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# Factors that influence hypothetical treatment decisions for newborns with mental retardation and an accompanying life-threatening medical disorder

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**Factors that influence hypothetical treatment decisions for newborns with mental retardation and an accompanying life-threatening medical disorder**

**Flint, David Bruce, Ph.D.**

**University of New Hampshire, 1988**

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FACTORS THAT INFLUENCE HYPOTHETICAL TREATMENT DECISIONS FOR  
NEWBORNS WITH MENTAL RETARDATION AND AN ACCOMPANYING  
LIFE-THREATENING MEDICAL DISORDER

BY

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DISSERTATION

Submitted to the University of New Hampshire  
in Partial Fulfillment of  
the Requirements for the Degree of

Doctor of Philosophy

in

Psychology

September, 1988

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Date

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David B. Flint

## DEDICATION

This dissertation is dedicated to my wife, Shirley, with love and gratitude for her support and understanding during the seemingly endless hours of waiting for this offspring to develop.

## ACKNOWLEDGEMENTS

I am grateful to my dissertation director, Victor Benassi, for his continuing support and encouragement, for his challenges to produce the best document of which I was capable, and for his friendship during the past years.

I am also grateful to the members of my dissertation committee, who each approached this project with unique interests and ideas, but who as a group contributed to the development of a study of which I am proud.



## PREFACE

Research involving emotionally charged issues such as those discussed in the following study is difficult to conduct without bias. Although strict attention was paid to avoid presenting my beliefs to the participants, it may be that I was not completely successful. Therefore, I feel that the reader should be aware of my position prior to reading this paper. I originally felt that treatment should be provided in all cases, but uncomfortably acknowledged that in some rare cases, withholding or withdrawing treatment would be preferable to a painful existence. As a result of this research, I am now more willing to accept the need to decide not to treat newborns. Finally, I believe that parents facing actual treatment decisions must be allowed to do so based on complete and accurate information, and to make those decisions with no fear of prosecution or rejection.

## TABLE OF CONTENTS

DEDICATION.....	iv
ACKNOWLEDGEMENTS .....	v
PREFACE.....	vi
LIST OF TABLES.....	ix
ABSTRACT.....	x
CHAPTER	PAGE
INTRODUCTION .....	1
I. HISTORY, LEGAL AND ETHICAL ISSUES.....	8
History .....	8
Ethical Issues .....	12
Legal Issues .....	23
II. MORAL REASONING .....	28
III. ATTITUDES TOWARD AND AWARENESS OF PEOPLE WITH MENTAL RETARDATION.....	39
IV. METHODS.....	50
Dependent Variables .....	51
Independent Variables .....	53
V. RESULTS.....	68
Basic Treatment Choice .....	69
Relations Among the Independent Variables.....	74
Changes in Treatment Choice .....	76
VI. DISCUSSION.....	79
Relations Between Independent Variables and Treatment Choice .....	79
Changes in Treatment Choice.....	93

Limitations of the Study.....	94
Related Ethical Issues.....	97
LIST OF REFERENCES.....	102
APPENDICES.....	111
A. TABLES .....	112
B. SAMPLE QUESTIONNAIRE.....	125

LIST OF TABLES

TABLE	PAGE
1. Demographic Profile of the Participants.....	112
2. Pattern of Ethical Position and Treatment Choice.....	113
3. Pattern of Treatment Choice and Ethical Position Controlling for Level of Retardation.....	114
4. Pattern of Religious Affiliation and Treatment Choice.....	115
5. Relation Between Quality of Life Prediction and Treatment Choice Within Each Ethical Position...	116
6. Summary Table for Multiple Analysis of Variance of Basic Treatment Choice and Independent Variables.....	117
7. Means of Sanctity-of-Life and non-Sanctity-of-Life Groups.....	118
8. Summary Table for Multiple Analysis of Variance of Sanctity-of-Life Justification and Other Independent Variables.....	119
9. Correlations Between Independent Variables.....	120
10. Group Means and Differences on Quality of Life Projection.....	121
11. Treatment Choice Change at Each Level of Information.....	122
12. Treatment Choice at Different Levels of Information Listed by Ethical Position.....	123
13. Pattern of Changes from Full to Conditional Treatment Choice with Additional Information.....	124

ABSTRACT

FACTORS RELATED TO HYPOTHETICAL TREATMENT DECISIONS FOR  
NEWBORNS WITH MENTAL RETARDATION AND AN ACCOMPANYING  
LIFE-THREATENING MEDICAL DISORDER

by

David B. Flint  
University of New Hampshire, September, 1988

Treatment decisions made on behalf of newborns with mental retardation and an accompanying life-threatening medical disorder were studied. A group of 360 college students answered a set of questionnaires and responded to a vignette which asked for treatment decisions. The options ranged from full treatment including surgery to no treatment at all. The relationship of a number of variables to the treatment choices was assessed. The variables included level of moral reasoning, level of knowledge about and attitudes toward individuals with retardation, prior experience with individuals with retardation, religious affiliation, level of religious belief, prediction of quality of life for the infant, and ethical justification. The majority of participants selected full treatment. Level of retardation, quality of life projection, prior experience, and ethical position were all significantly related to treatment choice. Additionally, changes in treatment choice after additional information was provided were assessed. Quality of life projection and ethical position were also significantly related to changes of

treatment. Implications for public policy concerning treatment of newborns, public education concerning people with mental retardation, and counseling provided to parents faced with treatment decisions were discussed.

## INTRODUCTION

In 1982, the death of Baby Doe in Bloomington, Indiana, caused a major controversy in the medical, legal, and psychological professions, a controversy that is still unresolved (Loewy, 1987). Baby Doe was born with Down's Syndrome and atresia, which is a blockage of the esophagus that prevents digestion. In addition, physicians suspected that the infant had a heart defect. Corrective surgery would be necessary to save the infant's life. The infant's parents decided against the surgery and requested that feeding of the infant cease. The hospital complied with the parents wishes following a court order and the infant died six days later. Two other newborns with Down's Syndrome have also died under similar circumstances at other hospitals (Annas, 1983). These deaths focused public attention on an issue that had been confronting physicians since Duff and Campbell's (1973) description of withholding treatment from severely impaired newborns.

The decision to withhold essential treatment from severely impaired newborns has had an impact in a number of areas. Medical ethicists have attempted to explain such decisions by focusing on right-to-life, quality of life, and similar issues. The legal implications of decisions to withhold treatment are complex and as yet unresolved (Lenow, 1983), although most legal opinions grant the parents the authority to make the final decision (Shelp, 1986). The

Federal Government has responded to the controversy with a policy requiring hospitals to provide the maximum treatment to all infants, with the only exceptions being in cases of irreversible coma, harmful treatment, or futile treatment. This final policy evolved after earlier ones, including the establishment of the "Baby Doe Hotline", were strongly opposed by members of the medical profession.

The above describes the major moral, ethical, and policy issues that have been addressed concerning the decision to withhold treatment from a severely impaired newborn. It is equally important that the decision-making process itself be better understood at the level of the parent making the decision. Specific factors that influence an individual's decision to withhold treatment in such situations should be identified. With such factors identified, counseling provided to parents at critical times would address the most important issues. Additionally, an understanding of the factors that are crucial to parents making such decisions may provide an appropriate focus for the ethical, legal, and public policy issues described above. A number of possible factors have been found to influence the decision-making process in general. These were the focus of interest in the present study.

One factor which was investigated was the participant's moral reasoning that formed the basis for the treatment decision. Kohlberg's (1984) theory of moral reasoning included the assertion that in many instances, moral reasoning affects both interpretation of moral dilemmas and



moral behavior. Although subject to criticism, Kohlberg's theory suggested one basis for studying treatment decisions made by parents. Rest's (1986) modification of Kohlberg's assessment technique, the Defining Issues Test (DIT), was used in the present study.

A second approach to understanding the decision to withhold treatment was to evaluate the parents' awareness of, and attitudes toward, people with developmental disabilities. It has been demonstrated that both awareness and attitudes have at least a limited impact on behavior (Ajzen & Fishbein, 1980). One's attitudes toward the developmentally disabled may lead to a decision that differs from one made for a non-disabled infant. Similarly, one's understanding of the nature and consequences of developmental disability may have an impact on the decision. In fact, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavior Research (1983) suggested that parents in such situations often do not have the correct information, and may make decisions based on misinformation.

A related issue addressed the relation between prior experience with the developmentally disabled and the treatment decision. The literature reviewed suggested that experience with the developmentally disabled influences one's awareness of and attitudes toward them. However, in some cases the direction of such influence was found to be positive, while in others the influence was negative (Yeates & Weisz, 1985; Begab, 1976; Hagen et al., 1983; Williams,

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1986). The present study attempted to further identify the relation between attitudes and experience as it related to the treatment decisions made.

Religious affiliation may also have an impact on the treatment decisions people make concerning severely impaired newborns. A number of authors have identified a relationship between religious affiliation and attitudes toward euthanasia in general (cf. President's Commission, 1983), and euthanasia of severely impaired newborns in particular (Shelp, 1986). It was expected that similar relationships would be identified concerning the decision participants made in the present study.

The severity of handicap that the child exhibits may also influence the decision made by parents of handicapped and medically-at-risk infants. A child who is expected to be mildly retarded will have much less an impact on his/her family than a child who is expected to be profoundly retarded. The influence of the severity of the child's anticipated handicap could be identified by assessing the parents' predictions of the quality of life for the child and its family. Both of these variables were studied as potential influences on the decision made concerning treatment of a multiply-handicapped newborn.

As described above, ethical justifications for denying treatment to newborns are often presented as components of general theoretical discussions rather than in response to specific situations. It may be that the justifications offered by parents who actually make decisions to treat or

withhold treatment from their newborn are consistent with the theoretical positions. However, a review of the literature failed to identify an attempt to assess the relation between theoretical principle and the specific decision-making process of parents in such situations. The present study assessed the participants' ethical justification for their decision by asking them to choose from a group of summary descriptions of each theoretical model.

The purpose of this study was to evaluate the relation between the above factors and the treatment decisions people make on behalf of brain damaged or developmentally disabled newborns with life-threatening medical disorders. Kohlberg's assertion that moral reasoning predicts behavior was further evaluated, as was the relation between attitudes and behavior. Information about the relation between awareness of and attitudes toward the developmentally disabled and treatment decisions were studied because of the potential impact on public policy.

The format of this dissertation will be as follows. The discussion will proceed with a summary of the history and current status of the problem of treatment of the newborns in question. The summary will focus on the ethical and legal implications of treatment decisions. An in-depth discussion of each of the variables described above will follow, including a review of similar studies involving the variables. Kohlberg's theory and its implications for the present research will be discussed in detail because of the

major impact his theory has had on reasearch concering moral behavior in situations similar to the one of interest in the present study. Each of the variables described above will be assessed and their relationship to treatment decisions will be identified.

## CHAPTER ONE

### HISTORY, ETHICAL, AND LEGAL ISSUES

#### History

In 1973, Duff and Campbell published an article reviewing their experiences in a special-care nursery. They described the withdrawal of treatment from, and subsequent death of, 43 infants during an 18-month period. Many of the infants were suffering from a severe medical disorder as well as suspected brain damage or obvious retardation. Examples included a child with Down's Syndrome and atresia, and a child with hydrocephaly and anomalies of all organs in the pelvis. Duff and Campbell described the ethical issues raised among the hospital staff and parents who had shared in the decision to withhold treatment. These included the issues of whether an infant facing a painful life should have the right to die; who should pay for treatment of the infant, whether heroic effort should be made to save a child with little chance of meaningful existence, the anticipated burden on the family (stigma, financial impact, social isolation); and whether a physician's commitment to preserving life has any limits. Legal concerns were also discussed including the question of who makes the final decision and how such decisions affect the legal rights of the infant, parents, and medical staff. In sum, Duff and Campbell described an intensely emotional issue, with little

resolution of the numerous ethical and legal issues available.

Although Duff and Campbell's (1973) description of the issues was provocative and demanded response, it generated little public interest. More recent events have, however, sparked the interest of the public. These events include the death of Baby Doe, described earlier. The extent to which the parents were willing to pursue their wishes to withhold treatment of their child was difficult for the public to understand (Shelp, 1986). The hospital's medical staff and administrators disagreed with the parent's decision to withhold treatment and the parents sought a court order supporting their decision. With the court's support, surgical treatment was denied, as were food and water. The infant was given medication to ease pain and restlessness. The infant died 6 days after cessation the treatment (Shelp, 1986). News of the death of Baby Doe, of thirteen-year-old Phillip Becker, and of an unnamed baby at Johns Hopkins University Hospital were well publicized (Will, 1980; Slade, 1983).

Public reaction to the news of the deaths was strong (cf. Shelp, 1986) and the federal government was quick to respond. One month after Baby Doe died, the Secretary of Health and Human Services (H&HS) (May, 1982) notified hospitals the the Department was assuming a major role in decisions previously made by parents and physicians. This policy warned hospitals that they were risking loss of federal funding if they intentionally withheld treatment

from handicapped newborns. A subsequent version of the policy (1983) established a toll-free hotline which parents, nurses, or any interested party could use to report suspected violation of the policy in a hospital. Announcement of this hotline was to be posted in public view in all hospitals. This policy was strongly opposed by professional medical groups such as the American Hospital Association (Annas, 1984; Strain, 1983; Weir, 1984). The opposition focused on procedural issues, such as failure to provide appropriate notice of the policy before it was implemented, and alleged vague definitions of situations in which it was permissible to withhold treatment. The professional groups asked for a court ruling regarding the validity of the policy and, after a negative court decision, the policy was revoked. In January, 1984, a new policy was implemented. Under the new policy, hospitals were encouraged to establish committees to review the care provided to handicapped infants, including the decisions to withhold or withdraw treatment. The penalties under the earlier version were discontinued. Additionally, the notice described above was allowed to be posted out of view of the public. The role of state protective agencies was strengthened, and definitions of instances in which treatment could be withheld were clarified.

Although the 1984 policy addressed many of the concerns expressed about earlier versions, it was not greeted enthusiastically. As described by Shelp (1986) and Murray (1985), medical professionals were dissatisfied with the



policy's continuing bias toward prolonging life while overlooking the wishes of the parents and the projected quality of life for the infant. This version of the policy was also invalidated by a U.S. Appeals court, ruling on the case of Baby Jane Doe. As in earlier cases, the parents refused treatment for a handicapped newborn who, in this case, was afflicted with spina bifida, microcephaly, and hydrocephaly. The court ruled that the Department of H&HS was wrong to attempt to override the parents' decision. Rather than appealing further and facing both a lengthy proceeding and a probable ruling in support of the decision of the Appeals Court, H&HS changed its approach. The regulations protecting children from abuse were modified (1986). States would receive funding only if they had an active program to protect the rights of handicapped newborns consistent with the goals of the rejected H&HS policies. States are assuming a variety of positions while implementing these new regulations, and therefore public policy remains confusing and unfocused. (Turnbull, Guess, & Turnbull, 1988).

It may be that public policy remains confusing because of the failure to focus on treatment decisions at the level of the decision-maker, the parent. Attempting to regulate decision-making in these situations may be fruitless because of the combination of factors that may influence parents. It was expected that identifying the factors that most strongly influence parents would help clarify the situation. Additionally, the hospital review committees mandated in the

1984 H&HS policy and others who will counsel and support parents making such decisions, will need to be armed with accurate information that will enable them to properly perform these tasks. Factors identified in this study may give the committees some of the information they will need to best advise and support parents as they face these decisions.

#### Ethical Issues

The recent deaths of handicapped newborns and the attempts of the federal government to regulate treatment have generated a debate among medical ethicists. A number of ethical questions have been addressed in an attempt to understand the withholding or withdrawing of treatment from handicapped infants. The questions of interest in the present study are: Is it ever morally or ethically right to terminate the life of an infant? and: If decisions must be made to withdraw or withhold treatment, resulting in the infant's death, what are the criteria upon which such decisions are made? A number of positions have been taken in response to these issues. The basic approach of each position will be described below, followed by a review of the criticisms of the position. It will become apparent that the various ethical positions offer differing interpretations of the issue. It will also be evident that these different interpretations do not identify the factors that influence parents making a decision in a specific situation.

### Sanctity-of-Life Model

The first position addresses the major ethical issues by asserting that all humans have a right to life, no matter what the severity of their handicap or illness. Life is sanctified, and all efforts must be made to continue the life of ill and handicapped infants. The sanctity-of-life model would suggest that a retarded child has exactly the same rights as a non-handicapped child, and therefore should receive the same treatment. This view has strong religious foundations, especially evident in the Roman Catholic dogma. Such a view emphasizes that only God decides when life should end and the role of physicians should be to preserve life rather than to end it (Rachels, 1986).

The major criticism of this view is that, in some cases, continued life would be harmful to the child. Shelp (1986) discussed the case of a child born with open lesions covering 75% of its body. A child with this condition lives a short and painful life, doomed to die from loss of fluid and infection. Shelp suggested that to assume a strict sanctity-of-life position is at best avoiding the reality of such severe cases, or at worst, prolonging the suffering of a doomed child. The 1984 H&HS policy recognized this potential, and granted exceptions to the mandate to preserve life in cases of futile or painful treatment. The Catholic Church has also recognized that in some cases the sanctity of life dogma must be modified. This awareness has resulted in the concept of extraordinary vs. ordinary means, to be discussed below. In any case, it is clear the the

sanctity-of-life model is an incomplete approach for dealing with the major ethical question of interest to the present study.

### Decision-Based Models

Personhood Models. A second model for answering the ethical questions described above asserts that decisions must sometimes be made to withhold or withdraw treatment for reasons which involve neither prolonged suffering nor futile treatment. A number of criteria have been offered as bases for deciding which infants should receive treatment and which should not. One criterion frequently mentioned is that of personhood. Shelp (1986) identified the basis of personhood models as possession of a minimal, or threshold, level of a specific quality. Newborns who do not exhibit such a minimal level or threshold would not be considered persons and would have treatment denied or withdrawn. Several specific criteria for personhood have been identified in the literature.

One approach suggests that a certain level of intellectual promise must be evident to assume personhood. Joseph Fletcher's (1979) paper is representative of this approach. Fletcher named twenty qualities necessary in order for a person to be called human. Intelligence was the first quality on the list. According to Fletcher, anyone with an IQ less than 20 is not a person, while the personhood of anyone with an IQ between 20 and 40 would be in question. Because people with IQs below these criteria would not be

considered persons, withholding treatment from them should not cause any ethical distress.

Another criterion for personhood that has been described is that of self-consciousness. As described by Tooley (1972), a sense of self is a necessary quality of life, and anyone lacking such a sense of self is not human. The crucial feature of this quality of self-consciousness is the ability to acknowledge oneself as a being with experiences, and to desire to continue existing.

A number of theorists have listed the ability to form meaningful human relationships as the basis for personhood. McCormick's (1974) paper is representative of this model. He stated that without something called the "relational potential" one is not human. Life is meaningless without human relationships and one who is projected to not benefit from these relationships is not considered a person.

One of the major criticisms of the personhood approach suggests that few infants would meet the criteria listed by the models described above. As reviewed by Slack (1983), these critics contend that it is difficult to predict with any success the degree to which a newborn child will be able to relate to others, the level of self-consciousness the child will have, etc. Therefore, one would have to assume that such potential existed in most newborns. In fact, the only newborns to be denied treatment in this model would be those who have obvious severe physical damage. Critics of the model contend that this is an arbitrary process, having

little to do with the criteria described as determinants of personhood.

The personhood models of ethical decision-making have been criticized as arbitrary for additional reasons. Slack (1983) explained that such criteria as intelligence, potential for relationships, self-consciousness, and others represent only one aspect of life. Focusing on a single aspect is arbitrary and narrow-minded, as is the assumption that deviation from the standard in one aspect of life makes one a non-person. Similarly, measurement difficulties are present. Such constructs as IQ, potential for meaningful relationships, and self-consciousness are difficult to reliably measure (Anastasi, 1976). Further, measures of intelligence administered early in life do not correlate well with later performance (Kopp & McCall, 1982). To decide a child's fate based on these arbitrary and difficult-to-measure constructs is an unsatisfactory process.

A final criticism of the personhood models of decision-making focuses on the extermination of mentally retarded people during the Nazi era. As explained by Murray (1985), if one assumes a personhood position and fails to acknowledge the sanctity of life, one is treading on dangerous ground, the slippery slope as it is commonly called. Making such exceptions to the sanctity-of-life edict can easily lead to elimination of whole classes of people for reasons other than originally intended. If a child with a medical condition and retardation can be

allowed to die because its future is meaningless, it may be hard to prevent the judgment that infants with similar handicaps will also have a meaningless life. If such a judgment is made, lives may be terminated for children with no medical complications.

Value-of-Life Model. A second model based on the assumptions that decisions may sometimes be necessary to terminate a newborn's life is the value-of-life model described by Shelp (1986). In this model, the question of significance is not personhood or lack of it, but rather, the value of life anticipated for the infant. Value of life is considered to have two components (Buchanan, 1987): personal value and social value. The former includes the effect of life on the individual, the level of pain or pleasure, happiness or unhappiness. The social value of life includes such components as the emotional value, the ability to benefit from meaningful relationships, the individual services or skills one has to offer others, and the economic contribution one makes to society. Two approaches are identified for evaluating the value of life, a modified sanctity-of-life approach, and the quality-of-life approach.

The modified sanctity-of-life approach is based on the principles of the sanctity-of-life model described earlier, which suggested that all life has value and should be maintained. The modified version acknowledges that sometimes a decision must be made against initiating or continuing treatment for a newborn, based on the possibility

that the treatment may not always be beneficial for the child or its family. This approach focuses on the personal value of life and offers a framework for such decision, the notion of extraordinary vs. ordinary treatment. This distinction is important in the Catholic Church's current interpretation of the issue (Buchanan, 1987). Extraordinary treatment involves excessive cost, pain, or creates a great burden on the child or family, without a reasonable chance that the child will survive. Such treatment is not mandated by the Church. In such cases, ordinary treatment is acceptable.

The quality-of-life model bases treatment decisions on more flexible criteria than do the personhood and sanctity-of-life models. Shelp (1986) emphasized the changing nature of the criteria for quality of life, indicating that a variety of circumstances, facts, and values influence the quality of life. The quality-of-life model is described as case-specific, focusing on the prospective quality of life for a single infant, including both personal and social dimensions. Important considerations include: environmental issues (the setting in which the child will live), the ability of the child's parents to provide care and comfort for a child with a long-term handicap, the impact on siblings, and the potential contribution the individual would make to the lives of others (Buchanan, 1987).

The value-of-life and quality-of-life models for ethical decision-making have been subjected to similar criticisms as the personhood models reviewed above. The



criteria for making decisions, e.g., environmental issues, potential impact on family, and potential contribution to society may be arbitrary and difficult to measure. Similarly, the potential for a slippery-slope process has been associated with these models (Shelp, 1986).

#### Utilitarian Model

The fourth and final model for answering the ethical questions of interest is the utilitarian model. As described by Van de Veer (1987), this model stipulates that one should act in ways that result in equal or more utility than any other act. Utility refers to the balance of pleasure over pain, with pleasure referring to satisfaction. Appropriate actions are those which maximize net utility, that is, they provide maximum good (pleasure) while minimizing bad effects.

In the utilitarian view, decisions regarding action are not based on personhood, sanctity of life, or quality of life, but on the criterion of the greatest net utility for the greatest number of people (Slack, 1984). The utilitarian perspective differs further from the decision-based models in its definition of personhood. According to Van de Veer (1987), all living beings capable of experiencing pleasure or pain are members of the moral community and should be considered when determining the balance between good and bad effects. This criterion would normally include all but the most severely retarded newborn (Slack, 1984). However, the utilitarian viewpoint would support withholding treatment from an infant if the right to

life of that infant conflicted with the rights of others to an extent that the net utility would be compromised.

As in the personhood and value-of-life perspectives, the utilitarian perspective involves a selection process. Important questions to consider in forming a treatment decision are the effects on the family, the cost of treatment, and the projected worthwhileness of life for the child. In Slack's interpretation of the utilitarian model, a child who is projected to have worthwhile potential could still be untreated because of other factors. This potential has been identified as one of the weaknesses of the utilitarian model, which will be discussed further below.

Van de Veer (1987) described the major criticisms of the utilitarian model of ethical decision-making. The first focuses on the measurement of pleasure/good, a basic construct of the model. People may vary widely in their concept of what is good or pleasurable, so that finding a consistent measure for the construct is difficult. A second criticism of the utilitarian principle also relates to the values people place on different behavior. A sociopathic person may feel pleasure committing the crimes he is guilty of, even though most people find them unacceptable. According to the utilitarian model, one should include the pleasure felt by the perpetrator in the overall assessment of the utility of the crimes. Critics of the model find it difficult to accept this approach, contending that it condones behavior which most would find reprehensible.

A third criticism involves what Van de Veer (1987) refers to as superogatory, acts which would be condoned by the utilitarian principle, but which are considered morally wrong by most people. By focusing on the net amount of pleasure, it is easy to overlook the bad things that happen to a minority. In the ethical dilemma of interest in the present study, many critics have suggested that the means to achieve good results for a family or society, i.e., withholding treatment from a newborn, are immoral and criminal.

A model of ethical decision-making that is related to the utilitarian model involves the concept of distributive justice. This model acknowledges that society does not have the resources to treat all people completely. Decisions must occasionally be made to withhold treatment from one individual to better serve others, that is, to maximize the net good effect for the greatest number. A variety of criteria have been suggested as bases for deciding whether an individual should receive treatment (Russell, 1977). These include the extent of medical need, the ability of the patient or guardian to pay for the treatment, the social contribution the patient has made or can be expected to make, the responsibility the patient has for his or her illness (i.e., illness caused by self-regulated habits such as smoking), and a lottery system. The criticisms appropriate for the utilitarian, personhood, and value-of-life models have been lodged against the distributive justice model as well.

In summary, the ethical questions that have been raised by the deaths of Baby Doe, Baby Jane Doe, and others, have not been answered. A variety of positions have been offered to justify withholding treatment from a handicapped newborn. The personhood and value-of-life models of decision-making have been offered to justify withholding treatment in several landmark cases. Duff and Campbell (1973) described the decisions involving the death of infants who faced life with no meaningfulness. The cases of Phillip Becker and the Johns Hopkins baby were described as involving individuals whose lives were not worth preserving (Slade, 1983). Similarly, the President's Commission (1983) suggested that the quality of life may be an appropriate criteria for decision making in such cases.

As is evident from the discussion above, medical ethicists subscribe to different positions, and there is no clear answer to the major ethical questions. For example, the utilitarian perspective is based on assumptions which are very different from those basic to the sanctity-of-life or decision-based models. As Campbell and Duff (1979) suggested, disagreement about the major theoretical controversies fails to address the crucial issue, helping parents make treatment decisions.

Identifying the specific ethical influence, if any, guiding parents as they make such decisions may address this issue. That is, if the utilitarian perspective is used by a majority of parents, counselors may want to focus on such issues as overall impact of the newborn's condition and

treatment. On the other hand, if sanctity-of-life were the basis, one would focus on accepting the child and supporting the family in its care.

#### Legal Issues

The legal response to the issues raised by the withholding or withdrawing of treatment from handicapped newborns is inconsistent (Weir, 1984). Traditional criminal law dictates that anyone who fails to provide ordinary life-sustaining treatment to newborns is subject to criminal liability for murder and/or child abuse. Such traditional law severely restricts the behavior of both parents and physicians. However, Loewy (1987) and others have indicated that traditional law fails to fully address the complexity of the issue, a weakness which was evident in some of the ethical models described above.

Buchanan (1987) described the legal concepts that currently guide the decision-making process for individuals making treatment decisions for incompetents, including handicapped newborns. The Principle of Best Interest states that one should choose treatments which would best serve the patient's interests as they are identified at the time the decision is made. The Principle of Substituted Justice is based on the need for parents to choose treatment which the individual would choose for themselves if capable of understanding the medical options and the condition itself.

According to the President's Commission (1983), the state can assume the power of *parens patriae* to protect children from harm. With such power, the state can punish

parents or invalidate their decision in order to prevent abuse or neglect of the child. However, governments rarely intervene in situations involving withholding of treatment. In such cases, there is a strong presumption that parents have the legal right to make such decisions. Parental wishes that are within the range of reasonable medical treatment are seldom questioned. As evidenced by the Baby Doe decision, courts favor parental decisions even in cases resulting in the death of the child. Parents who follow these principles when making treatment decisions should be, according to Buchanan (1987), free from legal prosecution.

According to applicable laws, physicians can also be liable when care that could save the life of a infant is withheld. Charges that may be brought against physicians in such cases range from murder to involuntary manslaughter. Physicians also face potential prosecution as accessories to murder if they advise parents to withhold treatment. Finally, merely consenting to parental wishes to withhold treatment places the physician in danger of prosecution for neglect and abuse. Weir (1984) indicated that prosecution of physicians in such cases is rare. He suggested that this limited prosecution reflects the presumption of parental authority and responsibility.

Although prosecution in cases of selective non-treatment is rare, the legal debate continues, focusing on three issues. The first is the distinction between ordinary and extraordinary treatment. The distinction is based on the principle that one is legally bound to provide

only a level of care that society would expect. Important considerations in deciding an appropriate level include: the risk to the child, the available treatments, and the potential benefits of the treatments.

A second issue is whether active or passive euthanasia is any different from murdering the child. In most views, euthanasia of either type is considered to be the same as infanticide. Shelp (1986), however, indicated that a trend is developing toward viewing euthanasia as less than murder. These issues will be discussed later.

The final legal issue that is still being debated involves non-maleficence, the principle that protects individuals from harm. Weir (1984) described this debate, which focuses on whether withholding of treatment is sometimes less harmful than continuing the life of the child. Some suggest that there are cases where an infant would be better off dead than alive, as in the case presented earlier involving the infant with the skin disorder. The issues in this debate are as yet unresolved (Loewy, 1987), and the result is confusion and limited legal action.

In summary, the potential exists for criminal prosecution of parents and physicians who participate in the decision to withhold treatment from handicapped newborns. However, prosecution rarely occurs, and decisions of parents are usually honored. Attempts by the Department of Health and Human Services to become actively involved in decisions, such as the Baby Doe regulation described earlier, have been

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In summary, the potential exists for criminal prosecution of parents and physicians who participate in the decision to withhold treatment from handicapped newborns. However, prosecution rarely occurs, and decisions of parents are usually honored. Attempts by the Department of Health and Human Services to become actively involved in decisions, such as the Baby Doe regulation described earlier, have been



unsuccessful to date. If parental decisions continue to be honored, it is essential to better understand the factors that influence those decisions, which is what the present study proposed to do.

## CHAPTER TWO

### MORAL REASONING

Lawrence Kohlberg (1984) proposed a theory of the development of moral reasoning which has relevance to the present study. Kohlberg studied the development of moral reasoning by focusing on the individual's perception of moral situations, evaluating what the individual thinks is right, or what ought to be. Kohlberg was interested in the development of reasoning about justice, which he described as the rights and duties of individuals in society. In assessing moral development, Kohlberg and his associates have focused on what an individual thinks about the behavior of others in a given situation, not how the individual would themselves behave. They designed a model of six stages of moral reasoning, divided into three levels. Progression through these stages is hierarchical. That is, each stage requires and builds on passage through earlier stages, and the sequence is universal and unchanging (Lerner, 1986).

Kohlberg named the first level of moral development the pre-conventional level. As described by Kohlberg and Elfenbein (1975), thoughts about moral conflicts involve assessment of observable events and the punishing or reinforcing consequences of specific behavior. Stage 1 is termed the punishment and obedience orientation. During this stage an act is judged as right or wrong based on its

physical consequences. Blind obedience to a powerful authority figure and avoidance of punishment guide an individual's behavior. During Stage 2, the instrumental relativist orientation, satisfaction of one's own needs determines behavior. Interactions with others are initiated and continue based on the benefits each participant in the interaction receives from the other.

Level 2 is the level of conventional moral reasoning. The expectations of family, friends, and society are seen as critical determinants of behavior. Moral behavior conforms to the rules of others and society. In Stage 3, the good boy-nice girl orientation, the basis is a desire to please others. Behavior which meets the expectations of others, especially the family, and gains their approval is considered good behavior. During Stage 4, the law and order orientation, the rules of society are emphasized in determining behavior. Individuals at this stage believe that rules are necessary to preserve social order, and obedience to those rules is of paramount importance.

The third level of moral reasoning is termed the principled, or postconventional level. Rules of society are not absolute, but are considered relative to the individual's own beliefs and values. Society's need for such rules is acknowledged, but they are valid only in terms of the individual's values. In Stage 5, the social-contract legalistic orientation, there is an implied contract between the individual and society. If one obeys society's rules, one has a right to be treated well by society. Laws can be

changed through formal legal procedures, but until they are changed, they should be obeyed. Stage 6 is termed the universal ethical principle orientation. In this stage one's conscience dictates behavior. Moral behavior is that which is consistent with one's personal set of ethical principles. Abstract rather than concrete principles are evident in this stage, including such concepts as justice, equality of rights and the respect for the dignity of others.

According to Lerner (1986), change from one stage to another is gradual. Consequently, an individual can demonstrate reasoning at more than one level at a given time. What is crucial in determining one's actual level is the frequency with which reasoning representative of each stage is used. A process of disequilibrium initiates passage from one stage to another. In this process, the child recognizes a discrepancy between his/her level of reasoning and the next higher one, and modifies his/her thinking to be consistent with the higher level.

The moral dilemma forms the basis for Kohlberg's system of identifying the stage of moral reasoning. There are 10 components of any moral situation, and in every dilemma at least two of them are in conflict. These components include: punishment and guilt, property, affectional relationships, authority and governance, law, value of life, liberty, distributive justice, truth, and sexual values (Kohlberg & Elfenbein, 1975). At various stages of moral reasoning, one weighs these components differently. In

Kohlberg's original procedure, subjects were given a set of moral dilemmas which involved conflicts between these components. The individual was asked to evaluate the behavior of characters in the dilemmas, and to explain the reasons for their evaluation. Based on the justification provided, a stage of moral reasoning was identified.

One component of Kohlber's model, the value of life, was of particular interest to the present study. Kohlberg and Elfenbein (1975) reviewed the development of reasoning concerning this component of moral situations. In Stage 1, the physical or social status of an individual determines his/her value. Individuals with authority and power to punish are highly valued, others less so. During Stage 2, value of an individual is based on the extent to which that individual satisfies the needs of others. In Stage 3, value is based on family ties and affection, one is valued because he/she is a member of a family. Stage 4 value decisions are based on society's rule that life is sacred. Being alive in itself is valuable because it is part of the natural order of events. In Stage 5, life is valued because it is both a human right and essential to the continuity of the community. An individual's impact on the community is weighed in decisions about the value of life. Finally, in Stage 6, life continues to be seen as sacred, based on a universal principle that life takes precedence over any other value.

The issues addressed in the present study are related to the value of life component of Kohlberg's model or moral

situations. As discussed earlier, value of life decisions have, in some cases, been used to justify the selective non-treatment of newborns with mental retardation. It was expected that the treatment decisions and justifications given by the participants in this study would vary based on their level of moral reasoning.

Kohlberg's theory has been subject to criticism from a variety of sources. Kurtines and Greif (1974) focused on the interviewing and scoring procedures used by Kohlberg to identify an individual's stage of moral reasoning. Specifically, they asserted that instructions for administering and scoring the interviews were not standardized, and were therefore subject to individual interpretation. The content of the interviews varied from one study to another, making it difficult to identify a consistent pattern of responses. The issues discussed led Kurtines & Greif to conclude that the results were unreliable, and that the theory was not based on valid conclusions.

Other criticisms have focused on the perceived bias in Kohlberg's samples. Simpson (1974) attacked the cultural bias of the theory. She asserted that not all cultures have identical principles governing the behavior addressed in the dilemmas. Varying cultures would encourage different reactions to the same dilemma, yet the scoring is not adjusted to reflect the various value systems. Simpson concluded that the theory is biased in favor of middle class American values. Similarly, Carol Gilligan (1982)

identified a sexist bias in Kohlberg's theory. She suggested that because Kohlberg concentrated on males in his research, the results were biased in favor of males. Evidence supporting her contention included generally lower scores on moral development assigned to women. Gilligan suggested that there are two moralities, the first an ethic of care and responsibility that she characterized as a feminine morality. This type of morality was not addressed in Kohlberg's theory. A second type of morality, a male morality, is based on rights and justice, and was the focus of Kohlberg's research. Gilligan (1982) proposed a different model of moral reasoning, one which included both masculine and feminine classes of moral reasoning.

A third group of critics contend that Kohlberg did not present a complete theory of moral development. By focusing on moral reasoning specific to issues of justice, Kohlberg allegedly ignored other important aspects of moral behavior. Lieber (1984) proposed a theory based on the interaction of motivation and experience, expressed as increasing moral sophistication. The basis of this moral sophistication is an increasing grasp of the consequences of one's behavior. Burton (1984) claimed that Kohlberg ignored the conduct component of moral behavior, and offered an alternative model based on the interaction of the behavioral, affective, and cognitive components of behavior. Kurtines (1984) emphasized the effect of context on moral development, stating that both individual differences and attributes of situations influence the course of moral development.

A final group of theorists offered alternatives to Kohlberg's theory based on the social model of development. They deny the existence of cognitively based stages described by Kohlberg, and contend that development is determined by participation in specific social situations, which may include a reinforcement component. For example, Staub (1984) discussed moral development in terms of goal orientation and environmental impact. Hoffman (1984) and Gibbs and Schnell (1975) suggested a theory of development based on socialization, as did others (Nisan, 1984).

Kohlberg responded to some of the criticisms of his theory by modifying it. Levine, Kohlberg, and Hower (1985) summarized the major rebuttals. They expressed strong disagreement with the criticisms based on sexual and cultural bias, suggesting that the critics may have misunderstood the scoring system and contended that there is no bias in the theory. In response to the critics who have argued that there is more to moral reasoning than justice, Kohlberg and his colleagues suggested that his primary purpose was to focus on justice reasoning, but that there are other aspects of moral judgment that need to be studied. In fact, Kohlberg suggested that he and his colleagues had enlarged the scope of their studies to include more aspects of the moral process.

The most relevant controversy generated by Kohlberg's theory is the issue of the relationship between moral reasoning and behavior. As described by Rosen (1980), Kohlberg acknowledged that the relationship between the two



is complex, suggesting that a variety of factors influence behavior in moral situations. When facing a moral dilemma, an individual in a specific stage will be more likely to favor one behavior over another, but it is possible that people at different stages will choose the same behavior. An explanation involves the standards used for judging behavior at the various stages. Individuals at Stages 4-6 base their moral judgments on objective standards or principles rather than on situational factors. More consistency in judgments should be evident at the higher stages than at the lower ones, and this consistency should contribute to a more clear relationship between moral reasoning and behavior.

Two factors were mentioned by Kohlberg and his colleagues as potential influences on the relationship between moral reasoning and behavior. The first involves the nature of the dilemma itself. Kohlberg and Elfenbein (1975) suggested that one can be certain of a relationship only in minor moral dilemmas, which do not involve intense sacrifice. If intense sacrifice is involved, general principles may be ignored in favor of more individual, subjective principles. This factor was of special interest in the present study because of the emotional impact of the basic situation.

The second factor that may influence the relationship between moral reasoning and behavior involves the knowledge of the participant. In a study of attitudes toward capital punishment, Kohlberg and Elfenbein (1975) acknowledged that

the attitudes expressed toward capital punishment were influenced by knowledge of the deterrent effects of punishment. People who knew that capital punishment was not an effective deterrent to crime consistently expressed attitudes against its use while demonstrating different levels of moral development. Despite the mediating factors discussed above, Kohlberg and Elfenbein (1975) contended that there often is a clear relationship between moral reasoning and behavior. The present study evaluated the influence of each of these mediating factors to further clarify the relationship.

Although the relationship between moral reasoning and behavior may be subject to a number of influences, such as those described above, researchers have studied it in a variety of specific situations. To demonstrate the relationship between moral reasoning and behavior, Krebs and Kohlberg (see Rosen, 1980) studied resistance to temptation in 123 sixth graders. The students, mixed for social class and gender, were tested to identify moral stage, cheating, attentional stability, and resistance to temptation. Moral reasoning was most strongly related to resistance to cheating. At stage 5, 80% of the individuals resisted cheating, at Stage 4, 45%, and so on down to Stage 1, where only 19% resisted cheating. Krebs and Kohlberg suggested that this demonstrated the strong relationship between behavior and reasoning at the upper stages of moral development. Kohlberg and Elfenbein (1975) studied the relationship between level of moral reasoning and attitudes

toward capital punishment in a longitudinal study spanning 20 years. They indicated that at Stages 5 and 6 of moral reasoning, there was consistent condemnation of the death penalty.

Other studies have generated support for the presence of a relationship between moral reasoning and behavior. For example, Harris, Mussen, and Rutherford (1976) studied 33 boys in fifth grade, administering a variety of behavioral measures as well as Kohlberg's questionnaire. They found that higher levels of moral reasoning correlated with higher levels of prosocial behavior as rated by peers, and greater resistance to temptation involving cheating. Blasi (1980) reviewed studies relating moral reasoning to such behaviors as delinquency, honesty, smoking marijuana, leadership, human gregariousness, sexual activity, altruistic behavior, and resistance to authority. He concluded that there is strong evidence supporting a relationship between moral reasoning and behavior, and that this relationship varies according to the specific behavior. The relationship was strongest between reasoning and resistance to conforming to others' views, less strong involving honesty and altruism, and weakest involving resisting the tendency to conform one's behavior to the wishes of others.

A number of studies have failed to find evidence in support of the relationship between moral reasoning and behavior. Haan, Smith, and Block (1968) studied 500 California college students and Peace Corps volunteers. They administered a number of attitude and personality

measures, as well as the standard Kohlbergian interview. Profiles were developed of the participants who were assigned to the various stages of moral reasoning. Haan, et al. suggested that personality and attitude similarities between members of the same stage were strong. However, assignment to a specific stage of moral reasoning did not predict behavior. Students who participated in free speech demonstrations came from 2 different stages of moral reasoning. Some participated in the demonstrations because of their moral convictions, while others participated to be part of the crowd. In a second study, Jurs (1984) assessed the relationship between moral reasoning and decisions about birth control and pregnancy in a sample of teen-aged girls. No statistical differences in stage of moral reasoning were found between girls who had been pregnant and those who were never pregnant; those who carefully practiced birth control and those who never did; or those who aborted or who kept unwanted children.

Rest (1984) reviewed the body of literature which failed to find a relationship between moral reasoning and behavior, including attitudes about the right to free speech, civil rights issues, right to due process, and political opinions and concluded that the relationship between moral reasoning and behavior is complex and determined by a number of variables. Individuals differ not only in their levels of moral reasoning, but also in their application of moral principles to a specific situation, and in the level of influence held by their religious beliefs.

## CHAPTER THREE

### ATTITUDES TOWARD AND AWARENESS OF PEOPLE WITH MENTAL RETARDATION

#### Attitudes Toward the Mentally Retarded

Important factors to consider when seeking to understand decisions people make relative to the treatment of children with mental retardation are their attitudes toward and level of knowledge about retardation. Gottlieb (1975) has identified the impact of the general public's attitudes on the welfare of people with retardation. If the public-at-large holds positive attitudes toward those with retardation, the treatment and quality of life for the retarded is improved. Conversely, if the public's attitudes are generally negative, the treatment and quality of life for the retarded suffers. It may be that attitudes also affect specific decisions parents make concerning their newborns with mental retardation. Understanding the attitudes of the public may also provide a framework for program directions and public policy, which are assumed to be based on public attitudes.

It has been suggested by a number of authors that understanding one's attitudes can help understand one's behavior. This assumption is a controversial one. Although intuition favors this assumption, a number of studies have questioned it. An example is the work of La Piere (1934), who accompanied a Chinese couple to 251 restaurants and

motels in various sections of the country. Because of the generally negative attitude toward Orientals in the country at that time, it was expected that La Piere and his guests would be refused service at these establishments. However, service was refused at only one establishment out of the entire sample. Six months later, La Piere sent a letter to the establishments, asking if they would serve a Chinese couple. An overwhelming majority of the establishments responded that they would not serve such a couple. The study has been criticized because of demand characteristics, i.e., the owners' response to the letter may have been influenced by their perception of what they should do to appear consistent with prevailing attitudes (Penner, 1986). Despite the methodological flaw, La Piere's study raised significant questions about attitudes and behavior.

More recent research has questioned the strength of the relationship between attitudes and behavior. Wicker (1969) reviewed the research and concluded that attitudes were a poor predictor of behavior. Recent theoretical models proposed by Ajzen and Fishbein (1980) and others have specified the conditions under which attitudes may nevertheless be valid predictors of behavior. An important consideration is the level of specificity assumed when measuring the attitudes and the expected behavior. Ajzen and Fishbein (1980) suggested that an individual's general attitudes are poor predictors of specific behavior. Therefore, if one is interested in predicting a specific

behavior, one should assess specific attitudes related to that behavior.

Other researchers have discussed a number of factors that influence the relationship between attitudes and behavior. For example, Regan and Fazio (1977) suggested that direct experiences with the object of the attitude increases the consistency of the relationship between the the attitude and behavior. Similarly, the personal relevance of the attitude to individuals, and the tendency of individuals to be consistent in their behavior, influence the strength of relationship between behavior and attitude (Penner, 1986).

Despite the questionable strength of the relationship between attitudes and behavior, an extensive body of literature exists assessing this relationship relative to persons with mental retardation. The attitudes of the public at large, college and high school students, children, and professionals have been studied. Although attitudes in general have been the major focus of these studies, some studies assessed specific attitudes such as reaction to a community residence moving into the neighborhood. Other studies focused on factors that may influence one's attitudes toward people with mental retardation. The results of the research to date are inconclusive, as will be evident from the description below.

Public attitudes toward people with retardation have been investigated in a number of studies. A representative study is that of Roth and Smith (1983), who mailed

questionnaires to residents of Arkansas. They assessed the residents' knowledge of and attitudes toward people with mental retardation in general, and attitudes toward a community residence moving into their neighborhood. Knowledge was assessed in a multiple-choice format, while attitudes were assessed using a five-point Likert scale to indicate level of agreement with a number of statements. Results indicated that the attitudes of the public were generally positive, with the exceptions including an unwillingness to agree that people with mental retardation should marry, and a consensus that few people with retardation are able to live on their own.

Other studies found less positive attitudes expressed by the public-at-large. For example, Gottlieb and Corman (1975) found that a number of people favored segregation of persons with mental retardation from the community-at-large. One factor mentioned in several studies concerned the image the public has that people with retardation are usually physically impaired or abnormal (Budoff, Siperstein, & Conant, 1979; Gottwald, 1970), or that most people with mental retardation are moderately or severely impaired (Gottlieb, 1975). Such misconceptions could have resulted in a more negative set of attitudes toward the retarded in the sample.

Several studies assessed more specific attitudes, reaction to a community residence moving into one's neighborhood. Gottlieb and Corman (1975), in their study described earlier, assessed people's attitudes toward



integration of people with retardation in the community. They found that older people, parents of school-aged children, and people with little or no prior experience with people with retardation favored segregation of them from the rest of the community.

Cnaan, Adler, and Ramot (1986) studied public reaction to establishment of community residences in Israel. They assessed attitudes in general as well as specific reactions to the planned move, and the projected behavior of the respondents. A variety of both positive and negative attitudes were expressed, ranging from acceptance to rejection of people with retardation and from support to opposition towards the planned residence. Consistent with Ajzen and Fishbein's (1980) suggestion that specific attitudes predict specific behavior, Cnaan et al. developed a 3-component model for identifying the relationships between attitudes toward people with mental retardation and support of community residences. According to this model, people have a general set of attitudes which generated a specific set attitudes in reaction to a specific problem. In this case, one's general attitudes toward others encouraged a specific set of attitudes toward those with retardation in reaction to a specific issue, the planned establishment of a community residence in the neighborhood.

Children's attitudes toward their peers with mental retardation have frequently been studied, focusing of reactions to educable retarded children. As with assessment

of public attitudes, a variety of techniques and results are evident. Several studies have used sociometric techniques, that is, asking students to rank classmates, or to describe their feelings toward classmates in ways that can be systematically analyzed (Johnson, 1950; Miller, 1956). These studies found little evidence of social acceptance of peers with retardation. Attitudinal studies have reported the same variety of results. Some studies have reported that peers were more accepting of the mentally retarded than indicated in the sociometric studies (Clark, 1966). Others have found similar negative reaction to those with retardation (Bak & Siperstein, 1987a).

A number of factors have been identified as influences on the attitudes of children toward their peers with mental retardation. Attitudes were found to vary according to situation. For example, Gottlieb (1971) found that attitudes were more positive in play settings than in work settings. Retarded peers who demonstrated or were described as possessing relatively high levels of competence were favorably judged, while low competence individuals generated negative attitudes (Bak & Siperstein, 1987b; Johnson et al., 1986; Siperstein, Bak, & Gottlieb, 1977). The higher the level of verbal aggression observed, the more negative response was reported (Gottlieb, 1973). Finally, perceived similarity has been found to influence a child's attitude toward a peer with mental retardation. The more similar the non-retarded child perceived the mentally retarded child to

be, the more positive the expressed attitudes (Siperstein & Chatillon, 1982).

A final class of people whose attitudes toward people with retardation have been assessed are professionals and students majoring in human services or education. For example, Efron and Efron (1967) compared the attitudes of teachers and students in special and regular education with those of professionals and students in other majors. They asked the participants to provide written evaluations of educable mentally retarded individuals, focusing on six factors (institutionalization, cultural deprivation as a cause, non-condemnatory etiology, personal exclusion, authoritarianism, and hopelessness). Teachers and students in special education expressed significantly more favorable attitudes than did the others. In an earlier study, Semmel (1959) compared regular and special class teacher attitudes and knowledge about retardation. They found that the special class teachers had more accurate knowledge about retardation, but that there was no significant difference between the groups in attitudes toward those with mental retardation.

A number of studies reviewed above evaluated the influence of specific factors on attitudes toward people with mental retardation. Females tend to be more accepting than do males (Gottlieb & Corman, 1975; Greenbaum & Wang, 1965). Younger people tend to be more accepting than do older people (Gottwald, 1970; Hollinger & Jones, 1970). The impact of experience with the mentally retarded has been

assessed in several studies. Yeates and Weisz (1985) found that professional experiences with the retarded diminished the impact of labeling. Begab (1970) studied the relationship between knowledge and prior experiences and attitudes expressed by social work student. It was found that life experiences were more significant influences on attitudes than were age, sex, and religious affiliation. Hagen et al. (1983) assessed the impact of experience on attitudes toward people with retardation expressed by college students majoring in special education, education, and social work. Work experience, family relations, or acquaintances with mental retardation did not impact attitudes. Finally, Williams (1986) studied the effect of contact on college students, who were asked to compare retarded and non-retarded persons on 18 personality trait characteristics. Level of exposure was not found to have a significant impact on the students' ratings.

As described earlier, Regan and Fazio (1977) suggested that direct experience with the object of an attitude can affect attitudes. There is much inconsistency in the research relative to the effects of contact on attitudes toward people with mental retardation. Some researchers reported no effect, while others reported either a positive or a negative effect. The present study assessed the influence of contact on specific attitudes, that being the tendency to choose specific treatments for newborns with retardation.

Several concerns have been addressed relative to research on attitudes toward people with mental retardation. A variety of techniques have been used to identify the attitudes of the public concerning the mentally retarded. Adjective checklists similar to that designed by Gough (1952) and other have been extensively used (Jaffee, 1966; Hagen, Powell, & Adams, 1983; Johnson, Sigelman, & Falkenberg, 1986; Siperstein, Bak, & Gottlieb, 1985; Siperstein & Chatillon, 1982; Williams, 1986). Other tools that have been used include the Semantic Differential (Jaffee, 1966; Greenbaum & Wang, 1965), the Friendship Activity Scale (Siperstein, Bak, and Gottlieb, 1985), the Work and Play Rating Scale (Johnson et al., 1986), open ended questions about the mentally retarded (Budoff et al., 1979; Gottlieb & Corman, 1975), and interviews with the respondent (Cnaan, 1986). This variety of techniques makes interpretation difficult.

An important issue discussed by Gottlieb (1975) is that of the object referent. His argument was that the definition of mental retardation may be a significant factor in the attitudes expressed. That is, attitudes may be different toward a child with mild retardation than they would be toward an adult with severe retardation. The definition of retardation in attitude research has ranged from the abstract, e.g. "mentally retarded individual" to very specific, e.g. a case description being provided. Because retardation has been inconsistently defined in the research, the expressed attitudes may be the result of

misinformation, assumption, stereotypes, etc. A number of authors in addition to Gottlieb have discussed this issue (Roth & Smith, 1983; Jaffee, 1966). The need to clarify the object referent is especially important because of the tendency for the public to associate mental retardation with moderate or severe impairment, even though most who have retardation are mildly impaired.

The weaknesses of the research relative to attitudes are numerous. The issue of the object referent discussed above as well as the variety of techniques used to assess attitudes makes the interpretation of the studies difficult. Additionally, the nature of the relationship between attitudes and behavior is problematic. It is important to understand the relationship between attitudes and behavior, especially as it relates to the treatment choices made by the participants in the present study.

#### Level of Knowledge about Mental Retardation

As discussed earlier, several researchers found a relationship between level of knowledge about the mentally retarded and the attitudes expressed (Gottwals, 1970; Budoff, et al., 1979). Further, many people have an inaccurate image of mental retardation (Budoff, et al., 1979; Gottlieb, 1975), which may have been related to the negative attitudes they expressed. It is important to assess the level of understanding one has about mental retardation to more completely understand the treatment decisions they make. If decisions are based misinformation, public education efforts may be required.

A related issue concerns the judgments people make relative to the quality of life people with retardation have. As was discussed earlier, one of the major theoretical models for deciding the fate of infants is based on projected quality of life. This model has been used to justify withholding or withdrawing treatment by Duff & Campbell (1973) among others. It is important to identify the accuracy of their projection, especially because of the misinformation identified above. Further, the President's Commission (1983) indicated that in some cases, the parents' assessment of expected quality of life was wrong. Again, identification of an individual's quality of life predicted for the mentally retarded may help explain the decisions made relative to treatment.

## CHAPTER FOUR

### METHODS

The purpose of the present study was to identify the nature of the relation between a number of variables and the treatment choice made by the participants on behalf of newborns with mental retardation and life-threatening medical disorders. Understanding decisions made at the individual level may supplement the ethical, legal, and public policy insights that have been reviewed in earlier chapters. Additionally, important issues to be considered while counseling parents at the time such decisions are needed may be identified, enabling hospital staff to more fully assist parents. Finally, identification of these factors may also help illuminate problems in the decision-making process, such as misconceptions about the nature of or quality of life for individuals with mental retardation.

A second purpose of the present study was to identify changes in treatment choice as additional information was presented. The President's Commission (1983) reported that many decisions concerning treatment of handicapped newborns were based on incomplete or inaccurate information. Identification of changes in treatment choice with new information would provide valuable insight into the amount of information parents may require in similar situations.



An additional purpose was to provide an evaluation of a major component of Kohlberg's theory of moral development. The component of the theory evaluated was the suggestion that differences in level of moral reasoning may be related to differences in behavior. Specifically, the impact of differences in moral reasoning on treatment decisions for newborns with retardation in simulated situations was studied.

The general hypothesis of this study was that treatment decisions made by the participants would be related to the variables listed below:

1. Level of moral reasoning
2. Attitudes toward people with mental retardation
3. Prediction of the quality of life for persons with mental retardation
4. Knowledge of the nature and consequences of mental retardation
5. Prior experience with persons with retardation
6. Level of retardation of the infant in question
7. Ethical principle guiding treatment choice
8. Religious affiliation

#### Dependent Variables

The dependent variables were the levels of treatment a participant chose for an infant described in a short vignette (see Appendix B, page 143). The vignette described an infant born with brain damage caused by hypoxia, and the level of retardation varied from mild to profound. One fourth of the participants read vignettes describing each of

the four levels of retardation. Descriptions of the levels of retardation were adapted from the definitions currently used by the American Association on Mental Retardation (Grossman, 1983). All other content of the vignettes was standardized to reduce the possible effects of prior exposure to specific disorders, (e.g., Down's Syndrome), differential reaction to male and female infants, etc.

Vignettes involving simulated situations were chosen as the method for studying treatment choice for several reasons. First, finding a large enough sample of parents who had faced the actual choice would be difficult and time-consuming. Second, if parents were identified, asking them to re-live the emotionally difficult situation by participating in this research would be ethically unsound. Previous studies addressing similar issues have used a similar format (Shelley, Zahorchak, & Gambrill, 1987; Sugarman, 1986). It was assumed that the information derived from the present study would provide a model for studying such issues more directly in the future. The choice of young adults of child-bearing age who may eventually face such decisions in reality was expected to increase the usefulness of the results.

The impact of additional information on treatment decisions was evaluated in the present study. Participants were provided with supplemental information regarding the newborn's treatment and were again asked to indicate which treatment they would choose. The supplemental information included details about the medical risks and the costs of

the treatment. I attempted to study the level of resistance to change in the participants and the specific type of information that would lead to change.

#### Independent Variables and Assessment

There were eight independent variables in this study as follows:

##### Level of Moral Reasoning

As described earlier, moral reasoning may be a significant predictor of the treatment decision a person makes. Moral reasoning was judged an appropriate factor to study for two reasons. The first involves one of the basic ethical issues assumed to be addressed in situation similar to the one of interest in the present study, the value of life. This issue is one of the 10 components of moral situations identified by Kohlberg and Elfenbein (1975), who also offered a model of how individuals at each stage of moral reasoning would evaluate this component. It was felt that assessing the evidence for such a pattern of thinking as reflected in the treatment decisions made would evaluate the accuracy of Kohlberg and Elfenbein's model.

The second justification for testing Kohlberg's model as a predictor of treatment decisions relates to the impact of the theory. Although Kohlberg admitted that the theory was flawed and incomplete (1984), he and his associates have continued to develop and modify it. Any research that properly addresses moral issues must acknowledge the significance of the theory and evaluate it as it relates to the research questions of interest. It was predicted that

as individuals demonstrated higher levels of principled reasoning, evidence of Stage 5 or 6 thinking, they would be more likely to choose full treatment for the newborn. This was based on Stage 5 and 6 behaviors predicted by Kohlberg and Elfenbein and described earlier.

The Defining Issues Test (DIT) of Rest was used to assess level of moral reasoning (Appendix B, pages 125-139). The DIT was designed to offer a simple method of identifying level of moral reasoning. Its basic assumption is that at different levels of moral reasoning, people assign different weights to the components of a moral dilemma. These assignments will be evident in the choice of statements representing the most important issue in a dilemma.

The DIT describes six moral dilemmas, chosen after extensive reliability studies. Subjects read about a dilemma and are asked to decide what the character facing the dilemmas should do. They then evaluate twelve issue statements as to their significance in reaching a decision concerning the dilemma. Subjects are also asked to rank the four most significant statements. Scoring of the DIT in the present study was based on the P-index, one of several scoring protocols for the DIT. The P-index indicates the relative importance of Stage 5 and 6 statements in evaluating the dilemmas, and is expressed as a percentage, the range of which is 0 to 95.

The DIT has built-in safeguards to protect against the major threats to validity often evident in this type of research. Random checking of answers by subjects is

identified by a consistency check, and evidence of demand characteristics is checked by use of formal-sounding yet illogical answers strategically placed throughout the test. The DIT has been subjected to intensive reliability assessment with excellent results [test-retest reliability in the .70-.80 range; internal reliability the same (Rest, 1984)].

The DIT addresses a concern expressed by some authors pertaining to Kohlberg's stage model of moral reasoning. Specifically, it may be that individuals at different levels of moral reasoning identified on Kohlberg's original assessment tool would choose the same treatment level, but for different reasons. This was identified as a problem in the study by Haan et al. (1968), who found that students participated in anti-war demonstrations for reasons attributed to Stage 5 moral reasoning in some cases, and to Stage 3 in others.

The use of the DIT addressed these concerns. The P-index of the DIT indicates the extent to which an individual uses Stage 5 or 6 reasoning to reach decisions about a dilemma. The DIT does not suggest that an individual is "in" a particular stage. This scoring format is consistent with Kohlberg's claim that progression from one stage to another is gradual, and that the elements of more than one stage are sometimes evident in individuals. It is both possible and acceptable that individuals with varying scores on the P-index of the DIT would choose the same level of treatment. Such an occurrence would be

evidence that this type of moral situation is one of those for which an individual is reasoning at a higher (or lower) level than for most other situations.

The pattern of relationship between moral level and treatment choice was of interest in the present study. Evidence for a consistent relation would support Kohlberg's contention that reasoning can predict behavior in some cases. For example, if people who demonstrated high P-index scores on the DIT also chose high levels of treatment, the suggestion would be that a relation exists as Kohlberg predicted. On the other hand, if people with a wide range of P-index scores chose high levels of treatment, then level of moral reasoning would not be considered a good predictor. The suggestion would be that this type of behavior would be better predicted by other factors.

#### Attitudes Toward People with Mental Retardation

Because of the assumption that attitudes predict behavior to at least some degree, it was judged appropriate to study this relationship. Two of the major methodological concerns discussed in the review of the literature were addressed in the present study in an attempt to more accurately assess the relationship between attitudes and behavior. The definition of the object referent, individuals with mental retardation, was specifically stated (see Appendix B, page 142). The definition used was the one currently accepted by the American Association on Mental Retardation, as described in the most recent publication (Grossman, 1983). Use of a specific definition was expected

to diminish the possibility of misleading results caused by a confusing object referent as mentioned by Gottlieb (1971) and others.

The controversial assumption of a relationship between attitudes and behavior was a reasonable one to make for the present study. As described by Ajzen and Fishbein (1980), the strongest such relationships are evident between specific attitudes and specific, related behaviors. In the present study, the attitudes expressed were specifically focused on individuals with mental retardation. Similarly, the behavior in question was specific, choice of treatment in a specific medical situation involving a newborn with mental retardation.

It was predicted that as the attitudes expressed toward people with retardation became more positive, a choice of full treatment would be more likely. This was based on the work of Gottlieb (1975), who suggested that as attitudes toward the retarded improve, the care and acceptance of the individual also improves.

An Adjective Checklist designed by Rokeach (1973) and modified by Williams (1986) was used to assess the attitudes of the participants toward people with mental retardation (Appendix B, page 142). The Adjective Checklist has been used in a number of studies concerning attitudes toward the mentally retarded and other groups. It is an eighteen-item checklist, and has been determined to correlate well with similar attitude assessments (Williams, 1986). One of the problems identified with this type of assessment involves

the issue of the object referent discussed above. It is expected that a clear definition of the object referent will increase the validity of the Adjective Checklist.

#### Quality of Life Predictions

As discussed earlier, the quality of life one predicts for the newborn in question may be an important factor in the decision-making process. However, the President's Commission (1983) suggested that many times, the predicted quality of life is incorrect. Most often the error is in the direction of predicting a less favorable quality of life than can reasonably be expected based on the extent of the infant's disability. Gottlieb (1975) first identified this underestimation of the quality of life by the public-at-large and suggested it was a factor contributing to negative attitudes toward people with retardation. It seemed essential that the accuracy of the predicted quality of life be assessed in the present sample. The components of quality of life described by Powell and Hecimovic (1985) were the basis of this assessment. The specific prediction was that the more favorable the quality of life predicted for the child, the more likely the participant would choose full treatment.

#### Information About People with Mental Retardation

The literature reviewed suggested that one's level of knowledge about persons with retardation influences attitudes toward them (Roth & Smith, 1983; Begab, 1970). If attitudes are related to behavior, the treatment choice may be influenced. Assessment of the level of knowledge was



expected to further clarify the decision-making process. It was also expected to identify any consistently inaccurate conceptions about the nature and needs of those with retardation. It was predicted that the more accurate one's knowledge of mental retardation, the more likely the choice would be in favor of full treatment.

No standardized assessments were found in the review of the literature for assessing one's knowledge about, and quality of life projections for, individuals with mental retardation. Instruments were designed to serve that purpose in this study. Items for the Knowledge scale were included based on the following procedure. The knowledge assessments of Cnaan et al. (1986), Efron and Efron (1967), and Roth and Smith (1983) were reviewed. Items from those knowledge assessments were included if they were loaded heavily in factor analyses (factor loading  $>.40$ ) or had high reliability coefficients (above  $.40$ ) in the original studies. A pilot study was conducted using 44 items which met one of these criteria. Reliability coefficients were computed and 15 items were determined acceptable ( $r >.40$ ) for the final version of the questionnaire. (see Appendix B, page 141).

The items for the quality of life projections were chosen from a number of sources as well. The basis for choosing items was Powell and Hecimovic's (1986) description of the components of quality of life most appropriate to retarded individuals. These components were: educability, relationships, ideal residence situation, access to

essential services, impact of technology on the disability, and medical status. Some of the attitude assessments reviewed included items which were judged to be related to the quality of life as described by Powell and Hecimovic. Other items were selected from the Sickness Impact Profile (Gilson et al., 1975). Consistent with Powell and Hecimovic's hypothesis, it was expected that 5 factors would be identified in the quality of life questionnaire.

The main concern about the use of an assessment tool that has not been validated is that the results cannot be generalized to other populations. Similarly, poor reliability coefficients were possible in the final analysis. Despite these potential flaws, it was expected that the knowledge assessment and quality of life projections would provide useful information. At the very least, evidence concerning the practicality of these two tools would result.

#### Level of Prior Contact with People with Retardation

The literature reviewed identified inconsistent results concerning the influence of this factor on the attitudes toward people with retardation (Willias, 1986; Hagen et al., 1983). However, Regan and Fazio (1977) suggested that this was an important factor, one that strengthens the relationship between attitudes and behavior. They suggested that attitudes based on direct interaction with the subject of the attitude would show a consistent relation with behavior toward that individual. Attitudes formed by other means such as indirect or no contact would relate poorly

with behavior. The relation of direct prior experience and attitude toward people with mental retardation was assessed in the present study. It was predicted that the more contact a participant previously had with the retarded, the more likely they would be to choose full treatment.

Level of prior contact with persons with metal retardation was assessed as follows. Participants were asked to identify the types of involvement they previously had with individuals with retardation. A list of types of contact was provided, and the participants were asked to check the appropriate ones. A summed score of the values of each of these items checked was generated, with the range from 0 to 10. Values for types of contact were decided based on level of interaction the contact would provide as follows:

Casual contact (1 point; includes such contact as a child seen at school, a resident of the same town seen occasionally). The point value was based on the assumption that the contact would be incidental with little meaningful interaction.

Close contact (2 points; includes family other than immediate, neighbors, a member of a friend's immediate family). The point value was based on the assumption that this would be a more frequent, in-depth contact, and that the retarded individual would be discussed with informed individuals.

Continuous or trained contact (3 points; includes working in programs or care-giving situations with retarded

individuals, having an immediate family member with retardation). The point value was based on the assumption that these situations would provide opportunities for in-depth interaction with and discussion and learning opportunities concerning the retarded individual.

Additionally, participants were asked to identify any other type of contact not listed. Only thirteen participants took advantage of this option, so their answers were not included in the final analysis.

#### Level of Retardation

Several researchers reported that level of retardation affected the attitudes expressed concerning people with retardation (Gottlieb, 1971; Johnson et al., 1986; Siperstein, Bak, and Gottlieb, 1977). Shepperdson (1983) interviewed parents of children with Down's Syndrome to assess their opinions on abortion and euthanasia. One of the questions asked whether normal treatment should be given to all handicapped babies. Forty-eight per cent of the parents responding indicated that not all handicapped infants should be kept alive at all costs. Shepperdson reported that "almost half" of these parents used the degree of handicap of the child as the basic criterion upon which they based their decision. The more severely handicapped the child would be, the more willing the parents were to accept euthanasia. The study had several flaws including poor definition of normal treatment and levels of retardation, and no statistical analyses were reported. The

results of this study, however, encourage further investigation.

Several of the ethical and legal positions described earlier used such concepts as intelligence, potential to relate with others, and self-consciousness. Significantly, people with varying levels of retardation differ in their achievement in each of these domains (Grossman, 1983). It was appropriate to assume that such differences reflected in the vignette would influence the treatment decisions made, as they have affected the ethical and legal decisions that have been described earlier. It was predicted that as the level of retardation became more severe, the treatment choice would be less aggressive.

#### Ethical Justification

As described earlier, the justifications proposed by various ethical theories regarding the care of handicapped newborns address the issue differently. For example, the sanctity-of-life position supports life at any cost, which should be represented in the choice of full treatment in the present study. The decision-based models such as personhood and quality-of-life, would support full treatment of handicapped newborns in some situations, but would withhold or withdraw treatment in others. It was expected that the participants would be able to identify which justification they used to make their decision if the various justifications were described to them. It was also anticipated that the treatment choice would be related to ethical position. Specifically, it was predicted that

individuals choosing the full treatment option would identify the sanctity-of-life position as the one most descriptive of their thinking. It was further predicted that participants choosing less than full treatment would identify an ethical position other than sanctity-of-life as most representative of their thinking.

Participants were asked to identify their ethical justification for their treatment decision (Appendix B, page 147). Summary statements were prepared for each of the following ethical positions described earlier: sanctity-of-life, personhood, utilitarian, extraordinary means, and quality-of-life. The summary statements were based on the descriptions of each ethical position provided by Van de Veer (1987) and Shelp (1986). Participants were asked to identify which statement best represented their position. An opportunity was provided for the participants to describe their justification if it was not represented in the five summary statements. These self-portrayals were not included in the final analyses.

#### Religious Affiliation

The teaching of various religious denominations have included the issue of treatment of handicapped newborns (President's Commission, 1983). Similarly, Shelp (1986) described the impact that religious beliefs had on the decisions parents made in actual cases. Zuk (1959) found that Catholic parents of children with Down's Syndrome were more accepting of their disabled offspring than were parents with other religious affiliation. It was expected that

religious affiliation would also influence treatment choice in the present sample. Specifically, it was predicted that participants who were Catholic were be more likely to choose full treatment than participants with another religious affiliation.

A standard demographic format was used to assess the religious affiliation of the participants (Appendix B, page 140). A Likert-type scale was used to assess level of religiosity, with values ranging from 1 (not religious at all) to 5 (very religious).

The impact of additional information on treatment choices was assessed by providing three supplemental questions and asking for treatment choices after each (Appendix B, pages 145-146). In the first supplement, participants were told that the surgery described in the vignette was risky, and that medical complications develop in about 10% of the cases. The participants were asked to assume that complications had developed and were then asked to decide whether or not to continue treatment. This supplementary question was answered only by those who had chosen to offer full treatment, including surgery, in the first question. The second and third supplementary questions involved the high cost of treatment in cases similar to the one described in the present study. Participants were told that full treatment, including surgery and extensive post-operative care, would cost between \$50,000 and \$150,000 (Weir, 1984). They were told initially that they did not have insurance to cover the

expense of the treatment. Participants were then told that they did have insurance covering the infant's treatment. In both cases, participants were asked how much money they would commit to the child's treatment, ranging from whatever is necessary to a limit specified by the participant.

Information from these supplementary questions was expected to provide additional insight into the influence of issues crucial to the decision-based ethical positions described earlier. Specifically, if such issues as harmful, futile, or very complex treatment or the severe financial burden such treatment would place on the family or on insurance companies were deciding factors, it was expected that treatment decisions would change. If such issues as preserving life at all costs were crucial, responses would not change as more information was provided.

A further point concerning the pattern of treatment choices related to the President's Commission (1983) statement that such choices were often based on incomplete or incorrect information. It was considered important to assess the effect additional information would have on the participants. If treatment choice changed as more information was provided, the impact would be obvious on the counseling provided to parents in these situations. It would be most appropriate to provide maximum levels of information before the decision was made.



Procedure

Three hundred sixty students (152 males, 208 females) in introductory psychology participated in the study as partial fulfillment of the course requirements. The students participated in a two-hour session with 50-60 other students. The procedures of the session were described, and a warning was given concerning the sensitive nature of some of the issues to be addressed. Students were given the option of not participating if they were concerned about their reaction to these issues, and one student chose not to participate. The participants were then handed a packet of questionnaires, which were assembled in the following sequence: (See Appendix B for a sample):

1. Defining Issues Test
2. Demographic Survey (included prior experience with the retarded and religious information)
3. Knowledge Assessment
4. Attitude Assessment
5. Basic Vignette and Treatment Choices
6. Supplemental Information and Treatment Choices
7. Ethical Justification survey
8. Quality of Life Projection

## CHAPTER FIVE

### RESULTS

Participants' understanding of the situation described in the vignette was assessed by asking four questions about its specific details. Participants were asked to identify the nature of the infant's medical condition, the medical intervention needed, the level of retardation predicted for the infant, and the projected skills and deficits the infant would possess as it grew up. Participants' answers were scored as correct or incorrect. Twenty participants answered two or more of the questions incorrectly and four did not answer any of the questions. These 24 participants were eliminated from further analyses. Additionally, 32 participants were eliminated because of the consistency checks on the DIT, and 3 were eliminated by the consistency check described earlier for the Adjective Checklist. After these procedures, a total of 301 participants were included in the final analyses. Refer to Table 1 for a demographic profile of these participants.

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Insert Table 1 Here  
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Reliability analyses (Cronbach & Gleser, 1953) were performed on the items in the Knowledge Scale and on the Quality of Life Scale. A Cronbach alpha model was used and

the corrected item correlations in the Knowledge Scale ranged from .63 for item 9 to .86 for item 3. The reliability coefficient for the Scale was .93. The corrected item correlations in the Quality of Life Scale ranged from .64 for item 13 to .75 for item 11, with a reliability of the Scale of .95.

A factor analysis (Harman, 1967) of the Quality of Life Scale was performed. It had been expected that the five components of Powell and Hecimovic's (1985) model of the quality of life for retarded individuals would be identified in the analysis. However, a single factor was derived as a result of the analysis. A principal components analysis was used with varimax rotation using SPSSX (Norusis, 1985).

To confirm that the levels of retardation were randomly distributed, correlations were calculated between level of retardation and several of the independent variables. These included the DIT, Knowledge Assessment, Attitude, Prior Experience with the Retarded, and Religious Affiliation. These variables were chosen because they were assessed prior to presentation of the vignette. A significant correlation would suggest that assignment of levels of retardation was related to performance on one of these variables. None of the correlations were significant at the .05 level.

#### Basic Treatment Choice

A number of chi square tests were performed to analyze the relations between treatment choice in the basic vignette and performance on the categorical independent variables.

Because of low frequencies in some cells, variables were collapsed as follows prior to the analysis:

1. Basic treatment choice was collapsed from four choices to two: Full (the last choice offered in the vignettes) and Conditional (any of the first three choices offered in the vignette).

2. The Sanctity-of-Life and Personhood ethical justifications were not changed. The other ethical positions - quality of life, extraordinary measures, and utilitarian - were combined into one group (Other Ethical Position).

3. The Catholic religious affiliation remained a single variable. All other religious affiliations (Protestant, Jewish, and None) were combined into a single group (Other Religious affiliation).

The initial chi square analysis assessed the relation between ethical position and treatment choice. There was a significant relation [chi square (2) = 67.46;  $p < .01$ ; Cramer's  $V = .47$ ]. The pattern of response is summarized in Table 2. From the Table it is evident that more people who chose the Sanctity-Of-Life ethical justification selected Full treatment than expected by chance. In fact, only 1 of 131 participants chose Conditional treatment. Those who selected the other ethical positions were more likely to choose Conditional treatment than expected by chance, and were less likely to choose Full treatment.

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Insert Table 2 Here  
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To further describe the relation between treatment choice and ethical position, level of retardation was controlled. Again, to minimize the number of cells with expected frequency less than 5, the four levels of retardation were collapsed to only two, mild/moderate and severe/profound. Refer to Table 3 for specific details.

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Insert Table 3 Here  
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There was a significant relation between treatment choice and ethical position at mild/moderate levels of retardation [chi square (1) = 8.86;  $p < .05$ ; Phi = .24]. Specifically, fewer people who adopted Other Ethical position chose Full treatment, while more than expected by chance chose Conditional treatment. Adoption of the Sanctity-of-Life position was also related to treatment choice. None of those who adopted this position chose Conditional treatment, while more than expected by chance chose Full treatment.

There was also a significant relation between treatment choice and ethical position at severe/profound levels of retardation [chi square (1) = 43.66;  $p < .05$ ; phi = .54]. More people adopting the Sanctity-of-Life position chose Full treatment, while fewer people than expected by chance chose Conditional treatment. Participants adopting Other Ethical Position chose Full treatment less frequently than expected

by chance, but more selected Conditional treatment than was expected by chance.

An additional chi square procedure was performed to identify the relation between religious affiliation and treatment choice. Table 4 summarizes the pattern of religious affiliation and treatment choice. The relation was not statistically significant [chi square (1) = 1.49;  $p > .10$ ;  $\phi = .08$ ].

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Insert Table 4 Here  
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To identify the relation between treatment choice, quality of life predictions, and ethical position, additional chi square analyses were performed. As in the above analyses, the variables were collapsed to compensate for the occurrence of cells with expected frequencies less than five. For the present analysis, quality of life predictions were grouped into three levels: poor (scores ranging from 0 to 30), fair (31 to 44), and good (45 to 58).

Table 5 summarizes the pattern of relation between treatment choice and quality of life projection within each ethical group. Because only one member of the Sanctity-of-Life group chose Conditional treatment, this group was not included in the analysis. It is interesting to note that ninety-two of these participants projected a fair or poor quality of life and none of them selected Conditional treatment.

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Insert Table 5 Here  
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There was a significant relation between quality of life projection and treatment choice in the Other Ethical Position group [chi square (2) = 54.69;  $p < .05$ ; Cramer's V = .59]. More people in this group who predicted poor or fair quality of life chose Conditional treatment than was expected by chance. Fewer who projected a good quality of life for the infant chose Conditional treatment.

The influence of the continuous independent variables on treatment choice was assessed using a MANOVA (Bock, 1975). Differences on these variables between people who chose Full or Conditional treatment was analyzed. These groups were compared on the following continuous variables: DIT score, Quality of Life Projection, Knowledge about Retardation; Prior Experience with the retarded, Attitudes Toward the retarded; and Level of Religiosity. The multivariate test (Wilk's) was significant [ $F(6, 279) = 24.78$ ;  $p < .01$ ]. The two treatment groups differed significantly on quality of life projection [ $F(1, 284) = 129.97$ ;  $p < .01$ ], Level of Religiosity [ $F(1, 284) = 11.62$ ;  $p < .01$ ], and Prior Experience with the retarded [ $F(1, 284) = 4.22$ ;  $p < .05$ ]. Refer to Table 6 for more details.

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Insert Table 6 Here  
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A large percentage (43.5%) of the participants selected Sanctity-of-Life as their ethical justification. Since Sanctity-of-Life was related to treatment choice, further analysis of this ethical position was done. Specifically, a MANOVA was performed to identify whether the Sanctity-of-Life group differed from the Other Ethical Position groups on any of the other independent variables. The performance of the groups is summarized in Table 7.

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Insert Table 7 Here

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The multivariate test (Wilk's) was significant [F (6,281) = 6.32;  $p < .01$ ]. Further analysis indicated that the Sanctity-of-Life group differed significantly from the non-Sanctity-of-Life group on Quality of Life projection [F (1,286) = 24.57;  $p < .01$ ], on Level of Religiosity [F (1,286) = 12.25;  $p < .01$ ], and on Prior Experience with the retarded [F (1,286) = 3.98;  $p < .05$ ]. Refer to Table 8 for more details.

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Insert Table 8 Here

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#### Relations Among the Independent Variables

A series of correlation analyses (Lindeman, Merenda, & Gold, 1980) were performed to identify the relations between several of the independent variables which had been found to be related in previous studies. These variables were: Attitudes toward people with mental retardation, Prior



Experience with those with retardation, and Knowledge about retardation. Table 9 summarizes the results of these analyses.

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Insert Table 9 Here  
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The relationship between score on the DIT and the independent variables is also summarized in Table 9. Only DIT and Knowledge were significantly related ( $r = .166$ ;  $p < .05$ ). The relation between the score on the DIT and Gender was also analyzed with a chi square procedure. Prior to the analysis, scores on the DIT were re-coded to three levels (0-30; 31-60, and 61-90). There was no significant relation between DIT and Gender, or between DIT, Gender, and treatment choice. Similarly, a oneway analysis of variance (Lindeman, Merenda, & Gold, 1980) failed to demonstrate any differences in the DIT score based on ethical position.

A oneway analysis of variance indicated that Quality of Life projections were significantly related to levels of retardation. Participats reading vignettes involving each of the four levels of retardation differed significantly on Quality of Life projections [ $F (3,301) = 26.25$ ;  $p < .01$ ]. Scheffe post hoc multiple range tests indicated that each group was significantly different from the others on Quality of Life projectin, with the exception of group 3 (severe) and group 4 (profound). These results suggest that newborns with milder forms of retardation were given higher Quality

of Life projections than newborns with more severe retardation. Refer to Table 10 for specific details.

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Insert Table 10 Here  
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#### Changes in Treatment Choice

The second question of interest in this study involved the changes in treatment choice as additional information was provided to the participant. To identify the relations between treatment choice in the Basic situation and subsequent choices, correlations were computed. The correlations between treatment choices were all non-significant (range from  $-.02$  for Basic Treatment and Complications to  $.05$  for Basic Treatment and No Insurance). These results suggest that treatment choice in the Basic situation did not relate to the treatment choices in subsequent situations. The relation between changes in treatment choice and ethical position was then studied, because ethical positions were related to the original treatment choice in the earlier chi square analyses.

Some interesting patterns of change in treatment choice were evident as additional information was provided. Two hundred twenty-three participants chose Full treatment in the Basic treatment situation. Sixty-three modified their choice after additional information was provided. Table 11 summarizes the changes.

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Insert Table 11 Here  
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When ethical positions were considered, the patterns of change became more specific. Table 12 summarizes the changes within each ethical justification group.

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Insert Table 12 Here  
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I performed chi square tests to identify the relation between treatment choices and the new information that was provided. Specifically, I evaluated the relation between individuals within each ethical position and their pattern of treatment choice after each of the three supplemental statements. Because of the presence of several cells with expected frequencies less than five, Personhood and Other Ethical position were combined into a single group. This allowed two ethical positions to be used in the analysis, Sanctity-of-Life and Other. Refer to Table 13 for specific details.

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Insert Table 13 Here  
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The only significant relation between new information and treatment choice was in response to development of complications [chi square (1) = 5.91;  $p < .05$ ;  $\phi = .16$ ]. Specifically, more people than expected by chance who adopted Other Ethical position changed from Full to

Conditional treatment after learning of complications. Participants who adopted the Sanctity-of-Life position were less likely to change after learning about the development of complications than would be expected by chance. The results also suggest that participants choosing the Sanctity-of-Life position were less likely to change their treatment choice at all than were those adopting other ethical positions.

Thirty-five participants filled in the blank to indicate a specific amount of money they would commit for treatment in the No Insurance condition. The values ranged from \$5,000 to \$100,000. There was not a significant correlation between the amount filled in and the treatment choice in the Basic vignette.

## CHAPTER SIX

### DISCUSSION

As discussed earlier, there were two issues of interest in the present study. The first was the identification of variables that influenced the treatment choice in the Basic situation. The second was the influence that additional information would have on the treatment choices of the participants. I will first review the relation between the independent variables and treatment choice in the basic situation.

#### Relations Between Independent Variables and Treatment Choice

##### Level of Moral Reasoning

The DIT was not significantly correlated with any of the treatment choices. This result suggests that the relation between levels of moral reasoning and behavior, in the present situation the choice of treatment, are not as strong as Kohlberg and his colleagues have suggested. There are several possible explanations for this finding.

One explanation may be that there was not enough variation in the scores on the DIT. That is, there may not have been enough variation in the levels of principled moral reasoning, measured by the P-index on the DIT, to generate a correlation with treatment choice. Although the scores on the DIT ranged from 10.00 to 85.00, suggesting a wide variation in use of principled moral reasoning, the

distribution was slightly skewed in the direction of higher scores (skew = .140). This distribution is possibly due to the level of education of the participants, and may help explain the lack of a relation between score on the DIT and Basic treatment choice. Future research should attempt to assess a larger sample of participants to include a better representation of educational levels.

A second explanation is based on a suggestion made by Kohlberg and Elfenbein (1975). They suggested that in major moral dilemmas, one may not expect a clear relation between behavior and level of moral reasoning. That is, in situations involving intense sacrifice, general principles may be ignored in favor of individual subjective principles. The original vignette involved such potential sacrifice, deciding whether or not to treat a handicapped newborn, and the supplemental statements added further to the emotional and financial burden.

The above interpretation may be questioned because the situations the participants faced were simulated. Participants were not making real decisions and did not feel the emotional impact that parents in real situations would feel. However, the failure of the DIT to predict or be significantly related to treatment choice is more supportive of Kohlberg and Elfenbein's suggestion.

The present results do not support Kohlberg and Elfenbein's suggestion that level of knowledge influences the relation between moral development and behavior. In the present study, the level of knowledge was normally

distributed with a floor of 1 correct response out of 10 questions. There was no relation between level of knowledge based on the assessment used and treatment choice. This suggests that knowledge did not influence treatment choice as proposed by Kohlberg and Elfenbein (1975).

The present results also fail to support Kohlberg and Elfenbein's suggestion that the relation between moral development and behavior should become more evident as one uses the higher levels of moral reasoning. As discussed earlier, the basis of this suggestion was that at higher levels of moral reasoning, Stages 4-6 specifically, people follow objective standards in deciding what is moral behavior. Participants in the present study demonstrated a range of scores on the P-index which indicates the level of principled reasoning used to resolve the dilemmas. However, the pattern of treatment choice was not consistent with Kohlberg and Elfenbein's model. That is, those participants scoring highest on the P-index did not necessarily choose full treatment.

In summary, the results of the present study do not support the suggestion of a relation between moral reasoning and behavior, in this case choice of treatment. A number of factors may have contributed to the result, including the simulated nature of the tasks, the intense emotionality of the situation, and others. At the very least, these results support Rest's (1984) suggestion that the relation between behavior and level of moral development is a complex one.

### Quality of Life Projection

The quality of life projection was associated with the treatment decisions. The association varied according to the level of retardation projected for the child in the vignette. As the child's level of retardation increased from mild to severe, the participants projected a less positive quality of life and treatment choice was more likely to be Conditional. The result is consistent with those reported by Singer, Kuhse, and Singer (1983), cited by Szawarski and Tulczynski (1988).

The quality of life projection was also related to the treatment choices made by the different ethical justification groups. It was clear that the Personhood and possibly the Other Ethical Position groups were making treatment decisions that were related to the projected quality of life for the infant. The participants did not base their treatment decision on an ethical principle, but on the specific outcome they perceived for the child. The contribution of their ethical position was to encourage them to decide based on the situation.

The Sanctity of Life group based their decisions on their ethical principles supporting life at any cost. Although most of these participants were aware that the life quality for some of the infants would be only fair to poor, this awareness did not influence their decision to provide full treatment. Although the low frequencies make specific statistical analysis impossible, these trends suggest an important area for future research.



The above results have significant implications for efforts to educate the public concerning the nature and needs of people with mental retardation. The attitude research described earlier indicated that many people assume that the majority of individuals with retardation are severely impaired (Gottlieb, 1975). If quality of life decisions vary based on the perceived level of retardation, and if treatment choices vary based on quality of life projections, an important issue arises. Public education efforts should continue to accurately portray the quality of life and the abilities of mentally retarded individuals. This will decrease the chances of decisions being made based on inaccurate information.

Increasing public awareness could be accomplished in a variety of ways. One suggestion is to include issues concerning the nature and needs of the retarded as a standard component of the school curriculum. Such issues would be a logical part of health studies, family and consumer studies, or psychology courses. It is appropriate to include such issues in a high school program because high school students are approaching child-bearing age and may face decisions similar to the ones assessed in this study.

Continuation and expansion of mainstreaming and community integration efforts will also increase the awareness of the public about the nature and needs of people with retardation. Such interaction with the retarded may help diminish the negative images described by Budoff et al. (1979) and Gottlieb (1975) concerning the abilities of the

retarded. Quality of life projections made by parents and others would be based on interactions with real people rather than on stereotypes or written descriptions.

The hospital committees responsible for reviewing treatment of handicapped newborns suggested by H&HS should include a member who is knowledgeable about the nature and needs and quality of life of retarded individuals. Decisions made by the committee would be based on the most accurate information available. Such expertise would help assure that counseling provided to the parents would include an accurate description of the issues related to treating and raising an infant with retardation.

Future research should focus on the specific components of the quality of life that influenced the participants. Although Powell and Hecimovic (1985) identified five components, the factor analysis suggested that the questionnaire designed for the present study did not distinguish them. Additional research should seek to identify which of these components of the quality of life are most crucial and focus on those in public education efforts and counseling sessions.

#### Attitudes Toward People with Retardation

Although attitudes toward people with retardation may have influenced quality of life perceptions as described above, attitude was not significantly related to the treatment choice in the basic situation. This result is consistent with the suggestion of Wicker (1969) that attitude and behavior are not related. The finding is not

consistent with Ajzen and Fishbein's (1980) suggestion that measuring specific attitudes and specific situations would strengthen the relation. Although the object referent was specifically defined, and attitudes were expressed relative to a specific population, participants demonstrated a wide range of attitudes that were not related to treatment choice (see Table 6). Regan and Fazio's (1977) suggestion that increased experience with the subject of the attitude would improve attitudes was supported. The correlation between attitude and experience was .19 ( $p < .01$ ). Similarly, attitude and knowledge were also significantly related, as suggested by Gottwald (1970) and Budoff et al. (1979).

An additional point of interest in the attitude survey concerned the level of retardation. As Gottlieb (1975) indicated, people who perceived persons with mental retardation to be severely handicapped or who were asked attitudinal judgments concerning specific severely impaired individuals, judged them less positively than did those expressing attitudes toward mildly retarded individuals. In the present study, judgments were asked about the retarded before participants read the vignette. All were responding to a common definition, so attitude variation caused by misconception was at least partially controlled.

Participants in the present study were asked to make decisions in response to simulated situations. Asking the participants to identify what they would do if they were in such a situation may be interpreted as assessing behavioral intent. As Ajzen and Fishbein (1980) discussed, behavioral

intentions are the result of 1) the individual's attitude toward the act in question, 2) the individual's perception of what respected others would do in the same situation, and 3) the level of motivation to perform the specific behavior. Future research should address the participants' attitudes toward the treatment options, as was recently done by Savage et al. (1987), who looked at the attitudes of nurses toward treatment options in neonatal intensive care units. This and other components of behavior intent should be identified and a more direct relation with treatment choice may be established.

#### Prior Experience with People with Mental Retardation

Experience was related to treatment choice. People with more experience with individuals with retardation chose full treatment more frequently than people with less experience. This confirms Regan and Fazio's (1977) suggestion and offers one explanation for the decisions made by parents who have little prior experience. If people with more experience choose full treatment, an effort should be made to enhance understanding consistent with the type of insights that exposure to the retarded provides.

Experience was also related to knowledge, supporting the results of Yeates and Weisz (1985) and Begab (1970). In the present study, the correlation between knowledge and experience was .12 ( $p=.03$ ). Because the assessment was not standardized, it is difficult to generalize beyond the present sample. However, the consistency of the present

results with earlier research indicating a significant relation between knowledge and experience is interesting.

#### Knowledge about Retardation

Level of knowledge was not significantly related to treatment choice in the basic situation. There was a wide range of scores on the knowledge assessment, with no clear pattern of relation between score and treatment choice. the President's Commission (1983) contended that many times people who make judgments based on misinformation. Similarly, Gottlieb (1975) and others have stated that attitudes are often negative because of incorrect assumptions about the nature and impact of mental retardation. In the present population level of knowledge did not predict treatment choice. It may be that the ethical and other issues were more significant to the person making the decision. However, the importance of knowledge about the retarded must not be underestimated, because knowledge was found to be related to attitude.

#### Religious Beliefs

Level of religiosity was related to treatment choice in the basic situation. However, contrary to the prediction, Catholic participants were not more likely to choose any of the treatment options than were participants who were members of other religions. Individuals expressing higher levels of religiosity were more likely to choose full treatment. It may be that the important factor is not the doctrine of a specific religion, but an orientation toward preserving life. This interpretation offers an interesting

means for further investigation of Kohlberg and Elfenbein's (1975) suggestion that at higher levels of moral reasoning, the value of life is a more significant factor than at earlier stages. It would be informative to study the relation between level of moral reasoning and level of religiosity as they influence moral behavior.

#### Ethical Justification

The relationship between ethical position and treatment choice was consistent with predictions. Specifically, participants who selected Sanctity-of-Life as the ethical position most representative of their thinking strongly favored full treatment. Participants who adopted other ethical positions were more likely to choose Conditional treatment. This suggests that the participants in the Sanctity-of-Life group were committed to preserving the life of the child. Participants choosing Other ethical position, including utilitarian, quality-of-life, and extraordinary means, were displaying behaviors consistent with these ethical positions by not insisting on full treatment at any cost.

The differences in choice of treatment were consistent with predictions even when level of retardation was considered. At mild and moderate levels of retardation, all people who adopted the Sanctity-of-Life approach chose Full treatment, consistent with preservation of life. At severe and profound levels of retardation, the Sanctity-of-Life group again strongly favored Full treatment. Participants adopting Other ethical position were more likely to choose

Conditional treatment for both levels of retardation as well. Additionally, personhood was significant in the severe/profound level of retardation. That is, consistent with a choice model of ethical judgment, more people in this model chose conditional treatment than would be expected by chance.

In summary, people who adopted the Sanctity-of-Life position generally behaved in ways consistent with that ethical position. These participants chose Full treatment for the infant, they sought to preserve life. This commitment to preserving life was not influenced by the level of retardation. Participants choosing Other ethical positions also demonstrated behavior consistent with those positions. Conditional treatment, which in all cases would lead to the death of the child, was favored by more participants adopting these positions than was expected by chance. Level of retardation was a factor for these participants. Decisions in favor of Conditional treatment were more likely as level of retardation increased. See Table 3 for details.

Public policy dealing with the ethical dilemmas described in the present study should address all of the issues that are important to parents making treatment decisions. The present results provide a model for designing policies that address those issues. For example, most participants subscribed to a specific ethical position and responded to the vignette in a manner consistent with that position. In some cases, their response would result

in the death of the child, while in others, the child's life was preserved. Based on the ethical position adopted, each of these decisions would be appropriate and would represent the best interests of the parents and infant. Public policy should reflect this range of acceptable ethical justifications and decisions. The ideal policy would support the rights of the parents to make the final decision, a decision based on one of a variety of ethical positions. Rather than mandating a single perspective such as the Sanctity-of-Life, a plurality of ethical positions would be acceptable under the single principle of the right of the parents to decide without fear of condemnation or prosecution.

Selection of the Sanctity-of-Life position by 43.5% of the participants was an interesting result. Sanctity-of-Life as an ethical justification has been rejected by a number of ethicists (Shelp, 1986). The most consistent criticism of this position is its failure to acknowledge that in some situations life is harmful. In the cases that were reviewed by the President's Commission (1983), a Sanctity-of-Life model was rejected in favor of utilitarian or personhood justifications. Despite the weaknesses of the Sanctity-of-Life position, a large number of participants in this study adopted it.

An interpretation of the large number of participants choosing the Sanctity-of-Life model focuses on their lack of experience with the basic issue. Most of the participants were young college students who were neither parents nor



expecting a child. It may be that when first confronting the issues presented in the vignette, one chooses the Sanctity-of-Life position. As ne learns more of the details about the medical and financial burden accompanying continuation of treatment, changes from Sanctity-of-Life to other ethical positions would occur. This interpretation was not supported in this study because few of the Sanctity-of-Life group changed the level of treatment they selected for the infant. This resistance to change in the Sanctity-of-Life group and the large numbers choosing the model indicate that perhaps it should not be so readily dismissed. Future studies should explore more completely the Sanctity-of-Life justification and its resistance to change.

A related issue that has been addressed concerning the sanctity of life is the nature of life itself. Rachels (1986) identified two traditions in the sanctity of life model, an eastern and a western tradition. The former defines life widely, including all animals, and suggests that all life is sacred and should be protected. The western tradition limits sacred life to humans. It would be interesting in future studies to assess the scope of the commitment to life and its definition in those participants selecting the Sanctity-of-Life justification.

An additional suggestion for future research involves the identification of the consistency with which specific ethical positions are assumed. For example, euthanasia of an elderly, homeless, terminally ill person may present a

different ethical dilemma than the one described in this study. It may be that ethical positions vary according to the nature of the dilemma. It is also possible that people subscribe to a general principle that guides their behavior in all ethical situations. Future research should identify the specific pattern of ethical justifications used across a variety of ethical dilemmas.

#### Level of Retardation

Level of retardation was significantly related to treatment choice in the basic situation. Specifically, the mildly and moderately retarded infants were given Full treatment more frequently than were the severely and profoundly retarded infants. An explanation of these results includes a discussion of the quality-of-life projections offered by the participants.

Level of retardation was related to quality-of-life projection. Table 10 indicates that a less positive quality of life was projected for severely and profoundly retarded newborns than for mildly and moderately retarded ones. Participants in the Sanctity-of-Life group support life at any cost for all people and therefore choose Full treatment. They recognize that different children may have varying degrees of life quality but do not waiver from their commitment to preserving life. Individuals who assume a decision-based position (personhood, quality-of-life, utilitarian, and extraordinary means models) are more likely to choose a treatment that ends with the child's death.

These people also recognize that different levels of retardation lead to different life quality and may select Conditional treatment as a result of that recognition. In other words, for the decision-based models the quality-of-life prediction influenced the decision while the Sanctity-of-Life group was committed to treatment no matter what they perceived the quality of life to be.

#### Changes in Treatment Choice

The second area of interest in the present study involved the pattern of change of treatment choice as additional information was provided to the participant. The results concerning consistency of treatment choice reinforce the significance of understanding the ethical positions one assumes. Participants who adopted the Sanctity-of-Life ethical position and selected Full treatment in the basic situation were relatively resistant to modifying that choice. Participants adopting the Personhood or Other ethical position were much more likely to change after being provided with additional information. It is interesting to note that most changes occurred after the development of medical complications was discussed. Issues relevant to this supplementary question relate to the value-of-life, extraordinary measures, and utilitarian models of ethical decision-making. Fewer people changed in response to information about the financial impact, an issue basic to the utilitarian and extraordinary measures models.

The above pattern of change in response to additional information has relevance to the counseling provided to

their positions when the financial burden on themselves was eliminated. Additional research should be undertaken to confirm this interpretation.

#### Limitations of the Study

Several concerns need to be addressed relative to the research design used in the present study. The most critical is that of external validity. The sample in the present study was limited to college students, most of whom have never had children. It would be difficult to directly generalize the results from this sample to parents making decisions about the life or death of their child. It is important to stress that the purpose of the study was to identify the psychological processes that influence decision-making in a specific group of subjects, without generalizing to a larger population. This process will provide us with a model for accurately evaluating these crucial factors in other populations. That is, the results from this sample of college students may provide a format for studying the same issues with parents of handicapped children, with human service providers, or with medical professionals. A second justification for the present sample involves their age. Most of the participants in this study were of child-bearing age. Specific attitudes and knowledge levels that are identified in this sample may approximate those of parents making actual decisions.

A second area of concern involves the simulated nature of the decision-making situations. Treatment decisions evident in the present study may have little to do with

decisions parents make in the frightening and shocking situation of making such decisions in actuality. However, a study using this method of simulated decisions is valid for three reasons. As discussed above, the present study will provide us with information about the validity and practicality of the model for use with different populations in different settings. Second, there is a limited availability of subjects in actual situations of interest in the study. Third, there are obvious ethical problems involved in assessing a parent's attitudes or moral reasoning in the midst of such a crises. With such restrictions, it is appropriate to test the model in a limited setting before applying it to the affected groups.

An additional potential limitation of this study involves the collapsing of variables necessary to perform the analyses. Because of low frequencies in some of the response categories, treatment choice, ethical position, level of retardation, and religious affiliation were collapsed to one or two levels. There is a potential loss of information that results from this procedure. It is difficult to suggest, for example, that participants selecting medication only were influenced by the other variables in the same ways that participants selecting no treatment were influenced. Similarly, collapsing all non-Catholic participants into a single group may hide some specific relationships, for example, that between being an atheist and selection of a specific ethical position.

The loss of information resulting from collapsing of variable levels was kept to a minimum. Collapsed levels were logically consistent with the original groups. That is, a comparison of Catholics and non-Catholics on ethical position and treatment choice was consistent with predictions about the behavior of Catholic participants. Further, the effects that were sought were identified with the collapsed variables. For example, an effect of severity of retardation was identified with only two levels of the variable instead of the original four. Although these results suggest a minimal loss of information resulting from collapsing of variables, future research should seek to study all levels of the variables. Larger samples and alternative sampling strategies should help achieve this goal.

An additional concern is that of the power of the effects identified in the study. As described by Rosenthal and Rosnow (1985), power of an effect refers to the relative strength of the relations between variables. Power of effect varies according to sample size, the statistic used to analyze the data, and the level of significance chosen. Rosenthal and Rosnow's model suggests that some of the significant relations identified in this study would be described as "small" effects. However, the purpose of this study was to identify relations between variables so that a model could be developed for additional research. Presence or absence of an effect was considered to be more important than the relative strength of the effect.

Related Ethical Issues

Additional ethical and legal controversies have been created by the situations described in this paper. It is possible that the present results may help address these issues, which will be briefly discussed below. I have focused on the moral justification for needing to decide that some newborns will not receive treatment, and how such decisions are made. The major ethical concern not discussed involves the act itself which terminates the life of the infant. That is, if it is appropriate to deny or discontinue treatment in some cases, how is the act itself justified? In other words, what are the moral and ethical justifications for the act of withdrawing or withholding life-sustaining treatment, with the intent being the death of the patient? Slack (1984) reviewed one argument relating to this issue, that of acts vs. omissions. The key concept is that a person who fails to perform an action that would prevent or diminish a harmful event is less morally wrong than someone who deliberately instigated an event resulting in the same harmful effect. In the first case, the individual is guilty of an omission, while in the second the guilt is that of a specific act. A contrasting viewpoint comes from the utilitarian perspective, that is, an action is acceptable as long as it instills the greatest good for the greatest number of people. In this model, it is not the actual behavior, act, or omission that is significant, but rather the effect. Behavior that results in the most good and minimizes bad effects is morally

correct behavior, including behavior which results in the death of the infant.

A related ethical question that has been considered involves the specific act that is used to terminate the life of the infant. That is, what is a morally and ethically appropriate means of carrying out the act that been decided upon? This question is often discussed in terms of infanticide vs. selective non-treatment (Slack, 1984). Selective non-treatment is justified by some as an omission, and therefore is morally acceptable in some cases. Infanticide is not acceptable in this model because it is a specific act seeking to harm another. However, there is strong support for the suggestion that selective non-treatment is equivalent to infanticide. Death by selective non-treatment is often painful and slow. Infants who are denied food and water often linger on for several days. The Johns Hopkins baby was put in a side room and denied food until it died 11 days later; another infant lingered for 21 days before it died from starvation (Lusthaus, 1985). It is difficult to accept that these effects are the result of a procedure that is more acceptable than outright killing of the infant.

The issue of selective non-treatment vs. infanticide (often termed passive vs. active euthanasia or killing vs. letting die) has generated much controversy. Representative positions in this controversy are those of Harris (1981) and Lorber (1978). Lorber justified selective non-treatment as an acceptable alternative to infanticide based on a number



of ethical and legal problems related to the latter technique. These problems included the negative effects on medical staff, the slippery slope argument, issues of consent, the finality of the treatment precluding response to mis-diagnosis or innovative techniques, and perceived parental guilt. Harris (1981) countered each of Lorber's arguments and suggested that infanticide was a more humane, ethically valid technique. The controversy continues as ethicists attempt to address this very complex issue.

An additional area of ethical controversy related to the issues in the present study in prenatal diagnosis. Diagnostic techniques including amniocentesis allow detection of genetic disorders in a fetus. If such a genetic disorder is evident, parents are able to decide whether to abort or to continue the pregnancy. The procedures have resulted in ethical discussion focusing on issues similar to those discussed earlier (Mappes & Zembaty, 1986).

Karp (1986) discussed the issue of personhood as it related to prenatal diagnosis. He suggested that there is a period of time during prenatal development when a fetus is considered by some to be not-yet-human. Abortion of the fetus during this time would have different moral implications than would abortion after the fetus is considered a person. A variety of criteria have been suggested for determining the time at which a fetus actually becomes a person. This approach is based on the same

decision-based model for resolving ethical dilemmas as was discussed concerning handicapped newborns.

A sanctity-of-life approach has also been offered in response to prenatal diagnosis. Kass (1986) argued that genetic abortion, that is, abortion based on positive results from prenatal diagnosis, fails to acknowledge the right to life of all humans. Kass also warned of the slippery slope possibility. He claimed that decisions to abort based on potential quality of life issues would rapidly lead to a society which rejects any infant with less than perfect potential.

The present study did not directly address the ethical situations described above. The results of this study have, however, provided a model for studying these and other questions and have demonstrated that ethical issues are important factors in the decision-making process involving the treatment of multiply involved infants. In the sample studied, the best way to understand the treatment decisions made in the simulated situations was to look at the ethical and religious beliefs of the individual, the level of retardation and projected quality of life for the infant, and the individuals' prior experience with retarded individuals. It has been clear that parents should be provided with full and accurate information concerning the abilities and qualities projected for the infant. It is essential that public policy address the issues important to parents making these decisions to allow them to decide consistent with their ethical beliefs. Finally, the results

of this study have offered a model for studying the decision-making process in parents actually facing the situation and supporting them during the process. the emotional impact of facing these decisions will never disappear, nor will the ethical and moral controversies inherent in such situations. But perhaps this study has opened a door to support parents as they make these decisions, to strengthen governmental and legal responses to the dilemmas, and to provide further insight into these and similar questions.

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**APPENDICES**

**A. TABLES**

**B. SAMPLE QUESTIONNAIRE**

Table 1. Demographic Profile of the Participants

Variable	Mean	Standard Deviation	Range
Age	19.16	2.52	17-44
Level of Religiosity	2.65	1.08	0-5
Prior Experience with People with Retardation	1.90	1.93	0-7

Number of Participants = 301 (145 male; 179 female)

Table 2. Pattern of Ethical Position and Treatment Choice

Ethical Position	Full Treatment	Conditional Treatment
Sanctity of Life	n=130 E.F.=105.1 %=99	n=1 E.F.=25.9 %=1
Personhood	n=76 E.F.=81.8 %=74	n=26 E.F.=20.2 %=25
Other Ethical	n=33 E.F.=52.1 %=50	n=32 E.F.=12.9 %=50

Total N = 298

1. n= Number of Ethical Position Group Members  
Choosing this Treatment Option
2. E.F.= Expected Frequency
3. %= Percentage of Ethical Position Group  
Choosing this Treatment Option

Table 3. Pattern of Treatment Choice and Ethical Position Controlling for Level of Retardation

	Mild/Moderate Retardation		Severe/Profound Retardation	
	Full Treatment	Conditional Treatment	Full Treatment	Conditional Treatment
Ethical Position				
Sanctity of Life	n=71 EF=65.7 %=100	n=0 EF=5.2 %=0	n=59 EF=40.7 %=98	n=1 EF=19.3 %=2
Personhood and Other	n=67 EF=72.2 %=85	n=1 EF=5.7 %=15	n=42 EF=60.3 %=47	n=47 EF=28.7 %=53

Total N for Mild/Moderate = 149  
Total N for Severe/Profound = 149

1. n=Number of Ethical Position Group Members Choosing This Treatment Option
2. EF= Expected Frequency
3. %= Percentage of Ethical Position Group Choosing This Treatment Option



Table 4. Pattern of Religious Affiliation and Treatment Choice

Religious Affiliation	Full Treatment	Conditional Treatment
Catholic	n=129 EF=124.3 %=83.2	n=26 EF=30.7 %=16.8
Non-Catholic	n=110 EF=114.7 %=76.9	n=33 EF=28.3 %=23.1

Total N = 298

1. n= Number of Religious Affiliation Group Members Choosing This Treatment Option
2. EF= Expected Frequency
3. %= Percentage of Religious Affiliation Group Choosing this Treatment Option

Table 5. Relation Between Quality of Life Prediction and Treatment Choice Within Each Ethical Position

Ethical Position	Quality of Life Projection		
	Poor	Fair	Good
<b>Sanctity of Life</b>			
Full Treatment	n=13 EF=12.9 %=100	n=69 EF=68.5 %=100	n=48 EF=48.6 %=97
Conditional Treatment	n=0 EF=.1 %=0	n=0 EF=.5 %=0	n=1 EF=.4 %=3
<b>Other Ethical Position</b>			
Full Treatment	n=14 EF=33.5 %=27	n=54 EF=46.4 %=76	n=35 EF=23.0 %=100
Conditional Treatment	n=37 EF=17.3 %=72	n=17 EF=12.4 %=23	n=0 EF=7.3 %=0

Total N = 289

1. n= Number of Ethical Position Group Members who Projected this Quality of Life and Chose This Treatment Option
2. EF= Expected Frequency
3. %= Percentage of This Ethical Position Group who Chose This Treatment Option

Table 6. Summary Table for Multiple Analysis of Variance of Basic Treatment Choice and Independent Variables

Variable	SS	MS	F	Significance
DIT	47372.79	166.81	.61	.434
Quality of Life Projection	18987.79	66.86	129.97	.000
Knowledge	564.73	1.99	.32	.570
Experience	1052.11	3.70	4.21	.041
Level of Religiosity	315.81	1.11	11.62	.001
Attitude	4967.22	17.49	2.75	.098

Degrees of Freedom = 1,284

Multivariate Test of Significance (Wilks);  
[F(6,279)=24.78; p<.01]

Table 7. Means of Sanctity-of-Life and Non-Sanctity-of-Life Groups

Variable	Sanctity of Life		Non Sanctity of Life	
	Mean	S.D.	Mean	S.D.
Quality of Life Projection	41.37	8.15	35.56	10.51
DIT	36.26	11.88	36.45	14.00
Knowledge	6.24	1.32	6.27	1.50
Prior Experience	2.15	2.05	1.75	1.81
Level of Religiosity	2.89	1.03	2.52	1.05
Attitude	13.57	4.24	12.55	4.25

N = 130 for Sanctity-of-Life Group

N = 168 for Non-Sanctity-of-Life Group

Table 8. Summary Table for Multiple Analysis of  
 Variance of Sanctity-of-Life Justification and  
 Other Independent Variables

Variable	SS	MS	F	Significance
DIT	48290.36	18.26	.11	.743
Quality of Life Projection	25521.96	89.23	24.57	.000
Knowledge	566.47	1.98	.01	.903
Experience	1056.77	3.69	3.97	.047
Level of Retardation	315.45	1.10	12.25	.001
Attitude	5036.99	17.61	3.38	.067

Degrees of Freedom = 1,286

Multivariate Test of Significance (Wilks);  
 [F(6,281)=6.32; p<.01]

Table 9. Correlations Between Independent Variables

Level of Retardation	Prior Experience	Knowledge	Level of Religiosity	DIT	Quality of Life Prediction
Attitude .066	.167*	.184*	.024	.046	.231*
Prior Experience .005	-	.100	.064	-.026	.135*
Knowledge .082	-	-	.061	.166*	.068
Level of Religiosity -.040	-	-	-	-.095	.096
DIT -.019	-	-	-	-	.055
Quality of Life Prediction -.433*	-	-	-	-	-

N = 298

\* = Significant at .05 Level

Table 10. Group Means and Differences on Quality of Life Projection

	Group			
	Mild Retardation	Moderate Retardation	Severe Retardation	Profound Retardation
Mean	43.83	39.62	34.39	32.91

Differences

Mild Retardation \* \* \*

Moderate Retardation \* \*

Severe Retardation

\* = Significant at the .05 level

Sheffe's method of post hoc comparisons was used to test the differences between the group means

Table 11. Treatment Choice Change at Each Level of Information

Situation	Treatment Choice	
	Full Treatment	Conditional Treatment
Basic Vignette	223	49
Complications	202	70
No Insurance	163	109
Insurance	160	112
Total N =	272	



Table 12. Treatment Choice At Different Levels of Information Listed by Ethical Position

Situation	Ethical Position		
	Sanctity-of-Life	Personhood	Other
<b>Basic Vignette</b>			
Full	125	73	25
Conditional	1	21	27
<b>Complications</b>			
Full	119	65	18
Conditional	7	29	34
<b>No Insurance</b>			
Full	101	52	10
Conditional	25	42	42
<b>Insurance</b>			
Full	101	49	10
Conditional	25	45	42
	-----	-----	-----
<b>Total Changing   from full to   Conditional</b>	24	14	15
<b>Percent Changing   from full to   Conditional</b>	19	14	28

Total N = 272

Table 13. Pattern of Changes from Full to Conditional Treatment Choice with Additional Information

	Ethical Group	
Sanctity-of-Life	Other	
Original Vignette to Complications		
No Change	n=119 EF=113.2 %=95	n=83 EF=70.6 %=84
Change from Full to Conditional	n=6 EF=11.8 %=5	n=15 EF=7.3 %=15
Complications to No Insurance		
No Change	n=101 EF=96.0 %=84	n=62 EF=66.9 %=74
Change from Full to Conditional	n=18 EF=22.9 %=15	n=21 EF=16.0 %=25
No Insurance to Insurance		
No Change	n=101 EF=99.1 %=100	n=59 EF=60.8 %=95
Change from Full to Conditional	n=0 EF=1.8 %=0	n=3 EF=1.1 %=4

Total N = 224 (Table does not include the 49 participants who chose conditional treatment in the original vignette)

1. n = Number of Ethical Position Group Members in this Category
2. EF = Expected Frequency
3. % = Percentage of Ethical Group Members in this Category

## OPINIONS ABOUT SOCIAL PROBLEMS

This questionnaire is aimed at understanding how people think about social problems. Different people often have different opinions about questions of right and wrong. There are no 'right' answers in the way that there are right answers to math problems. We would like you to tell us what you think about several problem stories. The papers will be fed to a computer to find the average of the whole group, and no one will see your individual answers.

In this questionnaire you will be asked to give your opinions about several stories. Here is a story as an example:

Frank Jones has been thinking about buying a car. He is married, has two small children and earns an average income. The car he buys will be his family's only car. It will be used mostly to get to work and drive around town, but sometimes for vacation trips also. In trying to decide what car to buy, Frank Jones realized that there were a lot of questions to consider. Below there is a list of some of these questions.

If you were Frank Jones, how important would each of these questions be in deciding what car to buy?

## Instructions for Part A: Sample question

On the left hand side check one of the spaces by each statement of consideration. For instance, if you think that statement #1 is not important in making a decision about buying a car, check that space on the right.

## Importance

GREAT    MUCH    SOME    LITTLE    NONE

					1. Whether the car dealer was in the same block where Frank lives (Note that in this sample the person taking the questionnaire did not think this was important in making a decision)
				X	
					2. Would a used car be more economical in the long run than a new car (Note that an X was put in the far left space to indicate the opinion that this is an important issue in making a decision about buying a car).
				X	
					3. Whether the color was green, Frank's favorite color
				X	
					4. Whether the cubic inch displacement was at least 200. (Note that if you are unsure about what 'cubic displacement means, mark it NONE)
				X	
					5. Would a large, roomy car be better than a compact car.
				X	
					6. Whether the front connibilies were differential (Note that if a statement sounds like gibberish or nonsense to you, mark it NONE)

## INSTRUCTIONS FOR PART B: Sample question

From the list of questions on the previous page, select the most important one of the whole group. Put the number of the question in the first column below. Do likewise for your second, third, and fourth most important choices. (Note that the top choices in this case will come from the statements that were checked on the far left-hand side -- statements #2 and #5 were thought to be very important. In deciding what is the most important, a person would re-read #2 and #5 and then pick one of them as the most important, then put the other one as the second most important, and so on.

MOST IMPORTANT      2ND CHOICE      3RD CHOICE      4TH CHOICE

## HEINZ AND THE DRUG

In Europe a woman was near death from a special kind of cancer. There was one drug that doctors thought might save her. It was a form of radium that a druggist in the same town had recently discovered. The drug was expensive to make, but the druggist was charging ten times what the drug cost to make. He paid \$200 for the radium and charged \$2,000 for a small dose of the drug. The sick woman's husband, Heinz, went to everyone he knew to borrow money, but he could only get together about \$1,000 which is about half of what it cost. He told the druggist that his wife was dying and asked him to sell it cheaper or let him pay later. But the druggist said "No, I discovered the drug and I'm going to make money from it." Heinz got desperate and began to think about breaking into the man's store to steal the drug for his wife.

Should Heinz steal the drug? (check one)

Should steal it     Can't decide     Should not steal it

## IMPORTANCE

GREAT    MUCH    SOME    LITTLE    NONE

1. Whether a community's laws are going to be upheld.

-----

2. Isn't it only natural for a loving husband to care so much for his wife that he'd steal?

-----

3. Is Heinz willing to risk getting shot as a burglar or going to jail for the chance that stealing the drug might help?

-----

4. Whether Heinz is a professional wrestler, or has considerable influence with wrestlers.

-----

5. Whether Heinz is stealing for himself or doing this solely to help someone else.

-----

GREAT   MUCH   SOME   LITTLE   NONE

6. Whether the druggist's rights to his invention have to be respected.

---

7. Whether the essence of living is more encompassing than the termination of dying, socially and individually.

---

8. What values are going to be the basis for governing how people act toward each other.

---

9. Whether the druggist is going to be allowed to hide behind a worthless law which only protects the rich anyhow.

---

10. Whether the law in this case is getting in the way of the most basic claim of any member of society.

---

11. Whether the druggist deserves to be robbed for being so greedy and cruel.

---

12. Would stealing in such a case bring about more total good for the whole society or not.

---

FROM THE LIST OF QUESTIONS ABOVE, SELECT THE FOUR MOST IMPORTANT:

MOST IMPORTANT            2ND CHOICE            3RD CHOICE            4TH CHOICE

## MR. WEBSTER

Mr. Webster was the owner and manager of a gas station. He wanted to hire another mechanic to help him, but good mechanics were hard to find. The only person he found who seemed to be a good mechanic was Mr. Lee, but he was Chinese. While Mr Webster himself didn't have anything against Orientals, he was afraid to hire Mr Lee because many of his customers didn't like Orientals. His customers might take their business elsewhere if Mr Lee was working in the gas station.

When Mr Lee asked Mr Webster if he could have the job, Mr Webster said that he had already hired someone else. But Mr Webster really had not hire anybody, because he could not find anybody who was a good mechanic besides Mr Lee.

What should Mr Webster have done? (check one)

Should have hired Lee     Can't decide     Shouldn't hire Lee

## IMPORTANCE

GREAT    MUCH    SOME    LITTLE    NONE

1. Does the owner of a business have the right to make his own business decisions or not?

-----

2. Whether there is a law that forbids racial discrimination in hiring for jobs.

-----

3. Whether Mr Webster is prejudiced against Orientals himself or means nothing personal in refusing the job.

-----

4. Whether hiring a good mechanic or paying attention to his customers' wishes would be best for his business.

-----

5. What individual differences ought to be relevant in deciding how society's roles are filled?

-----

6. Whether the greedy and competitive capitalistic system ought to be completely abandoned.

-----



GREAT MUCH SOME LITTLE ONE

7. Do a majority of people in Mr Webster's society feel like his customers, or are the majority against prejudice?

---

8. Whether hiring capable men like Mr Lee would use talent that would otherwise be lost to society.

---

9. Would refusing the job to Mr Lee be consistent with Mr Webster's own moral beliefs?

---

10. Could Mr Webster be so hard-hearted as to refuse the job knowing how much it meant to Mr Lee?

---

11. Whether the Christian commandment to love your fellow man applies in this case.

---

12. If someone is in need, shouldn't he be helped regardless of what you get back from him?

---

FROM THE LIST OF QUESTIONS ABOVE, SELECT THE FOUR MOST IMPORTANT:

MOST IMPORTANT      2ND CHOICE      3RD CHOICE      4TH CHOICE

## NEWSPAPER

Fred, a senior in high school, wanted to publish a mimeographed newspaper for students so that he could express many of his opinions. He wanted to speak out against the war in Viet Nam and to speak out against some of the school's rules, like forbidding boys to wear long hair.

When Fred started his newspaper, he asked his principal for permission. The principal said it would be all right if before every publication Fred would turn in all his articles for the principal's approval. Fred agreed and turned in several articles for approval. The principal approved all of them and Fred published two issues of the paper in the next two weeks.

But the principal had not expected that Fred's newspaper would receive so much attention. Students were so excited by the paper that they began to organize protests against the hair regulation and other school rules. Angry parents objected to Fred's opinions. They phoned the principal, telling him that the paper was unpatriotic and should not be published. As a result of the rising excitement, the principal ordered Fred to stop publishing. He gave as a reason that Fred's activities were disruptive to the operation of the school.

Should the principal stop the newspaper? (check one)

Should stop it     Can't decide     Should not stop it

## IMPORTANCE

GREAT   MUCH   SOME   LITTLE   NONE

1. Is the principal more responsible to the students or to the parents?

---

2. Did the principal give his word that the newspaper could be published for a long time, or did he just promise to approve the paper one issue at a time?

---

3. Would the students start protesting even more if the principal stopped the newspaper?

---

4. When the welfare of the school is threatened, does the principal have the right to give orders to students.

GREAT   MUCH   SOME   LITTLE   NONE

5. Does the principal have the freedom of speech to say no in this case?

---

6. If the principal stopped the newspaper would he be preventing full discussion of important problems?

---

7. Whether the principal's order would make Fred lose faith in the principal.

---

8. Whether Fred was really loyal to his school and patriotic to his country.

---

9. What effect would stopping the paper have on the student's education in critical thinking and judgment?

---

10. Whether Fred was in any way violating the rights of others in publishing his own opinions.

---

11. Whether the principal should be influenced by some angry parents when it is the principal that knows best what is going on in the school

---

12. Whether Fred was using the newspaper to stir up hatred and discontent.

---

FROM THE LIST OF QUESTIONS ABOVE, SELECT THE FOUR MOST IMPORTANT:

MOST IMPORTANT      2ND CHOICE      3RD CHOICE      4TH CHOICE

## THE DOCTOR'S DILEMMA

A lady was dying of cancer which could not be cured and she had only about six months to live. She was in terrible pain, but she was so weak that a good dose of pain killer like morphine would make her die sooner. She was delirious and almost crazy with pain and in her calm periods, whoe would ask the doctors to give her enough morphine to kill her. She said that she couldn't stand tye pain and that whe was going to die in a few months anyway.

What should the doctor do? (check one)

Give the lady the overdose that will make her die     Can't decide     Should not give the overdose

## IMPORTANCE

GREAT    MUCH    SOME    LITTLE    NONE

1. Whether the woman's family is in favor of giving her the overdose or not.

---

2. Is the doctor obligated by the same laws as everybody else if giving her the overdose would be the same as killing her.

---

3. Whether people would be much better off without society regimenting their lives and even their deaths.

---

4. Whether the doctor could make it appear like an accident.

---

5. Does the state have the right to force continued existence on those who don't want to live.

---

6. What is the value of death prior to society's perspectives on personal values.

---

7. Whether the doctor has sympathy for the woman's sufferng or cares more about what society might think

GREAT MUCH SOME LITTLE NONE

8. Is helping to end another's life ever a responsible act of cooperation?

---

9. Whether only God should decide when a person's life should end.

---

10. What values the doctor has set for himself in his own personal code of behavior.

---

11. Can society afford to let everybody end their lives when they want to?

---

12. Can society allow suicides or mercy killing and still protect the lives of individuals who want to live?

---

FROM THE LIST OF QUESTIONS ABOVE SELECT THE FOUR MOST IMPORTANT:

MOST IMPORTANT    2ND CHOICE    3RD CHOICE    4TH CHOICE

STUDENT TAKE-OVER

At Harvard University a group of students, called the Students for a Democratic Society (SDS), believe that the University should not have an army ROTC program. SDS students are agianst the war in Viet Nam and the army training program helps send men to fight in Viet Nam. The SDS students demanded that Harvard end the army ROTC program as part of their regular course work and not get credit for it towards their degrees.

Agreeing with the SDS students, the Harvard professors voted to end the ROTC program as a university course. But the President of the University stated that he wanted to keep the army program on campus as a course. The SDS students felt that the President was not going to pay any attention to the faculty vote or to their demands.

So, one day two hundred SDS students walked into the University's administration building and told everyone else to get out. They said they were doing this to force Harvard to get rid of the army training program as a course.

Should the students have taken over the administration building?  
(Check one)

Yes, they should take it over     Can't Decide     No, they shouldn't take it over

IMPORTANCE

GREAT    MUCH    SOME    LITTLE    NONE

1. Are the students doing this to really help other people or are they doing it just for kicks?

-----

2. Do the students have any right to take over property that doesn't belong to them?

-----

3. Do the students have any right to take over property that doesn't belong to them?

-----

4. Would taking over the building in the long run benefit more people to a greater extent?

-----

5. Whether the president stayed within the limits of his authority in ignoring the faculty vote.

GREAT MUCH SOME LITTLE NONE

6. Will the takeover anger the public and give all students a bad name?

---

7. Is taking over the building consistent with principles of justice?

---

8. Would allowing one student takeover encourage many other student takeovers?

---

9. Did the president bring this misunderstanding on himself by being unreasonable and uncooperative?

---

10. Are the students following principles which they believe are above the law?

---

11. Whether running the university ought to be in the hands of a few administrators or in the hands of all the people.

---

12. Whether or not university decisions ought to be respected by students.

---

FROM THE LIST OF QUESTIONS ABOVE SELECT THE FOUR MOST IMPORTANT:

MOST IMPORTANT   2ND CHOICE   3RD CHOICE   4TH CHOICE

## ESCAPED PRISONER

A man had been sentenced to prison for 10 years. Afer one year, however, he escaped from prison, moved to a new area of the country, and took on the name of Thompson. For eight years, he worked hard and gradually he saved enough money to buy his own business. He was fair to his customers, gave his employees top wages, and gave most of his own profits to charity. Then one day Mrs. Jones, an old neighbor, recognized him as the man who had escaped from prison 8 years before, and whom the police had been looking for.

Should Mrs. Jones report Mr. Thompson to the police and have him sent back to prison? (Check one)

Should report him     Can't decide     Should not report him

## IMPORTANCE

GREAT    MUCH    SOME    LITTLE    NONE

1. Hasn't Mr Thmpson been good enough for such a long time to prove he isn't a bad person?

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2. Everytime someone escapes punishment doesn't that just encourage more crime?

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3. Wouldn't we be better off without prisons and the oppression of our legal system?

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4. Hasn't Mr Thompson really paid his debt to society?

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5. Would society be failing what Mr Thompson should fairly expect?

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6. What benefits would prisons be apart from society especially for a charitable man?

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7. How could anyone be so cruel and heartless as to send Mr Thompson to prison?

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8. Would it be fair to all the prisoners who had to serve out their full sentences if Mr Thompson was let off?



GREAT MUCH SOME LITTLE NONE

9. Was Mrs Jones a good friend of Mr Thompson's?

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10. Wouldn't it be a citizen's duty to report an escaped criminal, regardless of the circumstances?

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11. How would the will of the people and the public good be best served?

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12. Would going to prison do any good for Mr Thompson or protect anybody?

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FROM THE LIST OF QUESTIONS ABOVE SELECT THE MOST IMPORTANT:

MOST IMPORTANT    2ND CHOICE    3RD CHOICE    4TH CHOICE

Your gender \_\_\_\_\_ Your age \_\_\_\_\_

Major \_\_\_\_\_ Class \_\_\_\_\_

Do you have a mentally retarded brother or sister?

Yes \_\_\_\_\_ No \_\_\_\_\_

Do you have a mentally retarded aunt, uncle, or cousin?

Yes \_\_\_\_\_ No \_\_\_\_\_

If yes, please describe the relationship:

Is there a mentally retarded person who is a member of a friend's or neighbor's family?

Yes \_\_\_\_\_ No \_\_\_\_\_

If yes, please explain:

Have you ever worked with mentally retarded individuals?

Yes \_\_\_\_\_ No \_\_\_\_\_

If so, please indicate the setting below:

\_\_\_\_\_ retarded individual was a colleague

\_\_\_\_\_ I was a counselor in a program or camp

\_\_\_\_\_ I was a school aide or volunteer

\_\_\_\_\_ Other - please describe:

Have you ever had any other close contact with mentally retarded individuals?

Yes \_\_\_\_\_ No \_\_\_\_\_

If yes, please describe:

#### RELIGIOUS AFFILIATION

Please indicate your religious affiliation by checking the appropriate space below:

\_\_\_\_\_ Protestant

\_\_\_\_\_ Catholic

\_\_\_\_\_ Jewish

\_\_\_\_\_ Other

\_\_\_\_\_ None

On a scale of 1 to 5, indicate how religious you think you are. Circle the appropriate number (1 to 5) in the space below:

1  
not religious  
at all

2

3  
moderately  
religious

4

5  
extremely  
religious

In the space provided, indicate whether you agree (A) or disagree (D) with, or have no opinion (N) about the following statements:

1. \_\_\_\_\_ Most people who are mentally retarded look different from normal people.
2. \_\_\_\_\_ Mental retardation is usually inherited from the parents.
3. \_\_\_\_\_ Mentally retarded people can't learn.
4. \_\_\_\_\_ Mental retardation is usually caused by cultural or environmental impoverishment.
5. \_\_\_\_\_ Most mentally retarded people live in institutions.
6. \_\_\_\_\_ The majority of mentally retarded people are mildly retarded.
7. \_\_\_\_\_ Mental retardation and mental illness are the same.
8. \_\_\_\_\_ Mental retardation is always evident at birth.
9. \_\_\_\_\_ The older a pregnant woman is, the greater the chance that her child will be mentally retarded.
10. \_\_\_\_\_ Most mentally retarded people can perform at least basic work tasks.

Mental Retardation - Mental retardation refers to "significantly subaverage general intellectual functioning" and is accompanied by deficits in ability to care for oneself and in social adaptation. The IQ of mentally retarded people is 70 or below. Mental retardation can develop between birth and 18 years of age.

Based on your knowledge and experiences, please check which of the following characteristics are accurate descriptions of mentally retarded people. You may check as many characteristics as you feel appropriate.

- |                     |                       |
|---------------------|-----------------------|
| _____ Ambitious     | _____ Broadminded     |
| _____ Capable       | _____ Cheerful        |
| _____ Clean         | _____ Courageous      |
| _____ Useless       | _____ Unreliable      |
| _____ Honest        | _____ Imaginative     |
| _____ Sick          | _____ Intellectual    |
| _____ Logical       | _____ Worthless       |
| _____ Obedient      | _____ Polite          |
| _____ Responsible   | _____ Self-controlled |
| _____ Unpredictable | _____ Independent     |
| _____ Forgiving     | _____ Dangerous       |
| _____ Weak          | _____ Helpful         |
| _____ Loving        |                       |

An infant is born with the umbilical cord wrapped around its neck. It is obvious that the infant has suffered from a decreased supply of oxygen, which causes brain damage. The decrease in oxygen lasted for a period of twenty minutes. The extent of oxygen deficit and brain damage leads doctors to predict that the child will be profoundly retarded. That is, the child will be unable to speak; will understand only single words or gestures; will not be able to feed, dress, or toilet self, will not learn to walk,; and will need complete physical assistance to accomplish even the most basic tasks.

The infant also suffers from an obstruction in the stomach. It will need to spend a week in intensive care to stabilize its condition, and will need surgery to reconstruct the stomach. In about 5% of the cases, the infant dies during the surgery. After surgery the child will require about a month of recuperation in intensive care. After that, the child should be medically fine, but will still be retarded. The child will have no physical handicaps.

1. Assume that the child described above was your child. Please read the following statements and indicate the treatment you would want for the child. Indicate your choice by checking the appropriate space.

a. \_\_\_\_\_ I would want no treatment at all for the child. It would not receive food, water, or medication to ease pain and distress. The surgery described above will not be performed. The infant will die.

b. \_\_\_\_\_ I would not treat the child. I would give medication for pain and distress, but would not give food and water. The surgery described above would not be performed and the infant will die.

c. \_\_\_\_\_ I would provide food and water to the infant. I would also give medication for pain and distress. I would not allow the surgery described above to be performed. The baby will die.

d. \_\_\_\_\_ I would allow the surgery above to be performed. The child would receive food and water, and any medication to ease pain and distress. The infant would spend as long as necessary in intensive care to assure that it is healthy.

PLEASE EXPLAIN THE REASONS FOR YOUR ANSWER IN THE SPACE BELOW:

Alternative Descriptions of Infant (Each read by 25% of the participants).

1. The decrease in oxygen lasted for a period of ten minutes. The extent of oxygen deficit and brain damage leads doctors to predict that the child will be moderately retarded. That is, the child will not be able to read more than a few words, will demonstrate difficult-to-understand speech, will be able to work at simple tasks with supervision, and will care for self with some help.

2. The decrease in oxygen lasted for a period of fifteen minutes. The extent of oxygen deficit and brain damage leads doctors to predict that the child will be severely retarded. That is, the child will not be able to read, will have no speech, will need maximum assistance with feeding, dressing, and toileting, and will be able to perform work tasks only with much supervision.

3. The decrease in oxygen lasted for a period of five minutes. The extent of oxygen deficit and brain damage leads doctors to predict that the child will be mildly retarded. That is, the child will be able to read at a third grade level, will drive a car, take care of self completely, and perform routine jobs independently.

IF YOU CHOSE OPTIONS A, B, OR C IN QUESTION 1 SKIP QUESTION 2. GO DIRECTLY TO QUESTION 3 (on the next page)

2. In less than 10% of the cases involving the surgical procedure just described, complications develop including the baby's heart stopping and /or the baby developing severe respiratory distress. These complications require immediate medical intervention, and increase the amount of time the infant must spend in intensive care before it is out of danger. Please read the following statements and indicate the treatment you would want if such complications developed. Indicate your choice by checking the appropriate space. Once again, assume that the infant is your child.

a. \_\_\_\_\_ I would want the baby to receive the full treatment described above, including whatever efforts were necessary to respond to the complications.

b. \_\_\_\_\_ I would want the medical team to respond to the complications, but only once. If a second complication were to develop during the surgery, I would stop the surgery.

c. \_\_\_\_\_ I would want the medical team to withhold treatment for the complications, which means that the baby would die in surgery.

3. The entire treatment described in the story (including surgery and time in intensive care) would cost between \$50,000 and \$150,000 according to current estimates. Please indicate your opinions regarding the cost of such treatment by responding to each situation below. Again, assume that the child is yours. Indicate your choice by placing a check in the appropriate space. Please answer both questions, and check only one selection for each question.

1. NO INSURANCE AVAILABLE

a. \_\_\_\_\_ If I didn't have insurance that would pay for the treatment, I would agree to provide whatever treatment was needed, no matter what the cost. I would pay for this treatment myself.

b. \_\_\_\_\_ If I didn't have insurance that would pay for the treatment, I would agree to provide whatever treatment was needed, up to an expenditure of \$\_\_\_\_\_ (please fill in an amount. I would pay this amount myself.

2. INSURANCE AVAILABLE

a. \_\_\_\_\_ If I had insurance that would pay for the treatment, I would agree to provide whatever treatment was needed, no matter what the cost.

b. \_\_\_\_\_ If I had insurance that would pay for the treatment, I would agree to provide whatever treatment was needed, up to an expenditure of \$\_\_\_\_\_ (please fill in an amount).



Indicate below which ONE of the following statements BEST represents your thinking about the infant described earlier. Place a check in the space next to the statement you choose.

All infants, no matter what their condition, have a right to life and medical treatment. In no cases should medical treatment be withheld.

In some cases, a child is so severely brain damaged that it is not capable of being a person.

If you chose this answer, please check which one of the following criteria you would use to decide whether a child is a person or not:

Level of intelligence  
 Ability to relate to others  
 Awareness of being alive and wanting to continue living  
 Other (please describe):

In some cases, a child will be such a burden to its family or others, that to continue its life would be unfair to everyone.

In some cases, the effort and money needed to keep a child alive are more than can be justified for one child.

In some cases, a child will have such a poor or unhappy life, that it is better to allow it to die.

None of the above statements describe my thinking. The following is a better description of what I thought about when deciding about the infant in the story: (please describe in a few words):

Indicate on the line to the left of each statement how much you agree or disagree with it. All statements apply to the child described in the vignette you read a few minutes ago. Please mark every item. Use the following response categories:

- 1 = strongly agree
- 2 = agree
- 3 = uncertain
- 4 = disagree
- 5 = strongly disagree

1. \_\_\_\_\_ The child described will need to live in a special institution where it can be supervised and protected.
2. \_\_\_\_\_ The child described will be able to understand who it is and will be aware of its impact on other people.
3. \_\_\_\_\_ The child described will not be capable of making and keeping friends.
4. \_\_\_\_\_ The child described can live just as happy a life as a normal person.
5. \_\_\_\_\_ Expecting the child described to fit into our highly competitive society is expecting too much.
6. \_\_\_\_\_ Because of its mental retardation, the child described will be easily led into criminal ways.
7. \_\_\_\_\_ With the current trend in industrial technology, there are going to be fewer jobs that the child described can fill.
8. \_\_\_\_\_ The child described really won't benefit from education.
9. \_\_\_\_\_ The child described will contribute much to its family.
10. \_\_\_\_\_ The child described will cause severe financial hardship for its family.

11. \_\_\_\_\_ The child described will cause severe stress on its family because it will need so much attention.
12. \_\_\_\_\_ The child described will be accepted by its peers.
13. \_\_\_\_\_ The child's family will be stigmatized (though poorly of) because they have a mentally retarded child.
14. \_\_\_\_\_ It will be impossible to teach the child described the skills needed to hold a job.
15. \_\_\_\_\_ The child described will not be able to enjoy such recreational activities as attending football games, bowling, etc.
16. \_\_\_\_\_ The child described will be able to live with its family without any special arrangements.