemmas in health care, there are indications that this does not always occur. Moreover, there is no assurance that all stakeholders would agree that community involvement in resource allocation is a goal towards which to work. In addition, there has been little research examining who ought to be involved in the discussions about resource allocation, at what level of the system they should be involved, and whether a collaborative model of health care decision making will result in the just allocation of resources. Finally, there has been a paucity of empirical work describing public or provider reasoning about the ethical issues emerging in the resource allocation debate. Little is known about the views or attitudes consumers and health care providers hold in relation to resource allocation in areas such as organ transplantation. Before community/provider groups can begin to work together to fairly distribute resources more needs to be known about these critical domains.

**Purpose and Research Questions**

Given the need to develop a better understanding of consumer and health care provider views and moral reasoning about resource allocation for organ transplantation, and given the

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3 The terms moral reasoning, ethical reasoning and ethical decision making are used interchangeably in the literature to describe a variety of different processes. For the purpose of this study, the term moral reasoning will be used to
emphasis on moving to a more collaborative model in health care where consumers and providers have a shared role in discussing how resources ought to be allocated, this study was designed to answer the following major questions:

1) What is the reasoning process used by stakeholder groups when discussing ethical issues related to resource allocation for solid organ transplantation?

2) How do these groups describe their own role as well as the roles of other stakeholder groups in resource allocation for transplantation?

Specifically, the manner in which these questions were addressed was by engaging stakeholder groups in a discourse to answer the following research questions.

1) What are the beliefs, attitudes, values, and principles held by selected stakeholder groups about specific ethical problems/dilemmas in organ transplantation?

2) How do the stakeholder groups tend to express the beliefs, attitudes, values and principles that influence their thinking about ethical problems/dilemmas in organ transplantation at the micro, meso and macro level of the health care system? (for example, allocating health care resources to transplantation, presumed consent for organ donation, transplantation of animal organs into humans, living organ donation, selection criteria in organ transplantation).

3) What moral considerations are evident as these issues are discussed? (for example, are the participants able to identify a moral problem, are alternative solutions for the dilemmas presented?)

4) What is the moral reasoning process(es) used by the various stakeholder groups?

5) Are there moral theories guiding the discussion of the different stakeholder groups? (for example, theories of justice)

6) Are there identifiable differences among, and within, stakeholder groups in the way they view or reason about the ethical issues?

7) What role do the stakeholder groups believe that consumers and health care providers ought to have in regard to these ethical issues?

describe the process that includes the recognition and identification of moral problems, the exploration of alternative courses of action, the selection of an appropriate course of action, and the evaluation of the action chosen.
Significance

There are several areas of significance for this research. As health care delivery changes, research that adds to the body of knowledge about the types of considerations that enter into moral decision making about resource allocation, how the various stakeholders identify, discuss and debate ethical dilemmas in transplantation, and views of the stakeholders about who should be involved in these decisions, will facilitate the dialogue needed in society about these issues. Particularly, the constructions from this study have the potential to provide a perspective about how selected groups of consumers and health care providers reason about ethical issues in transplantation, thereby, adding to the theoretical body of knowledge about how persons reason about ethical problems related to resource allocation generally. Knowing more about the values, attitudes, beliefs and moral reasoning of various stakeholder groups will assist in determining whether there is divergent thinking in this area. This knowledge can, in turn, assist in the development of the best mechanisms and structures for allocational decision making.

Questions within the transplant realm about allocation of scarce resources, including the financial, organ, and human resources required to develop and operate transplant programs, epitomize many of the allocation questions that face society at large. It is hoped that this descriptive work will provide direction for normative discourse in the health policy arena in order to establish effective methods for dialogue about resource allocation and development of public policy. Moreover, there is a need to have a better understanding of public views about transplantation in order to develop the best strategies to maximize resource allocation and utilization. In particular, the constructions developed during this inquiry will have significance for groups such as the Kidney Foundation of Canada and the B.C. Transplant Society in their mandate to increase organ donation, ensure that organs are distributed in a fair and equitable manner, and improve the quality of life of people living with end stage organ failure.

As health care decision making becomes more collaborative in nature, learning more about the attitudes and moral reasoning of various stakeholder groups can be of assistance in improving communication as groups learn more about each others' perspectives. In addition, the method of
data collection for this study can provide an opportunity to determine if focus groups are a means of opening up moral space and encouraging ethical discourse in society about resource allocation. This information will not only add to the theory already developed in the area, but also provide direction for the involvement of the public in the future.
CHAPTER TWO

Literature Review

In this chapter, I will explicate the major concepts informing this work through a review of the empirical and theoretical literature related to resource allocation for organ transplantation, theories of justice, consumer and health care provider participation in health care decision making, moral theory, and consumer and health care provider moral reasoning. The goal will be to summarize the current state of knowledge in these areas, and to highlight significant issues that the inquiry has left unresolved.

To begin, I will review literature in the solid organ transplant domain to identify the research related to societal determination of the level of resource commitment required for organ transplantation. Studies focusing on the allocation of resources generally, and organ donation specifically, will be reviewed. Inquiry devoted to understanding more about consumer and health care provider attitudes will be highlighted. In addition, the role of the media in the debate about allocation of resources for transplantation will be reviewed. Furthermore, since the allocation of resources in health care leads to major decisions about what is just and fair, an understanding of the principles of distributive justice will be required to inform this work. Hence, a brief overview of the various theoretical approaches to distributive justice will be discussed.

Decision making about resource allocation has been dominated in the past by providers, however, current theoretical work supports the involvement of both the lay public and health care providers in resource allocation decisions. A review of the literature examining the evolution and role of consumers in health care decision making will be conducted to explore the work completed in this area, as well as to identify gaps in the research. Theoretical perspectives from critical theory will be examined to inform this work, since one of the underpinnings of the development of a consumer and provider partnership is the belief that certain groups are currently disenfranchised either by oppression, or because they are believed not to have the knowledge, skill and expertise to participate in any meaningful manner in health care decision making.
The choices of consumers and health care providers, and their decisions about the competing goods in the resource allocation debate, are influenced by the values, attitudes and beliefs they hold as well as their ability to reason about moral issues. It is important to understand what theoretical perspectives guide the moral thinking of different groups in order to make these perspectives explicit to enable stakeholders to work together “knowing where others are coming from.” Therefore, to this end, I will highlight literature examining moral theory and consumer and health care provider moral reasoning.

Finally, to collaborate effectively with consumers, health care providers must be communicating and collaborating effectively amongst themselves. Hence, I will review the research examining ethical decision making among health care providers to further inform this work.

Resource Allocation for Organ Transplantation

Despite an abundance of literature on ethical issues in organ transplantation and resource allocation in general, there are few studies examining the allocation of health care resources in transplantation. The major focus of transplant research has been on developing and testing new techniques to improve patient and graft survival, immunosuppression, and organ preservation (Meloche, 1993; Ostrow, Fradet, Howard, Gudas & Nelems, 1993; Scudamore, Shackelton, Forward, Randall, & Erb, 1993); patient adjustment to transplantation and quality of life (Evans et al., 1985; 1990; Hicks, Larson, & Ferrans, 1992; Molzahn, 1989; 1991); psycho-social concerns and decision making of patients and families undergoing organ transplantation, (Craven, 1991; Hilton & Starzomski, 1994; Simmons, Marine & Simmons 1987); and examining public attitudes and opinions about organ donation (Bowden & Hull, 1993; Filthaut, Li, & Wright, 1991; Gallup Organization, 1993).

Although most studies concerned with resource allocation for transplantation have focused on surveys of public and professional attitudes about organ donation, two studies were located that examined selecting patients for dialysis and transplantation (Kilner, 1988), and public attitudes about resource allocation for transplantation (Storch & Dossetor, 1993). A study by Lemieux-
Charles, Meslin, Aird, Baker and Leatt (1993), although not focusing solely on transplantation, will be included in this review as it was the only Canadian study located by this author that focused on ethical issues faced by health care providers in resource allocation decisions.

In the 1992 Canadian study conducted by Storch & Dossetor (1993), a series of twelve questions about resource allocation (four of which focused on allocation of resources for transplantation) was added to an annual all-Alberta telephone survey conducted by the Population Research Laboratory in Edmonton. The study sample consisted of 1200 respondents, of whom 49.1% were males, and 50.9% were females. When asked whether too much money was being spent on medical technologies that benefited only a few, approximately 55% of those surveyed were ambivalent, choosing responses between three to five on a seven point Likert scale.

Furthermore, older Albertans had a higher level of agreement with this statement than younger Albertans. Of the remaining questions, 72% did not agree with the statement that transplants should be limited to those persons between 20-30 years, 75% disagreed with the statement that there should be a yearly quota on transplants, and 93% disagreed with a statement to stop all transplants. Interestingly, Albertans with higher incomes disagreed with the transplant resource allocation statements more than did those with lower incomes.

Given the high rate of disagreement about reducing services such as transplantation, the investigators were puzzled by the ambivalence in the responses to the statement that too much money was being spent on medical technologies that benefit only a few. They postulated that the responses might be attributed to a lack of knowledge about the issues involved in choices about resource allocation. Also, they suggested that public awareness of resource allocation, as a result of the recent major health care funding cuts in Alberta, might elicit different responses if the study were conducted at another time. Moreover, the researchers indicated that one limitation of the study was that it did not allow further investigation of why people responded in the manner they did -- a limitation of attitudinal surveys raised by other researchers (Blendon & Donelan, 1991; Jacich-Toth & Roper, 1991). Therefore, Storch & Dossetor (1993) recommended future research focused on
obtaining qualitative data about views and attitudes of the public about resource allocation in health care.

Kilner (1988) surveyed 453 medical directors of U.S. dialysis and transplant centers to determine the selection criteria being used in the centers, as well as what criteria might be used if resources were limited. Directors were asked to complete a questionnaire rating sixteen defined selection criteria. They were asked to rank each criterion twice, once with regard to the criterion's importance in present patient selection decisions and once with regard to similar decisions in the future, assuming scarcity of resources. All of the criteria, except gender, were used by a substantial number of the directors. The greatest common ground among the directors was on medical considerations and medical benefit that were ranked as very important. Psychological stability and age were considered somewhat important. Criteria such as social value, ability to pay and random selection were considered least important. In times of scarcity, length of survival with treatment, the quality of life of recipients, ability to pay, and age were rated higher than in the present situation. Kilner described the directors as having a "utilitarian bent" and raised concerns about the changes they made in criteria in the scenario when resources were scarce. The range of scores and the standard deviations for most of the criteria were quite high, leading Kilner to suggest the need for scrutiny of the medical and ethical justifications for each criteria, since some criteria were in direct conflict with others. He proposed that as resources become limited there is a need for more open discussion of selection criteria.

Lemieux-Charles et al. (1993) conducted a study with four homogenous focus groups of 28 clinicians/managers in a Canadian teaching hospital with a decentralized management structure. The groups included nurse managers, managers from other professional groups, and physician managers who were brought together to discuss ethical issues they faced when making resource allocation decisions. Focus groups were chosen as the data collection method as the investigators wanted the groups to interact together to stimulate discussion, and they believed that focus groups would allow a better view of the way the respondents “thought” and “talked” about ethical issues (p. 270). In brainstorming sessions, 97 issues were generated by the groups. In the discussion
phase of the group, 74 of the 97 issues were defined as ethical, with an average of 17 issues per group. A number of recurring ethical issues were raised by the groups, including fairness, concern with preventing harm, consumer/patient choice, balancing needs of different groups of patients, conflict between financial incentives and patient needs, and professional autonomy. The investigators concluded that the ethical issues raised by the groups showed that they were concerned with meeting ethical requirements and were able to recognize ethical concerns. They further suggested that decentralizing resource allocation and utilization decisions does raise ethical issues for clinician/managers, and that a better understanding of these issues can be obtained by using an interdisciplinary point of view (p.267).

These three studies indicate a beginning interest in exploring the general issues related to resource allocation by health care providers and consumers. However, the paucity of research points to the need for additional inquiry in this area.

In addition to examining research relating to allocation of resources generally, there is a larger body of research that focuses specifically on one resource requirement for transplantation — that is, availability of organs. Examining public and health care provider views about organ donation comprises the largest body of research in the area of resource allocation for transplantation. Studies have been located that focus on opinions, attitudes and perceptions about organ donation.

Over the past three years, while the number of organ donations has remained constant, or in some places decreased (Kane, Ferre, Bannon, Fradet & Shackelton, 1993), the demand for organ transplantation has increased by more than 30 percent (Prottas, 1993). Some claim the shortage of available organs for transplantation has reached crisis proportions (Bowden & Hull, 1993). In 1995, there were 1,484 transplants performed in Canada with 2,554 persons on transplant waiting lists by year end (Canadian Organ Replacement Registry, 1996) (See Appendix 2 for Canadian Transplant Statistics).

In recent years, because of the chronic, and indeed growing shortage of organs, research has been conducted to determine public attitudes and awareness of organ donation, with the
ultimate goal of increasing the number of organs available for transplantation. Although there is
public support for organ donation, there are members of the public who remain reluctant to
consider donating their organs. Public surveys have shown that from 40.6% (Filthaut, Li &
Wright, 1991) to 85% (Gallup Organization, 1993) of those surveyed would donate their organs.
Filthaut et al. (1991), in their telephone survey of 150 people in Saskatchewan, found that a small
percentage of the respondents (21.3%) would not consider organ donation, with 40.6% of those
persons unable to give a specific reason why they would not do so when asked. In a telephone poll
of 504 adults (50% male and 50% female) about organ donation, B.C. investigators found that
62% said they would be donors and either had organ donor designations on their driver's license
(47%), or another type of organ donor card (15%). A large number of those who did not sign any
document indicating they wished to be an organ donor (46%) were unable to give a reason why
they did not do so. Others said they had not really thought about it (12%), had health problems
they believed precluded them from being donors (12%), were unaware they could (9%), believed
hospitals might kill for body parts (4%), or it was against their religion (3%). The results of these
studies suggested that there were significant numbers of people for whom organ donation was not
an option, although why this was so remains unclear (BCCODA, 1991).

In addition to the studies examining the attitudes of members of the public, there have been
a number of studies examining the attitudes and knowledge level of health care providers about
organ donation. Prottas & Batten (1988) studied a random sample of 222 hospital administrators,
227 directors of nursing, 878 intensive care unit nurses, and 246 neurosurgeons regarding their
commitment to organ procurement and the impediments limiting their cooperation with
procurement programs. They found that virtually all the health care providers surveyed were in
support of organ donation and would donate their organs. Lack of time, the emotional difficulties
of dealing with donor families, and fear of legal ramifications (by the neurosurgeons) were cited as
limiting cooperation with procurement agencies.

Falvo, Woehlke and Tippy (1987) found that, although a sample of 51 family practice
residents had positive attitudes about organ donation, only 25% had completed an organ donor
card. The results of a survey of physicians, nurses, staff and hospital administrators in 176 U.S. transplant centers revealed that, although attitudes about organ donation were overwhelmingly positive; levels of knowledge about organ donation, donor maintenance, brain death and transplant statistics were astonishingly low (Ettner, Youngstein & Ames, 1988). These findings were supported by Borozny (1988) in her study of 76 intensive care nurses in Vancouver. She found that knowledge about brain death criteria was often limited, with less than 50% of the nurses listing apnea or unresponsiveness as criteria for a diagnosis for brain death. Moreover, many nurses reported having great emotional difficulty in caring for “brain dead” organ donors. They expressed negative attitudes about the organ donor process and commented on the difficulty maintaining patients on life support who they knew were actually dead.

In another Canadian study, Kiberd and Kiberd (1992) found that 62% of nurses surveyed had a signed donor card. Although support for organ donation was nearly unanimous, operating room nurses were less willing to donate than their colleagues in other units, leading the investigators to speculate that being involved in the difficult procurement process itself, and a lack of exposure to successful transplant recipients, may influence attitudes about organ donation. From a research perspective, the findings from these studies illustrate the need for increased discussion and further research to learn more about health care professional attitudes toward organ donation, and the reasons why, if they support organ donation, they themselves are not always willing to be organ donors. Moreover, from an education and practice perspective, these findings highlight the need for continued professional education and emotional support for health care professionals involved in the organ donor process.

A comprehensive study of public and professional attitudes about ethical issues related to organ donation was conducted by the National Kidney Foundation (NKF) (Bowden & Hull, 1993). The widening gap between the number of people on the transplant waiting list, and the number of available organs prompted the NKF to embark on a two year research project about American attitudes towards organ donation. The Foundation’s aim was to reexamine the basic concepts underlying organ donation and determine whether there were new approaches that could
be considered to increase organ donation in the U.S., and to bring four controversial issues to the
fore of the U.S. consciousness in the hope of coming closer to solving the organ shortage crisis.
These controversial issues included financial incentives, presumed consent, living donation, and
minority donation. The NKF acted as a neutral catalyst for discussion, taking no stand on whether
or not these concepts should be implemented in the United States.

The project began with a Consensus Conference of “invited experts” in New Orleans in
February of 1991, at which over 50 leaders in the field of organ donation and transplantation
convened to discuss the four issues. The conference was followed by four regional public forums
to further debate the issues raised. Following the forums, the NKF collaborated with the United
Network for Organ Sharing in conducting a two phase study. The qualitative phase consisted of
ten focus groups in five cities across the country where paid informants (selected by a marketing
firm) were asked to provide their opinions about issues related to organ donation. The quantitative
phase consisted of a telephone survey of 1200 households to elicit opinions about the four issues
mentioned above.

The findings of the study revealed that participants in the consensus conferences and public
forums believed that it was important to “maintain the spirit of altruism implicit in the act of
donation to avoid abusive practices” (Bowden & Hull, 1993, p. 4). However, there was support
for offering limited and “modest” financial incentives to cover the burial costs of organ donors and
to provide aid to eliminate the financial disincentives for living related donors. Most participants
were not supportive of the idea of presumed consent, considering “the concept as particularly un-
American in its abrogation of individual freedom” (Bowden & Hull, p. 4). Finally, there was great
concern about the treatment of minorities in the transplant process, where they were found to be
underrepresented in every way except for their need. For instance, there were fewer health
professionals from minority groups in the transplant network, fewer potential donor families were
asked, fewer donated, fewer received organs, more people were at risk for end stage organ failure
(especially kidney failure), and more were on waiting lists. There was a call for major system and
attitudinal changes to rectify this situation. In addition, there was general support for increasing the
number of biologically and emotionally related living donors in all ethnocultural groups, although
donations from altruistic strangers were considered suspect (Bowden & Hull, p. 4).

Following the public forums, ten focus groups were conducted in five cities representing
the major regions in the continental U.S. In each city two groups were held, one consisting of
informants who had expressed a desire to be organ donors, and another group who had not.
Attempts were made to include people who had incomes below and above $30,000, and who were
between the ages of 18-64. Moreover, two African-American non-donor groups were recruited in
order to provide a forum for participants to discuss minority issues, since it had been discovered in
one earlier group that African-Americans were uncomfortable discussing the lower rate of donation
among minorities when they were in racially mixed groups. The focus of the groups was to
discuss perceptions and knowledge about transplantation, donor status, feelings about presumed
consent, racial and ethnic issues, and to have the groups evaluate a public service announcement
developed about organ donor awareness.

Findings of the study indicated that most of the groups knew nothing about the allocation
process for organ donation or the different possibilities for donation. Reasons non-donors gave for
not wanting to donate included a general distrust of the medical community and a worry that the
health care providers would not try to save them, uneasiness about the concept of brain death, a
lack of understanding of the process and religious concerns. Donors were more accepting of their
mortality than non-donors. The African-Americans believed that the major reasons for the lower
donor rates was a strong distrust of the “white” medical community and alienation from the rest of
society, as well as cultural, economic and religious concerns. In general, most groups were
opposed to presumed consent for organ donation as it violated the American value of free choice.
All groups were opposed to financial incentives for organ donation suggesting that attaching a price
to human life was “outrageous”, although some considered providing money for funeral expenses
to be acceptable (Bowden & Hull, p. 101). All groups were uniformly opposed to governments
being involved in increasing organ donation, and expressed tremendous levels of skepticism about
the government (Bowden & Hull, p. 102). Moreover, all groups were aware of the need for
organs, the shortage, and almost all groups knew about the third-world black market for organs. Finally, all groups were in favor of the public service announcement and encouraged more public awareness and education.

The results of the sixteen minute, consumer telephone survey indicated that 42% of the 1204 respondents were in favor of some form of financial or non-financial compensation to donors and/or families. More younger than older respondents were in favor of this method of increasing the number of organ donors. Two-in-five (38%) favored presumed consent, younger respondents were more in favor than older people for this method of organ donation. Those with higher education, and those from households with an income over $50,000, were substantially more likely to support presumed consent than those with lower levels of education. When asked who they would most trust to answer questions about organ donation, the three considered most trustworthy were members of donor families (53%), physicians (48%), and television (29%). In this study, 33% of the respondents had signed organ donor cards or had designated on their drivers licenses that they would like to be donors. The incidence of being a potential donor increased significantly with household income and decreased with age. The findings of this study illuminated some of the barriers to organ donation and also pointed to areas where public education is required. The values held by Americans about individual freedom were clearly articulated in several phases of this study, raising the question about whether the socio-political and ethnocultural differences in Canada might lead to different findings in this country.

In summary, there are few studies in either Canada or the U.S. that have examined allocation of resources (other than for organs), or have examined other ethical issues in transplantation. Although there is some preliminary research in the area of resource allocation for transplantation, there are major gaps about the knowledge, attitudes, beliefs, and values Canadians hold in this area. The majority of the inquiry has focused on survey research, usually with the goal of learning more about the attitudes people hold about organ donation. Although this research is useful, the methods have precluded further probing for the reasons people hold the views they do, or for an opportunity for individuals to discuss their views with others, either in small groups or in
larger public forums. There is a need for further exploration of consumer and health care provider views and reasoning in this area. Moreover, the results of the NKF study point to a need for discussion of some of these same issues in Canada, since because of the potential differences in values about health care between the two countries, the U.S. results are unlikely to be generalizable to this country.

Some authors are critical about the direction in which research and practice has moved in relation to organ transplantation. Teo (1992) raises a question about whether the organ shortage is the major obstacle to the performance of more transplants as popularly portrayed. He posits that, although the methods to improve the efficiency of organ procurement may be inspired by laudable motives to save lives, they may ultimately prove to be myopic if the larger ethical issues raised by organ transplant programs for the allocation of national and organ resources are not given their due consideration. He argues that before a society decides on its policy of organ procurement it ought to make prior assessments of its social priorities, the policies for ensuring fair access to organs, and the extent to which it is willing to support transplants. In addition, Fox and Swazey (1992b), are concerned about the increasing focus on organ donation, and are critical of the direction in which the field of transplantation has headed in relation to living organ donors, particularly in the wake of the increasing need and shortage of organs. They state:

In the context of the growing organ shortage “crisis”, the theme of organ transplantation as a gift of life was framed and addressed primarily as a social policy problem of supply and demand. Exhortations “to make a miracle” happen through organ donation were accompanied by a structured forgetting of some of the darker emotional and existential implications of what is involved (p. 45).

The media has been very involved in directing the focus in transplantation on specific issues. There has been considerable media attention focused on transplantation in general, and specifically to the plight of individual, potential organ recipients (Brooks, 1993; Rettig, 1989). Rettig (1989) posits that although there is no empirical basis for determining the influence of the media on transplantation, the print, television, and radio media have exercised and continue to exercise a powerful influence. He states “although we lack good analyses of media impact on transplantation policy, we can speculate with confidence that identified lives benefit even more
from publicity than do the statistical lives of other legitimate, less visible claimants on scarce collective resources" (p. 222).

Two very different examples illustrate the power of the media and the effect on public response. One situation occurred in Oregon in 1987 when the state legislature determined there would be a budgetary shortfall in the funding of health services for Medicaid recipients (Klevitt, Bates, Castanares, Kirk, Sipes-Metzler, & Wopat, 1991). The legislature decided, with little discussion and no public debate, to direct funds away from heart and liver transplants in favor of prenatal and other forms of preventive care (Crawshaw et al., 1989; Jennings, 1988; Welch & Larson, 1988). Citizen meetings were conducted by The Oregon Health Decisions group as a result of the public outcry that occurred when two Oregon children in the Medicaid program were denied necessary transplants. The first child denied care was an infant with neuroblastoma, whose family subsequently moved to Washington state and established Medicaid eligibility there in order to receive care for their son. The second case was that of a seven year old boy with leukemia who required a bone marrow transplant, and who reportedly died before his relatives could raise the money they needed for him to receive the care he required. After a period of intense discussion and media attention, state coverage for transplantation was eventually reinstated, although some changes were made to the coverage offered (Boisaubin, 1988; Welch & Larson, 1988).

Another case was that of Laura Davis, a five year old child from England, who underwent a seven organ transplant in September, 1993. As a result of a massive publicity campaign, several hundred thousands of dollars were raised to support her experimental transplant in Pittsburgh, where she received a liver, stomach, pancreas, large and small intestine, and two kidneys. Money for the surgery was contributed from Diana, Princess of Wales, from donors responding to television shows and media campaigns where Laura appeared with various celebrities, and from King Fahad of Saudi Arabia, who contributed $270,000 to the cause. Laura never thrived after the 15 hour operation and died on November 11, 1993 of a massive stroke (Associated Press, 1993; Molloy, 1993). These scenarios point to the fact that individuals and groups with influence, using the heart-wrenching stories needed to mount media campaigns, can influence the public and
government and receive what they are requesting. Programs that support the most vulnerable persons in society such as the poor, the elderly, the institutionalized and the mentally ill do not have the same voice, or as exciting a story, with which to elicit the same support. These members of society often suffer as a consequence (Molloy, 1993; Wachter, 1992), once again pointing to the need for more discussion about the just allocation of resources; a discussion that requires an understanding of the different theories of justice.

Theories of Justice

Applying theories of justice to health care is a relatively recent endeavor, as theories of justice have traditionally advanced general principles, but have not illuminated the particular problems facing society with respect to health care (Buchanan, 1991, p. 552). Furthermore, allocation issues have focused mainly on whether there is a right to health care (Buchanan, 1984).

Buchanan (1991) succinctly describes three theoretical approaches to justice, and reviews the position, within each theory, of a right to health care. He categorizes the theories as: the utilitarian approach, Rawls' theory of justice as fairness (liberalism), and the libertarian approach. Furthermore, Nielson (1991) puts forward a description of an egalitarian theory of justice. Since stakeholder groups may be using one or another of these perspectives as they deliberate on the questions about resource allocation for transplantation, a very brief review of the main tenets of these theories is presented to inform this research.

In Nielson’s (1991) account, he suggests that justice requires that social institutions work on the premise of moral equality where the life of everyone matters equally. Hence, similarities or equalities among individuals are emphasized. Nielson posits that there is a moral right to health care. Distribution of health care ought to be carried out according to need, with the provision of health care of the same extent and quality to everyone in society (p. 562). Nielson proposes that the underlying aim of health care should be to meet the health care needs of all, equally. He goes on to say that different treatment is justified only where the need is different, or both needs cannot be met. Where these circumstances occur, then priority should be given to the greater need that feasibly can be met (p. 565).
Utilitarian theories reference the rightness or wrongness of actions or policies to the good or bad consequences they generate. Right acts and policies are those that achieve the greatest net good or happiness for the greatest net number (Buchanan, 1991). Buchanan (1991) distinguishes between act and rule utilitarianism, suggesting that the distinction is important as rule utilitarianism must include an account of when institutions are just. In this case, he posits that the utilitarian justification of an action or decision may not be that it maximizes utility, but rather that it falls under a rule of an institution that maximizes utility (p.553). Buchanan discusses the disagreements among various utilitarian theorists in regard to the question of a right to health care, concluding that depending on their perspective, some utilitarians may argue that there is a right to health care. According to McDonald et al. (1992) “while utilitarianism is sensitive both to welfare and equal consideration, it is unfortunately insensitive to distributive considerations. In principle, a utilitarian approach would sanction sacrificing the vital interests of members of a smaller group in order to promote the less vital or even non-vital interests of a majority” (p. 38).

In his review of justice, Buchanan (1991) summarizes Rawls' theory. The theory is based on the idea that inequalities in the distribution of the primary goods of a society can be condoned only if these inequalities are to everyone’s benefit, especially the least advantaged. His theory is based on three central principles; 1) the principle of greatest equal liberty, 2) the principle of equality of fair opportunity, and 3) the difference principle. In the first, Rawls contends that each person is to have an equal right to the most extensive system of equal basic liberties compatible with a similar system of liberty for all. In the second, he suggests that offices and positions ought to be open to all under conditions of equality of fair opportunity and that people with similar skills and abilities ought to have equal access to offices and positions. Finally, he proposes that social and economic institutions are to be arranged so as to benefit the maximally worst off (Rawls, 1971 as cited in Buchanan, 1991, p. 554). According to Buchanan, Rawls does not explicitly include health care in his discussion of justice. Furthermore, it is unclear whether Rawls would suggest that there is a right to health care.
In a libertarian conception of justice, individuals have moral rights, to life, liberty, and property, that any just society must recognize and respect. From a libertarian perspective, coercion may only be used to prevent harm, theft, fraud, and to enforce contracts (Buchanan, 1991, p. 556). Libertarian theorists, such as Nozick, state that attempts to force anyone to contribute any of his holdings for the welfare of others is a violation of property rights. However, libertarians do say that although justice does not require it, charity requires that those who seek aid are helped. Finally, libertarians believe there is no moral right to health care, and no societal obligation to provide it (Buchanan, 1991).

Following his review, Buchanan concludes that each of the theories of justice offers a theoretical basis for answering some basic questions concerning justice in health care, but that none of them provides unambiguous answers to all of the questions. Each depends for its application upon many empirical premises that are not necessarily available (p. 561).

It is clear that the discussions about resource allocation for transplantation are, and will continue to be, complex. Kluge (1993) suggests that public involvement in decision making about resource allocation is required as a way of moving to informed consent at the macro level of the health care system. The idea of including the voices of consumers and health care providers and increasing public debate about resource allocation, is explored in the next section.

Consumer Participation in Health Care Decision Making

In Canada, there has been limited consultation with citizens to determine public opinion and community values about health care priorities and allocation of resources (Charles & DeMaio, 1992; 1993; Center For Health Economics and Policy Analysis (CHEPA), 1991; Emson, 1991). The best examples have been Royal Commissions on health care issues, such as the Royal Commission on New Reproductive Technologies (Proceed with care, 1993). More recently, there has been a National Forum on Health Care (1997) directed by the Prime Minister to collect information from across Canada from different public and provider groups about the health care system, and to make recommendations about the future of health care in Canada. Moreover, there has been very little research in the area of public participation in health care, although it is an area
that is generating considerable debate among many societal groups. The concept of consumer participation in health care, the emerging issues, and the areas requiring further study are best understood by exploring the history and the development of consumerism in health care, and recent theoretical literature.

Consumerism in health care has its roots in the civil and human rights movements that arose in North America in the 1960's. Efforts by consumer advocates, such as Ralph Nader, highlighted consumer rights and the role of the public in lobbying for services that met their needs. This momentum extended to health care, as the public became more informed about health care issues, their rights within the health care system and the benefits and potential power they, as citizens, had within the system (Checkoway, 1981; CHEPA, 1991; Rosen, Metsch & Levey, 1977). During this period citizens became disillusioned with a health care system they saw dominated by providers, particularly physicians, where their voices as consumers were not being heard (Crichton & Hsu, 1990; Illich, 1975; Starr, 1982). Many consumers perceived physicians as arrogant, unwilling to cooperate on an equal basis with other allied health professionals and patients, too oriented to medical technology, and unwilling to listen to the social needs of consumers (Crichton & Hsu, 1990, p. 243). Concerns were raised about the asymmetrical power structure in health care and the inability of consumers and allied health professionals to have a voice in decision making (Illich, 1975). Illich (1975) highlighted the need for teamwork in health care, acknowledging the requirement for greater recognition of the contributions of allied health professionals, such as nurses, in improving patient outcomes. Moreover, he emphasized the importance of the role of the consumer in the health care system, believing that consumers needed more control and decision making authority in what he saw as a professionally dominated system.

In order for these collaborative partnerships between consumers and health care providers to occur, it is suggested that traditional hierarchical, vertical decision making structures, where only some groups have power, require change (Knaus, Draper, Wagner & Zimmerman, 1986; Mitchell, Armstrong, Simpson, & Letz, 1989). This change is necessary in order to allow consumers, and indeed some health care providers, to have an active voice in resource allocation
decision making. In this proposed research, exposing these asymmetrical relationships and power imbalances can be facilitated by employing critical theory, developed from Marxist philosophy by theorists such as Habermas (1989) and Freire (1989). These critical theories have been embraced recently by investigators in health care and nursing (Allen, Benner & Diekleman, 1986; Campbell & Bunting, 1991; Hedin, 1986; Kendall, 1992; Stevens, 1989). Methodologically, in critical theory, the purpose of knowledge is to release individuals from domination (emancipation), thus studies informed by critical theory are designed to expose hidden power imbalances and enlighten agents about how they ought to act rationally to realize their own best interests (Campbell & Bunting, p. 5; 1990; Schwandt, 1990). Critical theory can inform this work as it offers an approach to inquiry that advocates emancipation, freedom from oppression, action and ultimately normative direction for change (Bronner & Kellner, 1989; Campbell & Bunting, 1991) -- the key constituents to enabling consumers and health care providers to be meaningful participants in resource allocation discussions.

Over the past 30 years, consumers have been attempting to be more involved in health care decision making. For example, involvement of the public in ethical decision making is first noted in the literature in the early 1960's and 1970's, occurring around discussions about protecting human rights in research (Beecher, 1966; Culliton, 1975; 1976; Ghio, 1980; Nelkin, 1978; Veatch, 1975). As a result of the controversy over violation of human rights, representatives of the lay public became part of research ethics committees, a role that continues to be important today. For instance, the composition of the Canadian National Council on Bioethics in Human Research (NCBHR) reflects the belief that there must be public participation in the ethics review involving human subjects. Among the 17 members there are 5 public positions (Lamb, 1992, p.5). In addition to the desire to have the public included in discussions about research ethics, there was a movement in the 1970's to include the public in discourse about the regulations required in the area of genetic technology and research (Callahan, 1973), an area that continues to be controversial (Proceed with care, 1993).
The move toward healthy public policy and a change in focus in health care from elimination of disease (cure) to prevention of illness, maintenance of function and chronic symptom management (care) spurred the consumer movement on its way as more people became active participants in their health care (Hall, 1980; Cluff, 1981; Milio, 1985; Thorne, 1993). Furthermore, the influence of the women's movement had a profound effect on the health care system as feminists attempted to redefine women's health issues, began to reorganize reproductive and maternity services, and suggested that a different voice needed to be heard in the health care arena (CHEPA, 1991; Gordon, 1990; Schwartz & Biederman, 1987). As a result of these changes, a variety of self help and self care groups emerged as citizens responded to their own health care needs and attempted to gain control over their care in a professionally dominated health care system (Checkoway, 1981; Schwartz & Biederman, 1987). Although the involvement of the lay public in decision making about health care and governance of health care organizations has not occurred in a major way, there have been strides achieved by lay health groups. For instance, self help, volunteer groups dealing with women's health issues such as less intervention in childbirth, organizations that represent the disabled, and groups advocating less medical intervention for the dying have gained a place in the Canadian health care system (Coburn, D'Arcy, Torrance & New, 1987, p. 658). In addition, health charities such as the Kidney Foundation of Canada were created to address the pressing health needs of the consumers they represent. More recently, advocacy groups for AIDS (Wachter, 1992) and breast cancer are highlighting the needs of consumers with these health problems. When discussing the rise and encouragement by government of volunteer organizations in Canada, Crichton & Hsu (1990) state, "...individual electors have not been happy about the bureaucratic centralization of power in welfare states, so the public has tried to preserve traditional structures[health charities] for involving consumers when all else has failed" (p.245).

Siler-Wells (1987), in a review of Canadian and international trends in health care, predicted that there would be a move beyond the patient role to a more egalitarian and empowered partnership role for consumers. This trend is now a major theme in recent government reviews of provincial health care systems (CNA, 1992; National Forum on Health, 1997). In addition to the
consumer movement and the reports of Royal Commissions and government task forces, there is now considerable dialogue in the political arena, and a growing discussion throughout a wide body of literature, about involving the public in health policy development and instilling public values in decisions about health care resource allocation. This discussion is evident in the literature of health care practitioners as well as in the health policy, health economics, bioethics, and technology assessment (or outcome evaluation) literature (Charles & DeMaio, 1992; Crooks, 1985; Drummond, 1987; Evans, 1984; Goldsmith, 1988; Goodman, 1992; Hadorn, 1991a).

The perceived need for citizen participation in health care is based on a number of factors. On an individual level, these factors include the view that the expertise of professionals is no longer sufficient to assure a responsive health care system, and that individual preferences become important as people make decisions about specific treatment options. These consumer values influence the goals for health care as well as the evaluation of treatment costs and benefits (CHEPA, 1991; Starzomski, 1986). On a community level, the limitation of professional expertise is recognized since health is defined as broader than health care. Hence, the public is demanding that the system be capable of responding to an extensive array of community defined needs, and not simply the needs defined by health care “experts” (Charles & DeMaio, 1992; CHEPA, 1991; Danis & Churchill, 1991; Reiser, 1992a). Moreover, governments are also stressing the involvement and accountability of consumers as health care costs rise and decisions about health care priorities are required (Emson, 1991; Manga & Weller, 1991).

Many authors support the inclusion of consumer values into health care decision making. Eyles (1993) describes technical decisions about health care as those based solely on the application and extrapolation of scientific information and, therefore, within the domain of experts. On the other hand, he proposes that there are value decisions concerned with resolving important societal issues where citizens are seen as the best qualified to resolve disputes over goals and directions. Hurley et. al (1992) posit that one of the challenges for allocating resources efficiently in the health care sector is combining expert knowledge about the effectiveness of medical treatments and the structure and financing of the system with information about the needs, values,
preferences, and local circumstances of communities (p. 3). The crux of the problem is that, although providers possess better knowledge about the expected effectiveness of health care in improving health status, individuals are the best judges of how these improvements affect their well being (Evans, 1984). Reiser (1992a) states: "experts and consumers can benefit from a view of health care that emphasizes human diversity and focuses on particularistic solutions bearing the mark of the individuals whom illness affects" (p. 1515).

It is acknowledged that "good" health care decisions are not possible until the lay person or public supplies the value framework to be used (Caws, 1991; Jennings, 1991; Veatch, 1985a; 1991a; Veatch & Moreno, 1991). Veatch (1985b) suggests that value systems drawn from cultural, religious and philosophical ideological systems are central to planning health care directions. He posits that value systems provide a framework for choosing among policy alternatives, who the policy makers will be, and whether there is any possibility for cooperation among the various stakeholders in the policy arena. Pellegrino (1985) suggests that a nation's or community's health policy is its strategy for controlling and optimizing the social uses of its knowledge and resources. Human values, he concludes, are the guides and justifications people use for choosing the goals, priorities and means that make up a strategy. According to Pellegrino, ethics acts as the bridge between health policy and values by examining the moral validity of the choices that must be made as well as seeking to resolve the conflicts between the values that inevitably occur in making these choices. He goes on to describe health policy as reflecting the fundamental beliefs and commitments that tie a nation most closely to its identity and integrity as a human community. These commitments, he states, are society's human values, allowing communities to exert their influence over the momentum of technological advance through expression in the choices and priorities of their health policies. Furthermore, according to Veatch (1985b), there is a need for persons to discover whether they share a tradition of values about health care that would help them define the package of health care services that best serves the common good. Veatch (1985a) proposes that the role of the public in ethical decision making is an essential one, and this includes roles related to making policy decisions about the allocation of resources.
Many potential benefits to the health care system have been suggested as a result of consumer involvement in health care. These benefits include defining the needs of the community, developing effective ways to meet those needs, as well as fostering a sense of civic responsibility, and a sense of belonging to a community. Furthermore, there is potential for an enhanced level of concern for fellow citizens, a greater sensitivity to the social causes of many health problems and sensitivity to the needs of different ethnocultural groups (Charles & DeMaio, 1992; Checkoway, 1981; CHEPA, 1991; Eyles, 1993; Wachter, 1992).

Concerns have been raised about consumer involvement in health care decision making. There is no clarity about what the goals of citizen participation are or ought to be, or whether citizen participation is a means to an end, an end itself, or both (Charles & DeMaio, 1992; 1993; CHEPA, 1991; Hurley et al., 1992). In addition, there is little consensus about what the terms lay or citizen participation mean, leading to conceptual confusion about where and how consumers would actually be involved in the system. These concerns have led to the development of analytic frameworks by a variety of scholars (Charles & DeMaio, 1992; Feingold, 1977), adding to Arnstein's (1969) citizen ladder of participation model. These frameworks are a major contribution to the theoretical body of knowledge about consumer participation in health care and help to establish that citizen participation is not a homogenous concept.

Other concerns about consumer involvement in health care decision making center on the potential emphasis on individual responsibility, and an undervaluing of the expertise of health care providers. Stated in another way, lay involvement may encourage interest group politics and decision making based on emotional or personal responses rather than on facts and input from those with expertise. Health care providers and bureaucrats who prefer to retain centralized power are worried that their power base may be eroded (Crichton & Hsu, 1990). On the other hand, there are concerns that, in some cases, citizen participation may in fact consolidate the power of bureaucrats rather than the community groups they are charged to represent (O’Neill, 1992). Furthermore, there may be a move to emphasize majoritarian decision making to the detriment of small disenfranchised groups, and there may be opportunities for regional disparities to emerge.
(Boisaubin, 1988; Wachter, 1992). Finally, some writers have suggested that the process of decision making may be slower if there is public consultation in decision making about health care issues (Charles & DeMaio, 1992; Checkoway, 1981; CHEPA, 1991; Eyles, 1993).

Discussions about including citizens and their values in health care parallels discussions in the forestry literature (Tanz & Howard, 1991) and environmental movement (Wiseman, Vanderkop, & Nef, 1991), where at one time, consumers were involved only as part of radical special interest groups. There is a growing desire to have consumers, experts, government and industry working more closely together to help resolve some of the problems in regard to forestry practices and the environment. In these areas, consumer participation has developed to become more of an accepted part of responsible citizenship.

However, it is not enough to merely state that consumers should be involved in health care decision making. Several conditions have been proposed for meaningful public participation in decision making including assuring that: citizens have adequate information, there are a majority of citizens in the group, there is a strong mandate from the community with formal and informal access to constituents, and that people selected to represent communities have strong personalities so as not to be intimidated or dominated by the so-called experts within the group (O’Neill, 1992).

Consumer theory is developing with the intent of providing frameworks to determine where and how consumers are involved in health care in order to facilitate the research that is needed to evaluate the effectiveness of consumer contributions. Although, I was unable to locate empirical work in the literature that evaluated the role of the consumer in health care decision making, the “social experiment” that occurred in Oregon, although not designed as a formal research study, shed light on a number of areas reviewed previously about citizen involvement in health care decision making (Dixon & Welch, 1991; Oregon Department of Human Resources, 1992).

The most extensive attempt to include consumers in resource allocation decisions occurred in Oregon, where a phenomenal amount of attention and debate has been directed at Oregon's effort to reform certain pieces of health care legislation, a debate that has come to be known as the
"Oregon Experiment" (Nelson & Drought, 1992). In an attempt to deal with the rationing questions that had been plaguing the state, elected officials, community leaders, consumers and health care professionals attempted to define an adequate, minimum standard of health care for their citizens (Daniels, 1991, Eddy, 1991a; 1991c). Fox and Leichter (1991) suggested that this was a process where Oregonians were seeking to discover whether they shared a tradition of values about health care that would help them define the package of health services that constituted the common good. Fox & Leichter stated further "if one was looking (searching) for a classic exercise of American democracy in the sunlight, it is Oregon's debate" (1991, p.7). The Oregon program has become a focal point for debate on virtually every aspect of U.S. health policy: access, cost effectiveness, rationing and basic care (Garland, 1992; Garland & Hasnain, 1990b; Eddy, 1991b). The plan has sparked a major debate around the complexities and ethics related to resource allocation and involvement of citizens in developing health policy (Golenski & Thompson, 1991; Menzel, 1992a; 1992b). Eddy (1991b) points out that the plan has provided "a focus for national debate, a target to shoot at, a starting point for improvement" (p. 2135). Proponents of the plan praise its boldness and suggest that it will bring discussions of appropriate care to the forefront so that the issues can be debated in the public arena (McPherson, 1991; Author, 1993). Opponents suggest that the plan discriminates against poor women and children and illustrates many of the problems that arise when using quality of life indicators as a means of determining how resources should be allocated (Goodman, 1991; Gore, 1990; Fox & Leichter, 1991; Veatch, 1991b).

The Oregon situation illustrates that the task of prioritizing health services involves a judgment composed of facts and values. Hence, it becomes essential to incorporate citizen values about what they wish to see in a health care system, with ethical, economic and outcome approaches to policy decision making, in order to make the best possible societal decisions. Hadorn (1993) suggests that, despite the efforts of many researchers, there are still uncertainties about how society might use outcome data to set priorities in the health care system. He says that, although the idea of determining the health outcomes associated with different treatments, determining how people feel about those outcomes, then giving priority to treatments that produce
more preferred outcomes sounds simple, it is fraught with complications, not least of which is discrimination against some individuals (Hadorn, 1992; 1991b). Hadorn, (1993), when speaking about the Oregon attempt to involve consumers and providers in an outcome and preference based effort to set priorities, says;

“Unfortunately, although the Oregon project provided a wealth of experience on one possible approach to estimating and dovetailing preferences, the result of that project -- a priority list containing 688 condition-treatment pairs -- is of questionable utility. Because of the wide range of procedures and indications contained within each “line item” on the list, substantial additional specification will be needed before the list can be applied to actual patients (p. 2).

He goes on to say:
An important unresolved issue in the field of resource allocation is whether people's preferences differ significantly based on demographic characteristics or, particularly, on whether they have experienced (or are experiencing) medical conditions or disabilities. Concern over such differences was the stated reason for the initial denial of the waiver needed by the State of Oregon to implement its much-discussed effort to set health care priorities in its Medicaid program (p. 5)

In summary, this review of consumer involvement in health care decision making indicates that there is a need to conduct research about the role of the consumer in health care, and to determine at what level of the system consumers should be involved. The Oregon experience points to the need for Canadians, both providers and consumers, to escalate the debate about the many ethical issues related to health care priority setting and reform. In Canada, there are no examples where public opinion and community values about health care priorities have been determined to the same extent as Oregon (Charles & DeMaio, 1992; Emson, 1991). Moreover, with the exception of the research presented earlier (BCCODA, 1991; Filthaut, Li & Wright, 1991; Lemieux-Charles et al., 1993; Storch & Dossetor, 1993) there were no studies identified by this author where resource allocation (including transplantation) was discussed in a manner that involved the public and health care providers. However as Hurley et al. (1992) propose, this is a major challenge as;

... it is very difficult to design a decision making structure that represents community interests and values fairly and which integrates them with expert knowledge in a balanced fashion. Designing such structures is perhaps the most formidable challenge facing those who truly wish to develop decentralized systems that are responsive to the needs, values and preferences of the communities they serve through decision making processes that reflect their values (p. 18).
Moral Theory

As has been described in the previous sections of this chapter, consumers and health care providers are being encouraged to participate together in determining the best methods for allocation of scarce resources for areas such as transplantation. These discussions require an ethical framework and an understanding of the various values, beliefs and attitudes of the different stakeholders. Since this research was informed by moral theory and theoretical developments in the area of moral reasoning, it is helpful to review the debate emerging in the ethics literature about principle-oriented and contextual ethics. In this study, there was no a priori, theoretical assumptions about what the moral reasoning of the participants would look like. Instead, this brief review of the current discourse and critiques about ethical theory illuminated some of the possibilities and provided a contextual backdrop for data collection and subsequent analysis.

Pellegrino (1993) views the development of ethical theory in medicine as comprising several distinct periods. Although, focusing on medical ethics, Pellegrino's classification is applicable to health care ethics in general. The first period described by Pellegrino is the interval in which the Hippocratic tradition, enhanced by contact with the Stoics and religious traditions, was the predominate ethic. Principle-oriented ethical theory development began the second period in the mid 1960's, when philosophical inquiry began to reshape the Hippocratic ethic (Pellegrino, 1993, p.1158). Philosophers brought a variety of well established moral traditions to health care ethics such as deontology and consequentialism (utilitarianism). The deontological theory of prima facie principles quickly became the dominant way of "doing ethics" (Beauchamp & Childress, 1983; Pellegrino, 1993, p. 1159-1160; Ross, 1930/1988). The third period, or anti-principle period, occurred when competing moral theories began to challenge the primacy of principles, and when nurses began to question whether biomedical ethics was the ethical foundation for their practice (Fry, 1989a; 1989b). Finally, the fourth period of ethical theory development is the contemporary era. Pellegrino describes this era as, "... one of crisis in which conceptual conflicts in ethics and the skepticism of moral philosophy challenge the very idea of a universal, normative ethic for
medicine" (p. 1158). This same concern can be raised about health care ethics in general, where there is considerable discussion and tension among various ethical theorists.

This tension is particularly evident in the debate about the principle-oriented approach to ethics and the "ethic of care". In the past, some suggested that the principle-oriented approach to ethics was based on a lexical ordering and application of principles (such as autonomy, beneficence, justice and nonmaleficence), with the ordering occurring in a rational, objective and impartial manner, where the central issue is judging whether a person's actions are right or wrong (Ackerman, 1983; Cooper, 1991; Penticuff, 1991; Veatch, 1991c). In this cognitive approach, an action was considered morally right if it could be justified by a valid argument appealing to a valid moral principle as instituted in the social contract (Omery, 1989; Toulmin, 1981). Principle-oriented ethics, it was argued, was based on a model where reliance upon rules and principles was primary in moral action and justification (Cooper, 1991). Proponents of this theory believed that principles represented the "moral truth", and that there was a hierarchical ordering of principles where they were applied in a deductive, objective manner. In this ethic, there was a requirement of impartiality where the moral agent must not be influenced by personal feelings or special relationships to others. This requirement of universalizability implied that an action was right if, and only if, any other person in a comparable situation ought to act in the same way.

There has been considerable criticism, particularly in the nursing ethics literature, about the principle based approach to ethics (Cooper, 1991; Penticuff, 1991). Principle-oriented ethics has been described as an "ethics of strangers" because of the detached way in which the theory is applied (Cooper, 1991). Critics have stated that there is a lack of consensus about the nature of fundamental ethical principles, and that a hierarchical ordering of principles applied in a prescriptive, decontextualized manner, is not practical in actual, complex ethical situations (Ackerman, 1983; Cooper, 1991). The approach has been criticized as actually representing a "formula" approach to ethics (Ackerman, 1983; Toulmin, 1981). Authors, such as Ackerman (1983), point out that principles may be more useful as heuristic devices or guidelines rather than absolutes. As a result of the criticism, and as part of moral theory evolution and development, there
has been a move to explore other moral theories, several of which are described below.

Furthermore, more recent discussions about the use of principles in ethical decision making have become less focused on the rigid application of rules and more focused on applying principles in a heuristic fashion (Beauchamp & Childress, 1994; Tri-Council Working Group, 1996). For instance, in the draft of a new Canadian document the "Code of Conduct for Research Involving Humans" being prepared by the Tri-Council Working Group there is reference to an ethical framework for the Code that is "fundamentally heuristic as opposed to algorithmic" (p.2-2). The intention of the framework is described as being focused on evoking thoughtful action, as opposed to providing formulae or algorithms to be applied in ethical decision making (p. 2-2), and it is noted in the document that a "keen and lively sense of the context of one's actions is indispensable in exercising moral virtues or using principles to guide choices." (p. 2-3-2-4). These points illustrate the movement away from the traditional approach to using principles as rules to using principles as heuristic guidelines.

There is growing interest in a return to contextual ethics in moral theory development. More interest is being expressed in virtue ethics and casuistry, two theories that arose in the first period of development explicated above (Jonsen, 1990; Pellegrino, 1993; Toulmin, 1981). The first of these, virtue ethics, describes a moral theory where the character of the moral agent is considered critical to ethical decision making. According to Pellegrino, virtue ethics cannot stand alone and should be anchored in some form of prior theory of right or wrong. He suggests that virtue ethics does not provide sufficient clear action for ethical decision making. Moreover, virtue ethics is prone to individual definitions of virtue or of the virtuous person (Pellegrino, 1993, p. 1161). However, Pellegrino believes that virtue ethics ought to be part of any ethical theory that becomes predominant in modern society.

Casuistry is based on case analysis where the decision maker looks for cases that are examples of principles, then moves from these clear cases to more perplexing ones, ordering them by paradigm and analogy under a specific principle (Jonsen, 1990; Pellegrino, 1993, p. 1161). In casuistry, principles are valuable, however, not absolute. A criticism of casuistry stems from its
development in the middle ages within Catholicism, where consensus was more easily obtained on certain principles. In a pluralistic, modern society consensus is not always possible, thus, leaving casuistry as a method of case analysis rather than a guide to moral theory or practice (Arras, 1991; Pellegrino, 1993).

Further work in contextual ethics arose when theorists postulated that a theory conceptualized around the notion of care might actually be more useful in describing a nursing ethic than the justice based model used in principle-oriented ethics. Historically, theories about moral development and moral reasoning had been strongly influenced by the work of psychologist Kohlberg (1978; 1984) and his Piagetian based cognitive theory of moral development (Blum, 1988). Gilligan (1982/1993) and Noddings (1984) challenged the field of moral psychology arguing that Kohlberg's singular focus on justice in his theory of moral development obscured another dimension of the moral concerns of individuals. Gilligan suggested that issues other than rights and fairness, the concerns of justice outlined in Kohlberg's model of moral development, helped to shape the way individuals frame moral conflict and choice. These included concerns about interdependence, maintaining connections and attachments among individuals, and assuring that someone not be excluded or hurt in the situation being examined (Bebeau & Brabeck, 1989; Fry, 1991). Gilligan described care as a "different voice" and not a voice lesser than Kohlberg's justice based voice. She found that girls and women tended to approach ethical dilemmas in a contextualized, narrative way, looking for resolution in particular details of a problem situation. She identified this orientation in her research calling it an "ethic of care". In contrast, boys and men seemed inclined to try to apply general abstract principles without attention to the unique circumstances of the case (Sherwin, 1992b, p. 18). Gilligan describes her theory as one way of changing the voice of the world by bringing women's voices into the open, thus starting a new conversation (p. xxvii).

In contrast to principle-oriented ethics, a care ethic has been described as a situational, intuitive process where the central issue is judging an action in terms of its web of relatedness (Fry, 1991). In this theory, moral concern deals with needs and responsibilities as they evolve in a
relationship (Cooper, 1991). Caring implies mutuality and reciprocity in relationships and is not unidirectional. An individual is considered moral when in a relationship with another, and not because of a social contract as in the principled approach. The caring approach to ethics has been described as an ethic of "intimates" versus an ethic of "strangers" (Cooper, 1991; Fry, 1989a; 1989b; 1991; Penticuff, 1991).

There have been criticisms levied at those who suggest that caring is unique to women and to nursing, thereby excluding males and other health professionals (Gillon, 1992; Nelson, 1992). Gillon (1992) points out that Gilligan's theory describes a developmental process that involves a fundamental difference between men and women in their starting perspective on morality. He states, "... as she [Gilligan] points out in her last chapter, as men and women mature, they increasingly come to appreciate the importance of both perspectives (p. 172). Critics have pointed out that the ethic of care may not provide direction at the macro level of health care because of its individualistic, relativistic and relational underpinnings (Nelson, 1992), and that an ethic of care could lead to an impoverished self if individuals were required to care for all persons at all times (Fry, 1991; Nelson, 1992).

There have been some authors who have suggested that justice and care moral reasoning perspectives are not mutually exclusive. For instance, Flanagan (1991), when discussing justice and care perspectives, suggests that "most people use both orientations some of the time, and the choice of orientation depends at least in part on the type of problem posed" (p. 213). He goes on to say that there is no logical reason why considerations of both care and justice cannot be introduced, where relevant, into one and the same reasoning episode (p. 215).

Interestingly, while principled ethics and contextual ethics are depicted in the literature as distinct theories, there are those who are proposing that there may be room for a principle-oriented ethic, woven with contextual features such as care and compassion (Sherwin, 1992a; 1992b; Tri-Council Working Group, 1996). Bergum, Boyle, Briggs, & Dossetor (1993) have suggested that there should be a dialectic between the two processes of principled and contextual ethics. They state, "From the dialectic of close up and distant ethics comes synthesis, and this synthesis, in the
narrative of our lives and those of our patients/clients, is what ethics is all about (p. 1). These theoretical positions in ethics have influenced the research into how individuals reason about ethical issues, an important dimension of determining the just distribution of health care resources.

Moral Reasoning and Collaboration of Stakeholder Groups

The empirical investigation of moral reasoning is a recent phenomenon in the ethics literature. In much of the investigation about moral reasoning researchers have used measures based on the work of Kohlberg (Ketefian, 1987; Ketefian & Ormond, 1988). These include the Defining Issues Test (DIT), derivations of the DIT for specific professional groups, such as the Nursing Dilemma Test (NDT), and the Moral Judgment Interview (Ketefian & Ormond, 1988; Rest, 1986). Research-based and theoretical literature has been described that examines the moral reasoning of nurses (De Jong, 1984; Gaul, 1986; Ketefian, 1989; Omery, 1989), physicians (Christie, Hoffmaster, & Stewart, 1987), social workers (Fleck-Henderson, 1991), accountants (Gaa & Ponemom, 1993) and other professionals, such as dentists (Bebeau & Brabeck, 1989).

For example, a Canadian study of family physicians was conducted by Christie et al. (1987). They surveyed 918 physicians asking how they would handle the ethical problems illustrated in six hypothetical cases. The varied responses of the physicians suggested that they resolved ethical issues on a case-by-case, rather than a theoretical basis. The only characteristic associated with a consistent pattern of decision making was certification in family medicine, where certified physicians were more likely than other physicians to include patients in decisions.

There have been a number of studies conducted in which the moral reasoning of nurses has been examined. A majority of the studies have been conducted with the intent of learning more about moral reasoning to improve moral education. The findings of many of the studies have been somewhat contradictory (Bebeau & Brabeck, 1989; Ketefian & Ormond, 1988). For instance, Ketefian (1981a; 1981b; 1985) found that critical thinking and moral reasoning were related positively, and that nurses with baccalaureate degrees had higher moral reasoning levels than nurses with associate degrees or diploma preparation. Results of other studies revealed that increased intelligence (De Jong, 1984), a higher grade point average (Kellmer, 1984) and graduate
nursing education (Crisham, 1981; Felton & Parsons, 1987) were associated with higher levels of moral reasoning. These findings provided support for Kohlberg's (1978) claim that certain conditions, such as education, may account for, or stimulate, the level of moral development. Other researchers refuted these claims reporting that factors such as length of time in nursing (Nokes, 1985) and increased years of nursing education (Holzman, 1984) were related to lower levels of moral reasoning.

Examination of this body of research on moral reasoning points to conceptual, measurement, and methodological concerns (Corley & Selig, 1992; Duckett, Rowan-Boyer, Ryden, Crisham, Savik, & Rest, 1992; Ketefian & Ormond, 1988; Omery, 1989). A large number of the studies used students as subjects, although in cognitive development theory higher stage thinking does not occur developmentally until individuals are well into their twenties (Ketefian & Ormond, 1988). In addition, because most of the measures rely on hypothetical cases to assist in determining moral reasoning, there are concerns that the results obtained using these measures may not have a direct relationship to the moral behavior of practitioners when confronted with an ethical dilemma in clinical practice. (Corley & Selig, 1992; Ketefian, 1989; Omery, 1989).

The tension and controversy about the different approaches to moral theory are extended to the research on moral reasoning. Controversy has arisen about the use of Kohlberg's work in studies about the moral reasoning of women, since the theory was generated in studies using men as subjects. Duckett et al. (1992) challenge these criticisms to Kohlberg's theory suggesting that it has been validated in over 1000 studies in the past number of years, where results have shown that men and women do not score differently using measures derived from Kohlberg's work. Duckett et al. (1992) criticize many investigators for lack of rigor in research and for improperly analyzing and reporting DIT scores, therefore, erroneously coming to the conclusion that when using Kohlberg's model women demonstrate consistently lower than expected levels of moral reasoning as compared to men. Nevertheless, Duckett et al. (1992) and many researchers (Bebau & Brabeck, 1989; Fry 1989; Ketefian, 1989; Omery, 1983; 1989) have called for studies investigating whether there are alternate methods of reasoning that women may prefer to use.
Recently, research investigating moral reasoning has been conducted that uses Gilligan's work. Millette (1993; 1994) conducted a two phase study of over 200 nurses examining client advocacy and moral orientation. She found that the concept of client advocacy had appeal to staff nurses while nurses in management roles preferred a bureaucratic advocate model. Although nurses in the study displayed both caring and justice orientations, those who favored a client advocacy model were more likely to approach moral decisions within a context of care.

A descriptive study by Sherblom, Shipps and Sherblom (1993), building on the work of Gilligan, was conducted to describe the ethical decision making of nurses. Using hypothetical ethics case examples, 31 nurses were interviewed and their responses to a hypothetical case were analyzed to understand more about their ethical decision making. The authors concluded that the nurses used both justice and care based perspectives when discussing ethical concerns. In addition, they found that contrary to previous work that nurses were involved in complex and sophisticated ethical decision making in the clinical setting.

In addition to studies describing moral reasoning in nurses, a study was located that compared the reasoning of both nurses and physicians. In this study, conducted in two Canadian hospitals, Grundstein-Amado (1992), reported that nurses and physicians approached patients with what were often quite different philosophical stances. She studied 18 health care providers (9 female nurses and 9 male physicians) using a two-phase interview to learn more about their ethical decision making. In phase one of the interview she used semi-structured questions to elicit responses about past personal experience with ethical decision making. In the second phase, she asked recipients about their ethical decisions concerning a hypothetical case. In her study, she found that nurses placed the highest value on a "caring perspective", involving responsiveness and sensitivity to the patient's wishes. On the other hand, physicians valued patients' rights and the scientific approach, that, according to the investigator, implied a major concern with disease and its cure. Grundstein-Amado concluded that nurses and physicians acted out of different values, motivations, and expectations. Moreover, she called for more research examining moral reasoning and ethical decision making of different professional groups.
The results of the studies about moral reasoning indicate that controversy about this construct remains, particularly about whether there are differences in how men and women reason, and whether there are differences in moral reasoning among different professional groups. In addition, the work has consisted primarily of quantitative studies with individuals reacting to specific cases with forced choice answers. Few studies examined the values and views of individuals. Moreover, no studies were identified that examined how health care professionals might reason about ethical problems in a group setting. Finally, no studies were found that investigated the moral reasoning of the lay public, an area that requires further study if the public are to be more involved in discussions about ethical issues.

In addition to the work conducted about moral reasoning, several studies were located that examined the attitudes of patients, families, physicians and nurses about issues such as: treatment of low birth weight infants (Lee, Penner & Cox, 1991; Todres, Guillemin, Grodin, & Batten, 1988); intensive care (Danis, Gerrity, Southerland, Patrick, 1988); chemotherapy (Slevin, Stubbs, Plant, Wilson, Gregory, Armes & Downer, 1990); clinical ethical problems; (Gramelsprecher, Howell & Young, 1986); and withdrawing life support (Silva & Kjellstrand, 1988).

Lee et al. (1991) studied a Canadian group of 36 pediatricians, 39 neonatal intensive care unit nurses, 104 parents of surviving very low birth weight (VLBW) babies (< 1500 g.), and 15 parents of normal term babies to compare attitudes toward active treatment of VLBW babies. Data were obtained using a mailed questionnaire. The findings of the study indicated that both pediatricians and nurses tended to overestimate the mortality, morbidity, and costs of care for VLBW babies. In addition, they had similar deficits in their knowledge about those areas. The majority of parents (>80%) believed that physicians should do “all they could” for VLBW infants, even if the babies would be severely handicapped or mentally retarded. Physicians were evenly divided on the same question, and the majority of nurses were opposed (79.5%). There was a direct correlation between the degree of overestimation of mortality, morbidity, and costs of care, and the negativity of attitudes towards saving VLBW babies. Furthermore, there were marked differences in opinion about who should make the final decision about treatment for VLBW babies.
Although the majority in all groups believed strongly that parents should be involved in making the final decision to stop treatment, surprisingly 30.8% of nurses and 11.1% of physicians disagreed. The majority of pediatricians (88.9%) and nurses (84.6%) supported the doctor's role in this decision, but parental support was not as strong (VLBW parents 59.3%, Normal term parents, 62.9%). The majority of pediatricians (72.2%) and nurses (74.3%) supported a role for nurses in the final decision to stop treatment. However, only 14.6% of the parents of the VLBW babies, and 14.8% of the parents with normal weight babies agreed that nurses should have a role.

The researchers acknowledged that because only parents of VLBW babies who survived were surveyed in this study, the sample could be biased toward active treatment. The findings clearly indicated some of the attitudinal differences among parents and health care professionals, leading the investigators to propose that nurses who have more contact with the babies in an ICU setting, and who do not see the babies when they leave the ICU and are well, may have more negative attitudes about the prognosis of these infants. The investigators concluded that there was a need for more education of health care professionals about neonatal outcomes, a greater recognition of parents wishes, and the need for physician involvement in treatment decisions.

Another study about life-saving therapy for newborns was conducted by Todres et al., (1988). Although the investigators did not examine the attitudes of different provider and consumer groups, this research is interesting because it illustrates a major difference in physicians attitudes as compared to the study above. In this research, a questionnaire was mailed to 449 Massachusetts pediatricians who were asked to give their opinions about three hypothetical cases, and to answer several general questions about life-saving therapy for newborn care. One of the scenarios illustrated a case of an extremely low birth weight infant of 700g., 28 weeks gestation, who was suffering from birth asphyxia. When asked to select a response, 90% of the physicians recommended continued resuscitation of the infant and referral to an intensive care unit. Younger physicians were more in favor of active treatment than were older physicians, and for 65% of the respondents parental objection to resuscitation would not affect their decision. Catholic and married physicians were most likely to decide to treat the infant. The investigators compared the results of
this research to studies done in the 1970’s, concluding that physicians are more in favor of aggressive treatment of low birth weight babies than in the past.

Although it is useful to compare the Lee et al. (1991) and Todres et al. (1988) studies, there are some problems with doing so. There is a lack of information about how the questions were worded in both studies, as well as a lack of data about why the subjects hold the views they do. For instance, there may be a number of reasons why certain choices would be made in both studies, including as demonstrated in the Canadian study, a lack of knowledge about outcomes. In addition, the Canadian study was conducted in Newfoundland, where there may not be as litigious a climate as in the U.S. Therefore, physicians may feel freer to practice in a manner that is more in keeping with their ethical stance.

Other studies have examined attitudes of various provider and consumer groups. A study by Danis et al. (1988) was conducted to compare patient, family, and physician assessments of the value of medical intensive care. Interviews were conducted with 76 patients who were previously admitted to an intensive care unit (or family members of non-surviving patients), and the 32 physicians who cared for them. They were asked to determine, on a scale of 0 to 100%, how valuable they each believed intensive care would be to the patient under actual and ideal life circumstances. The results showed little correlation between individual patient, or family member and physician responses. Interestingly, physicians’ evaluations of intensive care for patients under ideal life circumstances were strongly correlated with physicians’ personal preferences for intensive care.

Although not specifically related to attitudes about an ethical issue, the following study is included in this review since it illustrates differences in attitudes between health care providers and those who actually have a medical problem. In a study examining attitudes about chemotherapy, Slevin et al. (1990) compared responses of 100 patients with cancer with those of 100 matched controls, 60 medical oncologists, 83 radiotherapists, 790 general practitioners and 303 cancer nurses. The main outcome measure was the percentage chance of cure, prolongation of life, or palliation of symptoms required to make treatment worthwhile. These outcomes were assessed by
providing two hypothetical cases about chemotherapy treatments, one case where the outcome was severe side effects, and one where mild side effects were expected. Each subject was asked to rate their preferences in both cases. The results suggested that most patients were willing to accept intensive chemotherapy for a very small chance of benefit. Doctors and nurses, on the other hand, were less likely to accept radical treatment for minimum benefit as compared with the patients. In addition, significantly more patients than controls accepted treatments giving the minimal benefit. The results suggest that people with cancer are more likely to prefer radical treatment with minimal benefit than those who do not have the condition, once again illustrating the importance of patient or consumer preferences.

Gramelsprecher et al., (1986) interviewed 26 nurses and 24 physicians to determine their perceptions of clinical ethical problems. The nurses and physicians both discussed a number of similar, frequently encountered ethical problems -- usually decisions to limit treatment for patients who had a poor prognosis. There was significant variation about how they perceived such issues, with disagreements about the ethical decisions made in the clinical setting. In addition, there were differences between the groups about what constituted an ethical problem. An interesting finding related to team functioning, where nurses often described conflict with physicians, but physicians rarely recognized disagreements with nurses. The investigators attributed this finding, in part, to physicians believing they were accountable to other physicians, to patients and their families, but not to nurses. The investigators, who were all physicians, were surprised by the finding and raised concerns about leaving these differences unresolved in the clinical setting.

One study was found examining substitute decision making in withdrawal of dialysis, where it was suggested that physician, patient and family decision making was similar. Silva and Kjellstrand (1988) examined the charts of 122 patients who had withdrawn from dialysis in one medical center from 1966 to 1983. In this sample, 66 competent patients had made the decision to stop dialysis, and in the remaining 66 cases, the family or physician made the decision to stop treatment. They found that there was no difference in gender, diagnosis, age, time periods, decision maker (family or physician), site of residence, duration or type of dialysis, home or in-
center dialysis, or survival time after discontinuation, between the two groups. They observed that, in the early 1970’s, physicians initiated termination of dialysis in all cases of incompetent patients, whereas in the 1980’s this had decreased to 48%, with family members becoming more involved. No cases were decided by courts or ethics committees. The investigators concluded that substitute judgment was applied appropriately in the 66 cases where patients were unable to make their own decisions. Moreover, they suggested that the results of this study indicated that these decisions can be left to physicians and families when patients are unable to make their own decisions. Although, the results of this research are persuasive, without knowing what the wishes of the patients actually would have been, it cannot be stated conclusively that the choices were in fact accurate.

Baggs (1993) conducted a review of literature focusing on the collaboration and ethical decision making of nurses and physicians. She concluded that nurses and physicians have different beliefs about ethical decision making, about who should be involved in the decision making process, and what factors influence the decisions. Baggs recommended more research examining interdisciplinary ethical decision making.

Results from these studies indicate that there are differences in attitudes among nurses, physicians and the lay public about certain treatment decisions. Although interesting in eliciting attitudes about difficult ethical dilemmas, like the studies in the organ transplant realm, most of these studies have been conducted using survey designs. Therefore, although attitudes about ethical concerns were elucidated, the reasons people held the views they did were unable to be determined. Furthermore, there is a paucity of empirical work examining the attitudes of the public and health care providers about resource allocation for health care.

In conclusion, there are a number of dilemmas relating to resource allocation embedded in the decisions about organ transplantation. With the exception of the studies examining public attitudes about organ donation, there has been little research examining decisions about resource allocation for transplantation. There is a paucity of work examining the moral reasoning, attitudes, beliefs, and values of consumers or health care providers about allocation of resources for transplantation. Although there is growing recognition that resource allocation dilemmas will be
best resolved by collaboration of consumers and health care providers, there have been few studies conducted about how this should be done, who should be involved, and whether these groups are disparate in their thinking about resource allocation issues. There is some evidence, primarily from studies of nurses and physicians, to suggest that health care providers may be disparate in their moral orientation and reasoning around a variety of ethical issues.

A major criticism of the research reviewed is that it has been conducted primarily by surveys, with little opportunity to learn more about why people hold the views they do. Although survey data is useful in describing trends, caution has been suggested in using findings from public surveys for health care planning (Blendon & Donelan, 1991; Jacich-Toth & Roper, 1991). Too often, the studies report decontextualized results, where findings are taken in isolation from the theoretical, historical, and comparative contexts in which they are embedded (Calnan, 1988; Coburn, D’Arcy, Torrance & New, 1987, p. 661). Since decision making about health care resource allocation involves different stakeholder groups, collaborating together in various ways, it is apparent that there is a need for further study of these areas.

This study was designed to answer several questions that previous research has left unresolved. Specifically, to determine the views and moral reasoning of various stakeholder groups about resource allocation issues in transplantation, to learn more about why they hold the views they do, and to determine who they think should be involved in allocation decision making. Moreover, since ethical decision making about issues such as resource allocation do not occur in a solitary fashion, this research involved groups of stakeholders discussing the issues -- a situation that is part of the proposed method of allocating resources for health care.
CHAPTER THREE

Methods

Constructivist Inquiry

This qualitative, descriptive study was conducted using the constructivist (formerly known as naturalistic) inquiry approach explicated by Lincoln & Guba in 1985, and further refined in 1989 (Guba & Lincoln, 1989). This approach is based on an underlying ontology that there are multiple constructions of reality, with relativism being the key to openness and the continuing search for ever more informed and sophisticated constructions of reality (Guba, 1990).

The social dialogic nature of inquiry is central to constructivist thinking. Constructivist philosophy presumes that what is real is what is in the minds of study participants, and that there are multiple, often conflicting constructions that can be proposed, with all the constructions being potentially meaningful. Hence, truth (which is socio-historically relative), is a matter of the best informed construction on which there is consensus at a given time (Schwandt, 1994, p.128).

Methodologically, as the inquirer or investigator of this study, I proceeded along the journey of this inquiry with the aim of identifying, understanding and reconstructing the variety of constructions the participants (including myself) held, bringing them into as much consensus as possible, remaining open to new interpretations as information and sophistication improved (Guba, 1990, p. 27; Guba & Lincoln, 1994, p. 113). As I describe the constructions of the participants in this inquiry, I am putting forth one interpretation of the perspectives that the participants held, recognizing that other investigators and participants could proceed to build a different account of the meaningful constructions related to resource allocation for solid organ transplantation.

There is a characteristic flow or pattern of development that is consistent in constructivist inquiry (Erlandson, Harris, Skipper, & Allen, 1993; Lincoln & Guba, 1985). This flow includes the following: conducting the study in a naturalistic setting, using the human as instrument, admitting that tacit knowledge is a part of inquiry, using qualitative methods including purposive sampling, using inductive data analysis with theory that follows from data (grounded theory), and using an emergent design with negotiated outcomes. These phases all lead to research reports that
are idiographically interpreted and tentatively applied (Lincoln & Guba, 1985) (see Appendix 3 for a diagram of the flow of naturalistic (constructivist) inquiry). These key phases and features were incorporated as the methods for this study evolved, and are discussed in the description of the methods that follows.

Data Collection

Data were collected for this study using focus group interviews. A focus group is a carefully planned discussion, designed in such a way as to obtain perceptions on a specific area of interest (Krueger, 1994). Morgan (1988) suggests that discourse in a focus group resembles an animated conversation among friends or neighbors, therefore, he suggests that this form of data collection be used with topics that groups normally might discuss (Morgan, 1988). Morgan stresses that careful planning with respect to participant selection, environment, and questions are key components to successful focus groups.

Using focus groups as a method of data collection originated with the work of Merton and his colleagues in 1946, when they used focused group interviewing to examine the persuasiveness of wartime propaganda efforts (Merton et al., 1990, Morgan, 1988). Market researchers adopted and refined the method and in recent years, social science researchers have recognized the value of focus groups and have begun to use this technique in their research (Morgan, 1988; Morgan & Krueger, 1993). The main benefit of using focus groups in research is that the group interaction produces data and insights that would be less accessible using other methods (Krueger, 1994; McDaniel & Bach, 1994; Morgan, 1988). According to several authors, although focus groups are very useful in investigating what participants think, they excel at uncovering why participants think the way they do (Carey & Smith, 1994; Kingry, Tiendje, & Friedman, 1990; Morgan, 1993). Moreover, there is an opportunity to learn more about attitudes and to understand more about participants' experiences and perspectives (Morgan, 1988).

Since ethical decision making about resource allocation is not a solo activity, but rather a dialogic process, I believed that focus groups provided a way of eliciting information about how groups discuss and make decisions about resource allocation. Because there has been little
empirical work in the ethics domain using focus groups, prior to conducting this study, I held two informal focus groups of friends and colleagues, concluding that people were able to speak freely about specific ethical issues related to resource allocation in transplantation. Moreover, conducting these informal groups assisted me in determining appropriate group size for this inquiry, enabled me to trial the case study and sample questions, and afforded me an opportunity to observe how the group process might work in the larger study.

Because of my clinical background in the area of organ transplantation, and my experience as a group facilitator, I acted as moderator for the focus groups. Morgan and Krueger (1993) and Merton et al. (1990) suggest that the moderator of the focus group is an important research instrument who must be well prepared and knowledgeable; must strive to make certain that there is a permissive atmosphere in the group where people feel free to have open dialogue; must encourage the expression of different perspectives and; must help the group maintain its focus without acting as a disciplinarian. I made every attempt in this project to adhere to these fundamental principles.

As compared to positivistic methods, where the setting is primarily used to attempt to control variables, Lincoln and Guba (1985) point out that a study using the constructivist approach must be carried out in as natural a setting as possible since the phenomena of study “take their meaning as much as possible from their context as they do from themselves” (Lincoln & Guba, 1985, p. 189). In keeping with the idea of a natural setting, Morgan (1988) suggests that focus groups are appropriate when individuals might discuss the same issues being examined in a study, in their own natural contexts. This idea was compatible with the basic thrust of this research, as the Canadian public discuss ethical concerns about resource allocation with their family and with friends and colleagues. In addition, discourse around ethical concerns about allocation of resources is becoming increasingly more common among different professional groups.

In order to make participants feel as comfortable as possible, I conducted the focus groups for this study in as natural a setting as feasible, with the participants determining the location. Moreover, I organized, scheduled, and arranged each group to accommodate the times that many
of the groups might get together naturally to discuss issues. Morning, afternoon and evening
sessions were selected by different groups and the interviews were conducted in family homes,
private rooms in restaurants, conference rooms, schools, community drop-in centers and in the
workplace.

In keeping with the constructivist inquiry tradition, the persons involved in this study were
considered participants, (Lincoln & Guba, 1985). The use of this term implies that the human is
considered an instrument in the research, rather than someone from whom data are being collected.
Several characteristics acknowledged by Lincoln and Guba (1985) about the human as instrument
were important for this study. For instance, they discuss the opportunities provided throughout the
inquiry to explore atypical or idiosyncratic responses. This was an important consideration in this
study as all participants were discussing their views about transplantation resource allocation
ethical issues, thus providing an opportunity to examine all responses, including those that might
appear atypical. Moreover, when discussing trustworthiness of the participant, Lincoln and Guba
suggest that, because humans are able to learn and profit from their experiences, like any data
collection instrument they can improve over time. This was a significant notion in this study, as
during the focus group process, participants did have an opportunity to reflect on their comments
and learn from others. As the inquirer, I, too, had an opportunity to learn over time. My ability to
conduct and participate in the focus groups improved as the inquiry progressed.

Lincoln and Guba’s description of constructivist (naturalistic) inquiry includes an
acknowledgment that it is impossible to explain everything a person knows in language form.
There are certain things that must be experienced to be understood, therefore, becoming part of an
individual’s tacit knowledge (Lincoln & Guba, 1985, p. 195). When discussing statements
fundamental to the epistemology of social inquiry, Polanyi (1946;1967) differentiated between tacit
knowledge and propositional knowledge. He suggested that propositional knowledge (knowledge
of reason and gossip) was different from tacit knowledge (knowledge of experience). Lincoln &
Guba suggest that the tacit knowledge of the investigator should be recognized, and through the
research process be converted to propositional knowledge so the constructivist inquirer can think about the knowledge explicitly and communicate it to others (p. 198).

In this study, I attempted to communicate the knowledge I had, recognizing that I had the potential to influence individuals because of my knowledge about the areas under discussion. I reflected on this and devised a process that would also respect the knowledge that others brought to the group. For example, when a focus group participant wanted further information about a topic under discussion, or a point clarified about the transplant process, or resource allocation in the health care system, I waited to see if someone else in the group could provide the information, in order to ensure that all group members were respected for the knowledge they brought to the groups, and that I was not considered the only "expert" in the room. At the same time, as a nurse and a health care provider in the organ transplantation area, I was particularly concerned that people not leave the focus group with inaccurate factual information (for instance statistics about the need for organs, success rates for organ transplants, and the process currently used for recipient and donor selection). When necessary, as a group member with the knowledge about the topic under discussion, I would provide this information, often close to the end of the discussion, if a group member had not provided the clarification before that point. Also, in some circumstances, there were times when a group member disclosed inaccurate information. As I did not wish participants to be disadvantaged by having incorrect information, I would ensure that I clarified points when required, again waiting to see if another participant would do this first. I used my own knowledge carefully to facilitate discussion, at the same time not being too directive, other than to keep the group discussing areas that related to the inquiry. This was often very challenging, especially when participants became enthusiastic and several wanted to speak at once about a variety of topics.

In constructivist inquiry the investigator is seen as inseparable from the subject of inquiry (Lincoln & Guba, 1985). The investigator, and the manner in which the investigator conducts the interview, are major instruments in data collection (Anderson, 1991; Lincoln & Guba, 1985; Lipson, 1991). As part of the dynamic that is the research process, the investigator is affected by, and affects, the participants (Anderson, 1991; Hall & Stevens, 1991).
Therefore, it was important that I be knowledgeable about the background and perspectives I brought to the inquiry, including my own values, experiences and personality style (recognizing that no investigator is "tabula rasa"), and join in reciprocal relationships with the participants in an attempt to understand their world (Hall & Stevens, 1991; Lipson, 1991; Paterson, 1994). This reflexivity, and the resulting dialogue between researcher and participant, is a means of breaking down traditional investigator/subject boundaries, empowering the participants in the process, and negotiating construction of meaning (Anderson, 1991).

In this inquiry, since I was involved in a dialogue with the participants, it was essential to keep these perspectives in mind, and as described earlier, I reflected not only on what I brought to the group, but how I conveyed what I brought, in terms of knowledge, to the group members. In addition, I was conscious of the change in perspective that I experienced as being part of the groups, reading the research in this area, and having my "antenna up," so to speak, as I interacted in the transplant, academic, clinical and not-for profit communities where I was working, learning and volunteering. I became more heavily involved in initiatives to increase organ donation in Canada during the study period and, therefore, the constructions created in this study were no doubt influenced to some extent by my interest in this area. Furthermore, as I listened to the discourse in the focus groups, I became more conscious of the "darker side" of transplantation that I, as a proponent of organ transplantation, had not reflected on extensively before this study. Therefore, my own views about transplantation and organ donation were deeply affected by what occurred during the course of this inquiry.

Stimulus material, in the form of a case study and several questions, was used to encourage discussion about transplantation resource allocation issues at the micro, meso and macro levels of the health care system (see Appendix 4 for the case study and sample questions). A case about a combined heart/kidney transplant was chosen because these complex situations are arising more frequently as extrarenal transplantation becomes more common. These cases generate considerable discussion in the clinical setting about allocation of resources. In addition, the patient requiring a heart transplant cannot be maintained on another form of life support, such as dialysis. Therefore,
focusing on an extrarenal transplant narrowed the choice of responses when individuals were considering alternative courses of action. Furthermore, the possibility of a kidney transplant introduced a line of questioning related to living organ transplantation, thus, allowing for broad coverage of many germane ethical issues about transplantation.

Specifically, the case was used to illustrate a number of the ethical concerns related to transplantation at the macro, meso and micro level of the health care system. For instance, the case was used to focus on the level of resources to be allocated to transplantation at the macro level of the system. Moreover, the case illustrated the organ shortage problem, and it was used to explore views about methods to obtain organs for transplantation, such as presumed consent, buying and selling organs, and using other sources of organs such as xenografts. At the meso level of the health care system, the case helped raise questions about the development of selection criteria for transplantation. In addition, questions about the level of resource commitment at the institutional level were derived using the case as an illustration of the type of situation faced by providers when they determined the level of resource commitment for one program compared to another.

Reflecting on the micro level of the health care system, the case helped raise questions about how many organs to which one person was entitled. In addition to the case, an ethical decision making framework, incorporating features of both a principle-based and contextual approach to ethics was used to provide me with some direction during the discussions (McDonald, 1993) (see Appendix 5). Specifically, the framework helped provide a subtext for the development of several of the questions that were used in the discussions.

At the beginning of each focus group, a general introduction and explanation of the purpose of the research included reminders to the participants stressing that there were no correct or incorrect answers. After the explanation of the purpose and process of the discussion was given, the participants were asked to introduce themselves and to disclose a little about their background and personal experiences as they related to transplantation. This was done as a form of introduction, to gather specific information, and to give each of the group members an opportunity
to speak at the beginning of the meeting to allay fears of speaking up for the first time later in the process.

All participants were encouraged to participate in the discussion and were asked for their initial reactions to the case, followed by a discussion of the issues that emerged. Recognizing that each group was different, and that a structured interview guide was incompatible with a naturalistic design (Sandelowski et al, 1989), a set of possible questions was developed and was modified and adjusted according to the group and the discussion (Morgan, 1988) (see Appendix 4). Several of the questions used in the study were pre-tested at a Kidney Foundation of Canada national Annual General Meeting, when approximately 70 consumers and health care providers had the opportunity, in small groups, to discuss responses to the questions. Modifications were made to the questions based on this input. In addition, this meeting provided me with an opportunity to become sensitized to potential group process problems, such as one person dominating the discussion.

During the focus group interviews, I tracked the topics, redirecting the group and probing for meaning when necessary. Silence was used as much as possible, prior to probing, to allow for individual expression (Sandelowski et al., 1989). As the group progressed, I made modifications, as necessary, to the interview style (Merton et al., 1990), and if a new topic was raised in a group that I had not heard before, I would often explore that new idea with the next group.

Careful attention was paid to the case itself, and the language used in the focus groups, as there was ample evidence that material must be carefully written in order to assure comprehension (Merton et al., 1990; Spadero, 1983). Moreover, there was evidence that language, and the manner in which discourse was structured could affect the comfort level people have when talking about the issues under discussion (Fairclough, 1989). Since some groups were more knowledgeable about transplantation and more conversant with medical terminology than others, the case and questions were modified according to the needs of the group. Close to the end of the discussion, each group was asked if they wanted to add any additional material that had not already been covered.
Each focus group session was two to two and one half hours in length. Refreshments were served according to the expressed group preferences at the time the group was arranged. I organized the appropriate coffee, lunch or dinner refreshments with careful attention to preferences and quality, as there was considerable evidence that serving appropriate food in focus groups assisted people to relax and participate more naturally (Morgan, 1988).

All focus group sessions were audiotaped and transcribed for data analysis purposes. In addition, an observer (knowledgeable about group work, compatible with the groups and trained by me) attended the sessions to follow the discussion, and make notes about verbal and non-verbal interaction. In order to assist with the technical problem of recording the interviews and not having the speaker identified, the observer recorded the sequence in which people spoke and took detailed notes in order to facilitate transcription. The observer then typed the transcripts following the group sessions. In addition, fieldnotes and debriefing discussions between myself and the observer were recorded and transcribed after each interview. Participants were asked to identify two group members who agreed to be contacted if there were further questions or clarification required, and when possible, to review the constructions as they were developed.

I offered to meet with anyone, after the session, who wished more information about transplantation. In addition, resource material was available for those who wished it (for example, Kidney Foundation of Canada pamphlets, B.C. Transplant information). I also facilitated contact with other resource persons when desired by any group member.

During the data collection phase of this study, I paid careful attention to socio-political issues and media coverage of events or occurrences that might have impacted on individual responses and views. An historical account of such events is documented in Appendix 6.

Participants

In this study, purposive or theoretical sampling (Kuzel, 1992) was used to obtain a sample of 34 consumer and health care provider groups from those who had a stake in the development of organ transplantation in the health care system (see Appendix 7). In keeping with the naturalistic tradition, the sample was selected with the intention of choosing key stakeholder groups who
exhibited enough variation to provide different perspectives to the questions being posed. The aim of this sampling technique was to include as much information in all of its various ramifications and constructions as was possible (Lincoln & Guba, 1985, p. 201). An essential feature of this emergent constructivist design was that the sample required change as the process evolved (Lincoln & Guba, 1985). In selecting participants for the focus groups, I considered which data sources would be information-rich and whom I should interview first. As the constructions developed, I considered which data sources would confirm, challenge or enrich my understanding. As a result of these reflective questions, as this study progressed, groups included in the original proposed sample were altered, and some groups added, depending on the data collected and the need for new and different perspectives. For instance, originally, only one critical care nurses group was proposed, however, when I recruited volunteers from one agency, more than 20 nurses indicated an interest. As a result, I conducted two focus groups in the agency to capitalize on this interest. When a specific group perspective appeared to emerge, that I had not encountered in previous groups, I decided it was necessary to conduct a third focus group of critical care nurses who worked in a different context to determine if they had similar or different perspectives. Perspectives from critical theory informed the process of focus group selection in that the theory focuses on freedom from oppression, action and ultimately normative direction for change (Bronner & Kellner, 1989; Campbell & Bunting, 1991; Ray, 1992). These concepts helped me ensure that I included groups in this study of those who are often not heard from in discussions about resource allocation, however, have a valuable and unique perspective that would be needed for appropriate normative change in this area (for example, parents of handicapped children, students, participants with low incomes and seniors).

My past experiences (working with groups of providers, teaching health care ethics to students, and with the informal pilot focus groups conducted prior to this study) indicated that if more than six to eight individuals were involved in a group discussion about ethical issues not everyone was able to participate. Hence, 34 focus groups of stakeholders consisting of six to eight individuals, (six being the average) were conducted. Two exceptions occurred; one when a few
individuals were ill on the day of the group and only three were able to participate; and in one case, where nine participants wished to participate. The participants were volunteers that I recruited by using many contacts and resource people in health care settings, non-governmental organizations, the media, and the community at large. In order to be included in the study, all participants were required to speak and understand English, and be willing to volunteer their time. Only two individuals declined to participate because of prior commitments. In several cases, there were more persons who volunteered than needed.

As much as was possible, the consumer groups were comprised of members who were of similar age, educational background, and socio-economic class, as these variables have been demonstrated in previous research to affect and influence group interaction and responses (Bowden & Hull, 1993; Morgan, 1993; Storch & Dossetor, 1993). According to Merton, Fiske and Kendall (1990), the more socially and intellectually homogenous the interview group, the more productive the outcome of the discussion. Comparatively, when the members of the group are of widely disparate social status, or differ greatly in intelligence and education, the interview tends to be less productive (p. 137). Merton et al. propose that when the sample is large enough, it is helpful to match the members in education, occupation, and age. However, in cases where this is not possible, they suggest matching for educational homogeneity as this variable outranks all other kinds in assuring effective interviews with groups (p. 138). Every effort to follow these suggestions was made in this project.

Consumer groups were selected from three categories; those who had a major stake in transplantation (for instance, people with organ transplants), those who had a moderate stake in transplantation because of their concern about resource allocation for other health care treatments (for example, parents of handicapped children), and people who were members of the general public with a minimal stake in transplantation (adults and adolescents). These latter groups included adults from diverse areas of the Lower Mainland of British Columbia (thereby encompassing different socio-economic groups), as well as adolescents from both private and public high schools (see Appendix 7). In addition, representatives from the media (composed of
reporters from radio, television, and two major newspapers) were included as a consumer group, as there was considerable evidence that the media have had a major role in influencing decisions about resource allocation (Brooks, 1993; Fox & Swazey, 1992b; Rettig, 1989).

Health care provider groups were categorized into one of the three classifications described above. The membership of the groups were homogenous in order to examine views, and to allow freedom of expression of each health care provider group (for example, groups composed of physicians, nurses, social workers and so on). Efforts were made to match the group members with respect to age, as it was presumed that socio-economic status and education were comparable within the groups.

Toward the end of the study period, in keeping with a suggestion by Morgan (1993) groups that included a mix of consumers and health care providers were interviewed in order to simulate the situation for current and future health policy decision making. Naturally occurring mixed decision-making groups (such as a transplant organization board, an ethics committee, a not-for-profit executive board) were selected for the study (see Appendix 7).

In total, there were 188 participants in the focus groups, 85 consumers and 103 health care providers. The 34 groups were composed of 50 male participants and 138 females. The number of females in the focus groups was reflective of the large number of females in health care provider roles, particularly in nursing.

The participants ranged in age from 16 to 86 years (see Appendix 8), with the majority (60%) being in the 30-49 age range. Many of the participants (83%) had completed some college or university courses, or had obtained a university or post-graduate degree (see Appendix 9), however, it is interesting to note that most participants, in both the consumer and health care provider groups, had no formal background in ethics.

The majority of the participants described their religious background as being Protestant (42%), Agnostic (21%), or Roman Catholic (18%), with a smaller numbers of participants having

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4 Personal communication with Dr. David Morgan, 1993.
other religious beliefs (see Appendix 10). In addition, there were 76 health care provider participants (74%) who said they were organ donors and 27 participants (26%) who had not made the decision to become an organ donor. In contrast, there were 79 consumers (93%) who declared they were organ donors and 6 consumer participants who had not made that choice (7%) (see Appendix 11 & 12).

The majority of group members had household incomes greater than $46,000 per year (73%), with 27% of the group members having incomes below that level (see Appendix 13). The group members had a variety of occupations, representing the diversity of health care provider groups, and members of the general public, included in the study (see Appendix 14 & 15).

Data Analysis

Lincoln and Guba (1985) suggest that data analysis within the constructivist paradigm is inductive in nature and they present a method for analysis adapted from the constant comparative method by Glaser and Strauss (1967). This method, as explicated in detail by Lincoln and Guba, was used to analyze the data. Transcription and analysis of focus group data began following the first interview. Data analysis proceeded with the assistance of the NUD.IST computer software package (Qualitative Solutions and Research Pty. Ltd., 1995; Richards, & Richards, 1991; 1991; 1994).

NUD.IST is a text-database program designed to handle Nonnumerical, Unstructured Data in qualitative research, thereby, assisting researchers in theory-building and descriptive-interpretive functions by supporting processes of Indexing, Searching and Theorizing. The computer program was selected for the sophisticated search and retrieval capacities and the ability to accommodate diverse approaches to data. The NUD.IST program allowed me to employ both inductive and deductive approaches through features such as on-screen coding and memoing, and facilitated building and modifying the index system. As a result of the index system, and coded on-line documents, it was possible to construct and test ideas, generate reports on the constructions, and locate evidence that contradicted as well as confirmed emergent understandings. The NUD.IST program assisted me in working closely with the data to identify important concepts and ideas,
investigate comparisons of the responses/discussions of each type of focus group, as well as differences and similarities within groups. (Richards & Richards 1991; 1994)

Prior to introducing the transcripts and fieldnotes to NUD.IST they were analyzed line by line in order to assign appropriate NUD.IST subheaders. Each speech (consisting of a paragraph) made by a participant was assigned a subheader for that speaker. Each speaker's speech was also assigned subheaders that reflected a response to the questions asked in the group. The documents were then introduced into NUD.IST.

Following entry into NUD.IST, each document was indexed at a variety of nodes that reflected the content of the transcripts and the analysis of various themes and categories. This allowed me to examine and review the data continuously, changing codes and developing new nodes as the analysis progressed. Data analysis in this manner required a variety of checks to ascertain comprehensiveness, redundancy, fit and accuracy. Therefore, the data and analysis were discussed with a group of volunteers who agreed to review data, and the observer and dissertation committee members.

Trustworthiness

There are different methods used to establish reliability and validity in the naturalistic tradition as compared to studies based on a positivist approach to research (Sandelowski, 1993). Lincoln and Guba (1985) use the term "trustworthiness" to describe a variety of methods whereby the process of the study, and the credibility of the investigator are important components in determining the rigor of the research. They suggest several criteria through which trustworthiness can be operationalized. These include credibility, transferability, dependability and confirmability.

Several measures to ensure rigor based on these notions were integrated throughout this study. For example, there was a lengthy period of study with multiple focus groups ensuring depth in the phenomena to be studied, thus enhancing credibility and consistency in the sources of data. One observer was used over the study period and "member checks" with the participants were used when possible, with several participants reviewing parts of the data analysis or discussing the analysis with me during the writing of the dissertation. The audit trail established through this
process, through the use of NUD.IST, and through the use of fieldnotes helps to establish the dependability and confirmability of the data. Lincoln and Guba (1985) compare this inquiry audit to a fiscal audit of a business where the process and product of the company are examined. In addition, consultants experienced with the focus group process were utilized to assist with the process. Furthermore, special attention was given in this study to ensure that the 10 quality factors outlined by Krueger (1993) were integrated into the study design. The factors included: 1) clarity of purpose, 2) appropriate environment, 3) sufficient resources, 4) appropriate participants, 5) skillful moderator, 6) effective questions, 7) careful data handling, 8) systematic and verifiable data analysis, 9) appropriate presentation and, 10) honoring the participant, and the method.

Assumptions

There were several assumptions made at the outset of this study. Firstly, although there was no conclusive evidence that the involvement of the public in resource allocation decision making brings about a difference in how resources will be allocated, I made a major assumption that there was value in public and provider ethical discourse about resource allocation as a component of being part of a democratic, pluralistic society. This assumption is given prominence by Roy, Dickens, & Williams (1994) when discussing practical (ethical) reasoning in what they call public ethics (ethics at the macro level of society). They state:

... practical reasoning emphasizes the central methodological importance of Aristotelian dialectic in bioethics as public ethics. Aristotle's method to arrive at the best ethical judgments possible in any given situation is based on the assumption that people need to learn what they really think about a specific issue. The method pits both the many and the wise, that is, ordinary people and experts in discussion with each other. The aim is to unfold, to lay out, the values and judgments of people who come to an issue with definite intuitions and value commitments. The mutually corrective interplay of these different views, achieved as people work through alternatives in dialogue, is what Aristotle’s dialectic involves. The goal of this dialectic is that the people exercising practical reasoning in dialogue, will, both individually and in community with one another arrive at a harmonious adjustment of their initial beliefs or starting positions (p. 57).

A further assumption was that people wanted to take part in this study, on a voluntary basis, because of their interest in how resources were allocated for organ transplantation. This assumption was not based on speculation only, as resource allocation was a topic receiving considerable attention by many people in British Columbia at the time the data was collected. In
addition, since many citizens were aware of transplantation because of personal experience, exposure to media coverage of transplantation and/or requests to be organ donors (when renewing drivers licenses or health care cards), it was assumed that people would want to participate.

Limitations

Although every effort was made to include people from different ethno-cultural groups, a major limitation of this inquiry was that, because of language and cultural nuances, only people who could speak and understand English were included in the study. However, it is clear that in a pluralistic country such as Canada, there is a need to conduct research with input from many ethnocultural groups. In this study, because of the resources required (such as interpreters, facilitators skilled in different languages) it was not possible to include individuals from other ethnocultural groups who did not meet the above requirements. There was also a paucity of research discussing ethical issues using focus groups, and since I had not explored the literature in other languages, it was not known whether discourse about issues such as those proposed in this study, or focus groups themselves, were culturally acceptable. Another limitation of this work related to the fact that only people who volunteered were part of the study, thus limiting input to those who were most interested in responding, perhaps because of a particular connection to transplantation. In addition, this group of participants only included persons who lived in the Lower Mainland, so consequently, there were no participants who lived in a primarily rural area. Therefore, not all voices in the resource allocation debate in British Columbia were heard.

Furthermore, because individuals were asked about their perspectives related to a hypothetical case, the constructions described in Chapter 4 may not have a direct relationship to the moral behavior of health care providers when confronted with an ethical problem in clinical practice. Also, because of the hypothetical case discussion, the actual moral behavior of consumers when experiencing ethical problems in their personal lives, family or community may be different than the perspective described in this study. In addition, the hypothetical case was framed in such a way that it focused on an individual needing a kidney transplant and a second heart transplant. If the case had been framed in a different manner, highlighting potential recipients of more
controversial transplants (for example, bowel or multi-organ transplants of a more experimental nature), it is possible that the manner in which the participants reasoned about the issues, and the choices they made, might have been different than those reported in this study. Finally, because the case study was focused primarily on the clinical aspects of transplantation, it may not have provided the participants with the same opportunity to explore macro level resource allocation questions, such as how will choices be made between the competing goods in health care and non-health care related services.

Ethical Considerations

Participation in this study was voluntary and no remuneration was given to any participant. Approval to conduct the study was obtained from the University of British Columbia's "Behavioral Sciences Screening Committee for Research and Other Studies Involving Human Subjects". At the time of the focus group, individuals were asked to sign a consent form outlining the purpose of the study, the procedures to be used, any benefits, risks or discomforts to them, anonymity and confidentiality, and costs/reimbursements. The form also included assurances that participants could withdraw at any time (see Appendix 16 for a sample consent form). No individual was identified in publications arising from this study, or in this dissertation. In addition, confidential information that participants did not want included in the data analysis was not transcribed.

A written report of the research was offered to all participants who wished to sign a form with their name and address, and a hand written thank you note or letter was sent to participants after the focus group was completed.

Dissemination of the Study Constructions

As one of the goals of this inquiry was to encourage consumer and health care provider dialogue about resource allocation, every effort has been made, and will continue to be made to disseminate these constructions widely. Preliminary constructions from this study have been reported at scholarly meetings and at meetings of the lay public. Presentations of the final constructions will be reported at future professional and lay meetings. Publications will be sent to scholarly journals and magazines accessible to the lay public. Health professional libraries, general
libraries, organ procurement organizations, health charity offices, the various professional associations, and federal and provincial Ministries of Health will be sent copies of the final report.

Having provided a description of the methods used in this study, I will now move on to a description of the constructions developed during the course of this inquiry.
CHAPTER FOUR
Constructions: The Dialogue And The Meaning Within It

In this chapter, my goal is to present the major constructions of this study, using both the voices of the participants, through transcript excerpts, and my interpretations of the perspectives articulated, to reconstruct the variety of viewpoints the focus groups held, bringing them into as much consensus as possible. My construction of these perspectives is divided into three major sections.

I begin with a description of the focus group process to provide some context for the remainder of the presentation. To this end, I describe the experiences of the focus group participants, highlight the benefits of being part of the focus group discussions that were articulated by the participants, as well as explicate the outcomes achieved as a result of conducting this study using focus groups.

In the next major section of the chapter, to provide the context through which focus group members interpreted moral problems, I turn to a description of the general views held by participants about various resource allocation issues in organ transplantation. These general views, influenced by the beliefs, attitudes, and values held by the participants, provided them with a lens through which they reasoned about the ethical problems, issues and concerns identified within the focus groups. The general views held by the participants, about various ethical concerns related to resource allocation for organ transplantation, appeared to be part of a continuum from emphatically positive convictions about transplantation to emphatically negative convictions. Three patterns, that describe the participants' views, are explicated using the metaphors, "through a glass brightly" or positive convictions about organ transplantation, "through a glass translucently" or ambiguous convictions, and "through a glass darkly", or negative convictions about organ transplantation.

As part of the description of these major patterns, I describe the pattern characteristics, as well as the factors that influenced each pattern. To illustrate how the group members expressed these views, I present the major similarities and differences of their views about several areas related to organ transplantation. In addition, I provide an accounting of some of the influences
group members articulated as being important in the development of their views about resource allocation in organ transplantation, and I highlight the values the groups identified as important to their discussion about moral problems related to organ transplantation.

With an understanding of the views the participants hold, I then turn to a presentation of the main overarching moral reasoning processes that emerged as the participants considered the ethical problems, issues and concerns that were illuminated during the focus group discussions. Three different reasoning processes were identified in the course of the discussions; a "deliberative" reasoning process, an "examined emotion" reasoning process, and an "emotional" reasoning process. These processes, and the factors that influenced them, are described with attention given to illustrations of how they were determined from within the focus group discourse. In this commentary, I highlight the major similarities and differences in how group members reasoned about the moral problems that were emphasized during the focus group discussions.

In the last section of the chapter, I describe the roles the participants believed that consumers and health care providers ought to have in regard to the allocation of resources for transplantation. These roles include a distinction between involvement of consumers and health care providers at the micro, meso and macro level of decision making.

When discussing these constructions, reference will be made to the classification system that is outlined in Appendix 7 where the three levels of focus groups are described as: major, moderate and minor health care provider groups; major, moderate, and minor consumer groups; and major and moderate mixed health care provider/consumer groups. In addition, many of the terms that are used throughout this construction are defined in the glossary outlined in Appendix 1. The reader is invited to consult these Appendices as a guide to what follows.

The Focus Group Process

All group members participated actively in the focus groups, and discussed the case and the issues that were raised without any difficulty. In some of the consumer groups, and in the minor health care provider groups, at the beginning of the discussion, participants asked for clarification and more details about organ transplantation, with the intent of acquiring more contextual
information that would help in their discussion of the case. In a few situations, participants
requested specific information to facilitate their ability to participate in the discussion, for instance
more information about the type of transplants being done, and the success rates of the different
organ groups (e.g. liver, kidney, pancreas, heart, lung, and heart-lung). In some situations, when
requested, information about transplant statistics and the transplant process were conveyed to
groups during the focus group to further increase their knowledge level about this area.

In many cases, being involved in the focus group appeared to be therapeutic for some of
the health care provider participants who had limited opportunities to talk and debrief about ethical
concerns in their workplace. One of the nurses put it this way:

Just the venting process is good. Sometimes we get little options to [have discussion], our
frustration levels can get so high, and as the acuity of our patients rises...and we start to
question more and more, and feel less and less satisfied with what we are doing.... It's
just, you know, you need to continue to provide the treatment, but having a forum where
you can at least safely say I feel like this shouldn't be happening.... You feel like there are
an awful lot of decisions that are being pussyfooted around, and that as we do more and
more stretcher transfers [very ill patients] and all of this stuff, you really do feel less and
less satisfied with what you've done that day and why you are doing it, and so just having
this forum once in a while, you can get it out and make sure you can go back and be even
slightly better. Maybe you have changed your mind and can look at it differently which is
also nice. It might change your attitude about it, but even if you can just say it, that helps.

Many group members indicated that participating in the focus groups had been a very
enjoyable experience. This was particularly true of several of the major health care provider
groups, some of whom had never had the opportunity to discuss these issues in a group format
before. For example, a social worker in a mixed group of health care providers and consumers
observed:

You know, taking the time out to do this, and because I really appreciated the opportunity
to sit and talk to all of you, we don't always get to [this] in our day to day life, or in our
social life. But even at work, the work place, you don't get the opportunity, this is the first
time I've ever sat down with [a Co-worker] for a two hour period and listened to what he
had to say and what he thought, and I found it very interesting and very enlightening. So, I
appreciate all of your comments.

In many groups, participants articulated the value of hearing other people's perspectives
and having the opportunity to reflect on what others had said. During the discussions, they
indicated that they heard views presented that they had not considered before, and they believed
that in some circumstances they changed their own position on a topic as a result of the discourse, or at the very least, had some new ideas to reflect on in the future. One of the participants from a general consumer group put it this way:

I mean I've come to think of things with a very open mind, and for me I've learned a lot tonight, and some of my questions about how many are performed, and what they cost, and then just listening to everyone's view point, [although] I mean I'm still not certain where I stand.

A nurse consultant, from a minor health care provider group, talked about the value of the discussion, but also said the discourse made her aware of the need for this type of discussion and attention in other areas of health care. She disclosed:

It's always good to listen to other people's point of view, and you don't always agree with them. That's why the ethical things are very difficult, but because you focused on solid organ transplant and it seems like a, I want to say sexy, it isn't the word, but it's a topic that people latch on to, the media latches on to. And it always reminds me of the people who suffer because they don't have a sexy diagnosis like the mentally ill, the elderly. So I guess I'm feeling really ambivalent wishing that somehow we could have an opportunity to have somebody of your caliber look at those non-sexy topics and bring it forward to a much more visible level in society. And I don't know how you do that, because and as I'm talking to you, I have a real thing. I'm admitting a whole bunch of things to you so I might as well. Whenever I listen to the Children's Telethon and all this money comes out, and when I worked with the elderly, and how I had to kind of squeeze people to even get $50 for them so we could send [the elderly] to the PNE or what ever, like the values are so different in what we perceive as important and that kind of surfaced as we were talking about this. And I don't know how you deal with it, and the other thing is that even with the people who know, like we used to get the parents of very high powered people like you know the university president, people who were presidents of huge industries. I used to think maybe I can coerce them into doing a telethon, not a telethon, or something like that. And then I found out that, oh yeah, they were very kind and would kind of pat you on the head and walk their way, but then I really came to terms with that they didn't want the world to know. They had their mother or their father in a long term care facility, you know. There were all those kinds of things, but they would run down to Children's and put the money into the telethon pot. You know you wouldn't believe the different kinds of things that came to mind as we were talking here.

Participants, both those from the consumer groups, and those who were health care providers, acknowledged that participating in the focus groups had increased their knowledge about transplantation. As one high school student stated:

Like it's a fairly new thing, and it's basically a miracle that they've actually found a way to take an organ from one and put it into another human being's body, and if people don't know, some people might think well my body is going to be deformed or something, or like when you're buried your body is going to be deformed and when they open the casket
they are going to just [look] away. So a lot of people don't know about it, and people have to be well educated about it before it can start. I mean there is stuff I found out today that I had no idea about, so up to this point I hadn't really got into a discussion.

Other participants suggested that they had experienced other leanings as a result of their involvement in the discussions. One member of a general consumer group, as she was reflecting on the focus group process, realized that "Well really ethics is at the base of everything that we do. But we just don't [often] look at it."

Participants recognized that the issues being discussed were much more complex than they had originally thought. One renal technician declared:

I would just say that we kind of appreciate that the issue is a lot more complicated than we initially thought... There is so much different information, different considerations and questions, and I thought, gee, I never thought about that, I have to consider this and I have to consider that.

Participants were also surprised to find that, even when there was a common purpose in the workplace about transplantation, as was the case in many of the groups, they could have different perspectives. As one of the consumer participants from a mixed provider/consumer group said:

I was just thinking that you would expect that with a group coming from different backgrounds maybe professionally, but with having everybody having the general background with [this organization], and wanting organ donation to increase, that we would be able to reach consensus, and in fact we still have very different perspectives.

One of the members of a general consumer group, that periodically meets to have discussions about a variety of topics, suggested that he believed that he had an opportunity to reflect on some of his own thoughts during the discussion. He stated:

I mean we are a little group that gets together, although I suspect that sometimes we talk about things amongst ourselves, but this is the first time, I think, we've actually had some one come to talk with us that knew something about the topic, and to lead the discussion. And I think, yeah, for me this has been more reflective than some of the other sessions.

Some of the groups indicated that they wanted me to return to conduct future discussions. As one of the consumer participants from a mixed health care provider/consumer group put it:

The other thing is we never as a group, I often think about this in terms of different parts of the [organization], we don't ever get an opportunity to do just what we did tonight, talk about some of these issues that are very important to the [organization] and just really not with someone trying to persuade us or anything but just get out the true, people's true feelings about these things... so we want these at least once a month! (General laughter)
Members of many of the consumer groups (parents of handicapped children, residents of a less affluent area of Vancouver, college students, high school students and seniors) expressed their appreciation about being included in the focus groups, as they indicated that their voices were often not solicited, or heard, in debates about health care. Interestingly, this was also a comment made by members of the media as they claimed that, although they were required to report stories in what they considered an unbiased manner, they were seldom asked for their personal view.

Some participants were amazed that the focus group process worked to allow them to have a comprehensive discussion in their group. They acknowledged that having had some ground rules about how to conduct themselves during the discussion, and having a facilitator moderate the discussion gave them the opportunity to express their views. One of the physicians described it this way:

I think it was amazing, because for the most part there was only one person speaking at a time, and nobody raised their voice and nobody took any of this personally, which you know, is often a problem. And I think our profession where each of us has [a point of view], we're not in a profession where we are [usually] able to do this civily.

Letters, cards, notes, and phone calls were received from participants thanking me for involving them to be part of the process. One letter was also sent to the Director of the School of Nursing at the University of British Columbia indicating how much a participant had enjoyed the process and commending me on the design of the study.

Moreover, after the focus groups were held, several health care provider groups initiated further discussions to talk about issues related to ethics and transplantation. In particular, one agency established a Transplant Education Day, to address the issues that had been raised in the focus groups, and to provide support for staff caring for transplant donors and recipients. This group also began exploring more opportunities for hospital staff to become involved in the patient selection process, a strategy that was formulated during the focus group process.

As a result of the group discussions, many participants were committed to becoming more involved in discourse about resource allocation in their homes and communities. Also, as a result
of the discussion groups, I was invited to meet further with some groups, and to provide more information about ethics and organ transplantation. In a few situations, this involved being asked to give radio interviews, including an invitation to speak on a Seniors' radio program.

In several cases, group members made comments about having their consciousness raised about the issues discussed, and made commitments that they would ensure that family members knew their wishes about organ donation and end of life decision making. In one case, a consumer participant from one of the mixed groups planned to use the case study as a discussion point at a dinner party she was having the evening after the focus group was held.

Having examined the focus group process, and some of the comments that individuals articulated about being involved in the groups, I will now move on to describe the processes used by group members as they interpreted the moral problems and issues raised during the focus group discussions. First, I turn my attention to a description of the general views focus group participants held about resource allocation for organ transplantation, with the intent of highlighting the major similarities and differences within and among focus groups. In addition, I explicate some of the influences group members articulated as being important in the development of their views about resource allocation in organ transplantation, and I highlight the values the groups identified as important to their discussion about moral problems related to organ transplantation.

Interpreting Moral Problems

Patterns of Viewing of Organ Transplantation

The general views of the group members about organ transplantation appeared to be part of a continuum from emphatically positive convictions about transplantation to emphatically negative convictions. These perspectives of individuals within the focus groups have been captured within three broad explanatory patterns. The metaphors, "through a glass brightly", "through a glass translucently" and "through a glass darkly," have been chosen to describe these three major perspectives. These metaphors refer to the manner in which participants viewed transplantation when thinking about themselves, their family members and society in general. In most cases, participants had positive perspectives about transplantation, the lens through which they viewed the
topic was transparent and unclouded and they saw transplantation "through a glass brightly". In some cases, the participants had ambiguous convictions about transplantation. They recognized some of the potentially negative perspectives that were part of transplantation, but also articulated some positive features. The lens through which they viewed transplantation was clouded and hazy and their perspectives emerged as "through a glass translucently". In a few cases, the participants saw primarily the "dark side" of transplantation. This colored the participants observations to the extent that they had negative views about most issues related to transplantation and the metaphor "through a glass darkly" was used to describe their perspectives about organ transplantation. The patterns, and the factors and characteristics that influenced the convictions of the participants are described below.

**Viewing organ transplantation as through a glass brightly.** Within this perspective, the participants had unequivocally positive or very positive convictions about organ transplantation that remained steadfast throughout the focus group discussions. They thought positively not only about the present day status of transplantation, but were also positive, for the most part, about the directions being pursued through research and development to improve the success rates of transplantation, and to increase the numbers of organs available for transplant purposes.

All major health care provider focus groups, (nephrology and transplant unit nurses, nephrologists, renal technicians, transplant social workers, and transplant organization staff); the major consumer groups (organ transplant recipients and health charity staff), and major mixed consumer/provider focus groups (transplant organization and health charity staff) held positive convictions about organ transplantation. Some participants in the moderate and minor health care provider, moderate and minor consumer, and moderate mixed focus groups had very positive convictions about transplantation, but were not quite as emphatic about these convictions as were those persons described above. These included consumer groups such as the media, students, seniors, and general consumers. Health care provider groups included some members of the operating room nurses group, critical care nurses from non-transplanting hospitals, the nurse managers and clinical nurse specialists, palliative care physicians, and community/home care
nurses. In addition, some members of an hospital ethics committee, a moderate mixed provider/consumer group, also held positive views about transplantation.

In the case of the major consumer and provider groups, the participants had extensive personal or professional experience with transplantation, either as recipients, caring for potential recipients, or providing or designing services and programs for those who were recipients or on transplant waiting lists. They were knowledgeable about the process, had extensive knowledge about the subject, and many personal experiences to relate. In addition, they had a better understanding of the outcomes of transplantation than did the minor and moderate groups. These groups tended to be very engaged in transplantation, and attached to the process. They viewed transplantation with zeal and they talked about their resolute, or absolute commitment to transplantation, and the trust they had in the transplant process as it was currently designed. They had considerable knowledge about the organ donation and transplant process and had a strong personal belief in transplantation; in many cases in a very unquestioning manner. One significant point that was raised many times by these participants was the conviction they had about the value of transplantation as a life saving treatment option.

The moderate and minor focus group participants who had positive convictions were less engaged with transplantation and somewhat more detached from the transplant process, however, some of the moderate health care providers had as part of their job responsibilities caring for organ donors and/or recipients. Health care providers from these groups usually had some knowledge about transplantation, and in addition to those who were involved currently in caring for organ donors and/or recipients, a few had cared for a recipient or a donor at some time during their nursing or medical career. Several participants in the minor or moderate consumer groups had worked with people who had organ transplants, or had close friends or relatives who had been an organ donor, were waiting for a transplant or had been transplanted. A few participants knew someone who had received a solid organ transplant. For example, in one situation, a woman had a son who had received one kidney from each of his two brothers; sadly both kidneys were rejected. Another person had an uncle who had received a liver transplant, another a sister-in-law who had a
double lung transplant, and in one case, a close personal friend was waiting for an organ transplant. The health care providers also had experiences of knowing people who were recipients or donors of organs. In one particularly poignant case, an operating room nurse talked about being involved in an organ procurement case where she realized, just as the procedure was to begin, that the donor was a personal friend, clearly, a distressing situation.

I also have a personal thing that most people [in the group] may not be aware of, but one night we had a case here and I was circulating. Actually, I was in the holding room with the patient and it was the first [type of transplant of that organ] that we had done. The fellow... I forget his name now. And I met his family, and there was a delay for some reason, and for about two hours I was able to sit with him and his family and talk, which was actually quite a nice thing to do, because you don't often get a chance to talk to the patients and get to know their family with kids and all this different stuff. So, finally when we did go into the room and I helped them get the case started, I left to go for coffee and I happened to look at the list and the donor was a friend of mine. I hadn't seen her for a few years, she moved away from the Lower Mainland and she had a brain hemorrhage on [a location in B.C.] and I couldn't believe it. It was just, I didn't know what to say. And I went into the lounge and just sort of sat there and I was really glad that I wasn't asked to go in and help with the donor, because it really upset me, so I did not go in. But you know these things happen.

The participants discussed the trust they had in the health care providers involved with transplantation and the belief they had that the transplant team would act fairly in the application of just selection criteria. They did not articulate any religious, cultural, or personal beliefs that prevented them from being either transplant recipients, health care providers in the area, or organ donors. They believed that more resources should be available within the health care system for public awareness programs for organ donation and for transplantation programs in general.

Interestingly, most minor health care provider groups did not have a great deal more information about transplantation than the general public, and they asked similar questions about the success of transplantation, as well as about the selection process. Moreover, as with some of the consumers, these health care providers lacked knowledge or were unclear about certain aspects of the organ donation process. Although there was occasionally a lack of knowledge about the transplant process and the outcomes of transplantation, there was a general trust in the process. Furthermore, there was trust that the transplant teams would act fairly and implement just selection criteria.
For the most part, the individuals who had positive personal experiences had viewed positive human-interest media coverage about transplantation. In addition, they had gathered their information from the media, and from stories about transplantation that they had heard from family and friends. It is interesting to note that the stories from the media that impacted on people, and the ones they remembered most, were stories that had a human element, had a positive outcome for a patient and/or family, and/or where there was some controversy. There were comments about a variety of different situations that had received media attention during the course of the data collection for this study. For instance, a number of people discussed the circumstances around the transplantation of the late baseball player, Mickey Mantle, who had received a liver transplant in 1995. Participants had many questions about the selection process for organ transplantation as a result of the publicity around this case. For example, one high school student said when discussing Mantle's case: "Yeah, so why should he [receive an organ], I mean it's his own fault. It's not from natural causes. If it was, I wouldn't be angry, but he drank, so some one else should have the liver." (see Appendix 6 for a description of selected media stories that surfaced during the data collection period).

Individuals holding the perspective "through a glass brightly" expressed their desire to be organ donors. In fact, in the case of one staff member at a transplant organization, she jokingly said: "You can't work here without being an organ donor." Another major provider declared, "I think it's something about working here. It's about exposure to the area and seeing how it can be life saving for some people [that] gives you confidence. I don't see it as high tech, its just what we're seeing all the time."

Furthermore, people who held positive views about transplantation generally considered that, if necessary, they would be willing to have a transplant and would recommend this treatment option for their loved ones, or anyone who needed it. They were organ donation advocates and declared proudly that they were organ donors. Many asserted a desire to see more media coverage and general publicity about the need for organ donors and some said that as a result of being part of the focus group they would begin to become more actively involved in promoting organ donation.
As one major health care provider stated:

When I started here, I knew nothing about organ donation, and when we went to renew our driver's licences and they asked us, do you want to be an organ donor? I said [yes]. Now, my whole family are organ donors and the reason is we didn't know anything about it [before] and I learned so much from working here and I tried to talk to my neighbours who are now organ donors. And my family and like my kids ask me. I mean it's all word of mouth and I was, and want to after [this] to do a lot of things to make awareness.

**Viewing organ transplantation as through a glass translucently.** In these cases, the participants had ambiguous views about transplantation, and the lens through which they viewed transplantation was clouded, and not clear. Some members of the minor health care provider, and the moderate and minor consumer groups fluctuated between viewing transplantation positively during part of the discourse and negatively in other instances. These participants included members of the health care provider groups of nurse managers/clinical nurse specialists, community/home care nurses, nurse consultants, the palliative care physicians, the parents of the mentally handicapped, and the college students. For the most part, these participants were not as engaged with transplantation in their personal or professional lives and were, therefore, somewhat detached from the transplant process. Although they accepted the value of transplantation as a treatment option, they were ambivalent overall about their own attitudes about transplantation and in some instances, they had negative personal experiences or had viewed negative media coverage about transplantation that began the questioning process for them about transplantation as a treatment option, or about being an organ donor.

The participants who were part of this pattern had some negative attitudes toward transplantation and mistrust of the process and players. For example, a few members of the focus group made up of the parents of mentally handicapped children were extremely fearful for their children. They worried about a time when their children might be terminated for the benefit of others, including for organ donation. These concerns were raised in the context of medical experiments that they alleged had been performed on some of their children while institutionalized in the 1960's. The parents had a major concern that these things could happen again if society
continued to disvalue the handicapped in the search for so-called "perfect" children. One parent said:

I think our paranoia as a family has found that through the rejection of our sons and daughters over the years, that there have really been people who have said that they are at the end of the line for everything. So, it's not an unusual thing for us to be that way about it and when I say us, I mean, who are family, so maybe this time we should have more faith in society but to this point we don't have the confidence that they will not be weeded out because of the label that they have.

Although they worried about this, many of the parents still spoke positively about organ donation. They saw transplantation as a potential treatment option for themselves and for their family members.

In a few cases, other participants worried about vulnerable individuals being used as organ donors. For example, in one consumer group, some members suggested that racism was connected with the fact that the first heart transplant was done during apartheid in South Africa in 1968, where a white man received a kidney from a black donor. Although the story did not appear to be accurate, as both the donor and recipient were white, it was one of the stories that people had heard about and that indicated they had some mistrust of the transplant system.

Other consumers and health care providers talked about receiving negative information about the transplant process from stories that circulated about buying and selling organs and "organ snatching." Some people called these stories "urban legends" and as long as these negative stories were balanced with positive human interest stories, participants still had a positive view of transplantation. In one situation, a participant, who had lived in a Central American country, disclosed that she knew of parents who were living in such abject poverty that they had sold their children for adoption purposes. The parents found out later that the children had several organs removed that were then sold on the black market. Another consumer added to the story saying that, "there's people with such a desperate need that, yeah, I know families in the third world that have actually sold one of their children, not their organs, but their child, who was sick, you know, so they could keep the others alive!"
The participants with ambivalent views accepted the value of transplantation as a treatment option, although individuals asked questions about the resources used for transplantation and wondered if resources might be used elsewhere. They also spoke about the value of considering a balance when thinking about resource allocation for transplantation and the needs of other health care programs. Although they saw transplantation as a viable option for treating end stage organ failure, the participants were uncertain about how they thought the treatment should be applied and who should receive the organs. In some circumstances, participants believed that the transplant team would not act fairly to implement just selection criteria. They had more concerns about the allocation of resources for other health services and worried that high technological treatments such as transplantation would divert needed resources from geriatric, mental health, and palliative care programs. They did not suggest the reduction of resources for transplantation, but, rather that other health care needs should be addressed and appropriately funded. They worried about the "technological imperative" where transplantation would be carried out on inappropriate individuals just because it could be done, and not for therapeutic benefit and improvement in quality of life.

For instance a nurse consultant said:

I guess you know part of it is that kidney transplants have proven their worth in many, many ways. I guess I sort of step back and say with heart and lung, heart-lung, bowel, you start to really.... I don't know for some reason that is going too far almost in my mind, and I can't articulate that, but I wonder at what point it's experimentation for what quality outcome and I also have some concerns about everybody getting involved in the business. I think there is a need to do research in this area, and to prove I guess the benefits to the client, and to examine all costs, not just dollar costs related to that, before everybody starts doing them because I think it's a horrendous strain on our health care dollar. We know what the costs are, and we know what happened, too, when we tried to create a transplant unit. It's a very difficult thing to do and staff, and there's all sorts of hidden costs in doing these kinds of things. So, I'm not, I haven't thought about this for a long time, but I guess that there are things in me that were saying, oh, what are we doing here and why are we doing it.

One other nurse consultant said:

I, like everybody else, [in the group] share some of the ambivalent feelings that people have, and I think most particularly in the area of pediatrics. There were times when I felt that people were making decisions without as much information or time as they may have needed. And naturally were making decisions that they hoped would save their child without as much clear recognition and understanding of what kind of care. And what the actual chances of success and the quality of life, or extending the period of life that their child might have. So, I have some real concerns about that issue. The sort of informed
decision making and the shift from what is considered to be fairly accepted practice with
good outcomes that we know and understand, for example, kidney transplantation, corneal
transplantation, and transplantation that could be considered still to be fairly experimental,
and I did see some of that happen with children. I think the watershed issue for me in this
one is when they did the baboon transplant in the infant in Loma Linda. I had an enormous
amount of difficulty with the ethics of that, and with what the family thought they might be
consenting to and what was really happening. So those are my feelings on the issue. I think
that we are all coming from the same places in terms of our ambivalence.

Some of these participants with ambivalent views were organ donors, and others were not.
Reasons people chose not to be organ donors related to the previously described information, or
because they needed more time to ponder on the issues, or because they, or their family members
had religious or cultural concerns about organ donation. One nurse participant put her thoughts
about organ donation like this:

I was trying to think that one through in my mind and I don't know, I'm trying to anchor it
on something, if it's my upbringing the importance of body whole and keeping it all
together. Like, in our family, the losing of a tooth was a major catastrophe, and I really had
to come to terms with it, too, when my father died. There was a bit of a problem in the
hospital with a physician and my brother in terms of what went on and anyhow so the
doctor tried to clear the air, he asked our family if he could do an autopsy. Well, when I
raised that with my brothers and sisters, like the answer was such a strong no, and it was
like there has to be wholeness there, and Dad's gone through enough and so I thought well
isn't that interesting because my first gut feeling was that I wanted to say no, too, but it
wasn't just my place to say it. So I can't really articulate it but I think it's anchored
somewhere in relation to how I was brought up... And I believe in people's right to
choose, so when people say that they will be an organ transplant person or receive an organ
transplant, I would support them and facilitate them having all that, but I haven't even come
to terms with myself right now if I would accept an organ. You know like it's easy to talk
when the shoe's not on the other foot yet, but that's a question that I have in my mind, like
would I accept an organ if I really needed to, or will I let nature take its course. And that's
another kind of thing, too, you know like when you've been brought up on a farm you see
the seasons and like there's a beginning, and a middle and an end to life, and I am the kind
of person who wants nature to take its course and when my time comes my time comes.

Viewing organ transplantation through a glass darkly. In the remaining cases, participants
had unequivocally negative views about transplantation and this influenced their observations and
perspectives about transplantation. A large majority of the critical care nurses from a hospital where
transplants were occurring were included in this pattern, as were a fraction of the minor health care
providers. Their negative attitudes did not apply to kidney transplantation (they believed kidney
transplantation to be a cost effective method of treating end stage renal disease) but they had major
concerns about transplantation as an option for extrarenal end stage organ failure. Interestingly,
none of the consumer group participants expressed these emphatically negative views about transplantation.

The participants reflected within this pattern were not as engaged in the transplant process as other participants and they did not feel included in the transplant process, even though from time to time, in the case of the critical care nurses in the transplant center, their professional role required that they care for organ donors and/or recipients.

These participants had major suspicions about the transplant process and mistrust of many of the players. They did not believe the team always acted fairly in implementing just selection criteria. They had significant concerns about the impact of transplantation on the use of resources for what they considered other worthwhile treatments. None of the participants were organ donors, however, they did indicate that they respected the choices of those who were. The reasons that the participants gave for not being organ donors were sometimes related to religious or cultural beliefs (areas that others had identified), but most often because they did not trust the system that was designed for organ allocation, were concerned with selection criteria and mistrusted the key health care providers involved in the process of selecting and transplanting organ recipients.

**Similarities and Differences within and between Stakeholder Groups about Their Views Regarding Organ Transplantation**

Having described the general views people held about organ transplantation, I now proceed to explicate their views more specifically by discussing in more detail some of the major differences and similarities between and among the groups about their views. These similarities and differences were most evident when the participants were discussing certain topics in the focus groups, such as selection criteria for organ transplantation, whether or not the participants were organ donors, issues about obtaining consent for organ donation, xenografting, and buying and selling organs for transplantation.

There were major similarities among the groups when discussing selection criteria for transplantation. In most cases, group members believed that recipient selection for transplantation should be based on medical need, however this view changed for some groups when social worth
and merit criteria, such as the age of the potential recipient, was discussed. A number of
individuals had concerns about transplanting the "elderly", although there was no consensus on
how to define this term. In addition, concerns were raised about lifestyle issues and the extent to
which they should or should not influence transplant recipient selection. The discussions around
selection criteria appeared to raise many perplexing concerns for all the groups. These discussions
and concerns are described in more detail later in this chapter as the moral reasoning processes of
the participants are described.

In addition to the similarities in views about selection criteria, there were some differences
among and within groups related to their views about organ donation. The majority of persons in
this study viewed transplantation positively and indicated that they were organ donors (see
Appendix 11 & 12 ). Most of the participants in all the focus groups declared that they were
donors, because they believed they were acting in an altruistic manner by "doing good for others,"
and exhibiting caring for their fellow citizens. This included all the participants in the "through a
glass brightly" group.

On the other hand, there were a few participants who had not indicated (by either signing
their organ donor cards, or adding a sticker to their health care cards) their desire to be organ
donors. These participants had ambivalent or negative views about transplantation and suggested
their choice was either because of their overall concern about the idea of organ donation and/or
their concern about potential mutilation of the body. One nurse in a minor stakeholder group said:

I think [co-participant] did an excellent job of articulating what I was wrestling with, and
I'm not sure where my feelings arise from, but I think it has to do with that wholeness, that
it has to do with desecration, almost. And I'm not a religious person, but it's just a feeling I
have. I was really uncomfortable with, and I struggled with, is this right, I should be able
to, I've worked in the health professions I know what it [organ donation] can mean and I
just couldn't, and I, so I just let it go, and decided not to think of it. Till you brought it up.
I'm really into denial, hearing you has made it difficult.

Other participants said they were not organ donors because of some negative personal
experiences with transplantation, or because of their lack of trust in transplant teams, and the zeal
with which participants perceived the technology was being pursued. A few people did not wish to become organ donors because of religious or cultural beliefs. One critical care nurse said:

I'd like to mention a lot about my cultural background. A lot of Chinese don't believe in cremation. Like my mother says when I come back I don't want to be missing my kidney or my lungs, or what ever, so it really made me think. Like I'm not that much of a cultural mind, but I feel sort of torn between if I ever come back, I better have everything.

In addition, there were several persons who had not yet made a commitment about organ donation, and a few who had never thought about it, primarily because they had never been asked to be an organ donor. These participants were included in the pattern of those who viewed transplantation as "through a glass translucently". One consumer participant of Chinese origin, who was still not sure about his own wishes, said he was moving in the direction of thinking more positively about being an organ donor as he deliberated on the following story:

Education can change people's thinking. So for Chinese people, I think they have the belief that if you are born in this way, then you are born in this way, and then when you die, you are going to die this way.... I think it is individual thinking, but I think education can change people's thinking. They have some education regarding organs and donation so that two young kids eight and ten, they were, they watched the TV program and they said, oh, I like to do the donation. So later, I think, when they were waiting for the bus, and they were lining up at the bus stop, and the bus went out of control and just crashed into the crowd and then the two brothers died, and when the accident happened and they had said we want to donate our organs, so the mother gave consent and ...they gave their organs and what they did really [was] give a very good perspective on the donation issue and then there was a very long line up. But what these two brothers did was give a very good message, and they told their Mum, but we die, but our lives keep going on with other people. So that it is amazing, that all these people queue up for it [to become donors] after this happened.

Interestingly, a large number of people from all groups were dismayed to find that family members could veto an individual's expressed wishes about organ donation. The participants suggested that when they decided to become or not become an organ donor (in the event of their death) that they did not want anyone to have the right to overturn their decision. For instance, the focus group of seniors was concerned that someone could override their expressed wishes about organ donation, as were members of several other groups. One member of a transplant organization focus group described it this way:

I think that somebody's decision should be their decision. When I worked on the switchboard, we got at least ten calls a day on that saying, well I want to be an organ donor
but my husband doesn't want to let me, I want to be an organ donor but my mother doesn't want to let me. I had two already this morning, and they want to know what we are doing about it. So there's a Canadian law that says if you pass away then the next of kin are in charge of the body. And they are really, the general public is saying your wish is your wish, so I really think there should be a change in that legislation. And I was told they are working on it.

All consumer, provider and mixed consumer/provider groups supported the idea of living organ donation and believed the decision to be a living donor was an individual one, that was a matter of personal choice. The need for a strict process of informed consent was stressed, with particular attention being given to ensuring that donors were not coerced. Parents in several of the groups spoke about their immediate wish to donate an organ if one of their children required a transplant. One college student said this when thinking about donating an organ to her son:

I'd do it. I'd do anything and I would even probably rationalize buying an organ off someone who was still alive, even though I think it's horrific and said that it would set a terrible precedent, you know, with really dangerous implications for the future. But, I think if I needed it, I'd be able to rationalize that if someone wants to sell it. And I think if it was me living in another country, dirt poor, I don't know, I think I'd be happy if someone wanted to buy one of my kidneys.

Furthermore, all the groups believed that there should be no financial incentives given to living organ donors, but most believed that the donors should be compensated for out of pocket expenses. One participant in the group of college students talked about how she had never thought about this idea before and stated "This is really tough for me. I'm just starting to realize how uncomfortable I am. You know, this is really getting depressing. I can't even imagine, I can't even process it."

In a few groups, where participants had ambivalent views about transplantation and saw transplantation as "through a glass translucently" they disclosed that, although they themselves did not want to be living donors, they saw it as a matter of personal choice. A few individuals said they might be willing to donate an organ to a relative, if the relative had a transplant from a non-living donor first, and that organ failed. Interestingly, few of the groups saw a distinction between being a living related donor or an emotionally related donor. They saw these as the same situations,
and maintained that donating an organ, in both circumstances, should be purely a matter of personal choice.

When discussing the need to change the process of consent for organ donation, there was little support from the major and moderate health care provider groups, regardless of their view about transplantation, for the idea of requiring that hospitals ask, those families who had a loved one who would be suitable organ donors, about organ donation. They believed this would cause too much pressure at the level of the Intensive Care Units and cause a negative reaction in consumers. Critical care nurses agreed that this should not be something they were "forced to do", they believed they should be able to use their professional judgment about which families to ask. On the other hand, all consumers groups were surprised this was not happening already, thought it was a good idea, and believed that whatever necessary should be done to give the family the opportunity to respect an individual’s wishes, and prevent the waste of viable organs.

The issue of presumed consent caused more discussion in all the groups. At the beginning of the study period (prior to December, 1994), most consumer groups in the "through a glass brightly" and "through a glass translucently" patterns were in favor of the idea of presumed consent, that is, removing organs without seeking the permission of the next of kin, unless the individual had specified his/her wish not to be an organ donor. One member of the media focus group stated:

I think the community of man and persons, and the need for us all to be accountable to each other, dictates that consent should be presumed unless [otherwise stated]. And because it's so important, because it's life or death, there is every authority to get a donor. I think that reality and common sense both dictate that option, and of course anybody can opt out.

One of the nurses said:

Intellectually, you know, I can support this presumption of consent in this case... I like the notion of handing back the opportunity for people to consider whether or not they would like to be a donor, well before they have to actually face the situation in an intensive care unit, and I think maybe that is part of why I would want this presumed consent, as well. It is fraught with difficulties, not the least of which is to make sure that people actually mean it, and that they have let everybody around them know that they mean it and that there's a consent of society for that.
Some of the major health care providers and consumers who viewed transplantation positively believed that in our rights-based society, this might be an unpopular idea with consumers, although they thought it would encourage conversation among Canadians about organ donation. One transplant organization staff member said:

I would say if you are looking at this from an ethical point of view, of what's the most ethical option, presumed consent or presumed non consent, which is what we have now, I would say that presumed consent is probably more ethical, because I think it's more ethical to assume that people would want other people to survive rather than not survive. But, I think the whole health care industry protected itself from this debate for fear that if it's not communicated properly the whole transplant establishment would come crashing down, because there would be nobody willing to donate if they felt the state was coming in and making decisions on their behalf. So, we have been very careful not to touch this because we know it could go either way, and if it's not managed properly it could be very threatening to transplantation, and I think in the longer term, it needs to be brought up in the discussion to reverse the assumption that in effect we're saying that unless someone gives you consent someone is going to die, will probably die, without that consent, [that's how] it needs to be put.

A transplant recipient, who was in favor of presumed consent, declared:

Yeah it's like a living will... If that were the case, which I hope it is some day, that everybody has to be a donor unless they carry the little card saying no. Then don't you think it would be like some of the countries that are already like that? You get a hell of a lot of education going out there. I mean it would be so much better than it is now, where there is all of us going out and talking to this person and that person. But if it were presumed consent, the government obviously would come out with this huge campaign and all, you know, the nurses the doctors everybody would be talking about it.

Most consumers, on the other hand, seemed to think presumed consent was a good idea. However, after January, 1995, this attitude shifted, and consumers and providers alike recalled the experience of "negative marketing" with a cable television company, and thought the idea of presumed consent to be ill-conceived and unlikely to work in Canada, primarily because of the potential to override personal autonomy. Seniors described this as “getting organs through the back door”. Moreover, the health care providers who were part of the "through a glass darkly" pattern did not favor the idea of presumed consent, particularly after the negative marketing discussions.

One area where there was remarkable consensus across all groups, regardless of whether their general views about transplantation were positive, ambivalent or negative, was in the area of commercialization of organs, or in other words, developing a market for buying and selling.
organs. The groups objected to the idea of buying and selling organs when the topic was raised in the focus groups, calling it an abhorrent practice that would lead to the exploitation of the poor by bringing out the worst in humanity.

One consumer put it this way:

And [co-participant] mentioned the fellow that went and bought a kidney in India, and I think that is so immoral that he shouldn't be helped. That he bought that kidney... and he has no right to it. Let him be on kidney dialysis for the rest of his life.

This participant, and others, also believed that if buying and selling organs were illegal in Canada, then bringing an organ into the country as a transplant recipient, who had purchased that organ in another country, should also be illegal.

There was concern that the buying and selling of organs could lead to a more class-oriented society where the rich were transplanted and the poor were not. A fraction of people mentioned that they might consider this method, in desperation, if a family member were in need of an organ. One member of a mixed consumer/health care provider group, when reflecting on whether his wife (a transplant recipient) might ever need another organ transplant said, “I can absolutely guarantee you that if that was the [only] choice for my wife, I’d do it. In a second. Absolutely guarantee it, because I have the resources and I think there are a lot of people who also would.”

One physician who had grown up in India, who did not support the idea of buying and selling organs personally, nevertheless believed that some attention needed to be brought to bear on the fact that the issue was not often examined through the eyes and values of those living in other cultures. He pointed out:

Having lived in India, and having grown up in India, and knowing, that's been one of the big places where organs have been coming from, too. And seeing people who realize that they can sell their kidneys for a thousand dollars, which is about forty or fifty thousand rupees.... Yeah, but these people could revolutionize their entire family for that price. I mean their kids could end up going to school, and having a much better life than they would have. I mean, I can see why.
On the other hand, a mother who was not in favor of buying and selling organs, talked about the ideas parents consider in times of desperation and poverty, and how choice can be compromised when remuneration is offered. She said:

I had seen an ad in the New York Times eight years ago, about if you sell your heart, and if it could send my children to college, I would have gone for it....I guess knowing a little bit about human nature, you know, and how people react to things. For instance, as far as selling tissues and organs, I know how a need for the availability of money, or some other form of remuneration, affects people and how that actually limits their choice rather than increasing the choices....They are going to make a choice based on that moment of particular need. It's not a choice really, it really isn't a choice, as soon as you involve, I don't know what you would call it. It takes away freedom of choice and I really disagree with that.

When discussing the experimental procedure of transplanting animal organs (primarily pig organs) into humans, there was much difference of opinion between and among groups. A few participants in the "through a glass brightly" groups who objected to the idea, did so, not usually because of ethical concerns, or because of their concern about the treatment of animals, but because certain viruses might also be transplanted into humans at the same time as the animal organs. Media stories, about the safety of the blood supply, "Mad Cow" disease, and viruses, such as HIV, and Ebola, caused fear in some groups about the potential for disease transmission with xenografting.

Most participants who were very positive about transplantation had no concerns about moving in this direction. They saw no difference between xenografting and eating animals for food, or using them for clothing and other commodities. A member of the media focus group said: "It sounds like a good idea, we eat them anyway, so we're not that sentimental about them. I wouldn't like to see them terribly exploited, but we exploit all over the place". A critical care nurse from a non-transplant hospital said: "We're growing animals for fur, why not grow them for organs". A few of the university students had the following interesting perspectives.

I mean I don't see any ethical problems at all with putting an animal's heart into a human being if it functions well. I don't have any emotional attachment to the heart.

I don't think there are any ethical problems with this from what my understanding of what ethics is, but I think there are at some level, there may be something more akin to an esthetic idea that this is sort of an unpleasant vision of what we want our relationship to other creatures to be is.

Well, I guess I have a different ethical basis.... But here I have less problem
with this than with eating animals. We're killing one animal to save one human instead of killing say seventy animals to keep eating burgers for a long time. So, this at least seems like it does have a higher purpose and even though I do think the animals should have some consideration, like having to be well treated and all that. I think one human life is still more valuable than one animal and so I'm all for growing up lots of pigs, knowing that they are going to be, you know, the hearts are going to be used for transplants for human lives.

Furthermore, a transplant organization focus group participant took this pragmatic position when discussing xenografting:

You know, I mean we're God's creature and all that, but you can't compare the life of a pig to a life of a person, so I mean, someone could, but I can't. I used to work in a meat plant, remember that. The thing is, I just think that if that's the shortage and we're going to get maybe a couple of years out of a pig's heart, why not? The cost of it is horrendous, but I don't see that as an ethical. I don't see it as a big problem. I know it is a big problem but I don't see it as a big problem.

These participants who viewed organ transplantation positively claimed that the organ shortage required drastic measures to sustain human life. Proponents of this way of thinking came from all the groups in the "through a glass brightly" pattern, but, in general, more major health care providers were supportive of xenografting than those in the consumer groups.

A few of the consumers who viewed transplantation positively did have concerns. One transplant recipient noted "Nobody asked the pig. And that's one of the ethical problems, nobody asked the pig".

Another transplant recipient said:

The only thing is, and this is the insurance side of it, but when you get to the point of researching the scientific process you're altering the life cycle, so to speak, of man and at what point are we going to carry that to? When suddenly, because of modern science, we're able to live to over 150 or 200 because our resources aren't geared to that type of a society. And what happens if a sixty-five year old gets to retirement and can't live because our society doesn't have the resources? My point being that if we go to the point that we have established that we can use animal parts for sustenance to cure problems in humans, how far are we going to allow that to go before we can do it? Are we only going to do it up to the age of forty-five or fifty or sixty. I don't psychologically have any problem with having a pig's liver either, because, I want to live as much as the next person, so I wouldn't have a problem with that, but when you look at it from the point of view of what is it going to do to our society overall.

Another consumer, a member of a transplant organization board, declared:
I have trouble with it. I do, and I think for research, animal research, I can see where we have to use them, but I know the basis for it. I would not want a pig's heart. I think if I was that desperate, it was my time, and my number was up and that was it. I just don't think with the resources that we've got that we should be doing that kind of heroic thing....I think some of the heroics that they do at the special care nursery, and I really have a lot of trouble with that. You know you go in and see these kids who are as big as the palm of your hand and they're hooked up to all these things and I don't know, I think we push things a little too far. And going to another species if you would, just doesn't seem right to me and that's just my tune.

A few people who had positive views about transplantation were not certain what they thought about xenografting. One transplant nurse said: "I don't know. I have mixed feelings and I haven't crossed that point yet in my mind. Like using animals, but I have a porcine valve replacement using a pig and it's working fine. So really, is it different? I don't know?"

Organ transplant recipients supported the idea of xenografting if it would result in more transplants. They explained that if they were in the position of choosing between a xenograft and death, or between a xenograft and a living donor, they would choose the xenograft. As one recipient put it: "When you are sitting on dialysis after a while, anything that works, you take it."

Another organ transplant recipient who had received a living donor transplant added:

If I had my choice, I'd much rather take a xenograft rather than some kidney from someone else, like my brother. Even though my brother is healthy and has been healthy for ten years, I'd much rather do that, just to spare him the operation and the trouble at the time.

However, one individual believed that even in a life and death situation, she would be uncomfortable knowing she was the recipient of an organ from an animal, but, she admitted that she would not really be able to determine her true feelings about this until she was faced with that decision.

I'm not a hundred per cent. I remember thinking distinctly when I went on dialysis that, I mean, that someone would have to die in order for me to live. I mean, I just couldn't even initially face it. I didn't want anyone to die, so that I could have a kidney, but it's not that they have to, it just happens, and it's, you know, I've resolved that. But now, I'm not sure that I would want an animal organ, also I mean I don't know, I'm a farmer's daughter I mean really I'm not a hundred per cent sure.

For many of the participants in the groups who viewed transplantation with some ambivalence, or in a negative fashion, there were also concerns that society may have reached a
technological summit, and that xenografting would lead to more genetic manipulation and tampering with the human race, and as stated in one group, experimentation with their children. One of the parents of the mentally handicapped children said: "If they think they probably will have to lose the first six people before they are going to perfect it [xenografting], it's our kids they are going to want to use them on".

A few participants had objections because of religious or cultural concerns, as well as their concerns about prolonging the dying process. As one of the critical care nurses said:

I'm a Christian, and I feel that death all along is natural, we are not immortal, and I see it as the final course of life, isn't it? And that's why, when you mentioned the pigs, I go no way! Because that is going to the mad scientist stage, and it's just beyond. I just think, too, you know, we do all of these things and, there is a whole other aspect I'm very interested in. We don't prepare people and they say, oh no, you are not going to die we're going to give you another transplant, don't worry we'll give you two and this person has been cheated out of most likely, you know, who ever dies here, they don't get a chance to say, you know, say their good byes or to fix up their house. If they were given a more realistic view point they might tidy up loose ends, you know, and prepare for a more happy death.

Interestingly, some of the consumers and health care providers, who had positive views about transplantation, and who were in support of xenografting, changed their position as they came to realize, through the discussion, that some human DNA (in the form of human complement) would be necessary to create the transgenic pigs, thus decreasing the chance of graft rejection when the organs were transplanted into humans. This idea became more worrisome to some people as they began to think of the long term implications of the genetic manipulation of animals. One of the consumers from a mixed consumer/provider group put it this way: "But you know, that it's saving your own life, but it may destroy mankind, I mean that's pretty profound". And a palliative care physician declared: "It just seems like in medicine, the signs of medicine, the challenges are such that if you do it, or try and do it, you are going to do it anyway. [It's like] if you think about it, you can do it." While a consumer participant from a group of Downtown Eastside residents said:

You know at this point, I think it's [xenografting] a good idea, but where it will lead to. I'm not sure, and I don't think any of us know where DNA manipulation is going to lead. It could be really scary stuff, and we need the answers to the questions, I suppose to think about it at this point.
In a few cases, there were concerns that animals needed to be treated with more respect and that the idea of xenografting would be acceptable in certain circumstances with lower order animals.

As one of the participants from the nurse manager/CNS group said:

I would support it as long as we are using, in real valued things, a lower ordered animal like a pig, and I think there is still enough research done to know they already are lower ordered animals versus finding out later that they are actually smarter than we are, like the whales kind of thing. So, it's some scientific assurances that that is the case then somehow I could bring myself to accept that.

In addition to the differences in views expressed above, there were some major differences in views related to transplantation between focus groups of critical care nurses. These views are discussed separately here because their experiences were uniquely different from the other focus groups in the study, where professional perspectives were not as polarized. Also, critical care nurses were the only participants in this study who were responsible for identifying and caring for organ donors, a pivotal area in the discussion of the allocation of resources for transplantation, given that the treatment is almost entirely dependent on receiving organs from donors coming from critical care areas. Their views about transplantation were influenced by their unique experience in very important ways, and, therefore, further descriptions about these experiences are presented here in order to better understand these differences.

Most of the nurses in the two focus groups where unequivocal negative convictions about transplantation was prominent, in other words where they saw transplantation as "through a glass darkly," were employed in a hospital where multi-organ transplantation occurred, as compared to a third group that was comprised of critical care nurses from a variety of non-transplant agencies. All the nurses in the non-transplant hospitals reported being donors, as compared to only a fraction of the nurses in the agency where multi-organ transplants occurred. The nurses believed that many

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Following presentation of the preliminary constructions from this study at a National Transplant Forum, and after some discussion with colleagues across the country, there have been anecdotal reports that the differences between
transplant patients did not understand the risks associated with the procedure and wondered whether patients were truly giving an informed consent, since the nurses believed the information being delivered about the post-operative experience was usually given in an overly optimistic, biased manner. Two nurses expressed their views like this:

I had experience as a grad nurse on the ward with the first [specific organ] transplant pre and post op after ICU and also some rejection patients from other provinces who came to our unit. I think that's where my first bad feeling about transplant started. I saw some pretty bad attitudes. One lady developed hepatitis, post transplant and she was awful, not mentally, but physically she was a mess and that was when I first started to see the real side of transplant. And then, here you get the real views. You see them post op and they may do well, they may not, the families do expect them to do really well. And I have a personal friend who had a double lung transplant and she is in acute rejection right now. She feels good, but she's in acute rejection, she got very good lungs so to speak. The family was most upset because she had [problems] post op, she had complications and they just couldn't believe this was happening, it was so awful for them. She was in ICU a lot longer than they expected and this is interesting because the family has two nurses and two physicians in it, and they did not realize it themselves. And I just saw that they really were not prepared for the transplant. I know that I'm not prepared to give my organs from what I've seen.

I took the critical care courses and they had a very nice module on transplant. Just beautifully laid out, how they were supposed to chose the recipient, and the criteria and I thought, oh, this is wonderful. I come here, and it doesn't go by the criteria whatsoever, and I've gone from a very idealist point of view about transplants to a very realistic point of view about it, and I'm not very happy with the transplants that happen on this unit, and the way they chose the recipients, and just seeing that they are, knowingly, how they transplant these organs into patients knowing that they are not going to do well. They set up the family with high hopes and I think that is the saddest part. If they are going to come out and go back to the way they were. Some of them do, but most of them do not and these people who put the organs in know that they are not going to do well. And I think there is a lot of lying that goes on, which really upsets me, and it's gone to the point where I will not donate my organs.

The nurses in the transplant agency indicated that they were concerned about organ donation as a result of the worries they had about the transplant process, in particular in regard to selection criteria. In their discussion, many focused on lifestyle choices and several times made the distinction about things that just "happen to people" versus diseases people cause because of their lifestyle choices, such as smoking and alcohol consumption. One nurse described her thinking this way.

these critical care nurses are not an artifact of this study. Other investigators and clinicians have noted these occurrences and said that these constructions resonated as "truth" for them.
I was going to say that my frowning upon the program started quite early when we did our first [type of transplant]. Her, [recipient] who was in a parking lot smoking and drunk because she was upset that she wasn't the first transplant. Then I found out that the donor that we had, and transplanted into the woman, later they found after they biopsied, I think that was when she died, not the donor, the recipient had CA. And I was just baffled by the end of it. I was really having a hard time making sense out of the whole thing. First of all, the attitude of the recipient and was that an appropriate recipient. So the tissue matches and that seems to be it, you know? Hey we have a match, let's go for it, and I know that there is a lot more detail to it, but from our point of view, that's what we see... And I've had a bit of a hard time since then sort of lightening my attitude about that. I certainly looked after some recipients who you know are going to do well, they have a very positive attitude, they are taking a lot of responsibility for themselves and for their illness. They have a supportive family or perhaps they don't but they are still pretty together. I'd say on the whole they are all just about all dysfunctional, it seems like. Whether that is from their illness, and it has made them a more dysfunctional group or what is it, It's sort of like part and parcel with it you know. I think that plays a very negative role in the whole transplant scenario.

In these cases, the nurses also talked about the idea of patients "deserving" a transplant versus "needing" one. The nurses believed that there were patients who continued to smoke and drink alcohol post-transplant, and this distressed them as they believed the organs were then not providing maximum benefit. This concern was most evident in the two groups of critical care nurses, although lifestyle issues were raised by other consumer and health care provider groups.

The critical care nurses in the transplant agency also reported feeling a sense of powerlessness as a result of their lack of involvement in the selection process before patients were transplanted. They admitted that these negative views, and their concern that, in some cases, transplants were offered to persons who they did not believe were suitable candidates, affected their willingness to be organ donors. One nurse said:

I feel that the way it was set up, is not how it is going. I think that there is a difference in how they are choosing. It was supposed to be set up that it was to be selective and that there would be certain people rejected. I don't see that happening at all. I think that again that there's a difference in the clientele that are in the community, have been working and will go back to something like that, as compared to those that were unemployed and will be unemployed for ever. I feel that they are more a dependent personality and they have a different personality. I think the male and the female have a certain rate difference. I think that the males on the whole do better than the females, and I think that that has to be something with the hormones, although I haven't ever seen anything ever written on paper or researched on it but looking after them, there is a great difference.

The critical care nurses in the transplant agency disclosed that they had a lack of knowledge about the outcomes of transplantation and they admitted that they seldom ever saw well extrarenal transplant recipients, only those who spent considerable time in the Intensive Care Unit (ICU) who
were critically ill or dying. The patients who did do well, eventually, were still very sick when they were transferred out of the ICU to the transplant ward. They also talked about the difficulty of caring for both donors and recipients:

> When I was working in [another center] I most of the time dealt with recipients and very, very few donors. And then when I come here, and we have the donor goes out and then the next day the recipient comes in, and I cannot switch my emotions. I just feel very tense inside and because I was still thinking of the family of the person who just passed away and then trying to think of, oh, this person got his transplant. I don't, I just don't feel happy about that and I feel very worried. I just can't, you know have my emotions switched off, you know?

The nurses admitted to an overall lack of knowledge about the transplant process and the outcomes of the treatment. They also disclosed that they had never spoken so frankly to someone outside their unit about these issues, but that transplantation and organ donation were frequent topics of conversation at coffee and lunch breaks.

Although many of the nurses in the transplant agency had negative views about transplantation, they believed that families should be offered the choice of donating a loved one's organs. The nurses had concerns about how physicians approached family members about organ donation. They believed "the ask" was the role of the physician and said that the physicians often began with "I am required to ask you..." when speaking to potential organ donor families. The nurses did not believe this helped families think about organ donation in a positive light.

In contrast to the critical care nurses in the transplant agency, the critical care nurses from the non-transplanting hospitals were much more positive about transplantation, and saw organ donation as an altruistic act. These nurses were also much more involved in the process of organ donation, although they, too, saw "the ask" about organ donation as a physician responsibility. One nurse said:

> I, at times, initiate conversations with the families, and I would say for the most part our [team] are very supportive, and we have a very stable group of nurses and physicians who are committed to the program...Personally, I have discussed it with my family and they know that I really believe in it and I'm an organ donor.

The nurses, however, admitted to an overall lack of knowledge about the transplant process, and the outcomes of the treatment, and they, like most of the minor and moderate groups,
received their information about transplant outcomes from the media, and recounted many success stories about transplantation that they had heard.

Having described the views that were held by the specific stakeholder groups when discussing selected issues related to resource allocation for organ transplantation, I will now move to a description of some thoughts that the participants had about what helped to shape those views. I provide an accounting of some of the influences group members articulated as being important in the development of their views about resource allocation in organ transplantation, and I highlight the values that the groups identified as important to their discussion of moral problems related to organ transplantation.

Influences on the Views of Focus Group Participants

Participants suggested that family and religious upbringing, ethno-cultural influences, personal experience with transplant situations and media exposure were major influences on the development of their attitudes, beliefs, and values and thus the views they held about resource allocation for organ transplantation. One consumer said that there was a variety of things that helped him develop his views:

My religion, I think is probably the most, just because of the kind of reflection that it's bringing me in need. I think just a general reflection to see the experience in an environment where I can trust....Well, I see every decision as extremely important, and I'm not saying, not necessarily right or wrong but decisions that you have, you have to do the best you can. So my religion informs, in that it really enforces this idea of responsibility of, you know, you are very responsible for decisions you make.

Another consumer said that she was not convinced that her views were formed by religious beliefs, but, perhaps, more influenced by her own personal beliefs. She said:

And, I would say that part of the thing that has influenced my attitude towards organ transplants is the fact that I'm probably not, I probably don't believe in God or life after death. If I believe in God, I would be much more ready to say, well you know God will look after us, and we don't have to worry too much about it because you either look after my kidney or something like that, and I don't have that sense at all. I feel that we have very important [views] that we must make ourselves.

Another consumer said:

Living where I have, and all the people I've talked to in my life and the things that I've read, whether it's a newspaper article or a magazine, and what we are doing here tonight is
influencing and I think not just about this, but about anything, I mean you are always prodded and influenced about the information you have.

The health care provider groups included similar areas as those identified by the consumer groups, but also mentioned their professional education and work experience as being important in developing the views they held about these issues. One person described it this way:

I guess working in ICU because we are all trained, physicians and nurses, especially in an ICU setting, but you work so hard to try and save that person's life and sometimes you get caught up into the technology and you are able to do it, and the patient is there with all the machines and the monitors and everything and all these fanged, dangled medications and you tend to sometimes lose sight of the patients and you have to learn to stop and say no.

A few individuals, in both the provider and consumer groups, were not sure how they developed the views they had, and indicated that they needed time to reflect on this as they had never thought about the idea before. Members of the media believed that the "newsstand" was a great influence on the development of the views of both health care providers and consumers. Interestingly, only one group (the university students [a group of philosophy students]) mentioned ethics education as having any influence on the development of their views. One student said, "As with everything,...just the bioethics, just all the things we've had and have been thinking about and talking about". A student colleague added:

I think a large part of what influences my opinions is not so much just an education, but the fact that I've been in university this amount of time means I've had exposure to most of these questions before, and have had time to think about them. So it's not just the fact that I have learned factual information, but that I've been given time to consider them, and to reflect, and to think about my own values in relation to them. So, I think that's really important, the idea of being exposed to issues and being given time to think about them, that's what your uncle on the farm lacks, not necessarily, it's not going to be something like intelligence or it's not even going to be, it's probably not even going to be education as such, and you know in terms of acquiring a body of knowledge, but it's going to be the opportunity to reflect.

The participants articulated a number of values that they thought were important as they discussed issues about resource allocation for organ transplantation. These included respect for life, respect for the preservation of quality of life, respect for self and others, personal choice, commitment to moral equality, mutual dependency and avoiding harming fellow citizens. These values were pivotal in helping to shape the views they held.
Having argued that the beliefs, attitudes, and values held by the stakeholder groups, influenced the general view they held about resource allocation for organ transplantation, I will now move on to describe how these perspectives were used as resources and operationalized by group members as they discussed and made decisions about some of the major ethical problems raised during the focus groups.

**Moral Reasoning Processes**

In this section, I describe the moral reasoning processes used by the participants as part of their discourse about the issues, concerns and problems that emerged during the focus group discussions. As part of this reasoning process, I provide details about how participants identified ethical problems, discussed alternatives to solve problems, and arrived at decisions about these problems. I further describe the ethical principles that were identified by the groups as they reasoned about the ethical issues, concerns and problems that were illuminated during the discussion. It should be noted that, although the case study outlined in Appendix 4 was used as stimulus material to engage the participants in discussion, other cases and situations were raised by the participants throughout the discussion, particularly those that they had been exposed to through the media.

Three moral reasoning processes emerged as I examined the discourse that occurred during the focus group discussions. The first was a deliberative reasoning process, the second, a process I labeled "examined emotion", and the third an "emotional" reasoning process. Each of the three moral reasoning processes used by participants included the following phases - recognizing and identifying a moral problem, determining a course of action from the alternative(s) examined, and arriving at a moral choice about the action required to resolve the moral problem. In the three approaches to moral reasoning, participants used these components to reach a decision. In the deliberative approach to reasoning, participants began by identifying a problem, discussed the alternatives, enunciating what they would do as they reflected on abstract principles, and the context of the situation. In the "examined emotion" approach to reasoning, participants initially reacted emotionally to a problem, but then moved into a more deliberative discussion of alternatives.
as they examined other points of view that were raised in the discussion, when they often recognized the need to think about the problem in more detail. In the case of the "emotional" process, participants made a decision quickly without exploring alternatives. The choices that participants made were often based on a variety of contextual features, as well as what they thought was the "just" thing to do.

In the "deliberative" reasoning approach, participants attempted to identify moral problems, then moved on to discuss the information they had available about the problems, or asked for further information to continue their deliberations. They deliberated upon the information carefully, and were often very introspective before making decisions about alternative courses of action and arriving at particular choices. This approach is illustrated by the following description by a nurse from a minor stakeholder group when considering the case study:

The thing that strikes me and I appreciate that probably many people in and outside of nursing are going to look at this, and the situations surrounding this man, his age his family status, the health that he's had previously, the potential for quality of life years to be lived, and I know those are all factors that we consider when we are making decisions around transplantation or any kind of really aggressive medical management or treatment. And I know that one of the things that would bias me towards supporting transplantation in this kind of a situation given that the person wanted it, and I wanted to pick up on what both of you said because that crossed my mind too - gee what does he want to happen and what does his family want? Leaving aside that, though and on the assumption that they're consenting to this fully, understanding it, one of the things that weighs in the balance of action for me is that this is somebody who potentially could gain from that kind of aggressive treatment, were he seventy-seven I know that my feelings would be somewhat different, and I hope it's not an ageism position as much as it's a realization that there is a trade off in terms of pain and suffering and quality that may weigh in the balance for somebody that has a young family but may not for somebody that does not. So I know that's part of what's going on with my response to this.

In another situation, a deliberative process of reasoning was exemplified when a nurse manager discussed age as a factor in transplant selection in this manner:

In thinking about this, I guess I would like information that would help me around the age business better. I do realize that someone who is fifty, [could be] physically or mentally going on ninety-five, and some ninety-five year olds are more like thirty. But there's part of me that says that I believe, though, that good surgical risk at seventy is not as good a surgical risk as seventeen, for example, and that will change the criteria and the way they measure things. So, I'd want to know proportionally, does the outcome of rejection change with increasing age, across the spectrum, not just because he's a sixty-seven year old. Then there is also part of me that says, I have this belief and values system from my
family, that says when you reach a certain age, you do the honorable thing. You walk out on the ice flow, or you walk out in the storm, and you stay there, and let the young have their opportunity, or their chance, and we do that in times of very scarce resources. That's been very much the typical way of certain populations within this country, and so, so much of what we believe about age and about responsibility to society is very difficult when we have competing resources and competing values and different cultures. There are many things to consider, it's not straight forward.

A moderate health care provider reasoned in a deliberative manner and said when discussing whether Peter should be transplanted:

I think it depends on each individual case, because ... I don't think you can put a number on just how much a person can use. You have to look at the whole situation. You have to look at the other people's sides that say, well, he's had his chances and now it's the turn for someone else who's never had a transplant to get a heart or whatever before this guy gets a next one, but you also need to consider all the different sides, the resources available and the needs....We need much more information to make these decisions.

In contrast, in the "examined emotion" reasoning process that was employed by some participants, the participants had an initial emotional reaction to an identified problem and made a choice about a course of action without examining the alternatives in detail. Then, as the participants began to listen to information disclosed by others, or to think more about the implications, they began to reflect more critically on their original choices and, in some cases, to modify them, based on the additional input. For example, when reflecting on whether society should permit xenografting to occur, one consumer said:

Like immediately when I looked at this, I know I didn't think there was so much of a problem, but you know, I have thought about it for a bit, heard what [co-participant] said and maybe this decision that we have to make in this time is going to affect us for the rest of our time, for as long as people will be here. And that is a big concern because [if] the people, those who were responsible a hundred years ago, had done things a little bit better maybe we also wouldn't be in that much of a mess that we are now. We certainly have been known for being very uncaring of our habitat and I would even be willing to say I don't have an opinion on this until I have a heck of a lot more [information] about it and I have more time to think about it.

A major stakeholder from a transplant organization used an examined emotion approach when considering liver transplantation for people who had developed liver disease as a result of alcohol abuse. He said:

I have to admit I had some strong feelings about alcoholics and transplantation, and said no way, but then some of the statistics that were presented, and these points of view were news to me. I wasn't aware that I carried some of my own stereotypes about this situation with me. I now certainly feel if you look at other parts of society, we're prepared to parole
people who committed violent crimes and, maybe, why can't we give people who indicate that they want to make a change in their lifestyle a second chance at life.

Another major health care provider appeared to use an examined emotion reasoning style when deliberating on strategies to increase organ donation:

Essentially, I had some vehement opinions about these ideas, but I now realize I haven't given a whole lot of thought to any one of these individual ideas. I had some ideas, but I haven't done a lot of research on any one of these initiatives to try and increase organ donation....My ideas have changed as I think about this now because I see it is multifactorial ....You know, [I think] I see it as a composite.

The final moral reasoning process that emerged from the data was that of an "emotional" approach to reasoning where participants made a decision about a particular question or problem, very quickly, almost spontaneously, before they had deliberated on the other alternatives available, even though they might recognize that there were other alternatives. Not only did they make up their minds almost immediately, but in some cases, the participants also disclosed that it was unlikely that they would change their minds even if more information was made available to them about other perspectives or alternatives. These statements, from one consumer when considering commercialization of organ donation, reflected a more emotional form of reasoning. She said:

I am rapidly, rapidly, rapidly against! And I, again, one of the things that the media world wide doesn't want to touch. It was touched on a little bit in the Globe and Mail in 1989, a tiny little article, but what they've been doing in the country of Honduras is enough information and we've been trying to get this through the actual information. Very rich people in cahoots with them, and the establishment actually have farms in which they pick up, like chicken farms, where they pick up children from the street and the children are then actually, some have been put up for adoption but the other ones sold and organs of children are taken for profit and there is a market mostly in Europe, Israel, some in the United States, very little in the United States because it is illegal but it is such a hot issue that people from my country that are outside, everybody is interested. We had somebody from back east who flew to Vancouver to interview us and all that and after a week he was really interested but he said I can't touch this with a ten foot pole. So excuse me, but I need to say this, if you have buying and selling I think that would be a degeneration within the social society....We humans have sold our lives before so excuse me you know they probably wouldn't have too hard a time selling their organs. But I mean we are only a hundred years ago we came out of the slave mentality. In my country it is written in the law but it's 80% of the population against 20% of the population and it's because of economics and need and lack of health care and all of that. So I would think that that would be a total catastrophe, mistake to go that way.

A social worker used a more emotional style of reasoning when she was challenging another member of the group about why she believed Peter should be transplanted and she said:
Hold on a minute! This may hit at it, ... we've already said we're committed to transplant and my sense is that we owe him his life ...it seems unfair to pull out, unethical to pull out....We can't do this.

A high school student used an emotional style of reasoning when she was considering the issue of buying and selling organs. She said:

I think when you say that it makes me feel sick. Thinking that people are buying and selling bodies, like it makes me want to throw up. Just because it sounds disgusting and how people can just be really cold. I don't agree at all.

During the course of the discussions, a few participants also talked about times when they knew they used emotional reasoning. For example, when discussing xenografting, a social worker talked about recognizing the difficulty of making some moral decisions. He said: "I can't even stretch my mind right now when you talk about it. It conjures up, well, my values just flair right up sort of thing." Other participants recognized their views were developed through "gut reactions." One consumer participant declared:

I mean it would be interesting to talk to the media because I think their power is quite over rated and I think that human beings actually make a lot of decisions, as [co-participant] just said, based on their gut reactions and while the media has something to say, I think a lot of our decisions are made from here [pointing to abdomen] whether it's about organ transplant or [whatever].

Each of the three moral reasoning processes were reflected in every focus group, through language that was most commonly understood in that group. For example, many of the health care providers, general consumers, university students, and all of the mixed consumer/health care provider groups used more sophisticated language, because of their professional socialization and education, than did some of the high school students, some consumers and health care providers with less education, when discussing the problems that emerged during the discussions. However, although the language used in some of the discourse was less "sophisticated" than in others, the moral reasoning processes were the same. For example, high school students discussed xenografting in this way, reflecting all three processes, deliberative, examined emotion and emotional forms of moral reasoning:
I'm just thinking about it. [In other situations] I try to look at the other person and see what they are doing. Say like in a classroom, if I don't think something is fair I'm not going to rush and say it. I'll sit back for a couple of days and see if its the teacher or one student and then another. And then I speak out.

It could, but I really don't know about the topic, right, and I have to be more educated about it, right, maybe it would change my decision, but as far as I know right now that's where I'm at.

I would not want a pig's organ. And plus, maybe it would be different if they died of natural causes and someone wanted their organs then fine, but you don't kill them. Like, if I found out that, then I'd, I mean I'd be really, really mad....

Another observation about the moral reasoning approaches was that the same individual, at different points during the discourse that occurred in the focus groups, might use any one of the three processes described. In other words, participants did not always use the same approach for every problem that they considered. There were, however, some groups who used a deliberative process more frequently than other groups. These groups included the university students, the ethics committee members, the transplant society board, a few of the health care provider groups (such as nurse consultants, nurse managers/CNS's, and the physician groups) as well as a few consumer groups (such as the group from Downtown Eastside Vancouver, and the media). This is not to say that others did not use this process, only that these groups used the process more frequently. In some of the groups, for instance, the Greater Vancouver consumer group, staff from a health charity, and a few nurse groups, an examined emotion or emotional approach seemed to be more prevalent, although once again, there were times when the group members used a deliberative approach as well.

The moral reasoning processes that a participant used appeared to be dependent on a number of factors, including the overall general views they held about specific issues related to resource allocation for organ transplantation. For instance, when participants had a strong belief in a certain area, or had a highly personal experience or connection with a topic, it was more difficult for them to reason about the problem using a deliberative approach. Their moral choice was quickly, and often, very emotionally, put forward. Hence, an individual might discuss one ethical problem, such as whether people over the age of 70 should receive heart transplants, in a deliberative manner, weighing different points, risks, benefits and perspectives. Yet, when
considering whether xenografting should be considered in the transplant realm to increase the numbers of organs available for transplantation, they might use an emotional reasoning process. In some cases, although the participants might quickly come to a moral choice quickly, based on the strength of a particular view they held, because of new information that came forth, indicating there might be something they had missed in their cursory deliberation, an examined emotional approach might be used where they evaluated the new information and, in some cases, changed their perspective.

Another factor that also influenced the moral reasoning processes used by participants appeared to be whether the participants were discussing what they thought an action should be for a stranger versus when they were discussing someone who was close to them. In other words, the context surrounding the situation, particularly the relationship the participant had with the person for whom transplantation was being discussed, was an important factor as to whether they discussed the problem using a deliberative, examined emotion, or emotional reasoning approach. For instance, when reasoning about whether Peter (the transplant recipient in the case study) should receive an organ transplant, participants might use a very deliberative approach, however, when thinking about the same question as it would apply to a family member, the decisions were almost always made in an emotional fashion with participants admitting that they had lost their objectivity, and regardless of the data available to them, they would always want to do as much as they could for their family member.

As one consumer said:

I think anybody that says that wouldn't be a factor, really doesn't understand.... And when we talk about how we would react if our mothers or fathers or someone close to us were put in this position, 95% would be, even 99% would be saying well gee, that's my Mother why shouldn't she have the right to a transplant to save her life as long as she can get it. And if she is eighty-three or eighty-four and she is in great health. So, if there would be some way that I knew was medically possible to extend that life I would want it done. It's not a practical it's an emotional decision. And that's what I'm saying how are these people that are on the boards are making these kinds of decisions when they don't understand.

Another participant, made these statements when thinking about transplantation:

And when are we going to be able to die? If we can do this then conceivably there is no end. Because you could just keep replacing parts and then there would be no natural death...As a parent though, I've got a three year old, and if he had a problem and needed a
heart transplant and if that would solve the problem as a parent I would say, gee you know, poor pig, but I'd go for it. For a seventy year old person who has lived a long healthy life, I wouldn't.

Having argued that there were three different moral processes used by participants as they reasoned about moral problems, I will now proceed to examine in more detail some of the similarities and differences among groups with respect to the ethical problems they identified, the alternatives they discussed, and the moral choices they made. Moreover, throughout the description, I will include an elucidation of the similar and different principles, and moral perspectives that were most apparent during these discussions.

Similarities and Differences in Identifying Moral Problems. In order for the groups to discuss their moral choices about a problem, they first had to identify what the problem was. Regardless of what reasoning approach they used, whether it was a deliberative, examined emotion or emotional approach, they had difficulty naming ethical problems when the case study was introduced to them. Even though they demonstrated moral sensitivity to ethical issues that emanated from the case by talking about concerns they could see when asked for their initial reactions to the case, they had great difficulty naming a specific problem when they were asked "what ethical problems do you see in this case study?"

For example, when asked about initial reactions to the case, in many consumer groups, someone immediately asked what the patient (Peter) would want to do in deciding about whether or not to be transplanted, indicating a great interest in patient choice or autonomy, and concern about informed consent. One consumer put it this way:

One of the things that came to me, it doesn't say what Peter K is thinking or feeling about all this. And I also know, like I mean in my situation I don't think, I think of life as very precious but for myself I think that is very important that he consider his life and therefore, and again I can only talk about choices for myself, I would like for example the medical profession and in my case my daughter as well who knows what I think, and what I like but I feel that I would not want to be tied into a machine and I've thought about this before, not just today. That the quality of my life is very important not just the life, so therefore I don't like the idea of seeing myself tied into machines or anything like that so my children know about that, my doctor knows about that and I would expect cooperation to respect my wishes. I mean when someone, in fact if I pull the plug, I would hope that my wishes would be respected that someone would pull it because and again I also realize that ethics for that force must be displayed collectively as a danger, but for me I would like that. Then the piece of information that I don't see here is what does Peter think about this?
A few of the focus groups of nurses, social workers, renal technicians and palliative care physicians were also interested in Peter's ability to exercise his choice in this area. These group members asked questions about, and discussed, Peter's future quality of life, who he was as a person, and his contribution to his family and community. Interestingly, most of the health care provider groups, particularly the major groups, responded to this request for initial reactions by requesting more information about the medical details of the case, and in some cases debating about whether or not Peter was a good surgical risk. The issue of choice was seldom ever raised by these major provider groups.

However, having raised some of these points and illuminated many issues, when asked to identify the ethical problems that were evident in the case, many of the groups, both consumer and provider, had difficulty articulating specific problems. A few groups focused on the tragic nature of the whole case, and the concerns they had about Peter and his family. They discussed the various features of the case that led one to consider whether Peter should or should not receive the kidney/heart transplant. They often began to talk about selection criteria, but they had great difficulty articulating a specific problem, without my providing suggestions. Upon my offering a suggestion, participants would often say, "yes that is a problem I see", but actually stating the problem out of the facts and context around the case (which they had often discussed extensively before the question) was very difficult for many people. This included health care provider and consumers participants from many of the focus groups.

There were a few individuals in several of the health care provider, consumer and mixed groups who were able to identify ethical problems in the case study. For instance, some of the same individuals, who more often used a deliberative style of reasoning, the university students, the ethics committee members, the transplant society board, a few of the health care provider groups, and a few consumer groups, appeared to identify ethical problems somewhat easier than did other groups. Those that were able to identify ethical problems talked about; 1) whether Peter should be eligible for a transplant, 2) whether he was entitled to a second organ, or 3) whether
resources used for transplantation should be used elsewhere. The issue about whether one person should be entitled to a re-transplant when organs were in such short supply, and others had not received a first organ, was raised frequently. In these cases, the principle of justice or fairness was often illustrated as participants reasoned about whether the organs might be better used by other people who had not had their first transplant.

One nurse suggested an ethical problem in this manner:

Well, one other ethical problem is the fact that he's getting a second heart and there's lots of other people out there waiting for their first one, and there's a lot of need as well. But this is a young person with dependents so there's so many other things to think about. Like how many organs is he going to go through before he has at least one work.

In a few of the major health care provider groups, some participants did not see any ethical problems in the case. They thought this case, and others like it, were very straightforward and that there was one alternative, that is, that Peter should receive his second transplant. When some suggestions were made about problems that could be part of the case, they acknowledged that these could be problems in other dissimilar cases, but in Peter's situation, as long as he was a good surgical risk, he should be transplanted. One of the nephrologists described it this way:

So what's the problem? Given that heart transplantation is an accepted treatment, kidney transplantation is an accepted treatment that we are [doing]. Hemodialysis is accepted, he's thirty-seven, he's married with two children, he's been working. I mean, you know, not that that comes into it. I mean here's a man who has a major role to play, and can continue to play a role even if he continues on dialysis. I don't see the problem. If it's acceptable to do a second heart transplant, I think, that's the one thing I don't know. But assuming that a second heart transplant, or I mean assuming that that's okay, I don't see any other... I mean I know the Cyclosporine and this and that and the other thing and the renal failure but we've seen people who've had heart transplants who then get renal failure from Cyclosporine and then they have a kidney transplant. So if the second heart transplant is technically feasible, assuming that, I don't know, I don't have a problem with it.

Similarities and Differences in Developing Possible Courses of Action and Making Moral Choices. In addition to differences in the ability to identify the problems emanating from the case, there were several different courses of action and subsequent choices proposed by the groups for the problems that were articulated. Participants acknowledged that their own views about organ transplantation generally influenced their decisions. Occasionally, there were major differences in
the perspectives articulated in the groups, usually related to how the participants interpreted what was the “just” action in the situation.

Most members of all the groups agreed that Peter should receive the transplant, although some people thought he should not be given any special status on the list, and should start dialysis before his transplant. A few participants thought that Peter should not be transplanted, as he had already received one organ and, therefore, had his chance; transplanting him would be denying others the chance of receiving their first organ. With the exception of a few individuals, all those who said Peter should not be transplanted changed their minds when asked what their choice would be if a family member were in the same situation. They admitted that in the case of a family member they would no longer be objective and would do anything to aid someone they love.

The one exception to this point of view came from some critical care nurses who were not convinced Peter should be transplanted, nor did they necessarily believe that they would change their minds if Peter K. was a family member. The critical care nurses were skeptical that someone who needed a second heart transplant, and a kidney transplant, was "a good surgical risk" as described in the case study. One nurse as she was discussing patients like Peter said:

So, give them a chance to prepare for a happy death because some people, like my folks, they would never want to be on life support. They would never want a transplant, you know they are about sixty-seven, sixty-eight and we've talked about it even with our teenagers and it's a pleasant way to end a life. That is an unpleasant death. I had my friend come through ICU and he died of cancer and all I wished for him was to be out of his pain and die somewhere, and he did and I was very happy about that. And there was nothing wrong with the ICU care but whole thing of intubation and the IVs, and he was on Levophed, and the drugs in his poor little body and I thought my God my friend, and he was almost eighty years old and I saw him die, and everything around him that was familiar was gone there wasn't anything. He'd be hooked up to all these things and be in pain and he looked like a monster and there's the poor little man. And then I saw him in the surgical step down and I saw him just before he died, smiling, happy anyways it was a good ending. He was happy within himself and that was good.

All the groups talked about developing selection criteria that allowed for the fair and just allocation of organs and realized that this would require complex allocation criteria. There were a few criteria that participants in all the groups agreed on, almost unanimously. For instance, ensuring that patients would care for the organ post transplant (although they recognized the
difficulty in actually being able to predict this), and ensuring that there was a medical need. Also, some groups focused on the need to give others, who had not been transplanted, the organs before Peter. In this regard, participants suggested a number of different ideas, such as having a second list for re-transplants, or only transplanting those needing a second transplant if the organ was not suitable for all others waiting for their first transplant. There was consensus that much more work needed to be done to construct criteria that were fair and just. For instance, one of the nephrologists said:

We have to step back and distinguish two things, and I hate to come back to that. We've got to realize that we're talking about, either our responsibility to this patient in which case there is absolutely no argument, and the patient goes ahead and gets whatever needs to be done. And also we have to step back and say, well listen we have another responsibility and that is to the responsibility to society and I know, as well as you, that there is a whole discussion centering on that. In other words, we are now stepping back and cast our heads towards our own personal responsibility to this patient and say how would we rationalize the situation. And to me, I think you guys are spending too much time on details and what is the survival rate and how young is young. Is a married person more, you know, deserving of a kidney and a heart than an unmarried person, you have two children. Does it make you more deserving if you have or if you have one or none? I think it really doesn't matter. I think the crux of the matter is somebody, somehow, and I suggest that eventually it will boil down to physicians, with the help of society, will have to come down with criteria that is acceptable to all. It is written, it is objective and is applicable to every situation, that's it. We go along with that. It may change from time to time, it may be ten years from now a second transplant does better than the first transplants in which case we'll transplant a heart deliberately and then take it out and put in another one. I mean it doesn't really matter, the crux of the matter is these criteria will change and I suggest that you know if we want to ration kidneys or hearts or what ever you have, so long as it's acceptable, it's objective, it's ethical in every situation, let's go by it. The question we have is really, how do we ration these kidneys and hearts? And I think that position cannot be made by a physician alone.

In addition to thinking about transplant options, palliative care was discussed as an option for Peter by some of the minor and moderate groups, when considering the pain and suffering that Peter had already experienced, and the possibility that he might choose to forgo transplantation at this point. This alternative was rarely introduced by the major health care provider groups, although a few transplant recipients did raise the option in one focus group, and two transplant organization board members who were health care providers said:

I think what is important in the whole discussion is how unable we are in our society, to deal with death. You know often, there was a time when we had end stage anything, that was it. You made your separations, you did whatever and people died. And I think certainly when I was younger lots of people died, but it wasn't a sort of death that people
hear now. It was just, you know, just your time and you tried to help people die comfortably and those things are much like palliative care now. You don't know what's going to happen with this....

I think we are obsessed with living and we've got to do it and constantly intervene. We can't let our bodies take it's course.

Furthermore, when considering various alternatives one critical care nurse spoke about the difficulty members of society have in talking about death by saying "but, then you have to think of the parents who are afraid to introduce death to their child, and then you get the pediatricians who fast forward the "Lion King" [movie] when the Dad dies because they don't want to deal with the death."

One of the areas that generated some of the "hottest" debate and considerable controversy in all the groups was discussion about social worth and merit criteria, particularly, the idea that some people should be excluded from the transplant waiting list if they had "caused" their problem by indulging in practices such as smoking and substance abuse. In particular, in some health care provider groups, there was a good deal of debate about whether lifestyle practices like alcohol consumption, drug abuse, and smoking should exclude potential recipients from the transplant waiting list. In some of these health care provider groups, there was a distinct focus on giving the organ to the person who would receive the most benefit, and who would also not abuse the organ post-transplant by engaging in what some participants considered high risk lifestyles. In many cases, when discussing the moral problems around this issue, participants used a very emotional reasoning process, reacting very quickly, with minimal reflection on the topic.

Many other participants, from health care provider and consumer focus groups, disagreed with this position and believed that social worth and merit criteria should not be part of transplant selection criteria. These participants considered individual circumstances, and context surrounding the case, as being very important and often took a more deliberative approach to reasoning around moral problems related to social worth and merit. For example, the members of the focus group from the Downtown Eastside in Vancouver raised the issue of how one's life circumstances impacted on lifestyle choices, and that no one should be penalized because of choices:
The thing is I wouldn't be surprised if it took three hours or four or five or six because this is such a, it goes deeper and deeper and deeper into ethics and in moralities and I see it so much and when [co-participant] was saying that about the man smoking, and the risk, and I tend to agree with you. Immediately my pragmatic self says yes, however, I could only think of my own situation and you know this many times I can only say what would happen for me and I give you another side of that. I happen to be a survivor of torture. Now the country that took me in and took care of me physically, I imagine that I cost them about a million and a half dollars. I think you know, plus surgery, you name it, okay and I'm well now, I'm mostly well. But imagine if in this country, they would have said well look they almost amputated my leg, they almost amputated my fingers you know instead of rebuilding them, imagine if they would have said, well, we are not going to take care of you because guess what? After we take care of her she's just going to go back into her country and go back to what and they are going to torture her again. Which by the way they didn't torture me again, but that is exactly what I did. As soon as I was better, I went back home, you know what I mean? So in reality was my choice any less of a choice than that man, and I think to smoke like that when you are sixty when people have told you, you should pay for it. You would say to hell with it, I did it, but at the same time we're teaching my choice is good but yours is not, you know what I mean? Either all human beings have a right to choose, or no human beings have a right to choose.

Some of the group members, in several focus groups, but particularly the members of the group from the Downtown Eastside, had emigrated recently from poorer countries, or had experienced living in poverty in Canada. They pointed out that the poor had fewer opportunities than the wealthy to receive adequate nutrition, health care, and societal support, thus leading to more health problems and more reliance on substance abuse as an escape from dismal lives with little opportunity. They also pointed out (as did a few transplant recipients themselves), that a "brush" with death, and a subsequent organ transplant, might result in participants making major lifestyle changes as they perceived being given a second chance at life.

The members of the transplant recipient groups were very concerned about social worth and merit criteria, such as making decisions about whether an individual should or should not receive a transplant based on a judgment by another person as to what constituted a "good" versus "bad" lifestyle, or based on the type of condition they had (for example, diabetes, cystic fibrosis) or their intellectual ability. In two cases, recipients, while they were still very ill, overheard health care providers discussing whether they were worthy of being transplanted, either because of previous lifestyle choices, or because of the nature of their end stage organ failure. Both recipients reported how powerless and worthless they felt in those circumstances. These recipients believed that the comments were made by persons who, generally, did not understand the suffering and
despair faced by people requiring an organ transplant. The recipients believed that, if more people knew what it was like to be sick, there would be more understanding and compassion for patients in those circumstances. One recipient describes an imagined experience and another recipient talks about her "real" experience in the following transcript excerpt from the discussion:

I remember being in ICU ...well I had many experiences because I was in there for three weeks, but one of my most terrifying ones is that I got to the point that I was concerned because of resource allocation, maybe I was over staying the amount that had been allocated for my survival, and that if I didn't get out of there that they would say well we can't afford this guy any more, let's get on with it.

Mine wasn't anything imagining, there was a man sitting outside my room telling my nurse that he didn't know why they even did a transplant because we don't do well, people with [her condition]. She didn't know I could hear her. She said I don't know why we give these people transplants because they don't do well anyway. People with [my condition] she was saying. The right people know about it, but I don't know if anything will be done.

One transplant recipient became very emotional when discussing a case she had heard about of a person being denied a transplant in another province because he had Down Syndrome. She said: "Well I have to ask. What the hell is the difference between someone who is mentally ill whether or not he gets a transplant and someone like me who has an underlying condition? Diabetes, you know?" Another group who worried about social worth and merit criteria were the parents of mentally handicapped individuals. One of the parents said:

For me, nobody should be off the list. In other words, if my son matches the organs that are available, he should have just as much chance as anybody else. There has to be some other criteria, and the criteria should not be related to any kind of disability, any kind of race, any kind of creed, any kind of color, any of those things, because you know we feel so strongly about that, that we have a Charter of Rights, but we are all citizens of equal opportunity, and that should be followed. It should be absolutely no question [our children] can be there and matched as much as myself.

When discussion about age criteria was introduced into the discourse and, for example, participants were asked if their choice about transplanting Peter would change if he was over 70 years of age, the perspectives within many of the groups were split. This topic was one where there were divided views, both between and among groups. Some said age would make a difference in their thinking, as they believed that older persons had already lived long lives and the
organ would be more useful to a younger person. However, others believed that all people should be treated equally, and that there should never be age-based rationing.

For example one major health care provider took this position:

I must admit I think the whole issue, is an interesting one, and I have kind of changed my perspective a little bit since I have worked for this organization, because I've seen so many older people transplanted who have done extremely well, and whereas if you put those people, if you say they are a renal patient, and you put them on dialysis and you just watch them deteriorate... I know that for example because their immune system is a little less active, they are less active to reject, so they tend to do very well, if they don't have a lot of complex medical problems with a transplant. And that's exactly what I've heard from some of the people of that age, is that you know, I have contributed to the health care system, I have done this that and the other thing, why don't I have a right to have a transplant.

More members of the consumer groups thought age should not be a factor in patient selection for transplantation than did the provider groups. Interestingly, however, all the participants over 70 years of age shared the belief that age should be a criterion and that younger people should be given preference. One participant from the consumer group of seniors said:

I think from another point of view is the amount of time we have still to keep going. If it is a question that we had so many organs - when you hit, say 70, if there was a question of a young person versus say me, then I would say use it for the young person. I have already lived my life. If you ask me, I would say give it to a younger person, but there are the people who think they will live forever and want to keep going, and unfortunately, choices have to be made. I'd say if there were enough then give it to everyone.

Most transplant recipients said age should not make a difference and should only be a criterion in as much as it helped to determine the overall health of the individual. They were very clear that age alone should never be used to determine who would receive an organ. However, one recipient believed that age might be a criteria for organ transplant selection:

Well, I was just going to say, I guess this is interesting because this is something I've thought about personally, in terms of when the time comes that I need another kidney, you know, and my age, and if, and I mean how would I feel about that. And I guess all other things being reasonably equal, that is the younger person has, looks after themselves I mean I think that is critical. I would say that that is the most important thing in transplantation. If somebody does not look after themselves, like this person, we don't know if he's a smoker or not a smoker or any of those certain things. But those I think are important. All other things being equal and if it had to be, I would say yes if the thirty-seven year old should get the heart before the sixty-five year old, no question about it.
In addition to the moral choices that needed to be made at the micro level of the health care system, participants discussed some of the choices that were required at the meso level of the health care system. Most participants who had positive views about transplantation thought the service should continue to be funded, and some participants talked about ways of accessing more resources, as they believed access to health care was important for all who needed it. On the other hand, those who had more ambivalent or negative views about transplantation wondered about the need to consider using funds in other areas. One nurse participant from a minor stakeholder group said:

It's the issue of allocating resources, and huge amounts of resources, for one individual versus what you could do with those resources for a whole population, and the value you get back for putting money into preventative programs for newborns at risk versus the value you'd get for pouring that same amount of dollars into one individual. And it's that bigger picture resource allocation stuff.

Others thought that rationing was a solution, if more funds continued to be required for transplantation, although how the rationing should occur was not an easy process for them to outline. In a few groups, there was discussion about the level of resources available in hospitals and the need to be fair to others who were being denied resources as a result of expensive transplants. The groups all struggled with how these decisions might be made, and, in many cases, talked about the need to know more about outcomes of certain procedures before they could make a good decision. They also articulated the difficulty of balancing community and individual needs. As one health care provider said:

Very interesting, because I will say I'll talk out of both sides of my mouth and I don't know what the key issue is in this one. I think probably I would agree that it's a who decides issue, but I will say on the one hand, I disagree with all the money going into solid organ transplant when look at the amount of really good things we could do in prevention programs. But when it comes down to me lying in the bed there, if I need a heart transplant or something, I want to have it and I want the resources to be there and people to support my personal wish that I get to decide, and that it hasn't been a bigger picture decision. So I don't know how, and that where I keep coming back to, I think it ought to be a bigger picture decision like [co-participant] says, and yet when it's me lying in the bed, to hell with the big picture. This is me here, and I want you to do what I need done to live, because I don't want to die.
When putting themselves in the place of members of the legislature, many groups discussed the idea that much more public discussion was needed before rationing should occur at the macro level of the health care system. Some participants said that they would rather see the government deficit increase, than someone in need not receive the transplant they required. Others were in support of the idea of limits being placed on care, but were skeptical of the involvement of government in this process. Moreover, there were concerns, on the part of some participants that the health care system was in jeopardy. More detail about these discussions will be featured in the next section of this chapter, where public and health care provider involvement in discussions in about resource allocation are described.

In summary, consumers and health care providers used a variety of moral reasoning processes to come to decisions about moral problems related to resource allocation for organ transplantation. The processes the participants used were affected by their positive, ambivalent or negative views about transplantation. The groups highlighted a number of values and principles that were important as they reasoned about these moral problems. Values that participants articulated as they discussed the issues about transplantation included respect for life, respect for the preservation of quality of life, respect for self and others, personal choice, commitment to moral equality, mutual dependency and avoiding harming fellow citizens. Principles such as trust, integrity, honesty and justice/fairness emerged as important when thinking about health care provision and transplant resource allocation, in particular. However, there were differences in how these principles were conceptualized by the group participants. In particular, there were major differences in how people described justice and fairness, with some group members operating from a more utilitarian perspective in some cases, where the greatest good for the greatest number was considered most important, while others used a more contextualized, egalitarian concept of justice, where the needs of the individual were considered paramount.

Having argued that the focus groups used a variety of reasoning processes as they deliberated on ethical issues, problems and concerns, and that there were some similarities, but also some differences among the groups, I will now turn to a description of the perspectives that
participants had about who should be involved in making decisions about the allocation of resources for transplantation at the macro, meso and micro levels of the health care system.

Public and Provider Involvement in Making Decisions about Resource Allocation for Solid Organ Transplantation

Many of the groups, other than the major provider and consumer groups, were unaware of the way in which transplant decisions were made in B.C. Most thought that meso and micro level decisions were made by transplant teams, either based on medical need, on a first come first served basis, or by random selection. When responding to a question about how they thought the decisions should be made, all groups discussed the idea of receiving input from a variety of people, and stressed the need to develop criteria that were fair and just. One of the major health care providers argued that it was important for people to be more aware of the process, currently in place, to better understand the process, and also the experiences, of those involved.

One transplant organisation staff member put it this way:

And speaking of being in your safe zone, you know your zone where you work, that I think for me being personally involved with the patients makes their selection criteria and personal decisions about it very difficult, and I hope people who don't really get to meet the patients or work with staff members learn an appreciation of just how difficult the issues are. And the ethical decisions when deciding who does get transplanted and who doesn't, and that when we sit here in our early morning meetings at seven a.m. deciding who goes on the list or not, it's not a flip discussion, and it's sometimes it's very heated, and everyone has their own personal opinions and it's a very difficult process.

Although most groups believed that decisions about transplantation should be made by a cross-section of people, this was one area where there was some difference in the views of a few of the health care provider groups and the consumer groups. Consumer groups, and several of the health care provider groups agreed that there should be wide public representation on macro level decision making bodies where resource allocation was to be discussed, however some major health care providers had difficulty understanding the consumer role at the micro and meso level of the system.
Transplant recipients themselves articulated a desire to be more involved at the meso level of the health care system, particularly in helping to design appropriate selection criteria for organ transplantation. They believed strongly there should be consumer representation at the level of transplant organization boards, and that at least one of these consumers should be a recipient of an organ transplant.

Several of the groups (seniors, students, parents of the mentally handicapped) made it very clear that their groups needed to be more involved in resource allocation decision making at the meso level to be able to articulate the needs of people similar to themselves. For instance, one parent of a mentally handicapped individual said she saw a role for parents who have handicapped children:

I guess if we're going to go to a process I think the one thing I would want to make sure is it's all done above board, that the decision is made, it's seen to be made at the basic ground at which it is declared. So you've got to have somebody that has got a broad enough shoulder to take on the responsibility.

Many other consumer groups also believed that it was important to have members of the public involved at the meso level of the health care system with the development of selection criteria, and at the micro level with the selection of individual recipients. The consumers suggested that these individuals should be members of the general public, transplant recipients or someone on the transplant waiting list. The consumer groups also highlighted that there should be a variety of health professionals, as well as ethicists, clergy and economists involved in making decisions about transplantation and resource allocation at all levels of the system.

Many participants in all groups stressed the need to ensure that the decision making process was made transparent, and saw public involvement in the process as one way to ensure that the process was open and fair. One of the nurses in a moderate health care provider group said:

One of the groups that I would like to see represented very much in the committees that might be making decisions about establishing criteria and perhaps even making decisions in some cases, is the potential consumers, whether families and people in the public. My sense is that very often we've decided behind the walls on the allocation of resources without input from the community. That's probably one of the reasons they don't understand what the issues are and haven't wrestled with them in a way we think they should have. And I think the time has long since passed when we, as health care providers,
can say we can do this without considering the input of the people that we are hoping to do
to.

All of the minor and moderate groups believed there was a need for more public
involvement at the meso and micro level. Most of the major health care provider groups supported
the idea that the public should be involved at all levels of decision making, however, nephrologists
and many members of the transplant organization staff groups, had difficulty determining how this
would be possible, and worried that it would be very difficult to have the public involved in
resource allocation decisions because of their lack of knowledge. Two major health care providers
suggested:

Two or three desperate points. One is that we have to be careful of asking society, to use
that very vague expression, to make these decisions because I think that you know look
recent newspaper articles and the level of discussion that those things are aimed for reminds
us of the great unwashed out there really doesn't know what the hell they are talking about
here.

They're a lot more washed than we'd like to believe and we do need to play an important
role in driving this process but it's significant others in society will also have involvement
and when it gets to that stage then we should be just as important as anyone else. And not
necessarily driving decisions from the social and weighing one decision against the other.

There was overall support from all groups for both consumer and health care provider
involvement at the macro level of the health care system. There was a high degree of agreement that
decisions about macro allocation of resources should not be left up to the government. There was
much skepticism and cynicism expressed about the involvement of government in these decisions,
and in many cases when the question was asked about who should be involved in the decision
making at the macro level, the immediate response was "not the government." Interestingly, this
response was also given by high school students, who, at the age of 16 and 17 years, had already
developed some mistrust about politicians.

Overall, the consumers approved of the idea of involving more members of the general
public in decision making and believed there needed to be more societal input into designing the
best health care system possible. However, their focus was more on being able to exercise their
voice versus always being in a role where they had to make choices. One consumer described
some of the concerns about the public being involved at both the macro and meso levels of the system like this:

So, in answer to your question on this, well most people would say well a doctor and physicians and specialists, and the buzz word now is have the average Joe or the layman on the board because you have to get that kind of input. It's kind of like having a school teacher as a Minister of Finance in the government doesn't make any sense. There are people who are qualified and it should be managed as well as possible. And I don't know if I would want to sit on a panel everyday that decided that the person that I'm judging based on criteria that is going to live or die because of how I decide, and the people making those decisions should be really knowing about the ramifications at least psychologically as well as considering the medical factors that are involved and have some indication that, well, I think that some history of where that person is coming from.

Usually, when asked the question about who might be involved in decision making, each health care provider group included their own professional group in their response. Most often, they also included all the other health care provider groups. In a few cases, the non-physician groups mentioned that, although they thought physicians should be involved, there needed to be some physicians included in meso and micro level decision making who were not involved in transplantation, because the non-physicians were worried about potential for conflict of interest if this did not occur. One of college students said:

"Well, that's why I think it's important that people aren't from the medical field. you know because you have to have some people to balance the interests for, you know, like what we were talking about earlier, about the desire to save people's lives and I mean I'm not even sure that people question a lot of that if they are really in the field because I guess that's the purpose of your business basically. So you have to have people who are not in that business at all.

Interestingly, the two groups of staff nurses in the major provider category mentioned the need to include health care providers from a variety of disciplines, but did not see a role for themselves. More discussion on this point revealed that these nurses believed that they were not in positions where their voices would influence change.

Members of the media saw a role for both consumers and health care providers in the resource allocation debate. They were divided on whether they had a personal role related to decision making in health care. They were ambivalent in their responses; on the one hand they could see they had a great deal to contribute, and appreciated the opportunity to be involved in the focus group discussion, however, there was concern that they might be in a conflict of interest
position if they were part of a committee making decisions. A few of the group members mentioned that they were discouraged from being involved in these type of activities by their editors or superiors. They did see, however, that they had an obligation to ensure that, through their reporting, they made certain that the voices of minority and disenfranchised groups were heard in the debate about resource allocation. In other words, they saw themselves as advocates for people who did not have a voice. Both the consumer and health care provider groups acknowledged the value of the media in the health care resource allocation debate, and stressed the need for honest reporting of the facts, as well as education by the media to ensure that the public were knowledgeable about the issues. One reporter said:

I've done several columns and stories that have been on transplantation. Sometimes in a very advocate kind of role, because I firmly believe that one of the roles of the press is to sometimes serve as a bit of a notice board that things are needed.

When discussing the issue of how to select people to be involved in the processes of decision making at the micro, meso, and macro level of the system all group participants called for a much more transparent process than had been available in the past. They wanted to have an opportunity to ensure that their voice or the voice of people similar to themselves were in the debate.

Summary

In this chapter, I have described the constructions of focus group members as they reasoned about ethical issues related to resource allocation for organ transplantation. Group members expressed their views about organ transplantation using three different patterns; viewing transplantation as "through a glass brightly" or positively; "through a glass translucently" or ambivalently; and "through a glass darkly" or negatively. These views were constructed from a synthesis of the values, beliefs and attitudes participants held about organ transplantation, and were dependent on a variety of factors, such as personal experience, culture, ethnicity, religion, family upbringing, relationships, the context in which people were working, and their overall actual experience with organ transplantation.
Three moral reasoning processes were used by the participants as they reasoned about ethical concerns related to resource allocation for organ transplantation. These processes included a "deliberative" process, an "examined emotion" process, and an "emotional" reasoning process. The three processes were used by all groups at different times during their discussions, regardless of group membership. The process used by the participants was dependent on the problem, and the context of the situation, that in turn was influenced by the specific views the participants held about organ transplantation.

Most groups supported the idea of opening up space at the meso and micro level for more consumer involvement, an area that has been traditionally dominated by health care providers. A few of the major provider groups appeared to have some difficulty with this idea, and had problems seeing where consumers might be involved. It was interesting to note that some staff nurses did not see a role for themselves in the resource allocation debate.

All of the stakeholder groups saw a role for themselves in the debate about allocation of resources for health care at the macro level of the system, but pointed out some of the difficulties in selection of those individuals.
CHAPTER FIVE
The Search for Common Moral Ground

In this chapter, my project is to discuss my interpretation of the constructions of the focus group participants, as described in Chapter 4, within the context of relevant empirical and theoretical literature. I begin the discussion with a focus on the moral reasoning processes used by the focus group participants. I then move to a discussion about the views that participants held about organ transplantation, comparing these constructions to perspectives from the empirical body of knowledge about views regarding organ transplantation. I proceed with a discussion of my interpretations of the constructions that participants put forward about public and health care provider involvement in decision making around resource allocation for solid organ transplantation, and conclude the chapter with a discussion about the use of focus groups as a method for data collection in ethics related research. Hence, what follows is my interpretation of the constructions of the focus group participants about resource allocation for organ transplantation, and I acknowledge that, in congruence with the constructivist method, this is but one possible interpretation of the constructions.

As a way of providing clarity to my interpretations, prior to beginning the discussion of the constructions that participants held about resource allocation for organ transplantation, it is important to define more clearly my use of the term moral reasoning, as within the literature moral reasoning is often used interchangeably with ethical reasoning, ethical decision making, and moral development (Ketefian, 1989, Omery 1989, Sherblom et al., 1993). In this study, I am using the term to describe the process that includes the recognition and identification of moral problems, the exploration of alternative courses of action, the selection of appropriate courses of action, and the evaluation of the action chosen. In other words, when I am speaking about moral reasoning, I am referring to the process individuals use to arrive at moral choices.
**Moral Reasoning Processes**

Within the focus group discussions, three moral reasoning processes emerged that appeared to epitomize the approaches used by the focus group members as they discussed ethical issues about resource allocation for organ transplantation. These processes consisted of a deliberative reasoning process, an "examined emotion" approach, as well as an "emotional" approach to moral reasoning. The three processes were evident in each of the 34 focus groups and the use of one process versus another was dependent on the moral problem being discussed, as well as the context in which the problem was embedded. The context for the discussions in the focus groups was influenced by the views the participants held about transplantation, specifically whether they viewed transplantation positively, as through a glass brightly; ambivalently, as through a glass translucently; or negatively, as through a glass darkly. In other words, what the participants saw in the moral situations received meaning against a horizon of values, beliefs and corresponding views, suggesting that at different horizons, from different points of view, the moral situations might appear differently (Yeo, 1994, p. 90).

Each of the three moral reasoning processes used by participants included the following phases - recognizing and identifying a moral problem, determining a course of action from the alternative(s) examined, and arriving at a moral choice about the action required to resolve the moral problem. In the three approaches to moral reasoning, participants used these components to reach a decision. In the deliberative approach to reasoning, participants began the discussion about alternatives, enunciating what they would do as they reflected on abstract principles, and the context of the situation. In the "examined emotion" approach to reasoning, participants initially reacted emotionally to a problem, but then moved into a more deliberative discussion of alternatives as they pondered on other points of view that were raised in the discussion, when they often recognized the need to think about the problem in more detail. In the case of the "emotional" process, participants made a decision quickly without exploring alternatives. The choices that
participants made were often based on a variety of contextual features, as well as what they thought was the "just" thing to do.

When discussing the moral issues and problems that surrounded topics such as establishing social worth and merit as criteria for organ transplantation, buying and selling organs, or xenografting, many participants departed from a deliberative style of reasoning to one that was much more emotional in nature. This was also true when discussing the making of choices for family members who might need an organ transplant. Many group participants used an emotional approach to reasoning when examining what they would do if their mother, father, and, particularly, their children, required a transplant in a variety of circumstances. In these cases, participants responded immediately with a choice before any deliberation of alternatives occurred. An emotional reasoning approach was used in those cases where the identified issues and problems had more personal meaning to the participant, and they had strong personal convictions either because of their own past experiences, or, in some instances, their consideration of the question, "what would I think about this if it were happening to me, or someone I cared about". For example, there were several "gut reactions" (a label used by participants) when the topic of buying and selling organs was raised during the group discussions, as some participants had personal experiences of this in other countries, or because they believed that this went against a core value they held about respect for persons. An emotional reasoning process was also apparent in some situations, when social worth and merit were being discussed as criteria for recipient selection for organ transplantation. In these cases, some participants, for instance, the parents of handicapped children, used an emotional approach when considering how criteria should be established indicating that those with mental disabilities should never be discriminated against - - a subject for which they felt passionately.

On the other hand, an "examined emotion" approach was used more often when the participants encountered a problem for which they had an immediate response or made an immediate choice. After hearing the discussion, and other points of view, they realized that although they might have an initial reaction that led them to a particular choice, they would have to
think more about this to formulate what they would consider the "right" choice. For instance, the "examined emotion" style of reasoning was used when participants were confronted with problems that emerged when discussing topics such as xenografting, and although they had an initial emotional reaction, agreeing or disagreeing with the position, they would often recognize that they needed to reflect much longer on the problems before they came to a moral choice with which they would be comfortable. In other words, after using an emotional approach to reasoning, they moved into a more deliberative style, consequently the "examined emotion" approach was a hybrid of the emotional and deliberative reasoning processes.

Many times a more deliberative approach to reasoning was used by individuals when they discussed situations where they did not have such a close personal attachment to the problem being considered, for instance, examining whether Peter should or should not be transplanted versus someone in their own family. In other circumstances, a deliberative approach to reasoning was used when some participants had considered the specific problem, or a similar problem in the past, prior to the discussion in the focus group, and had some knowledge of the different potential alternatives.

The three moral reasoning processes were evident in every focus group, regardless of whether the participants were health care providers, consumers or mixed groups of health care providers and consumers. An interesting observation was that the same individual, at different points during the discourse that occurred in the focus groups, might use any one of the three processes described. In other words, participants did not always use the same approach for every problem that they considered. There were, however, some groups who used a deliberative process more frequently than other groups. These groups included the university students, the ethics committee members, the transplant society board, a few of the health care provider groups (such as nurse consultants, nurse managers/CNS's, and the physician groups) as well as a few consumer groups (such as the general consumer groups from the Downtown Eastside in Vancouver, Vancouver, and the media). In these groups, although the reasoning processes employed were often more deliberative in nature, nevertheless, there were still many occasions when the
participants departed from a deliberative approach to reasoning and discussed moral problems using examined emotion and emotional processes. In some cases, the group members recognized that they were departing from a more logical, rational approach to reasoning and moving to a more emotional approach, and were able to articulate they were doing so. In other cases, this did not appear to be as obvious to group members. This is not to say that other focus groups did not use a deliberative approach to reasoning, only that the groups described above used the process more frequently. In contrast, in some of the groups, for instance, the Greater Vancouver consumer group, staff from a health charity, and a few nurse groups, an examined emotion or emotional approach seemed to be more prevalent, although once again, there were times when the group members used a more deliberative approach.

To discuss these points further, the moral reasoning processes that a participant used appeared to be dependent on a number of factors, including the overall general views they held about specific issues related to resource allocation for organ transplantation. For instance, when participants had a strong belief in a certain area, or had a highly personal experience or connection with a topic, it was far more difficult for them to reason about the problem using a deliberative approach. Their moral choice was made quickly without deliberation and examination of alternatives. Hence, an individual might discuss one ethical problem, such as whether people over the age of 70 should receive heart transplants, in a deliberative manner, weighing different points, risks, benefits and perspectives. Yet, when considering whether xenografting should be considered in the transplant domain to increase the numbers of organs available for transplantation, they might use an emotional reasoning process. In some cases, although the participants might come to a moral choice quickly based on the strength of a particular view they held, because of new information that came forth, indicating there might be something they had missed in their cursory deliberation, an examined emotional approach might be used where they evaluated the new information and, in some cases, changed their perspective.

Another factor that also influenced the moral reasoning processes used by participants appeared to be whether the participants were discussing what they thought an action should be for
a stranger compared to when they were discussing someone who was close to them. In other words, the context surrounding the situation, and in particular, the relationship the participant had with the person for whom transplantation was being discussed, was an important factor as to whether they discussed the problem using a deliberative, examined emotion, or emotional reasoning approach. For instance, when reasoning about whether Peter (the transplant recipient in the case study) should receive an organ transplant, participants might use a very deliberative approach. However, when thinking about the same question as it would apply to a family member, the decisions were almost always made in an emotional fashion with participants admitting that they had lost their objectivity, and regardless of the data available to them, they would always want to do as much as they could for their family member.

Integrating Moral Perspectives - Moral Reasoning in Context

Participants in this study appeared to reason from different moral orientations and used a variety of moral theories as they contemplated the problems and issues that emerged during the discussion. Although there were differences in the processes the groups used to arrive at a specific moral choice for certain problems, there did not appear to be distinct differences in moral reasoning among the different consumer, provider and the mixed consumer/provider groups. Furthermore, there were no major differences among health care provider groups and consumers in their moral orientation or the ethical theories applied in the discussions. All participants, regardless of gender or group membership, used both justice based and care oriented perspectives as they reasoned about the ethical problems that emerged from their discussions about resource allocation for organ transplantation.

In the past, many empirical studies related to moral reasoning and moral development have suggested that men and women reasoned in different ways, with men reasoning from a more justice based perspective, whereas women reasoned from a more contextual, relational, or care oriented approach (Bebeau & Brabecck, 1989; Gilligan, 1982/1993; Kohlberg, 1978;1984, Noddings, 1984). More recently, there have been suggestions within the theoretical literature, and some empirical investigation, to support the idea that this may not be the case, that the processes
may not be mutually exclusive (Gillon, 1992; Milette, 1993; 1994), and that both perspectives may be integrated with one another (Sherblom, Shipps, & Sherblom, 1994).

For instance, Flanagan (1991), after a thoughtful and comprehensive review of both the theoretical and empirical literature, does not support the argument that there are distinctly different forms of reasoning used solely by either women or men. When discussing justice and care perspectives, Flanagan suggests that, in fact, most individuals use both perspectives, with the choice of orientation being dependent to some extent on the problem posed. He claims that there is no logical reason why considerations of both care and justice cannot be introduced, where relevant, into one and the same reasoning episode. Furthermore, he argues that moral personality is more variegated and heterogeneous than has been typically considered, heralding this as a liberating idea. Baier (1987) suggests that the best moral theory must be a cooperative product of women and men, where justice and care are harmonized (p. 56). Tronto (1994) supports this position arguing that there is a false dichotomy between justice and care that has grown out of using old moral boundaries as a starting point when describing life. She further explicates that any theory of care is incomplete unless it is embedded in a theory of justice, and correspondingly, justice without a theory of care is also incomplete (p. 166-167). Tronto claims that only in a just, pluralistic, democratic society can care flourish.

In addition to claims that men and women use different theoretical underpinnings as they reason about ethical issues related to organ transplantation, there have been suggestions in the literature that some health care providers, for example nurses and physicians, reason using different perspectives with quite different philosophical stances, where nurses place the highest value on a "caring perspective," involving responsiveness and sensitivity to the patient's wishes, whereas, physicians value patients' rights and the scientific approach (Grundstein-Amado, 1990; 1992). These findings are inconsistent with the constructions as they have been interpreted in this work, since caring and justice orientations were evident in the perspectives of both nurses and physicians, as well as the other consumer and health care provider stakeholder groups as they reasoned about ethical problems. Although, no studies were found that examined reasoning among
the diversity of stakeholder groups in this inquiry, there were two recent studies located that examined the reasoning ability of physicians and nurses and their use of ethical theory to solve moral problems.

A study by Holm, Gjersoe, Grode, Hartling, Ibsen, & Marcussen (1996) designed to examine ethical reasoning of nurses and physicians, supported the idea that men and women reason using both a justice and care based perspective and that there were no differences among groups in their use of these perspectives. The investigators conducted seven mixed focus groups of nurses and physicians, who deliberated on case studies during the discussions. The data were analyzed using content analysis, and the investigators concluded that physicians and nurses did not differ in the kind of ethical reasoning they used, and that both groups used care and justice based perspectives as they considered ethical problems. However, according to the investigators, physicians used more of the discussion time than nurses in the focus groups, and they used a more assertive style of argumentation. In addition, the solutions chosen in the focus groups usually were put forward first by physicians, rather than by the nurses. When they examined the reasoning processes used by the nurses and physicians, Holm et al. found that both groups considered the building and maintaining of relationships with patients as important, and were concerned about their professional responsibility to patients.

On the other hand, the findings of a recent ethnographic study by Robertson (1996) indicated that there were differences in the use of ethical theory by nurses and physicians in everyday patient care, a finding contrary to my interpretation of what occurred in this current study. Robertson studied 20 nurses and physicians, over 10 weeks and 21 shifts on a British geriatric psychiatric ward. He found that there were differences between doctors and nurses in their conceptions of the principle of beneficence and respect for patient autonomy. For example, nurses shared with doctors a commitment to liberal and moral conceptions of these principles, but also placed much greater weight on relationships and character virtues when expressing the same principles. Where doctors were more likely to advocate beneficence, nurses emphasized autonomy when the two principles conflicted. Robertson (1990) concluded that ethical theory can be relevant
to everyday health care, with two provisos, namely, that the theory must attend to social context, and also be flexible enough to draw on various schools of theory.

In the current study, reasoning from both care-based and justice oriented perspectives was part of the reasoning processes used by all focus groups, and depended very much on the problem that was being discussed, and the context of the discussion, particularly the views the individuals held about organ transplantation. As I was unable to locate any studies that have compared the reasoning processes of other professional groups (other than doctor and nurses), it is not known whether these constructions would be evident in other empirical work. However, the move away from considering one moral orientation to a more integrated approach is consistent with the general direction of the new theory being developed in this area.

In addition to reasoning from both a care based and justice based perspective, the participants also applied their identified principles and values using a variety of different theoretical perspectives. For example, justice was an important principle articulated at some point in the discussion by all focus groups, sometimes by using terms like fairness. Two predominant theories of justice appeared to be used by group members. The first was an egalitarian form of justice, where need and equality were considered paramount (Buchanan, 1991; Nielson, 1990). In other situations, when new contextual information was added (such as a change in Peter's age) often a more utilitarian form of justice was applied. These theoretical shifts were most apparent when the participants were discussing what they would consider to be fair or just regarding selection criteria for organ transplantation. There did not appear to be a dominant theory of justice that was supported either within or among groups when discussing selection criteria, rather individuals appeared to reason from a patient-centered, egalitarian theoretical perspective in most circumstances, focusing on Peter's need for a transplant. In other situations, particularly when dealing with the potential for scarce resources, or age-based rationing, the participants focused more on a utilitarian justice approach as they discussed maximizing the greatest good for the greatest number of persons (Buchanan, 1989; 1991). In other words, although participants often
articulated similar values\(^6\) (such as: respect for life, respect for the preservation of quality of life, respect for self and other persons, personal choice, commitment to moral equality, mutual dependency, avoiding harming fellow citizens) and similar principles such as: trust, integrity, honesty and justice/fairness), the way they interpreted and applied these values and principles during their reasoning about a problem was often quite different. Yeo (1996) describes a similar use of values and principles and suggests that people may have some agreement about a moral ideal, however there may be variation in how that ideal is applied.

Another example where people applied values and principles in different ways, was when they were considering whether a person's lifestyle should be taken into account in the selection of recipients for transplantation. In this discussion, the articulated values of personal choice and justice were interpreted and applied differently, as participants reasoned about what selection criteria should be developed. To a certain extent, the way people conceptualized personal choice was dependent on whether individual behaviors of potential transplant recipients were seen as being voluntary lifestyle choices or the result of social and environmental factors (Kluge, 1992; Starzomski, 1995; Veatch, 1991c). For example, in some situations a number of the nurses in the critical care nurses group, who viewed organ transplantation as through a glass darkly, maintained that people who chose to smoke, should not be considered for heart, heart-lung or lung transplants, as they were responsible for causing their problems. On the other hand, members of the focus groups from areas of the city where people had low incomes also valued personal choice, but did not see choice applying in this context in the same way, as they believed that socio-cultural circumstances were the determinants of these "so-called" choices, and, therefore, participants who had the misfortune to be born into a certain socio-economic class, and at higher risk to begin smoking, for example, should have access to transplantation. These participants believed that

\(^6\) Interestingly, these values were similar to those articulated during the recent National Health Forum. During the Forum, Canadians shared values about equality [or fairness], quality, compassion, collective responsibility, personal responsibility, efficiency and effectiveness, dignity and respect, collective support, and connectedness.
people should not be penalized for the circumstances in which they found themselves without choice, and over which they had little control.

These different conceptions of choice are discussed by Veatch, who proposed various conceptual approaches to the issue of "voluntariness" and described several models for examining whether or not health risks are voluntary. They include the voluntary model -- where individuals assume full personal responsibility for their health; the medical model -- where organic causal chains, almost totally outside human control, account for disease; the psychological model -- where it is suggested that the individual's personality and initial patterns of health behavior are developed at such an early point in life that they can be viewed as beyond voluntary control, and the social structural model -- where disease is correlated with social factors such as socio-economic class. Veatch (1991c) proposes that the most plausible competition to the voluntary model comes, not from a theory of organic or even psychological determinism, but from the social structural model. He points out that continuing to advocate the voluntary model of personal responsibility for health risk, in the face of a social structural model of the patterns of health and disease, could be nothing more than "blaming the victim". The broader determinants of health such as socio-economic class and poverty, all impact on how easily people are able to make choices about their health. The knowledge that some socially deprived persons have "pulled themselves up by their bootstraps" is cited as evidence for the voluntary model, but the power of the social system to hold most people in their social place cannot be ignored (Veatch, 1991c, p. 202). To account for these variations, Veatch proposes a multi-causal model where there is a place for organic, psychological and social theories of causation as well as voluntary elements. Furthermore, he raises concerns about the possibility that a theory of causation that includes only a voluntary element, may distract society from attention to the other social and economic components associated with health risks.

To illustrate further the different interpretation and application of values and principles, many participants in all the groups used an egalitarian conceptualization of justice when discussing whether Peter should have a transplant. They focused on the need Peter had for a transplant, asking for more information about who Peter was as a person, what his choices would be, what
his family relationships were like, indicating some connection to a more egalitarian application of the principle of justice as they thought about their choices for Peter. On the other hand, when the context of the moral problem changed to include whether Peter was entitled to a retransplant if he was over 70 years of age, many participants used a more utilitarian conceptualization of justice, attempting to obtain the greatest good for the greatest number, and indicated that in the case of Peter, as well as of other elderly persons, they would not support the idea of a transplant because the organ might benefit a younger person more. In addition to illustrating the different manner in which the principle of justice was conceptualized, this example also portrays integration and movement back and forth, in the same reasoning episode, of both a justice based form of reasoning and a more contextual approach. The manner in which participants applied this theory was not dependent on professional group membership or gender, as all participants used the different approaches.

To illustrate further the integration of different theoretical perspectives by participants during the focus group sessions, in the discussion of selection criteria, some participants, who took a very utilitarian approach to age based rationing changed their perspective to a more egalitarian perspective when talking about other criteria, such as whether mental ability should be considered as a criteria for organ transplantation. In these cases, they argued, no one should be denied access to transplantation as a result of mental ability, indicating again that context influenced the type of theoretical perspectives about justice that were employed as participants reasoned about the problems related to resource allocation for organ transplantation.

Having argued that gender and professional group membership were not factors in the moral orientation or theoretical perspectives participants used in this study as they reasoned about resource allocation in organ transplantation, I wish to turn to a brief discussion of whether education was a factor that influenced moral reasoning. It has been reported in the literature as a potential determinant of moral reasoning ability (Cox, 1985; Crisham, 1981; Felton & Parsons, 1987; Kellmer, 1984, Ketefian, 1981a; 1981b). In many of the focus groups in this study, the participants had a university education, having obtained a baccalaureate, and in many cases, a
master's or medical degree. However, there were many participants with less than a high school education who arrived at the same choices as the more highly educated individuals, using similar reasoning styles. For example, some of the participants with the least amount of formal education were the participants from the Downtown Eastside of Vancouver, and the high school students. Yet, these groups identified moral problems in the case, deliberated on them, and made many of the same choices as the other groups who had more formal education. Therefore, education did not appear to be linked directly with the ability of participants to successfully arrive at what they considered the "right" moral choice. This is an area that requires further study, as there is considerable controversy in the literature about the impact of education on reasoning ability and developing moral expertise (Gaa & Ponemom, 1993; Rest, 1986), with some investigators suggesting that higher education might have a positive effect on moral reasoning (Kellmer, 1984), and others suggesting there are neutral or inconsistent relationships (Cox, 1985; Crisham, 1981).

Although reasoning processes and moral choices in all groups were similar, what did differ among the focus groups was their ability to express their ideas and thoughts verbally. There was a difference in the language used in the focus groups, with persons in the groups who had more education, using more sophisticated language. For example, in the groups where participants had more advanced education, they used terms such as justice and autonomy during their discussions rather than terms like fairness, or letting people have their choice, that were used by others. Nonetheless, regardless of the sophistication of the language used during the discussions, the processes were the same for all groups and they identified similar problems, alternatives, and choices, thus, indicating that participants may have some expertise at dealing with ethical issues, regardless of their ability to verbalize those perspectives in a sophisticated manner.

Identifying Moral Problems. One area in which many participants appeared to have difficulty was in identifying moral problems. A concern in this regard has been reported when moral reasoning of students has been studied (Holly, 1986; Keller, 1985). For example, in some
studies it was reported that nursing students had difficulty identifying ethical problems and dilemmas as they examined hypothetical case examinations. Although focus group members exhibited moral sensitivity⁸ (Rest, 1986) to the issues and problems that were evident in the case study when giving initial reactions to the case and asking for more information and clarification about the information provided, generally they had difficulty identifying moral problems. In some cases, individuals who had more experience reflecting on ethical problems, such as the ethics committee members and university students, were able to identify problems more easily.

In many situations, participants reflected on the problems in a more narrative manner moving back and forth between different ideas. For example, by talking about analogous experiences in their lives, they identified what they saw as important in the case and why. Thinking about ethical problems in a sequential, logical manner was not part of the reasoning process of many groups, except perhaps for those who had some distinct educational experiences learning about logic and building a rational argument. However, for most people, the problem was embedded in the context of the case in such a way that distinct problem identification was not always clear. Benner, Tanner and Chelsea (1996) describe similar experiences when examining how nurses think about moral problems in their work place. Nurses, in particular those who Benner et al. call "experts," articulated moral problems and moral choices in a more contextualized,

⁷ Personal electronic mail communication with Dr. James Gaa at the University of Alberta (February, 1997) about this observation resulted in the interesting postulation that although there is little work in this area, my results invite the speculation that "ordinary" people naturally think in ways that trained people (e.g., in philosophy) don't think. Gaa suggested that the standard method of teaching cases in business school is that the instructor has decided in advance what the case is about, and how the discussion will proceed. It is his/her job, then, to steer or manipulate the discussion in the desired direction, so that the students will learn the appropriate lesson. He suggested that some university programs are quite explicit about working this way. There is a possibility that proceeding in such a way may have undesirable outcomes in the case of discussions of ethical issues, (depending on how the discussions are conducted). For example, this method could run the risk of leading to some form of indoctrination, if universities are consciously attempting to train students how to think like business people, or lawyers, etc. Gaa raised the interesting questions: "Do we/should we teach people to think like "ethical" people; what would that be like? What about nurses, doctors, IRBs, clinical ethics committees? Do we teach them how to think, or do they already know how to think?

⁸ Rest identifies moral sensitivity as the first component of moral reasoning, and defines moral sensitivity as an interpretation of a situation as a moral one.
narrative fashion, where meaning was part of the narrative. In this study, interpreting moral problems and arriving at moral choices were embedded in the context of the case and perhaps, because people do not find ethics problems labeled as such in everyday life, participants in this study required more time to think about the problems, identifying them in a narrative manner versus the more direct way that is encouraged with the use of some ethical decision-making frameworks. This is not to say that individuals ought not to identify problems, but that the process to do so may not be linear and explicit, and may require more opportunity for discussion and understanding of the context in which the problem is embedded.

In addition to some differences in the ability for all groups to identify moral problems, there were some specific differences among health care providers in the type of moral problems and issues that they saw in the transplant realm, in part dependent on their view of transplantation. For example, many of the major health care providers had difficulty seeing any moral problems in the case, whereas some critical care nurses saw many more problems than many of the other groups.

With the exception of the social workers in the major health care provider group, and a few individuals in the other groups, participants rarely asked what the patient would want in the situation. They examined the facts related to the case, and focused on what they saw as fact, for example, that Peter was a good surgical risk. They then readily assumed that since he had already begun treatment and had no surgical risks that he would be a good candidate for an organ transplant.

On the one hand, this may suggest that major health care providers do not lack moral sensitivity; rather they may not see problems because they examine the whole case, comparing it to similar analogous situations, reason more introspectively, quickly and intuitively about the potential benefits and risks and more quickly determine a course of action. For instance, Benner et al. (1996) discuss a process that occurs when individuals who have considerable expertise in an area, have difficulty describing why they arrive at a particular decision, because they use intuition and assimilation of previous experiences to derive the right course of action in a given situation. Moreover, individuals have difficulty articulating why and how they arrive at their decision in a
way that would lay out the process for examination, a phenomenon that may make elements in the moral reasoning of some health care providers less evident.

On the other hand, the difficulty identifying ethical problems may suggest that major health care providers, who are closely involved in the transplant process, have trouble focusing objectively on what the patient wants before making the assumption that transplantation might be the only option. It may be that the major health care participants could not see problems in the case because they held such emphatically positive views of transplantation and were so closely involved in "real" situations with real people whom they knew before, during and after transplantation. More than any of the other groups, because of this commitment to transplantation, they may have had difficulty distancing themselves from this context,

Sociologists Fox and Swazey (1992a; 1992b) discuss similar perspectives that they observed over time as they conducted ethnographic studies in the transplant field. They raised serious concerns about transplantation and what they considered the "overzealous" way in which transplantation sometimes was applied. Fox and Swazey left their research in the transplant field as a result of what they called "participant-observer burnout", because of their concern that those involved in the transplant field had lost some of their objectivity and were applying the treatment in some cases because "it was available."

The concern about the "technological imperative" or applying a treatment because "we know we can," was also voiced by some participants in this study (particularly some critical care nurses) who expressed similar concerns to those of Fox and Swazey. These groups saw the other side of transplantation, as they saw the "technological imperative" in action, given their experience of caring for patients during the most acute and critical part of their illness trajectory. In many cases, these nurses did not have the same experiences as the major health care providers of seeing the transplant recipients after their critical care experience when many had improved considerably due to the fact that, as soon as the recipients were extubated and able to interact with the nurses and their environment, they were moved to another ward. Therefore, as compared to the major health
care providers who may have had an unbalanced view of transplantation toward the positive side, the nurses may have had an unbalanced view of transplantation toward the negative side.

In their study of nurses and physicians in a neonatal intensive care unit and the parents of the children in the neonatal unit, Lee et al (1991) reported that there were major attitudinal differences among parents and health care professionals about the outcomes of babies treated in the neonatal unit, with health professionals making more dismal assessments of the quality of life of the children. This observation led the investigators to propose that nurses who have more contact with the babies in an ICU setting, and who do not see the babies when they leave the ICU and are well, may have more negative attitudes about the prognosis of these infants. The investigators concluded that there was a need for more education of health care professionals about neonatal outcomes, and a greater recognition of the wishes of parents. Similar findings were reported by Molzahn (1989) who found that nurses, physicians and dialysis patients had different perspectives about the quality of life of the patients, with physicians ranking the quality of life higher than patients, and nurses ranking the quality of life lower. Molzahn speculated that this may have been a result of the amount of time nurses spent with patients in the dialysis unit and the fact that they did not see them doing well in their home environment. Transplant recipients themselves indicated that they had concerns about the way in which some health care providers discussed the patients cases in a negative manner. They reported overhearing conversations while in critical care units that indicated to them that staff (not only nurses) rated their quality of life as quite low.

In this study, some nurses in critical care units reported concerns about the organizational context in which they worked, and the moral distress they experienced being "in between" the patients and families and the decision makers. They described a lack of trust between themselves and some members of the transplant teams and worried that selection criteria might not be applied appropriately. Because of this lack of trust, the little information they had about the selection process, and given their limited role in the development of the criteria or the selection process itself, these critical care nurses did not believe the process for decision making about organ transplantation was an open or transparent one. Several investigators claimed that, in pediatric
settings, when caring for both dying children and babies in neonatal units, there is a beneficial outcome in terms of better decision making and the development of a more trusting relationship as decision making becomes more transparent (Clarke et al, 1992; King, 1992), a concept that may be helpful in other areas such as critical care.

In summary, three moral reasoning processes were used by the consumer and health care provider focus group participants as they reasoned about ethical concerns related to resource allocation for organ transplantation. These processes included a deliberative process, an examined emotion process, and an emotional reasoning process. The three processes were used by all groups at different times during their discussions and the process used was dependent on the problem, and the context of the situation, which in turn was influenced by the views the participants held about organ transplantation. Participants used an integrated approach of justice and care based perspectives as they reasoned about the problems that emerged during the discussions. There were differences in how the participants applied the values and principles they identified during the focus group discussion. In particular, different theoretical perspectives about justice were used by the participants depending on the problem being discussed. Moral reasoning ability did not appear to be associated with education, gender or membership in a particular group, and there were similarities in the choices made about moral problems among all the groups. Focus group participants had difficulty identifying ethical problems in the case study under discussion, and there were some differences in the problems that were identified by specific groups.

Having examined the moral reasoning processes used by the consumer and health care provider groups, I will now move on to a discussion of the views participants held about transplantation that affected their moral reasoning.

Views about Organ Transplantation

The views the participants held about organ transplantation provided the background context for the moral reasoning processes and furnished the lens through which individuals interpreted those problems. The three views held by the focus group participants, as described in
this study, included viewing transplantation as through a glass brightly or positively, through a
glass translucently or ambivalently, and through a glass darkly or negatively. These views were
constructed from a synthesis of the values, beliefs and attitudes participants held about organ
transplantation, and were dependent on a variety of factors, such as personal experience, culture,
etnicity, religion, family upbringing, relationships, the context in which people were working,
and their overall actual experience with organ transplantation. Although the distinction among
views constructed in this current research has not been reported before in the empirical literature in
the same manner, there are various components that make up the views of participants that have
been studied. To begin, I will discuss the different perspectives of the focus group participants
about organ donation, and then move on to discuss their views about strategies to increase organ
donation such as presumed consent, buying and selling organs and xenografting.

Organ Donation

Consumer Views about Organ Donation. The views the participants held in this study about
organ donation were similar to the views reported by other investigators as part of attitudinal/
knowledge surveys about organ donation, the largest body of research in the area of resource
allocation for transplantation. Overall, there was major consumer support for the idea of organ
donation in this current inquiry, with most participants from all the focus groups believing that
organ donation was an altruistic act that would help others in need. In this study, 93% of
consumers indicated their desire to be organ donors (see Appendix 12). This number was higher
than that reported in consumer surveys of the public in Canada and the U.S. where reports have
indicated that between 40.6% (Filthaut, Li & Wright, 1991) to 85% (Gallup Organization, 1993)
of those members of the public surveyed would donate their organs. In a 1995 Angus Reid poll,
77% of adult Canadians indicated their willingness to be organ donors, while in a 1995 MarkTrend
Research study of adult British Columbians, 65% of those surveyed reported taking some action to
express their wishes about being an organ donor, by adding a sticker to their health care card, by
indicating their intention on their driver's license, or by talking to their family. Similar to the
perspectives of consumer participants in this study, the main motivation expressed by those who said they were organ donors in the MarkTrend poll was to help others.

The larger number of persons who were organ donors in this study, as compared to other reports, may be reflective of the fact that some participants who agreed to be part of the study may have done so because they had a major positive interest in organ transplantation and were, therefore, more likely to be organ donors. Those who were organ donors indicated strongly that they had great concerns about their wishes being overridden by their family at the time when they were declared brain dead, and stated that this was an area where public policy may be "out of step" with the wishes of the public. These consumer participants called for a change in public policy where their choice to be an organ donor would be respected, just as their will or an advance directive would be upon their death. This particular vehement perspective has not been noted in previous Canadian research, with this current inquiry indicating a shift in the views of some members of the public about this issue.

A small number of consumer participants in this study, who viewed transplantation either ambivalently or negatively, declared they were not organ donors, stating that they had not thought about this idea before, or that they had some religious or cultural concerns about organ donation. These perspectives were similar to reports in other studies and congruent with the results of a 1995 MarkTrend Research survey, where the largest number of British Columbians who were not organ donors said they had either not got around to it (29%), were unsure about their feelings (7%) or were not donors because of religious barriers (3%).

In this study, most persons who were not organ donors indicated that this was because of cultural beliefs, an area that has only recently begun to be explored in more depth in studies in other countries (Chan, 1990; Wheeler & Cheung, 1996; Wheeler, O'Friel & Cheung, 1994). Cultural beliefs about the body remaining intact in a natural state, and beliefs that in the afterlife all body parts would be needed, were expressed by some who said they were non-donors. These observations have been made by other researchers (Chan, 1990; Wheeler, O'Friel & Cheung, 1994), and are consistent with work by Prottas (1994) who concluded that, whereas geographical
location, age, and gender contributed remarkably little to attitudes about donation, ethnicity and culture had a significant influence. The views of the participants in this study indicate the need to explore these questions in different ethno-cultural groups in Canadian society.

Health Care Provider Views about Organ Donation. Most health care providers in this study reported they were donors (74%), with the large majority of those who were non-donors coming from the focus groups of critical care nurses employed in a transplant hospital (see Appendix 11). Although there have been no studies reported about organ donation with the same professional mix of health care providers as included in this inquiry, studies have been conducted that examined the willingness of nurses and physicians to be organ donors.

In a recent study by Molzahn (1996a), that examined knowledge and attitudes of physicians and nurses regarding organ donation, 77.5% of nurses and 82.1% of physicians expressed willingness to donate their organs after death; however, only 60.9% of nurses and 63% of physicians had actually signed an organ donor card. Of the 147 critical care nurses who responded in Molzahn's study, over 92% supported organ donation in principal; however only 65.3% had completed an organ donor card. Furthermore, Molzahn indicated that attitude was an important predictor of whether an individual was an organ donor - - a similar finding in this study, where the overall views individuals had about transplantation influenced their decision to become organ donors.

As all nurses, but especially critical care nurses, play a vital and unique role in organ procurement, are often the gatekeepers (Durand, Davis, Marymont, Reyes, & Nelson, 1993) and are involved throughout the entire process of organ donor identification, maintenance, and procurement, their views are particularly important to understand (Adams, Just, DeYoung, & Tommler, 1993; Stark, Reiley, Osiecki, & Cook, 1984). In this study, most nurses held positive views about organ donation. However, there were some who viewed organ donation negatively. In particular, these negative views were noted in some critical care nurses.

The negative attitudes reported in this study by some critical care nurses is inconsistent with other research in this area, where investigators have reported that nurses who worked in critical
care areas had more positive attitudes toward organ donation than did other groups (Bidigare & Oermann, 1991; Kiberd & Kiberd, 1992). Kiberd & Kiberd, in their study of Canadian nurses in one center found that, although support for organ donation was nearly unanimous, operating room nurses were less willing to donate than their colleagues in other units—leading the investigators to speculate that being involved in the difficult procurement process itself, with a lack of exposure to successful transplant recipients, may influence attitudes about organ donation. In this current inquiry, some of the concerns expressed during the focus groups suggest that critical care nurses share similar perspectives to those reported by operating room nurses in Kiberd and Kiberd's work. Interestingly, all operating room nurses in this study indicated they were organ donors. However, they did note that an important influence for them on keeping the process in perspective was having the opportunity to interact with potential recipients and their families. One of the perspectives of this study not reported in other empirical work about nurses and organ donation was the perspective raised earlier about concern expressed by critical care nurses that the organizational context in which they worked limited their input into decisions about transplantation, particularly the selection process for transplant recipients.

Although in some studies it has been identified that nurses are the most appropriate persons to ask the family about organ donation (Molzahn, 1991), the critical care nurses in this current study did not see this as part of their role. Moreover, they believed that they did not always have the knowledge and skill to do this appropriately, and in some situations they believed this was true of their critical care physician colleagues as well. Given the evidence that suggests that the act of organ donation gives positive meaning to the experience of losing a loved one, and reduces the distress associated with this loss, it is important that family members are asked about organ donation in a sensitive, supportive manner (Murphy, 1988; Pelletier, 1992). Furthermore, findings from a study examining donor and non-donor family experiences in the critical care area show a strong positive correlation between the care the family received and the frequency of consent for organ donation, once again underscoring the value of the nurses' role in ensuring that families are
cared for in such a way as to assist them to make this decision at a very difficult time (Weiss et al., 1991).

It was evident from the stories that were told by the critical care nurses in this study that their attitudes about transplantation were strongly affected by their perspectives about how transplantation standards were actually being applied. It was also clear that these nurses had a need to discuss these issues from the response I noted when I asked for volunteers to participate in the study, and the direct manner in which the nurses shared their concerns in the focus groups. Their experiences highlight how negative experiences with transplantation can result in negative attitudes about organ donation.

Living Donation. There was strong support about the idea of organ donation from living donors from almost all participants in the study. Participants considered this an area of personal choice, and suggested that the decision to become a donor should be left up to the individual. As long as the decision was made without coercion, participants had no difficulty with the idea and saw it as an altruistic and selfless act. Participants did not see a distinction between receiving an organ from a living related donor (parent, spouse, child) or from an emotionally related donor (spouse, or close friend), and once again believed this to be a matter of personal choice. This was a subject where emotional reasoning was noted when discussion about the potential of being a donor for a family member or a loved one, particularly a child, was raised. Parents said that they would do anything to help their child if the child required an organ transplant, and would immediately volunteer to be a donor. Hilton & Starzomski (1994), in a qualitative study designed to examine the experiences of families who had made the decision for a member to be a living donor, reported that this was not usually an individual decision, but a family one, as the decision impacted on the family and involved the entire family unit. Similar to the perspectives of individuals in this study, they also noted that parents made "instantaneous" decisions to become organ donors when they found that a child required an organ transplant, with little or no concern about the potential risks.

Presumed Consent. Many participants in this study supported presumed consent at the beginning of the data gathering phase of this research. However, about four months after data
collection began, a decision was made by a Canadian television cable company to implement negative option marketing. Consumers protested loudly about the decision, which also received considerable media attention. Participants who were part of the focus groups after the negative option "fiasco", as it was called, connected negative option marketing with presumed consent and transferred their displeasure with the former to the latter. Consequently, their perspectives shifted, and they saw presumed consent as a potential violation of human rights. It appears that this "taste" of the implications of negative option consent strategies made it clear to the participants in this study that this option would be unacceptable to them. Given that the B.C. government has spoken out against negative option marketing, it is highly unlikely that presumed consent will be seen as an acceptable way of increasing the number of organs available for transplantation in British Columbia.

The participants who viewed transplantation as "through a glass darkly" or "through a glass ambivalently" had major concerns about a presumed consent policy that would put utility above all else, without understanding the symbolic significance of organ donation for some individuals, or the cultural meaning of death for many people. Molzahn (1996a; 1996b) reported that there was little support from nurses and physicians for presumed consent, and Bowden & Hull (1993) indicated that participants in their study, that was designed to explore a variety of the attitudes Americans had about transplantation, were not supportive of the idea of presumed consent, considering “the concept as particularly un-American in its abrogation of individual freedom,” (p. 4). Interestingly, the one group of participants who did support the idea of presumed consent in this study were members of the media who saw this as a way that individuals could express a sense of shared community, which was consistent with the role the media articulated that they had in being community advocates and championing the cause for those who needed organ transplants.

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9 It is interesting to note that several times since the data collection phase of this study, when I have been involved in radio call-in shows or speaking to the public and health care providers about organ donation, the negative option experience with the cable company is mentioned when the idea of presumed consent is raised. Apparently, it has become indelibly imprinted on the minds of British Columbians.
Xenografting. One of the areas where there was considerable controversy and many emotional views presented was during the discussion about xenografting. Some participants had not heard previously about this possibility, and often had either very positive or very negative initial reactions when discussing whether they thought it was an option that should be made available in the future to increase organ transplantation in Canada. After their initial emotional responses, some participants realized that, as this was often the first time they thought about this option, they needed to reflect on it further to determine their true position.

For other participants, this was an area where they believed there was much more public dialogue required before the practice was approved in Canada. Their responses were influenced strongly by the idea that human genetic material would be required to manufacture transgenic pigs. This idea caused great difficulty for many individuals. For some participants, the concept of xenografting was akin to cloning and was very anxiety provoking for many of them. Participants saw the potential for transfer of diseases like Mad Cow disease or another AIDS-like virus into humans as extremely frightening. Some authors have indicated that these fears are not unfounded, as they suggest that current technology in antibody screening for potential xenozoonoses is fraught with problems and needs further study (Dilner, 1996; Michaels et al, 1996). Other participants supported the perspective of individuals like Singer (1992) who have spoken out against xenografting because of their concern about the treatment of animals and their position that all sentient creatures need to be treated with respect. In a 1996 Decima poll, when asked about the choice of using an organ from an animal if they were dying, 63% of the respondents said they would accept an animal organ. A 1995 survey conducted by the National Kidney Foundation indicated that many Americans needing organ transplants would be willing to consider having a transplanted organ from an animal, such as a pig. Although there were some reservations about the

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Xenografting has been approved for use in the U.S. since July, 1995 and was approved in the U.K. in 1996. However, the U.K. approval was rescinded in January, 1997 until issues about potential transmission of microorganisms and continuing ethical concerns can be addressed. Thus far, in Canada, there has been no formal approval given to xenografting. Interestingly, Nicholson (1996), indicates that successful xenografting would increase transplantation tenfold worldwide, thus producing a profit of more than 3 Billion US dollars annually for CIBA-Sandoz the pharmaceutical company that has exclusive rights to the transgenic pigs being produced by the company Imutran.
ability of the technique to work, 74% of the 2000 transplant recipients said they would accept a xenograft if they needed another transplant.

Most transplant recipients in this study would accept a xenograft if they required another organ, with only one person expressing some major reservations. All participants who viewed transplantation as through a glass darkly, or through a glass translucently, viewed xenografting very negatively. Many participants in the study indicated their concern about the slippery slope -- if we begin to tamper with animals genetically then where do we stop? They also raised the question about what would we call a species that is part pig and part human? For some, these questions brought attention to some very basic questions about the type of society in which they wanted to live, as well as basic questions about the value of human beings. In several situations this discussion brought people to a point where they spoke about their naturalistic, ecological views of the world, questioning how much tampering we should be doing with our planet and society. The discussions about xenografting hit at the very core of what many people thought about being a human, and the discourse around the topic often continued after the focus groups were over as focus group members continued to think about possibilities for the future.

Buying and Selling Organs. When discussing the idea of buying and selling organs, individuals generally used an emotional reasoning approach. With the exception of a fraction of individuals, there was no support for this idea as a strategy to increase organ donation. When discussing buying and selling organs most participants shared a similar value about respect for persons and had major concerns about treating humans as commodities rather than as persons. Some people who had lived in countries, where individuals had been exploited for organs, were adamant about their position that buying and selling of organs was an immoral practice and should never be allowed in our society. Buying and selling organs was synonymous with slavery for some participants. As a counterpoint to the discussion, one participant who had lived in India earlier in his life pointed out the difference that selling a kidney could make, not just for one individual, but for an entire family, and questioned whether a Western perspective of morality was
being imposed on a situation that is viewed differently in some places in the world (Wilkinson & Garrard, 1996).

The participants who supported this idea did so when considering it for a family member. They generally had higher incomes than those who were not in favor of this method of acquiring organs. They saw their decision to move in this direction as an extension of choice, and for one participant she would only consider this idea if it meant saving the life of her child.

The discussion about organ donation and strategies to increase organ donation provides an overview of some of the issues that influenced the views that focus groups had about organ transplantation. Those who viewed transplantation more positively generally favored most strategies that would increase the number of organ available for transplantation, whereas those participants who had negative or ambivalent views generally did not favor strategies that would override personal choice and/or would begin to violate some basic value that they held about respect for self and others.

Having discussed some of the perspectives that influenced the views participants held about organ transplantation, I will now move on to discuss the roles and issues that were identified by the focus group participants for themselves and others at the micro, meso, and macro level of the health care system.

Public and Health Care Provider Participation in Decisions about Allocation of Resources

Macro Level of the Health Care System. There was a great deal of support by members of the focus groups for better resource allocation in the health care system that would include collaboration among all stakeholder groups. At the macro level of the system, focus group participants indicated a desire to include more participants other than government in decisions about health care, and there was a call for more involvement of both consumers and providers, and more transparent decisions throughout the system - - ideas that are prevalent in the literature on consumer participation in health care decision making (Abelson, Lomas, Eyles, Birch & Veenstra, 1995; Charles & DeMaio, 1992; 1993, Crawshaw et al. 1990; Eyles, 1993 ). Consumers, in particular, wanted to ensure that the values they held about health care were integrated into a discussion about
resource allocation. They saw this occurring to some extent at the level of regional boards and community health councils in B.C. but also believed that more innovative ways of obtaining their input was required. Others believed that macro level decisions should be left up to the "experts" and although they wanted input they didn't see a role for themselves in making choices at this level. Most health care providers saw a role for themselves in this area, with physicians indicating that there was a need for more involvement at the macro level by members of their profession. Other professional groups supported roles for other health care providers, as well their own group, in having input into decisions about how resources should be allocated. It was interesting to note that some staff nurses in the focus group had difficulty articulating a role for themselves at any level in the system, a problem that may be related to their sense of a lack of power and decision making in their roles (Rodney & Starzomski, 1993).

Some authors have suggested that there is little opportunity for the public to be involved in macro level health care decision making, although it is a value espoused by many (Eyles, 1993). Given that communities are quite heterogeneous places, the challenge is determining who should be involved and how? Abelson et al. (1995) discovered that when they polled 280 citizens in Ontario from a variety of potential decision making groups (randomly selected citizens, attendees at town hall meetings, appointees to district health councils, elected official and experts in health care and social services) and asked their opinion about their willingness to be involved in devolved decision making, there were varying responses. Elected officials were most willing and thought their group most suited to this role, while average citizens were least willing, and thought their group least suited. These results challenged the assumptions that communities (or potential decision makers) all want to be involved in decision making.

In this study, health care providers and consumers wanted to ensure they had input into some decisions, but did not necessarily want to be making the decisions -- in other words, they wanted a voice but not necessarily a choice. Given the new structure in B.C. of regional health boards, community health councils, and advisory committees to these groups, there are more
opportunities than ever before to ensure that the public and health care providers have the opportunity to at least exercise such voice.

Although most focus group participants indicated that they thought there were sufficient funds in the system, they would support the idea of "hard rationing" versus "soft rationing" if rationing needed to occur. Soft rationing refers to an informal distribution of health care resources without conscious choices or public debate and "hard rationing" means making decisions after public debate (Kilner, 1988; 1990; Rhodes, 1992).

A recent macro level attempt to solicit some public feedback was undertaken by the National Health Forum (1997) where discussion groups were organized throughout the country to attempt to obtain some consensus about the values Canadians hold about health care. An important recommendation by the Forum was prefaced with comments that the present ad hoc approach in Canada of linking values with health policy issues is not acceptable. The Forum members suggested that, as an inaugural attempt to enhance the process of ethical reflection in Canada, the Federal Minister of Health should take the lead in discussing with his provincial/territorial counterparts, and key groups with a substantial interest in ethics, ways to establish permanent linkages among ethics networks and bodies. The Forum members saw this as a first step to establish a national body to provide this ethical direction, as they suggested, a "just in-time" method of creating working groups and committees to address ethical dilemmas that society debates is no longer acceptable" (p. 21-24). The idea of some type of mechanism to ensure ethical reflection on issues such as xenografting was raised during the focus group discussions in this study, and the groups recognized the need for Canadians to debate these issues.

**Meso and Micro Level of the Health Care System.** It is at the meso and micro level of the system that many participants recognized a need for change from the current process of making decisions. Participants identified a role for more consumers at both levels of the system, although major health care providers had some difficulty seeing a role for consumers when they discussed this idea in their focus groups. In particular, transplant recipients saw that they could have a role on boards of organizations like the B.C. Transplant Society and also selection committees for organ
transplantation, roles that have been predominantly held by health care professionals. For example, a recent study by Mullen et al (1996), examining access to adult liver transplantation across Canada, found that, when they examined who was making decisions about selection criteria in organ allocation, almost all were health care professionals. Most minor and moderate health care provider groups supported this role for consumers and also saw roles for themselves. For instance, critical care nurses saw a role in becoming more involved in recipient selection and criteria development. All minor and moderate groups of both consumers and providers wanted the process for transplantation to be a more transparent one and saw expanded consumer involvement as a beginning step. Furthermore, the Canadian public has limited knowledge about decision making in transplantation, with one-third of Canadians in a 1996 Decima poll being unable to comment on whether the allocation of donor organs is fair or not, implying a lack of understanding or awareness of the system. Therefore, a more open and transparent system might address this knowledge gap as well.

When participants discussed selection criteria in the focus groups, they moved away from processes like random selection, lotteries, and first come-first serve, to discuss more complex criteria that would include a variety of different constituents. All groups recognized the difficulty in doing this, particularly given the difference of opinion on a number of areas in the focus groups such as age-based rationing and social worth and merit criteria. These different opinions are reflected in a recent study examining resource allocation in Britain, where the majority of the 2005 adults who responded to a public opinion survey indicated that they would prioritize care for younger rather than older persons, and there was also some public support for people with self-inflicted conditions (for example - smoking) receiving lower priority care (Bowling, 1996).

Having discussed the moral reasoning processes used by the focus groups, their views about organ transplantation and stakeholder participation in resource allocation decision making, I now move on to the final section of this chapter where I discuss focus groups as a data collection method in ethics research.
Focus Groups as a Method for Opening up Moral Space

Focus groups have become much more commonly used in health research and the data collection method has evolved since the early days when the process was first transferred from use in market research to use in health care (Morgan, 1988; 1993; Krueger, 1994). When this study began, there were very few studies that had used focus groups in ethics research, however, this method of collecting data is becoming much more popular. Because of this paucity of experience, I had some uncertainty about the outcomes related to using this method to collect information about ethical concerns. I hypothesized that this process would be analogous to the discussions that occur frequently in a natural fashion around the country as individuals and families have discussions in their homes, workplaces and in the community. Two of the assumptions of the study were that individuals would want to participate in the study because of their interest in the questions about organ transplantation and resource allocation, and that they would have no difficulty discussing the issues under question as a result of their acquaintance with at least the idea of organ donation.

One of the interesting findings from this study related to the beneficial effect for the participants of being part of the focus groups. This beneficial effect of being a research participant has been reported in the literature (Hutchinson, 1994). In almost all cases, when a request was made for a participant to be part of the study, they readily agreed. Many times, the focus groups were over subscribed, indicating a great interest in being part of the construction of knowledge in this area. In a few cases, this resulted in my conducting more than one group in key areas, as I wanted to learn as much as I could from as many participants as possible. In many cases, the groups turned into very pleasant social occasions for the members who responded positively to the experience. I believe this interest occurred for a variety of reasons. I postulate that, in some cases, there were participants who when asked to be part of the study responded positively because of their real interest in the area of organ transplantation, and their desire to contribute to development of new knowledge in the area. In some cases, groups may have had a particular perspective that they wished to see articulated, for example, when they desired to see change in the system available for transplantation, and saw this as one way to be part of this transformative process.
Also, in some respect, because of my own contacts in the community, and my interaction with a variety of groups, both in the hospital and not-for profit arena, I was able to capitalize on these contacts and recruit persons who might not have contributed otherwise. I also believe that there were some persons who were anxious to be part of the study because they had a desire to see me be successful in completing my doctoral studies.

The focus group process was one that was enjoyed by all participants according to the feedback received, my observations, and those of the focus group observer. It was clear that the groups who participated in this study did not often have an opportunity to interact in this manner, a perspective expressed even by groups of individuals who worked together. Keeping the groups homogenous was an effective method of ensuring that no person was intimidated by the other participants, and that all persons were able to articulate their perspectives. In the case of the mixed groups, as they were groups who had been meeting together before the focus group occurred, there did not appear to be a problem in their articulating their perspective. Because of the comfort level within the group, there was an opportunity for people to reflect on their own ideas and those of others, one of the positive features of focus groups that has been articulated in the literature (Krueger, 1994; Morgan 1988; 1993). I had some misgivings that people would not be able to be totally frank in the groups and speak honestly and openly, as in some cases the group members did not know one another. This was one of the most incredible experiences for me as an investigator, because not only did the groups disclose the information I was interested in, but they also enjoyed the process as well. In some cases, very confidential and personal information was exchanged with the expressed desire that this information remain in the group.

The comments and experiences reported by the groups indicated the need for health care providers to have opportunities to discuss ethical issues that impact on their clinical practice in a safe environment, as a mechanism of debriefing and problem solving, to provide emotional support for the staff caring for patients on an ongoing basis in this area of life-saving care, and to also learn and construct new knowledge about ethical concerns. In the case of the consumer groups, many of the participants had their consciousness raised about issues related to resource
allocation in health care, particularly as it related to transplantation. Moreover, opportunities for public involvement in resource allocation were highlighted.

The focus group process provided an effective forum for discussion about resource allocation in health care and one that I think has some distinct advantages for those persons who have a difficult time being part of larger discussions at town hall meetings and community and regional board meetings (Mullen et al., 1996). The process allowed all participants to have a voice and allowed me to stretch my mind in ways I had never imagined.

**Summary**

All consumer and health care provider focus groups used a combination of moral reasoning processes and articulated similar values and principles related to the allocation of resources for organ transplantation. Three moral reasoning processes were used by the consumer and health care provider focus group participants as they reasoned about ethical concerns related to resource allocation for organ transplantation. These processes included a deliberative process, an examined emotion process, and an emotional reasoning process. The three processes were used by all groups at different times during their discussions and the process used was dependent on the problem and the context of the situation, which in turn was influenced by the views the participants held about organ transplantation. Participants used an integrated approach of justice and care based perspectives as they reasoned about the problems that emerged during the discussions. There were differences in how the participants applied the values and principles they identified during the focus group discussion. In particular, different theoretical perspectives about justice were used by the participants, depending on the problem being discussed. Moral reasoning ability did not appear to be associated with education, gender or membership in a particular group, and there were similarities in the choices made about moral problems among all the groups. Focus group participants had difficulty identifying ethical problems in the case study under discussion, and there were some differences in the problems that were identified by some groups. Group members expressed their views about organ transplantation using three different patterns; viewing transplantation as through a glass brightly or positively, through a glass translucently or
ambivalently, and through a glass darkly or negatively. These views were constructed from a synthesis of the values, beliefs and attitudes participants held about organ transplantation, and were dependent on a variety of factors, such as personal experience, culture, ethnicity, religion, family upbringing, relationships, the context in which people were working, and their overall actual experience with organ transplantation. These constructions indicated the differences in attitudes that people have about transplantation, and point to the value of having multiple voices involved in the debate about transplantation.

These constructions highlight that the majority of the consumer and health care provider groups support the idea of including multiple voices in the debate about resource allocation; an important finding as new methods are sought for optimal ways to deliver health care in this country. Moreover, collecting data by using focus groups was a way of opening up moral space for useful discussions about resource allocation in health care.
CHAPTER 6

Public and Health Care Provider Dialogue - Toward New Horizons

"The great thing in life is not so much where we stand, but in what direction we are moving"
Oliver Wendall Holmes

In this chapter, I present an overview of the study by summarizing the literature, describing the research problem, and elucidating the constructions, interpretations and conclusions that were created as part of this study. In addition, I discuss the major implications of the study and highlight recommendations for health policy, practice, education and research.

Summary and Conclusions

There is a need to discuss allocation of resources for transplantation in the public domain with the objective of developing public policy that is fair and just. A collaborative model of health care is proposed where it is suggested that consumers and providers have a role, in conjunction with government, in determining how resources ought to be allocated. There is much discussion about involving health care provider and consumer stakeholders in decisions regarding how resources are distributed, but, there are few examples in Canada to show how to do this. Although there is a stated preference for effective communication among stakeholder groups, and team work to solve ethical dilemmas, there are indications that this does not always occur. Moreover, there is no assurance that all stakeholders would agree that community involvement in resource allocation is a goal towards which to work. There has been little research examining who ought to be involved in the discussions about resource allocation, at what level of the system they should be involved, and whether a collaborative model of health care decision making will result in the just allocation of resources. Finally, there has been a paucity of empirical work describing public or provider moral reasoning about the ethical issues emerging in the resource allocation debate. Little is known about the views of consumers and health care providers in relation to resource allocation in areas such as organ transplantation. Before community and provider groups can begin to work together to distribute resources more fairly, more needs to be known about these critical domains.
As a way of beginning to examine methods to facilitate the debate about resource allocation, the purpose of this qualitative study using the constructivist method described by Lincoln & Guba (1985), was to: 1) describe the attitudes, beliefs, values and moral reasoning processes used by stakeholder groups when discussing ethical issues related to resource allocation for solid organ transplantation; and 2) describe how these groups envision their own role, as well as the roles of other groups, in allocation of resources for transplantation.

A purposive sample of 34 consumer and health care provider groups, consisting of a total of 188 participants, was selected from those who have a major, moderate and minor stake in the development of organ transplantation in the health care system. Data were collected through focus group interviews, where stimulus material in the form of a case situation about transplantation, and questions arising from the case, provided the focus for the discussion. Although every effort was made to include people from different ethno-cultural groups, a limitation of this inquiry was that, because of language and cultural nuances, only people who could speak and understand English were included in the study. Also, the sample included only stakeholder groups from the Lower Mainland of British Columbia, thus excluding persons from other areas of B.C. Furthermore, because individuals were asked about their perspectives related to a hypothetical case, the constructions from this study may not have a direct relationship to the moral behavior of health care providers and consumers when confronted with ethical problems in their everyday life, or when reflecting on the support required for health care versus non health care related services at the macro level of the system.

Three moral reasoning processes were used by the participants as they reasoned about ethical concerns related to resource allocation for organ transplantation. These processes included a "deliberative" process, an "examined emotion" process, and an "emotional" reasoning process. The three processes were used by all groups at different times during their discussions, regardless of group membership. The process used by the participants was dependent on the problem, and the context of the situation, that in turn was influenced by the specific views the participants held about organ transplantation.
Participants used an integrated approach of justice and care based theoretical perspectives, as they reasoned about the moral problems that emerged during the discussions. There were differences in how the participants applied the values and principles they identified during the focus group discussion. In particular, different theoretical perspectives about justice were used by the participants, depending on the problem being discussed. Moral reasoning ability did not appear to be associated with education, gender or membership in a particular stakeholder group, and there were similarities in the choices made about moral problems among all the groups. However, focus group participants had difficulty naming specific ethical problems in the case study under discussion, possibly because of the narrative, contextualized manner in which they interpreted the problems. There was some variation in the problems that were named by some groups, primarily as a result of the views participants held about organ transplantation and the effect their view had on the way they interpreted the problem.

Group members expressed their views about organ transplantation using three different patterns; viewing transplantation as "through a glass brightly" or positively; "through a glass translucently" or ambivalently; and "through a glass darkly" or negatively. These views were constructed from a synthesis of the values, beliefs and attitudes participants held about organ transplantation, and were dependent on a variety of factors, such as personal experience, culture, ethnicity, religion, family upbringing, relationships, the context in which people were working, and their overall actual experience with organ transplantation.

Most participants viewed transplantation positively, and expressed their wish to donate their organs upon their death. They were supportive of strategies such as, offering living organ donation as an option to families, honoring the expressed wishes of persons about organ donation, and using xenografting, as methods to increase the numbers of organs available for transplantation. Those participants who viewed transplantation ambivalently or negatively, were not interested in becoming organ donors at the time of their death, would consider donating an organ to a loved one who needed it, believed the expressed wishes of persons about organ donation should be honored at the time of their death, and had difficulty with the idea of xenografting as an option to increase
organ donation. Participants from all groups expressed their moral abhorrence about the idea of buying and selling organs, as they saw this as a lack of respect for persons and a commodification of the human body, although a few would consider this choice to save the life of a loved one. After an experience of negative option marketing for cable television services, most participants had reservations about the idea of presumed consent, because of the perceived infringement on their individual rights and freedoms. Furthermore, participants in this study were in favor of developing complex criteria for the selection of organ recipients for transplantation.

Participants in the study supported the idea of more consumer and health care provider involvement at the macro level of the health care system, although they usually expressed this as the opportunity to have input into the decisions, but not necessarily make them. However, at the meso level of the health care system there was more support to have consumers involved in decision making, including being part of institutional boards and transplant recipient selection committees.

In conclusion, these constructions suggest that consumers and health care providers reason about moral problems by using an integrated approach of justice and care based theoretical perspectives. They use different moral reasoning processes, depending on the problem being discussed and the context of the situation. The constructions illuminate the different views that participants had about organ transplantation, and point to the value of having multiple voices involved in the discourse about organ transplantation. These constructions highlight that the majority of the consumer and health care provider groups in this study support the idea of including multiple voices in the debate about resource allocation -- an important conclusion as new methods are sought for optimal ways to deliver health care in Canada. Finally, collecting data by using organized and well conducted focus groups, is a way of opening up moral space within the health care environment for useful discourse about resource allocation in health care.

This research adds to the body of knowledge about: 1) the types of considerations that enter into moral decision making about resource allocation; 2) how various stakeholders identify, discuss and debate ethical dilemmas in transplantation; and 3) opinions of the stakeholders about
who should be involved in these decisions. As we move toward new horizons in the health care system, the constructions from this study can provide direction for health policy, practice, education and research.

Implications and Recommendations

The constructions from this study have implications for consumers, health care providers, health care administrators, health policy makers and government. In this section, I will discuss the widespread implications of this study, and propose some recommendations that I believe will move us forward toward new horizons.

Implications for Public Policy

Public participation. As we move forward with health care reform across Canada, it will be essential to continue to find opportunities to include multiple voices in the debate. It is important to examine who is included in the debate and the discussions. What this study has demonstrated is the value of including multiple voices to develop a clearer picture of resource allocation by examining the input and contributions of many sources, as no one group of consumers or health care providers have all the expertise to assist in making the best resource allocation decisions that are possible. To that end, it is essential to ensure that there are opportunities for all to participate in these discussions, including some groups who in the past were disregarded (the elderly, those with very low incomes, caregivers of the mentally handicapped, the media, and students). Without their participation in this study, a large number of essential constructions would have been missed.

Not only is it important to ensure that all the voices are heard in debates about resource allocation, but it is also essential that the appropriate location be found where the discussion can occur. For example, town hall meetings, although suitable for some, will not encourage participation from all groups -- an experience that has been reported previously (Abelson, 1995; Crawshaw et al. 1985; 1989; 1990). In fact, there have been several reports indicating that people who attend these meetings are usually wealthier and better educated than most citizens, and when the focus of the discussions is on health care, are often health care professionals -- hardly a group that represents the pluralistic society in which we live. It is not a case of "we will build it, and they
will come." Therefore, we must go to the places where people live and work to engage them in discussions. One of the significant learnings from this study was that meeting with participants in places they chose encouraged participation and assisted in helping people to be as comfortable as possible, so that their voices would be heard without problems of discomfort with their surroundings or difficulty accessing the location.

**Dialogue about ethical issues.** One of the most fascinating experiences I had as an investigator was being part of the 34 discussions and seeing the value of this type of focus group to open space for ethical discourse. There is a need for opportunities to have discussions about ethical issues at all levels of the health care system. There are, currently, no permanent mechanisms in place for this to occur. One suggestion would be to consider the establishment of an Ethics Network (similar to those established in other provinces) to increase dialogue about issues. A group such as this could examine innovative ways of using meetings, focus groups, multi-media technology and the Internet to provide opportunities for people to discuss ethical issues. The resulting dialogue could provide useful information for public policy decision making. The media could be part of this network, as in this study, they articulated their commitment and responsibility of keeping the public informed about issues and concerns that affect them. For example, as I write these words, the announcement has just been made about "Dolly"-- the first cloned mammal (sheep). What an wonderful opportunity for an Ethics Resource Network to begin some public debate about a new area that encompasses a number of ethical issues. Certainly, the media have presented part of that debate to the public, but it would be valuable to have the discussion with the public.

**Transplantation/organ donation issues.** A variety of areas have emerged as having implications for public policy within the arena of transplantation and organ donation. A "snapshot" of consumer and health care provider views on this topic emerged from the diverse participants in this study -- helping to shed new light on old problems. There is a need for the development of partnerships of all stakeholders in this area, an idea that is beginning to come to fruition because of the initiatives taken forward by organizations such as the Kidney Foundation of Canada, organ
procurement organizations like the B.C. Transplant Society, and federal and provincial health ministries (Federal/Provincial Advisory Committee on Health Services, 1996). This continued collaboration needs to be expanded to include stakeholders from other consumer and health care provider groups, the media, and different ethno-cultural and religious groups in order to develop a comprehensive plan for transplantation and organ donation in British Columbia and in Canada.

This partnership would be useful to examine some of the traditional practices of obtaining consent from family members for organ donation. This is an area of continuing debate in the transplant community. In all situations in Canada (and many other countries, several of whom who have presumed consent laws), families are asked for consent for organ donation when an individual has been declared brain dead, with the ability to override a personal decision made by the individual when they were alive. The focus group participants in this study did not support this approach, and emphatically said that they did not want their wishes about organ donation to be overridden, a position taken also by the B.C. Provincial Ethics committee. The constructions from this study indicate that the practice of asking family members, when the intent of an individual is known, may not have the public support as originally thought by members of the transplant community. This process requires review at the level the provincial government, B.C. Transplant Society and the B.C. Renal Council, as there are individuals who are having their wishes overridden in the current system. Although the rationale for asking families for consent is laudable, this practice is not in keeping with the right of individuals to make choices for themselves. I am not suggesting that families be excluded from the process, as their involvement is essential, but that the choice should rest with the individual to decide whether or not to be an organ donor. An important component of a democratic society is that we should inform people and not choose for them. The media can work with policy makers, consumers, and providers, in helping to educate the public about this issue and, ultimately, succeed in providing people with the information they need to make an informed decision about organ donation. As one of the factors that influenced people's views about transplantation in this study was the media attention that had been given to personal stories of transplantation, portraying the difference it made in people's lives, it will be essential to
develop strong partnerships with this very significant group. In addition, there are major benefits in having the media involved to further the debate about resource allocation in the community at large.

The constructions from this study also support the move to help educate and provide culturally appropriate information about transplantation and organ donation for persons in the province -- another area where the media has the potential to be very helpful.

Because of the strong views people had about negative option marketing, and the link to presumed consent, there are significant indications that this is not an area to which the public would lend its support. However, another area that does require more discussion is xenografting. There was a good deal of discussion about this topic within the focus groups and obviously there is a need for people to have continued discussion and opportunities to have information in this regard.

There was considerable support for the position that consumers and health care providers ought to have more involvement at the meso and micro level in making decisions about selection criteria. Opportunities need to be available for individuals, particularly patients and their families to be part of boards of institutions such as the B.C. Transplant Society to ensure they have a voice in the discussions.

**Implications for Practice**

**Collaboration.** In order to promote health care providers working effectively with one another, there is a need for an institutional commitment to collaboration. Moreover, care delivery systems that promote and foster collaboration should be included as an important component of hospital settings.

**Institutional systems for organ donation.** An optimal institutional organ donation system must include elements that support the idea that family needs are the foundation of the system, and that families should be provided with support and counseling. In addition, there is a requirement for professional knowledge and skill on the part of all who care for potential donor families. Also, there must be institutional systems and commitment to ensure that the system functions optimally.
As knowledge deficits and institutional constraints on ability to be involved in decision making were identified by critical care nurses as problematic, it is necessary to find ways to provide nurses with opportunities to learn more about transplantation and to become more involved in the process, particularly, the selection process. As critical care nurses are often key personnel who are interacting with donor families, their views about this process are extremely important, and it is therefore, vital that they have an understanding of both the transplant and organ donation process and their role in it. Consequently, more opportunities ought to be made available within the practice setting to help support this role. Moreover, there needs to be opportunities for nurses to interact with patients post transplant to receive a more balanced view of patient outcomes.

Although it is clear that nurses have a responsibility to be involved in organ donation and transplantation, there are reciprocal obligations for the transplant community to provide information to critical care nurses, as well as opportunities for nurses to be involved in the selection process.

Implications for Education

Collaboration - partnerships and discourse. Finding solutions to the ethical challenges we face at all levels will require that we expand our thinking about teamwork and look at strategies that will lead to improved team collaboration. There is evidence that shows that good collaboration produces positive patient outcomes. It is no longer sufficient to think that people will learn to collaborate "on the job." Therefore, education about collaboration should be provided, and collaborative practice models should be encouraged, in health care agencies, to improve communication and promote optimal team work that leads to enhanced patient care.

Ethics education. There are few opportunities in health care to learn about health care ethics. There should be emphasis on increasing discussion in health care education programs about ethics, resource allocation, and organ donation and transplantation. In addition, there is a need for more discussion about the optimal manner to teach health care providers, and consumers about ethics, being sensitive to include content about a range of theoretical perspectives.
Implications for Research

There are a variety of areas that require study in the future that have emerged as this study has progressed. Many of these studies will also have major implications in the health policy, practice and education arenas. For example, although the results of this study do not outline whether the outcome of increased consumer involvement in health care decision making will be improved health care, it is clear that as the process becomes more open, there will be additional opportunities for the needs and concerns of various groups to be represented. More research in this area, examining the differences that consumer involvement makes in the system, will be valuable in helping to determine at what level, and how, the voices of consumers might be added to the debate about resource allocation. Other potential research questions are listed below.

Moral Reasoning.

- What factors have the greatest influence on health care provider moral reasoning?
- What processes will be effective in assisting health care providers and consumers with ethical decision making about resource allocation?
- Are there differences in moral reasoning in mixed groups of nurses and physicians, and interdisciplinary groups?
- What are the reasoning approaches used by mixed groups of health care providers and consumers?
- What are the reasoning processes used by regional health boards and community health council members?
- What processes will be effective in assisting regional health boards and community health councils about ethical reasoning?

Resource Allocation.

- What value do Canadians place on health care utilization for which the expected benefits, though positive, are quite small, especially in relation to other social uses of the same resources or expenditures?
• How will Canadians reconcile allocation decisions and policies based on a population health perspective with their own individual wants and values?

• What are the most effective methods to include consumers and health care providers in resource allocation discussions at the macro, meso and micro levels?

• Are there differences in outcomes at the micro, meso, and macro level of the system as a result of consumer involvement in health care decision making?

• Are focus groups a suitable method of encouraging discourse about resource allocation in other areas of Canada?

Transplantation and Organ Donation.

• What are the values and beliefs of specific cultural groups (e.g. aboriginal peoples, Indo-Canadians, and Chinese people) regarding transplantation and organ donation?

• How can organ donation be facilitated among critical care staff?

• How do individuals make decisions to become living unrelated kidney donors?

• What are the experiences of emotionally related donors and recipients?

• What are the experiences of organ donor families when confronted with the decision about donating the organs of a loved one?

• What are the attitudes of potential transplant recipients toward xenografting?

• Is a structured education/facilitation program effective in increasing the frequency of organ donation in critical care units?

• What practices are in use in Canadian transplant centers for the allocation of organs for transplantation?

• What are the best methods for Canadian hospitals to support organ donation?

• What are the best practices for obtaining consent for organ donation?

• How should the consent process be restructured to ensure that people's wishes are respected?
• How might health care providers be more involved in decision making in transplantation programs at the micro and meso level?

• What are the attitudes and beliefs of individual Canadians about extending the organ donor pool to include non-heart beating donors, non-therapeutic ventilation of potential organ donors, preferred status (if a family member donates an organ then the family has preferred status if another member needs an organ), third party pooling (two living donors and/or families share organs), retrieving organs from anencephalic donors, altruistic donor pools?

In conclusion, at all levels of the system there needs to be a collaborative approach to health care among consumers, health care providers and government to improve the health status of all citizens. We need to move beyond rhetoric to a place where there is true collaboration and consultation among these three groups. Consumer involvement will provide direction by identifying societal needs and helping to resolve some of the difficult ethical questions that emerge from the resource allocation debate. The discussion about priorities in health care will never be finally settled as our priorities will continually change. However, we can concentrate on the processes and structure of decision making, ensuring that the debate is reasoned, informed and transparent, drawing on a variety of perspectives and interests (Klein, 1993).

Transplantation has saved thousands of lives. I stand in wonder and awe at the number of amazing and courageous people for whom these treatments have made a remarkable difference, and for the health care provider pioneers who made it happen. What this study has shown is that we need to use these treatments wisely, and not let the technological imperative drive what we do.

As we move into the next millennium, what choices will we make? Will we learn to use technology appropriately to enhance our humanity, preserve peace, and improve quality of life as exemplified in the optimistic future portrayed in Gene Rodenberry’s "Star Trek", or will we choose more pessimistic futures such as those portrayed in Aldous Huxley’s "Brave New World" or George Orwell’s "1984", in which people have truly become the "tools of their tools." The choices we make today are harbingers of what we will become as a society tomorrow. Let us use make our choices wisely as the dialogue continues.
REFERENCES


Teo, B. (1992). Is the adoption of more efficient strategies of organ procurement the answer to persistent organ shortage in transplantation? *Bioethics, 6*(2), 113-129.


APPENDIX 1

Glossary of Terms*

Transplantation and Stakeholder Groups

*Consumer - a person who uses a commodity or a service (Random House Dictionary, 1987, p. 437). For the purposes of this study, the term is used to identify a member of the public who may require health care services (synonymous with lay person, citizen, community and public).

*Health care provider - for the purposes of this study, an individual with an occupation that focuses on the development and/or delivery of some type of health care service (can include health care professionals, managers, and government bureaucrats).

*Stakeholders - individuals or groups who have an investment, share or interest in something (Random House Dictionary, 1987, p. 1855). The term appears to have been invented in the 1960’s in the business world as a deliberate play on the word ‘stockholder’ signifying that there are other parties having a stake in the decision making of modern companies other than those holding equity (Goodpaster, 1993). For the purposes of this study, societal groups who have an interest in the development, administration, and/or outcome of organ transplantation in British Columbia.

*Transplantation - in the context of this study, signifies solid organ transplantation unless otherwise indicated.

*Solid Organ Transplantation - transplantation of solid organs such as the heart, kidneys, liver, lungs and pancreas. Does not include other human tissue such as bone marrow, corneas, skin or bone.

Ethics, Morality and Moral Reasoning

*Attitudes - dispositions of feelings toward a person, object or idea (includes cognitive, affective and behavioral components). Attitudes are considered to be rather constant feelings and are made up of many beliefs (Steele & Harmon, 1983).

*Beliefs - the epistemic attitude of holding a proposition $p$ to be true where there is some evidence,
APPENDIX 1 (cont.)

although not conclusive evidence, for the truth of $p$. Beliefs are related to knowledge, and may be characterized as stronger than mere ungrounded opinion, but weaker than knowledge (Flew, 1984, p. 41).

**Ethical decision making** - involves the application of various skills of ethical analysis and reasoning in an attempt to reach a well grounded solution to an ethical problem (Benjamin & Curtis, 1986, p. 11).

**Ethical problem** - occurs when a person or a group is faced with a conflict between ethical principles, both of which are values that are accepted. Can also arise when persons or groups are faced with a decision and do not know which ethical principle to use in making a decision (Zucker, Borchert & Stewart, 1992, p. 395). For the purposes of this work, synonymous with ethical dilemma.

**Ethics** - the science or study of morals. In particular, ethics is concerned with right and wrong actions, policies, and practices; with duties, obligations, and rights; with fairness in the correction of wrongs (corrective justice); with the fair distribution of benefits and burdens within society (distributive justice); with virtue, vice, and just deserts; with good and evil, benefits and disbenefits, welfare and illfare, the valuable and the disvaluable for individuals and communities. It is concerned with the resolution of disputes, controversies, and uncertainties about the forgoing types of issues. Ethics is divided into normative ethics (opinions in morals) and meta-ethics (which is about morals), including both descriptive and theoretical ethics (McDonald, Stevenson & Cragg, 1992, p. 5).

**Justice** - a concept traditionally defined by the Latin term *suum cuique tribuere* (to allocate to each their own) (Flew, 1984, p. 188). Justice is a social ideal concerned with the distribution of society’s benefits and burdens. In contemporary philosophical writings, such as those by John Rawls, justice is treated as a principle of fairness. Justice can relate to various spheres of action, such as economic justice, distributive justice and criminal justice (Zucker, Borchert & Stewart, 1992, p. 396). Since the time of Aristotle, distributive justice has been
distinguished from corrective justice; the former being concerned about who ought to receive which goods and the latter with punishment for offenses committed (Flew, 1984, p. 188).

Moral considerations - constituents of the moral reasoning process.

Moral reasoning - Moral reasoning is the decision making process by which people choose among their moral values to come to some decision as to the appropriate response and/or behavior to some moral dilemma. Values are operationalized during moral reasoning (Omery, 1989, p. 501-503).

Morals - that which is concerned with conduct, character, intentions, and social relations insofar as they are appraised as excellent, right, deserving, virtuous, just, or proper (McDonald, Stevenson & Cragg, 1992, p. 5).

Moral dilemmas - those situations where the individual must choose between two mutually compatible choices related to right and wrong (Omery, 1989, p. 502).

Opinion - a conclusion or judgment held with confidence, but falling short of positive knowledge (Funk & Wagnalls Standard Dictionary, 1980, p. 554).

Principles - a rule of personal conduct or moral standards collectively (Funk & Wagnall’s Standard Dictionary, p. 632).

Resource allocation - distribution of resources among alternative uses (Buchanan, 1989, p. 294).

Value - an affective strongly motivational preference or disposition towards a person, object or idea (Omery, 1989; Steele & Harmon, 1983). Values are usually organized in a hierarchical manner, form the basis for making choices and are operationalized in moral reasoning (Omery, 1989). Both attitudes and values determine behavior but persons generally hold fewer values than they do attitudes (Steele & Harmon, 1983).

* The terms have been divided into two groups to reflect the domains discussed in the study.
### APPENDIX 2

#### TRANSPLANT STATISTICS - BRITISH COLUMBIA

<table>
<thead>
<tr>
<th>Transplants Performed - 1996 (December 31, 1996)</th>
<th>Waiting for Transplant (February 27, 1997)</th>
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</thead>
<tbody>
<tr>
<td>KIDNEY</td>
<td>KIDNEY</td>
</tr>
<tr>
<td>125</td>
<td>320</td>
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<td>KIDNEY/PANCREAS</td>
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<td>HEART</td>
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<td>18</td>
<td>8</td>
</tr>
<tr>
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<td>HEART/LUNG</td>
</tr>
<tr>
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<td>1</td>
</tr>
<tr>
<td>SINGLE LUNG</td>
<td>SINGLE LUNG</td>
</tr>
<tr>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>DOUBLE LUNG</td>
<td>DOUBLE LUNG</td>
</tr>
<tr>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>LIVER</td>
<td>LIVER</td>
</tr>
<tr>
<td>32</td>
<td>8</td>
</tr>
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<td><strong>TOTAL</strong></td>
<td><strong>TOTAL</strong></td>
</tr>
<tr>
<td>193</td>
<td>358</td>
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#### TRANSPLANT STATISTICS - CANADA

<table>
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<td>KIDNEY</td>
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</tr>
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<td>2115</td>
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<td><strong>TOTAL</strong></td>
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<tr>
<td>1484</td>
<td>2554</td>
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#### TRANSPLANT STATISTICS - CANADA

Included in the above total transplants are the combination transplants

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<th>Combination Transplants - 1994</th>
<th>Combination Transplants - 1995</th>
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<td>KIDNEY/LIVER</td>
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<tr>
<td><strong>TOTAL</strong></td>
<td><strong>TOTAL</strong></td>
</tr>
<tr>
<td>15</td>
<td>9</td>
</tr>
</tbody>
</table>

Source: British Columbia Transplant Society, 1997  
Source: Canadian Organ Replacement Register, 1996
## APPENDIX 2

### TRANSPLANT STATISTICS - USA

<table>
<thead>
<tr>
<th>Transplants Performed - 1995 (December 31, 1995)</th>
<th>Size of OPTM Waiting List at End of Year, by Organ - 1996</th>
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Note: Double kidney, double lung, and heart-lung transplants are counted as one transplant. All other multi-organ transplants are being included in the total for each individual organ transplanted. Based on UNOS Scientific Registry data as of February 17, 1997.

Source: United Network For Organ Sharing, 1997
Figure 8.1: The flow of naturalistic inquiry.

Source:
APPENDIX 4
Case Study and Discussion Guide

Peter K. is a 37 year old teacher, married with two children. He received a heart transplant almost 6 years ago because of cardiac myopathy. When various diagnostic tests were performed at the time of his transplant, it was discovered that Peter had only one kidney. At that time, the health care team assured him that this would not be a problem as many people had only one kidney and had no major problems. Unfortunately, over the past few months Peter has been experiencing some signs and symptoms of rejection. A biopsy shows that he has chronic rejection. His physicians believe that with some changes in immunosuppression his heart could last for some time. Because of the organ shortage and the length of time he will have to wait on the list until a new heart becomes available, the team are contemplating adding Peter to the transplant waiting list now.

A few days before the sixth anniversary of his transplant, Peter is injured in a car accident, severely damaging his solitary kidney. His physician informs Peter that he will require a nephrectomy and dialysis immediately. His surgeons are convinced Peter is a "good surgical risk" and are contemplating a combined kidney/heart transplant.

Format and Discussion Guide for Focus Groups
- General introductions. Have refreshments available. When asking people to introduce themselves, ask them to comment on what they know about transplantation, and about personal experiences they might have had relating to transplantation. For example - What knowledge do you have about organ transplantation? Have you ever known anyone who has had a transplant?
- Review purpose and ground rules for the discussions.
- Hand out copies and read the case.
- The facilitator will phrase and pose questions depending on the flow of conversation.

Questions

1) Can you tell me what your general reactions are to this case?

2) What do you see as some of the problems in this case? For whom?

3) What do you see as some of the possible courses of action?

4) What influences your decision about these courses of action?

5) Do you think Peter should get another transplant? Why or why not?

6) Depending on the response, at certain points may add would your opinion change if:
   a) this was your family member? Why?
   b) Peter was 70 instead of 37? Why?
   c) you were a member of the cardiac transplant team and there were funds available for only three more transplants this year, yet there were 10 people on the waiting list. Why?
   d) you were a member of the legislature and there was a need to limit how much money was to be spent on transplantation. Why?

7) What would you think about someone in Peter’s family or a friend wanting to donate a kidney now so that Peter does not require dialysis three times a week, and is able to return to the lifestyle he had before the accident?

8) Can you tell me how you think decisions are made about transplantation? How do you think they should be made? Who should make them? What role do (other) consumers, or specific groups (name each group) of health care providers have in this area?


10) What helped you reach this decision?

11) Have your views changed as a result of this experience?

The following are other questions to be asked as the discussion proceeds.

12) What are your views about a law requiring that hospitals ask families of brain dead patients who are suitable donors about organ donation?
13) Should Canada consider a system such as that used in other countries whereby organs of potential donors could be removed with "presumed consent" that is, without seeking the permission of the next of kin unless the individual had specified his or her wish not to be a donor?
14) Should donor organs from animals be used to transplant into humans?
15) Should financial incentives be offered to donor families?
16) What are your views about buying/selling of organs?

For some groups

17) Have you ever been involved in caring for an organ donor?
18) What was this experience like for you?
APPENDIX 5

AN ETHICAL DECISION MAKING FRAMEWORK

Developed By: Dr. Michael McDonald (1993)

A decision procedure for ethical decision making. To be used as a guide, rather than a ‘recipe’, remembering that ethical decision making is a process, best done in a caring and compassionate environment.

1. Identify The Problem

   a.) State the case briefly but with all the relevant facts and circumstances.
   b.) What decisions have to be made?
   c.) By whom? Who are the relevant decision makers?

2. Specify Feasible Alternatives

   What are the alternatives? State the live options at each level of decision-making.

3. Use Your Ethics Resources To Evaluate Alternatives

   What are the critical considerations? Relevant resources.

   a.) Principles:
      i) Autonomy: What does the patient want? What explicit or implicit promises have been made to the patient?
      ii) Non-Maleficence: Will this harm the patient?
      iii) Beneficence: Will this benefit the patient?
      iv) Justice: Consider the interests of all those - including the patient’s - that have to be taken into account?

   b.) Policies:
      Professional norms, standards and codes, legal precedents, hospital policy.

   c.) Contextual features of the case that seem important:
      Family relationships, past history etc., spiritual and ethno-cultural considerations.

   d.) Personal judgments:
      Yours, your colleagues and other members of the health care team.

   e.) Organized procedures for ethical consultation:
      Case conferences, use of an ethics committee or ethics consultant.
4. Propose And Test Possible Resolutions

a.) Propose a resolution or select the best alternative, all things considered.

b.) Perform a sensitivity analysis. Consider your choice critically: which factors would have to change to get you to alter your decision?

c.) Think about the effects of your choice upon others’ choices: are you making it easier or harder for relevant others - other health care providers, patients and their families, etc. to act ethically?

d.) Is this what a compassionate health care professional would do in a caring environment?

e.) Formulate your choice as a general maxim for all similar cases. Suggest cases where it does not apply. Consider cases where it does apply.

f.) Are you still comfortable with your decision? If you are, then go with it. If not, consider the factors that make you uncomfortable with the choice, with a view to coming up with a new general maxim that you are comfortable with. Repeat until you are convinced that you have done your best in the time you have.

Remember that you are not aiming at the perfect choice, but a good choice.
APPENDIX 6

Chronology of Events/Publicity Related to Topics Discussed During Data Collection Period

In addition to being aware of many of the stories below, several participants mentioned that they had read articles in Nursing BC, the BCMA Journal, CMA Journal, Time, MacLean's, and a contemporary German magazine about organ donation and transplantation at some point before they participated in the focus groups. Also, several mentioned seeing columns by Ann Landers in local newspapers about the positive aspects of organ donation.

There was also extensive media discussion about Health Care Reform in Canada and in B.C. Many people had seen/read several stories on this topic.


June, 1994 - KFOC AGM focused on organ donation.

Summer, 1994 - Suzanne MacLean's bicycle ride across Canada to raise awareness about organ donation. BCTV story, Several stories in the Province newspaper and hundreds of media pieces across Canada.

Fall, 1994 - Child from U.K. had 7 organ transplant in U.S. - died shortly after - money received from Princess Diana and King Fahad in Saudi Arabia to support transplant. Man transplanted with 7 organs in U.K. - newspaper article highlighted that he had survived for several months.

Fall, 1994 - "Registry for Organ Donors" idea being discussed, Organ Donor Task Force at KFOC, KFOC begins to refocus mission on organ donation.

Fall, 1994 - Young B.C. child who received bone marrow meets her donor (RCMP officer 5 years later) Extensive media coverage.

September, 1994 - 7 year old Nicholas Green (visiting with his family from the U.S.) shot in a random act of violence in Italy. Family donated organs in a country where the organ donor rate had been low - increased the organ donor rate - a number of TV and print media stories - many people had heard of this.

Nov/Dec., 1994- TV Shows -
- Law & Order - Buying and Selling Organs- Central Park
- 20/20 - Human Interest Stories

Dec. 20, 1994 - Case of Mavis McArdle receiving bridging liver from a pig at the Royal Victoria Hospital in Montreal - announced in late Jan. that the transplant had taken place in December - stabilized for 14 hours until cadaveric liver found.

Dec., 1994/Jan/95 - Bowen Island patient buying kidney - Roger Kinnee - debate about whether he should have done it, as well as who was going to pay for the drugs.

Dec., 1994 - Television show- Chicago Hope man received a heart from a baboon. Another show where heart was dropped on the floor during transplant procedure.

April, 1995 - Suzanne MacLean receives kidney from adopted Mom in Montreal.
Fall, 1994/Winter 1995 - ER - several shows featuring organ donation.

Fall, 1994/Winter 1995 - Increased LD’s - emotionally related - two nurses transplanted who were best friends.

January, 1995 - Case of Baby Diego Carpino in Prince George (who weighed less than 10 kilos) going to Minnesota to receive an LRD from his Dad. Received kidney on March 2, 1995. Lots of publicity re: family raising money for trip and whether the Minister of Health would fund this out of province transplant.

Feb., 1995 - Baboon marrow transplanted into recipient with AIDS in California.

Feb. 22, 1995 - Time Magazine - "An Abominable Trade" - story about people in Bangalore, India who had agreed to sell their blood only to wake up realizing they had lost their kidneys.

March 2, 1995 - Vancouver Sun reporter Rebecca Wigod following patient waiting for a heart transplant, Nicholas Klaver. Received transplant on Wed. May, 31, 1995. Front page of Vancouver Sun several times. Picture of team in OR.

March 10, 1995 - Appeal Court in U. K. upholds decision by health care providers that a 10 year old girl be refused her second state-funded bone marrow transplant because it was expensive and her case is considered futile (less than 2-5% chance of survival).

Winter, 1995 - Public appeals for bone marrow donors (high school group particularly aware of this)

April 22, 1995 - Globe and Mail did a large profile on liver recipient - Janis Barlow (she wrote the story).

April 26, 1995 - Donor registry announced at BCTS.

March and April, 1995 - More than 50 stories in B.C. papers about individual donors and recipients as part of a KFOC and BCTS campaign. Also more than 500,000 organ donor stickers handed out by KFOC volunteers during the March Drive door to door fund raising campaign.

March, 1995 - Minister of Health announced that $500,000 was allocated to BCTS to use for organ donor awareness programs, including a pilot study of the Organ Donor Registry

March, 1995 - Prime Minister Jean Chretien states an attempt will be made to reduce Canadian spending to be within nine percent of the GNP (similar to European countries)

March, 1995 - Several people had seen the movie “Jesus of Montreal” where organ donation was mentioned as a charitable act.

March, 1995 - Several people talked about seeing the movie “Outbreak”, starring Dustin Hoffman when discussing the idea of transmitting viruses from animals to humans.

March, 1995 - Many people discussed the story of entertainer David Crosby receiving his liver transplant for alcoholic cirrhosis.

Winter, 1995 - B.C. adolescent Rachel Daigle made a ward of the court because her family did not want her to have a liver transplant. Overturned and she eventually went to Mexico where she had alternative therapy and later died.
Winter, 1995 - The case of Terry Urquhart, a young Edmonton man with Down Syndrome, not being added to the waiting list for a lung transplant. Later overturned and he eventually was added to the list, but died before he could be transplanted.

March 29, 1995 - CBC did a 30 minute program on xenografting.

March, 1995 - An LRD is shown on the Learning Channel on the show "Operations".

April, 1995 - Last week of April, Organ Donor Week. Numerous stories in the media about a large number of personal interest stories about transplantation.

Spring, 1995 - Nurse Rebecca Anderson - struck on head by concrete trying to save people in the Oklahoma City disaster. Died of massive head injuries 5 days later. Had wanted to be an organ donor and family did donate her organs.

Many stories about her courage and altruism, including several articles by Bob Stahl in the Province newspaper.

Spring, 1995 (July) Ike Bryldt advertises in the Edmonton Sun for his second kidney-offers to pay donor. Advertised first in 1984 - then received a cadaveric kidney. Gertrude Bacon advertises (in the Edmonton Sun in the classified ads) for a kidney. She asks that the donation be a gift as she did not support the idea of buying and selling organs. Received dozens of offers from people who wanted from 10-50 thousand for their kidneys. Edmonton Sun criticized for running the ad. State they will not carry such ads in the future.

Spring, 1995 - A number of media stories about interesting transplants done in the U.S. including one where a young woman receives 1 lobe of a lung from each of her 2 brothers.

May 15, 1995 - Time magazine story "On a pig and a prayer" talks about xenografting program at Duke University and the role of the company Nextran in this endeavor.

June 8, 1995 - Mickey Mantle receives liver transplant in Dallas. Died several weeks later from lung cancer. Much media attention to this story. Many people had heard about it.

June, 1995 - KFOC AGM focused on organ donation.


1995 - A comedic sketch about xenografting aired several times on the CBC show "This Hour has 22 Minutes."
APPENDIX 7

FOCUS GROUPS

N = 34

Health Care Providers

MAJOR

- Nurses
  - Nephrology (1)
  - Transplant (1)
- Nephrologists (1)
- Renal Technicians (1)
- Social Workers (1)
- Transplant Organization Staff (4)

MODERATE

- Nurses
  - Critical Care (3)
  - Nurse Managers/CNS's (1)
  - OR Nurses (1)
  - Palliative Care Physicians (1)

MINOR

- Nurses
  - Community/Home Care (1)
  - Nurse Consultants (1)

Consumer

MAJOR

- Health Charity Staff (1)
- Kidney Transplant Recipients (1)
- Extrarenal Transplant Recipients (1)

MODERATE

- Media (1)
- Parents of the Mentally Handicapped (1)

MINOR

- Students (4)
  - High School
    - Private
    - Public
  - College
  - University
  - Seniors (1)
  - General Consumers (4)
    - Downtown Eastside Vancouver
    - West Vancouver
    - Vancouver
    - Greater Vancouver

Mixed

MAJOR

- Transplant Organization Board Members (1)
- Health Charity Board Members (1)

MODERATE

- Ethics Committee (1)

Legend: Number included in brackets represents the number of groups conducted
APPENDIX 8

Age Range of Participants
N = 188

![Bar Chart showing the age range of participants with specific numbers and percentages for each age group.]

- 11 (6%) aged 10 to 19
- 21 (11%) aged 20 to 29
- 50 (26%) aged 30 to 39
- 65 (34%) aged 40 to 49
- 22 (12%) aged 50 to 59
- 15 (8%) aged 60 to 69
- 1 (1%) aged 70 to 79
- 3 (2%) aged 80 to 89
APPENDIX 9

Education Level of Participants
N = 188

- Post Graduate Degree
- University Graduate
- Some College/University
- High School Graduate
- Some High School

Number of Participants
APPENDIX 10

Religious Affiliation

N = 188

Religious Affiliation

<table>
<thead>
<tr>
<th>Affiliation</th>
<th>Number of Participants</th>
</tr>
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<tbody>
<tr>
<td>None</td>
<td>2 (1%)</td>
</tr>
<tr>
<td>Taoist</td>
<td>1 (1%)</td>
</tr>
<tr>
<td>Atheist</td>
<td>15 (8%)</td>
</tr>
<tr>
<td>Agnostic</td>
<td>40 (21%)</td>
</tr>
<tr>
<td>Sikh</td>
<td>0</td>
</tr>
<tr>
<td>Hindu</td>
<td>1 (1%)</td>
</tr>
<tr>
<td>Buddhist</td>
<td>5 (3%)</td>
</tr>
<tr>
<td>Muslim</td>
<td>2 (1%)</td>
</tr>
<tr>
<td>Jewish</td>
<td>8 (4%)</td>
</tr>
<tr>
<td>Roman Catholic</td>
<td>33 (18%)</td>
</tr>
<tr>
<td>Protestant</td>
<td>81 (42%)</td>
</tr>
</tbody>
</table>
Organ Donors - Health Care Providers
N = 103

Non-Donors 27 (26%)

Donors 76 (74%)
APPENDIX 13

Total Household Income
N = 188

Income Level

Number of Participants

> $90,000
$86,000 - $95,000
$76,000 - $85,000
$66,000 - $75,000
$56,000 - $65,000
$46,000 - $55,000
$36,000 - $45,000
$26,000 - $35,000
< $25,000

(5%)
(7%)
(6%)
(5%)
(3%)
(14%)
(9%)
(4%)

13
11
11
25
34
17
7
27

50
45
40
35
30
25
20
15
10
5
0
APPENDIX 14

Occupations
N = 188

- Realtor: 1 (1%)
- Geologist: 1 (1%)
- Writer: 2 (1%)
- Labourer: 1 (1%)
- Librarian: 1 (1%)
- Homemaker: 6 (3%)
- Community Organizer: 4 (2%)
- Engineer: 1 (1%)
- Interior Designer: 1 (1%)
- Advocate for the Mentally Handicapped: 2 (1%)
- Journalist, Reporter: 4 (2%)
- Unemployed: 1 (1%)
- Retired: 11 (6%)
- Self Employed: 2 (1%)
- Developer/Consultant: 3 (2%)
- Accountant: 3 (2%)
- Sales: 3 (2%)
- Cashier/Clerk/Secretary: 9 (5%)
- Fund Raiser: 3 (2%)
- Teacher: 5 (3%)
- Student (UNIV): 5 (3%)
- Student (COLL): 5 (3%)
- Student (HS): 11 (6%)
- Managers: 8 (4%)