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Support for non-therapeutic research with incompetent children an argument from an ethical perspective

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SUPPORT FOR NON-THERAPEUTIC RESEARCH WITH INCOMPETENT CHILDREN

AN ARGUMENT FROM AN ETHICAL PERSPECTIVE

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THESIS

Submitted to the Faculty of Waterloo Lutheran Seminary
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1990

RESEARCH PROJECT ABSTRACT

SUPPORT FOR NON-THERAPEUTIC RESEARCH WITH INCOMPETENT CHILDREN

AN ARGUMENT FROM AN ETHICAL PERSPECTIVE

The thesis of this paper contends that the judgement rendered in the case re Eve v. "E." by the Supreme Court of Canada on October 23, 1986, from an ethical perspective demonstrates limitations in the legal judgement. Moreover, the thesis maintains that the legal arguments presented in the judgement are narrowly developed. If this paper should demonstrate the above mentioned, then, it of necessity questions the adequacy of the present case law!

It is the hope of this paper that the evaluation of the "Eve" case from an ethical viewpoint will evoke further discussion from both the legal and medical communities.

Furthermore, the decision rendered on the "Eve" case by the Supreme Court of Canada has serious negative implications for non-therapeutic research with incompetent subjects including children. This decision severely limits the possibility, potential and progress of any non-therapeutic research on subjects unable to give consent in Canada!

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INTRODUCTION

This paper is not a legal brief nor is it an attempt to judge the legal correctness of the decision rendered in the "Eve" case. However; this paper is an evaluation of the "Eve" case from an ethical point of view and questions the adequacy of the present law from that perspective.

The thesis of this paper contends that the judgement rendered in the "Eve" case by the Supreme Court of Canada on October 23, 1986, from an ethical perspective demonstrates the limitations in the legal judgement. Moreover, the thesis maintains that the legal arguments presented in the judgement are narrowly developed. If this paper should demonstrate the above mentioned, then, it of necessity questions the adequacy of the present case law!

It is the hope of this paper that the evaluation of the "Eve" case from an ethical viewpoint will evoke further discussion from both the legal and medical communities.

Furthermore, the decision rendered on the "Eve" case by the Supreme Court of Canada has serious negative implications for non-therapeutic research with incompetent subjects including children. This decision severely limits the possibility, potential and progress of any non-therapeutic research on subjects unable to give consent in Canada!

The "Eve" case judgement has become the sole standard that sets the limits for essential and vital non-therapeutic ie. (paediatric) medical research in Canada. A call for amelioration and change to the Medical Research Council of Canada "Guidelines on Research Involving Human Subjects 1987"[1] is being asked for. The "Eve" decision stands before medical research as a roadblock that obstructs and inhibits the way to a more promising and improved paediatric care.

The structure of the paper is built into the ordered progression of its chapters. Chapter I provides the "Eve" case overview. Chapter II examines the legal arguments put forth with respect to the three key case issues under consideration: 1) proxy consent, 2) best interests-substituted judgement, and 3) the case definition of health. Chapter III identifies the ethical dilemmas related to the legal arguments in respect to the three case issues under consideration. Chapter IV offers an ethical solution to each of the ethical dilemmas stemming from the legal determinations in regard to the aforementioned three key issues under investigation. The ontology ascribed to by Paul Tillich and supported by Richard Crossman provides the resource foundation for this author's ethical argumentations and perspective. Although it is acknowledged that Paul

Tillich's "systematics" applies both a theological and an ontological worldview, the focus for the purposes of this paper is weighted upon the latter ontological insights. Through, what this writer refers to as Paul Tillich's "ontology" (that which pertains to the nature of being), the self-world, lived reality, so to speak, a developmental method of ethics is derived and applied to evaluate the merits of the legal arguments and the implications of the case law decision.

As it has been noted above, if it can be demonstrated that each of tne key issues under consideration from the ontological perspective indicates an inadequacy then it of necessity also identifies a deficiency in the case law decision and therefore, its implications in regard to new contexts of application ie. paediatric research.

Chapter V demonstrates some of the implications of the "Eve" case upon paediatric non-therapeutic research and what those implications can mean in light of the ontological insights and thus, upon a developmental method of ethics.

CHAPTER I

THE "EVE" CASE

The proceedings commenced with an application by a mother to the Supreme Court of Prince Edward Island, Family Division. The mother was applying for permission to consent to the sterilization of her mentally retarded daughter for the purpose of contraception. In the interest of privacy the daughter was known as "Eve" and her mother "Mrs. E."[1]

This helpful overview of the case is presented in Bernard M. Dickens, "Case Comment Eve v. E."[2]

> The case concerned an at least mildly to moderately retarded woman, aged 24 in 1979, who suffered extreme expressive aphasia and was therefore unable to communicate and perhaps to perceive thoughts or concepts. She was pleasant, affectionate and capable of being attracted to and attracting the opposite sex. She would have no concept of the implications of marriage, the possible consequences of sexual intercourse, or mothering a child. The woman, protectively referred to as "Eve", had attended a school for retarded adults. She formed a close friendship with a male student, and talked of marriage. Eve's mother, "Mrs. E.", a widow then approaching 60 years of age, feared the emotional effects of pregnancy and childbirth on Eve, and also the responsibility that would fall on her to care for and rear Eve's child.

> Believing that Eve should be sterilized for the purpose of contraception, Mrs. E. asked the Prince Edward Island Supreme Court, Family Division, for declarations under the Mental Health Act: (i) that Eve was mentally incompetent, (ii) that Mrs. E. be authorized to consent to a tubal ligation operation to be performed on Eve. McQuaid J. reviewed Canadian, English and United States case law, and found that Eve's right to inviolability of the person was a right that superseded her right to be protected from pregnancy. He held that the Court had no authority by statute or its inherent parens patriae jurisdiction to authorize contraceptive sterilization, and therefore declined to make the third declaration Mrs. E. sought.
>
> On appeal to the Supreme Court of Prince Edward Island. in banco, this decision was reversed. The appellate court was unanimous that, in proper circumstances, it had authority under statute, or its parens patriae powers, to authorize the sterilization of a mentally incompetent person for non-therapeutic reasons. The majority (Large and Campbell JJ.) found evidence to warrant Eve's sterilization by a method to be approved. After further representations, the Court later ordered Eve's sterilization by way of a hysterectomy. MacDonald J., dissenting, expressed fears of the potential for abuse of the disabled, and proposed exacting medical and related criteria that would have to be satisfied before such an exceptional procedure could be undertaken. On request of Eve's guardian ad litem, the Prince Edward Island Supreme Court, Appeal Division, granted leave to appeal to the Supreme Court of Canada.[3]

The Supreme Court of Canada's judgement in the "Eve" case was rendered by the Hon. Mr. Justice LaForest on October 23, 1986. In that decision "...the court reversed the decision of the Court of Appeal which appeared to reverse the first level court prohibiting contraceptive sterilization on a substitute consent basis."[4]

The Court's unanimous judgement in Eve v. Mrs. "E.", "held that neither the Prince Edward Island Mental Health Act nor the Hospital Management Regulations vested Mrs. E. with authority to have her adult mentally retarded daughter sterilized."[5]

Further, the Supreme Court also held that under the parens patriae jurisdiction sterilization "should never be authorized for non-therapeutic purposes".[6] In the case of an individual unable to give consent Mr. Justice LaForest argued, "it can never safely be determined that such a procedure is for the benefit of that person".[7] "The grave intrusion on a person's rights and the certain physical damage that ensues from non-therapeutic sterilization without consent, when compared to the highly questionable advantages that can result from it, have persuaded me..."[8]

Mr. Justice LaForest concurred with Mr. Justice McQuaid of the Supreme Court of P.E.I., Family Division, that non-therapeutic sterilization cannot be authorized in the exercise of the parens patriae jurisdiction. "McQuaid J. was, therefore right in concluding that he had no authority or jurisdiction to grant the application."[9] The parens patriae jurisdiction of the court, is the crucial legal concept in this particular case.

> Its origin is found in English common law where the king could act as guardian to persons who were legally incompetent (eg. infants, the mentally infirm, and the mentally ill). The concept is invoked to protect such interests as health, comfort, and welfare.[10]

In Mr. Justice LaForest's view the parens patriae justification is "...founded on necessity, namely the need to act for the protection of those who cannot care for themselves."[11] Moreover, "The courts have frequently stated that it is to be exercised in the 'best interests' of the protected person, or again, for his or her 'benefit' or 'welfare'."[12]

According to Mr. Justice LaForest, while the parens patriae jurisdiction may be considered to be unlimited in its scope of operation, it is not unlimited in its exercise.

> It must be exercised in accordance with its underlying principle. Simply put, the discretion is to do what is necessary for the protection of the person for whose benefit it is exercised;... The discretion is to be exercised for the benefit of that person, not for that of others.[13]

Elsewhere he has stated that parens patriae may be applied, "to authorize the performance of a surgical operation that is necessary to the health of a person...".[14] Justice LaForest's definition of health made reference to "mental as well as physical health".[15]

Mr. Justice LaForest rejected the substituted judgement test contended by the counsel for the respondent. He commented that, "the primary purpose of the substituted judgement test is to attempt to determine what decision the mental incompetent would make, if she was reviewing her situation as a competent person..."[16] The thrust of his commentary emphasized that there was "an obvious logical lapse in this argument."[17] "What the incompetent would do if she or he could make the choice is simply a matter of speculation."[18]

The Supreme Court of Canada in restoring the decision of Mr. Justice McQuaid has clearly ruled out the validity of substitute authorization either in the form of substitute, proxy or next-of-kin consent for the contraceptive sterilization of persons unable, on account of mental incapacity, to make the choice for themselves.[19] Furthermore, "although the case may be read as resolving only that it was not in Eve's interest to be sterilized, it has significant implications for any medical intervention based on substitute consent."[20]

Eve v. Mrs. "E." is the first Supreme Court of Canada case to challenge the validity of substitute consent.[21] The case outcome has set a precedent, limiting the possibilities for any future "non-therapeutic interventions, such as medical research, the removal of tissue such as bone marrow from a healthy child to help a sick one, and so on".[22]

The "Eve" case in Canada is of critical importance. Beyond resolving that it was not in Eve's interests to be sterilized, the case is pivotal in the fact that it holds significant implications for non-therapeutic medical interventions.

The task in this portion of the paper will be to examine three key issues in the case and the legal interpretations applied to them:

1) substitute consent
2) best interests - substitute judgement
3) case definition of health

Subsequently, these issues will be examined from an ethical perspective. Should it be possible to demonstrate that the legal arguments regarding these issues raise inadequacies and are ambiguous, then; the door is left open to invite further dialogue to determine whether the case law in itself is adequate!

NOTES TO CHAPTER I

1. Eve v. Mrs. "E.", [1986] 2 S.C.R. 393 (S.C.C.) Supreme Court Report Vol. 2, Supreme Court of Canada, p. 388.

2. Dickens, Bernard M., "Case Comment Eve v. E. No parental or parens patriae power to authorize non-therapeutic sterilization of mentally incompetent persons." Canadian Family Law Quarterly, Vol. 2, No. 1, June 1987.

3. Dickens, Bernard M., Case Comment Eve v. E., p. 109-106. See also [1986] 2 S.C.R. 393-399. (S.C.C.).

4. Sharpe, Gilbert, "Casenote: "Eve" v. Mrs. "E.", and the Canadian Mental Health Association, the Canadian Assoc. for the Mentally Retarded, the Public Trustee of Manitoba, and the Attorney General of Canada (intervenors)." Health Law in Canada, Vol. 7, 1986: 90-91.

5. "The Eve Case and the Validity of Substitute Consent". Westminster Affairs the Newsletter of the Westminster Institute for Ethics and Human Values, London, Canada. February, 1987.

6. [1986] 2 S.C.R. 431 (S.C.C.).

7. [1986] 2 S.C.R. 431 (S.C.C.).

8. [1986] 2 S.C.R. 431 (S.C.C.).

9. [1986] 2 S.C.R. 431 (S.C.C.).

10. "'Parens patriae', literally 'parent of the country', is a reference to the traditional role of the state as guardian of those who suffer a legal distability." See "Viewpoint. Westminster Affairs The Newsletter of the Westminster Institute for Ethics and Human Values, London, Canada. February, 1987.

11. [1986] 2 S.C.R. 426 (S.C.C.).

12. [1986] 2 S.C.R. 426 (S.C.C.).

13. [1986] 2 S.C.R. 427 (S.C.C.).

14. [1986] 2 S.C.R. 426 (S.C.C.).

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17. [1986] 2 S.C.R. 434 (S C.C.).

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19. Sharpe, Gilbert. Health Law in Canada, Vol. 7, 1986: 91.

20. "The Eve Case and the Validity of Substitute Consent". The Newsletter of the Westminster Institute for Ethics and Human Values, London, Canada, February 1987.

21. The Newsletter of the Westminster Institute for Ethics, February 1987.

22. Sharpe, Gilbert. Health Law in Canada, Vol. 7, 1986: 91.

CHAPTER II

THE LEGAL ARGUMENTS

1) Substitute Consent

An account of the Canadian Law of Substitute Consent[1] is outlined in the following commentary:

> It is a well-established principle of law that, except for an unforseen medical emergency in which it is impossible to obtain the patient's consent, a healthcare professional must obtain consent to undertake any medical examination, operation or other procedure. Without the patient's consent, any physical intervention constitutes an assault in criminal law and a battery in tort law. The patient's consent to be valid must be based on a full and frank disclosure of the general nature of the procedure and its risks. Moreover, the consent will be valid only if the patient has the mental and intellectual capacity to understand and appreciate the nature of the procedure and its risks.
>
> Many children are incapable of consenting to medical procedures and consequently the common law has recognized a parent's or guardian's right to consent on their behalf. Under the Criminal Code, parents and guardians have a corresponding legal obligation to obtain medical treatment for their children. Although it is standard practice to obtain the next-of-kin's consent to treat adult incompetent patients, the common law and statutes have not always specifically identified which relative is empowered to give such consent.

> Provided that the patient did not have capacity to consent, the next-of-kin acted in good faith, and the procedure was in the patient's best interests, the courts would probably uphold the validity of the next-of-kin's consent.[2]

The legal analysis of the "Eve" case precludes the virtual elimination of substitute (proxy) consent for non-therapeutic medical interventions! Further, "the case law albeit limited, indicates that substitute consent must be exercised in the patient's best interests".[3] In light of this statement, it becomes apparent that only medical treatment that is deemed to be therapeutic[4] and of direct benefit to an individual is now permissible by law under proxy or substitute consent in Canada. Moreover, following this case law precedent, even a proposed therapeutic procedure can be scrutinized by the legal process.

> The Court confirmed that the burden of proof of justifiable grounds of intervention always rests on a person proposing a medical procedure that, in the absence of the subject's free and adequately informed consent, would constitute battery or assault. This applies both to guardians proposing sterilization and, for instance, public or quasi-public officers proposing blood transfusions or like treatment for children that their parents have refused on religious grounds.[5]

Presently, "only courts have authority to approve invasive forms of management, and to say what consent process will be adequate for invasive non-therapeutic procedures".[6] Meanwhile, "in the absence of statutory authorization, it is difficult to see how a parent or guardian could give a valid substitute consent for any non-therapeutic intervention".[7]

In the case of "Eve", Robert Solomon recognizes and this writer concurs with his assessment, that the judgement rendered reflects the specific facts of the case:

> ...a case in which major surgery was proposed solely for contraceptive purposes. There appears to have been little evidence introduced to justify the need for contraception, let alone the drastic procedure chosen. It is very difficult to see how a hysterectomy could be justified as being in Eve's or, for that matter, anyone's interests. The "Eve" case did not force the Court to balance the competing interests that can arise in other types of substitute consent cases. For example, the courts may have far greater difficulty in determining the validity of parental consent authorizing a potentially lifesaving bone marrow transplant from a healthy child to his or her sick sibling.[8]

Moreover, the case law judgement has overriding implications of significant import.

> ...the definitive statements of principle in 'Eve' would all but rule out any non-therapeutic intervention based on substitute consent. It is impossible to determine if this was the Supreme Court's intention or just an inadvertent result of the Court's strong reaction to the 'Eve' case. Unfortunately, it may be years before the Court has another opportunity to clarify its position. In the interim, the 'Eve' case will heighten the grave doubts about the validity of substitute consent for non-therapeutic interventions, increase concern among the medical and research communities and fuel debates about whether the current law is ethical.[9]

The "Eve" judgement is having a major impact on the medical and research community. As the validity of substitute (proxy) consent is being questioned, concerns "have halted virtually all research involving invasive procedures with children, Alzheimer's patients and other incompetent subjects at one major Ontario university".[10] "The current law also calls into question a broad range of other procedures, such as the circumcision of male infants for religious reasons and bone marrow transplants from a healthy child to a sick sibling."[11]

The law at present seems to prohibit all non-therapeutic interventions that are proposed on the basis of substitute consent, irrespective of any risk/benefit analysis. For instance minimal risk and invasion and maximum benefits has no relevance any longer. "Nor has the law recognized any legitimate realm of family decision-making...in a benign research project that holds great promise of medical advances."[12]

ii) Best Interests and Substituted Judgement

In respect to the "best interests" and "substituted judgement" tests in the exercise of the parens patriae jurisdiction, the Supreme Court of Canada opted to adjudicate the "Eve" case by the former approach alone. Benjamin Freedman comments:

> The scope of this parens patriae power is virtually unlimited, ie. it may imaginably encompass virtually any course of action to be undertaken with respect to, or on behalf of, the incompetent. Yet it is controlled by its subjection to a single principle or criterion: to be justified under parens patriae, any decision reached must serve the best interests of the incompetent. In the court's view, it has not been demonstrated that sterilizing Eve would serve her own best interests; hence, the request for authority to sterilize Eve cannot be granted.[13]

It is apparent that this jurisdiction though unlimited in scope is indeed limited in discretionary power. "Simply put, the discretion is to do what is necessary for the protection of the person for whose benefit it is exercised,...The discretion is to be exercised for the benefit of that person, not for that of others."[14] The parens patriae jurisdiction "is to be exercised in the best interests of the protected person, or again, for his or her 'benefit' or 'welfare'."[15]

The degree to which the "best interests" approach is exclusively exercised over the protected individual is evident in Supreme Court Justice LaForest's summary views:

> The importance of maintaining the physical integrity of a human being ranks high in our scale of values, particularly as it affects the privilege of giving life. I cannot agree that a court can deprive a woman of that privilege for purely social or other non-therapeutic purposes without her consent. The fact that others may suffer inconvenience or hardship from failure to do so cannot be taken into account. The Crown's parens patriae jurisdiction exists for the benefit of those who cannot help themselves, not to

> relieve those who may have the burden of caring for them.[16]

Case law, albeit limited in Canada has interpreted that the parens patriae jurisdiction of the Court can only be exercised in the "best interests" of the individual under its protection. It is only for the benefit or welfare of that person alone!

The contrast in interpretation of the "best interests" approach, is reflected in cases that have more recently come before the courts in the United States.

A significant change occurred in jurisprudence following the decision of the Supreme Court of the U.S. in Stump v. Sparkman (1978). This case has apparently had both a precedential value as well as a catalytic effect upon the courts in the U.S.[17] "Since that decision, the vast majority of state courts before which the question has been raised have held that they have equitable authority, in the absence of statute, to order sterilization of the mentally retarded;..."[18]

In the case of Matter of Sallmaier (1976), a pre-Stump v. Sparkman case "the rationale on which state courts have acted in recent years is conveniently summarized in a passage..."[19]

> The jurisdiction of the court in this proceding arises not by statute, but from the common law jurisdiction of the Supreme Court to act as parens patriae with respect to incompetents...The

> rationale of parens patriae, as was stated by the court in Matter of Weberlist, supra, ...is that the State must intervene in order to protect an individal who is not able to make decisions in his own best interest. The decision to exercise the power of parens patriae must reflect the welfare of society, as a whole, but mainly it must balance the individual's right to be free from interference against the individual's need to be treated, if treatment would in fact be in his best interest.[20]

There is a marked contrast between the U.S. Supreme Court's interpretation of the parens patriae jurisdiction and its exercise over against that of the Supreme Court of Canada. The latter court has ruled that its parens patriae jurisdiction can only be exercised in the "best interests" of the protected person and not for that of others.[21] Whereas, the U.S. state Supreme Court's interpretation here appears to be much broader in scope. Not only is the welfare of the individual who is under protection inherent in the parens patriae jurisdiction but also and most significantly the "welfare of society"! "...The decision to exercise the power of parens patriae must reflect the welfare of society, as a whole..."[22]

It has been noted that subsequent to Matter of Sallmaier, "another New York court expressly refused to authorize sterilization in the absence of legislative guidelines; Application of A.D. (1977), 394 N.Y.S. 2d 139".[23] This indicates that while some state courts more recently have recognized "an inherent power in courts of general jurisdiction to authorize sterilization of mentally incompetent persons", the view is not universally held.[24]

The case of Matter of Guardianship of Hayes (1980) and others have demonstrated that the United States courts, "in acting under the best interests test have a very wide discretion".[25]

Although the Supreme Court of Canada firmly adopted the "best interests" test in the exercise of its parens patriae jurisdiction, as the only appropriate approach in adjudicating the "Eve" case, the court also acknowledged, what it considered, limitations in the tool. Mr. Justice LaForest commented:

> Many of the factors I have referred to as showing that the best interest test is simply not a sufficiently precise or workable tool to permit the parens patriae power to be used in situations like the present...[26]

The Supreme Court made reference to the case of Matter of Guardianship of Eberhardy (1981)[27] which it maintained raised the pertinent concerns regarding the insufficiency in the "best interests" test. In that case Heffernan J. indicated that the "best interests" test under the parens patriae jurisdiction has primarily been applied "in the determination of the custody of children and their placement..." He also reflected that the concensus of those who have had some experience with this standard have not "expressed complete satisfaction with it." Further, because "it is not an objective test...The substantial workability of the test rests upon the informed fact-finding and the wise exercise of discretion by trial courts engendered by long experience with the standard..."[28]

In light of the above-mentioned concerns, notably the fact that no concrete or objectifiable criteria had been determined for the "best interests" test and also the fact that the Supreme Court of Canada did not have the advantage of any lengthy case law experience with this standard, it is understandable why the court proceeded in Eve v. "E." with caution, reservation and to a degree with uncertainty. However, one redeeming and thus attractive quality inherent in the "best interests" test was described as its ability to be corrected. Heffernan J. contended that decisions rendered under the "best interests" standard "are not irreversible" and "errors of judgement or revisions of decisions" can be rectified.[29]

Thus, the "best interest" test allowed for "appellate review"[30] whereby corrections could be made to errors of discretion. Heffernan J. emphasized this aspect of the "best interest" standard and this was noted in Supreme Court of Canada Justice LaForest's commentary.

> Importantly, however, most determinations made in the best interests of a child or of an incompetent person are not irreversible; and although a wrong decision may be damaging indeed, there is an opportunity for a certain amount of empiricism in the correction of errors of discretion. Errors of judgement or revisions of decisions by courts and

> social workers can, in part at least, be rectified when new facts or second thoughts prevail. And, of course, alleged errors of discretion in exercising the "best interest" standard are subject to appellate review. Sterilization as it is now understood by medical science is, however, substantially irreversible.[31]

Following this commentary on the "best interests" test in his summary and disposition notes, Mr. Justice LaForest had fittingly juxtaposed a discussion on the social implications of "problem" cases ie. Eve v. "E". The overall focus on the subject "alluded to the limited capacity of judges to deal adequately with a problem that had such general social overtones..."[32] Once again he concurs and cites from Heffernan J.

> What these facts demonstrate is that courts, even by taking judicial notice of medical treatises, know very little of the techniques or efficacy of contraceptive methods or of thwarting the ability to procreate by methods short of sterilization. While courts are always dependent upon the opinions of expert witnesses, it would appear that the exercise of judicial discretion unguided by well thought-out policy determinations reflecting the interest of society, as well as of the person to be sterilized, are hazardous indeed...[33]

The above stated apologetical infers that there are two limiting factors which have inhibited the courts from dealing adequately with such cases.

Firstly, the courts lack in medical expertise and secondly and more importantly the courts are being asked to adjudicate such cases in the absence of "well thought-out policy determinations".[34] He has stated:

> ...it would appear that the exercise of judicial discretion unguided by well thought-out policy determinations reflecting the interest of society, as well as of the person to be sterilized, are hazardous indeed...[35]

The "Eve" case reflected such a need for the development of policy guidelines in this area.

> A properly thought out public policy on sterilization or alternative contraceptive methods could well facilitate the entry of these persons into a more nearly normal relationship with society. But again this is a problem that ought to be addressed by the legislature on the basis of fact-finding and the opinions of experts.[36]

Moreover, in the absence of public policy guidelines the court proceeded to discern the merits of the "Eve" case with great caution and by means of its adopted approach, the "best interests" test alone.

> I simply repeat that the utmost caution must be exercised commensurate with the seriousness of the procedure. Marginal justifications must be weighed against what is in every case a grave intrusion on the physical and mental integrity of the person.[37]

Elsewhere Mr. Justice LaForest has stated:

> To begin with, it is difficult to imagine a case in which non-therapeutic sterilization could possibly be of benefit to the person on behalf of whom a court purports to act, let alone one in

> which that procedure is necessary in his or her best interest. And how are we to weigh the best interests of a person in this troublesome area, keeping in mind that an error is irreversible? ...That being so, one need only recall Lord Eldon's remark, supra, that 'it has always been the principle of this court, not to risk damage to children...which it cannot repair' to conclude that non-therapeutic sterilization may not be authorized in the exercise of the parens patriae jurisdiction...[38]

Thus, Mr. Justice LaForest concurred with McQuaid J.[39] that he (McQuaid) was correct in concluding that "he had no authority or jurisdiction to grant the application" for sterilization.[40]

> The court undoubtedly has a right and duty to protect those who are unable to take care of themselves, and in doing so it has a wide discretion to do what it considers to be in their best interests.[41]

Substituted Judgement

The Supreme Court of Canada "in concluding the substance of its judgement"[42] rejected the substituted judgement test. The Court determined that the parens patriae jurisdiction in this country is to be exercised solely on the basis of the "best interests" test. In notable contrast, this second approach, that of "substituted judgement" has been adopted in the exercise of the parens patriae jurisdiction by some state courts in the United States. Thus, it is appropriate to include a discussion on this subject at this time.

The "Substituted judgement" standard has been defined as that "which allows the proxy decision-maker to make a decision approximating that which the incompetent patient might have made if he/she were competent."[43]

In regard to the "Eve" case Mr. Justice LaForest made these comments:

> The primary purpose of the substituted judgement test is to attempt to determine what decision the mental incompetent would make, if she was reviewing her situation as a competent person, but taking account of her mental incapacity as one factor in her decision...[44]

This was to allow the court to consider a number of issues such "as the values of the incompetent, any religious beliefs held by her, and her societal views as expressed by her family". It was an attempt "to determine the actual interests and preferences of the mental incompetent".[45]

> This...recognizes her moral dignity and right to free choice. Since the incompetent cannot exercise that choice herself, the court does so on her behalf. The fact that a mental incompetent is, either because of age or mental disability, unable to provide any aid to the court in its decision does not preclude the use of the substituted judgement test.[46]

In the "Eve" case counsel for the respondent contended that the court should adopt the substituted judgement test "recently developed by a number of state courts in the United States".[47] According to Mr. Justice

LaForest, the counsel's submission stated that this test is to be preferred to the best interests approach because "it places a higher value on the individuality of the mentally incompetent person. It affords that person the same right, ...as a competent person to choose whether to procreate or not."[48]

Mr. Justice LaForest responded:

> There is an obvious lapse in this argument. I do not doubt that a person has a right to decide to be sterilized. That is his or her free choice. But choice presupposes that a person has the mental competence to make it. It may be a matter of debate whether a court should have the power to make the decision if that person lacks the mental capacity to do so. But it is obviously fiction to suggest that a decision so made is that of the mental incompetent, however much the court may try to put itself in her place. What the incompetent would do if she or he could make the choice is simply a matter of speculation.[49]

Describing the arguments supporting the substituted judgement approach as "sophistry", Mr. Justice LaForest cited Matter of Guardianship of Eberhardy (1981) in which that court discussed the case re Grady (1981) and concluded in a similar manner.[50]

> The fault we find in the New Jersey case is the ratio decidendi of first concluding, correctly we believe, that the right to sterilization is a personal choice, but then equating a decision made by others with the choice of the person to be sterilized. It clearly is not a personal choice, and no amount of legal legerdemain can make it so.[51]

> We conclude that the question is not choice because it is sophistry to refer to it as such, but rather the question is whether there is a method by which others, acting in behalf of the person's best interests and in the interests, such as they may be, of the state, can exercise the decision. Any governmentally sanctioned (or ordered) procedure to sterilize a person who is incapable of giving consent must be denominated for what it is, that is the state's intrusion into the determination of whether or not a person who makes no choice shall be allowed to procreate.[52]

Further to these arguments in support of the substituted judgement test developed primarily from a common-law perspective, counsel for the respondent contended that there is "a fundamental right to free procreative choice", so stated Mr. Justice LaForest. He continued that counsel not only submitted that "there is a fundamental right to bear children; there is as well a fundamental right to choose not to have children and to implement that choice by means of contraception."[53]

Mr. Justice LaForest replied:

> ...he appears to base this argument on S.7 of the Charter. But assuming for the moment that liberty is used in S.7 protects rights of this kind (a matter I refrain from entering into), counsel's contention seems to me to go beyond the kind of protection S.7 was intended to afford. All S.7 does is to give a remedy to protect individuals against laws or other state action that deprive them of liberty. It has no application here.[54]

Counsel for the appellent urged that "a court-ordered sterilization of a mentally-incompetent person, by depriving that person of the right to procreate, would constitute an infringement of that person's rights to liberty and security of the person under S.7 of the Canadian Charter of Rights and Freedoms".[55] Differing in Charter interpretation the respondent's counsel "countered by relying on that person's right to equality under S.15(1) of the Charter".[56] Counsel stated:

> ...that the most appropriate method of ensuring the mentally incompetent their right to equal protection under S.15(1) is to provide the mentally incompetent with a means to obtain non-therapeutic sterilizations, which adequately protects their interests through appropriate judicial safeguards.[57]

A similar argument in support of the above was presented by counsel for the Public Trustee of Manitoba.

> It is submitted that in the case of a mentally incompetent adult, denial of the right to have his or her case presented by a guardian _ad litem_ to a Court possessing jurisdiction to give or refuse substituted consent to a non-therapeutic procedure such as sterilization, would be tantamount to a denial to that person of equal protection and equal benefit of the law. Such a denial would constitute discrimination on the basis of mental disability, which discrimination is prohibited by Section 15 of the Canadian Charter of Rights and Freedoms.[58]

Mr. Justice LaForest in review of the above arguments concluded that "Section 15 of the Charter was not in force when these proceedings commenced but, this aside, these arguments appear flawed."[59]

> They raise in different form an issue already dealt with, ie. that the decision made by a court on an application to consent to the sterilization of an incompetent is somehow that of the incompetent. More troubling is that the issue is, of course, not raised by the incompetent, but by a third party.[60]

The arguments submitted by the counsel for the respondent and by the counsel for the Public Trustee of Manitoba based upon S.15 of the Charter were interpreted by Mr. Justice LaForest as "raising in different form an issue already dealt with".[61] He perceived in these submissions a request for the application of the "substituted judgement" standard by the court to authorize the sterilization of an incompetent. In light of the fact that the court had determined that the "substituted judgement" test to be sophistry and appeared to be flawed "ie. that the decision made by a court on an application to consent to the sterilization of an incompetent is somehow that of the incompetent,"[62] these arguments were rejected. Earlier, Mr. Justice LaForest responded:

> But it is obviously fiction to suggest that a decision so made is that of the mental incompetent, however much the court may try to put itself in her place. What the incompetent would do if she or he could make the choice is simply a matter of speculation.[63]

Elsewhere he concurred with the court in Matter of Guardianship of Eberhardy (1981).

> Any governmentally sanctioned (or ordered) procedure to sterilize a person who is incapable of giving consent must be denominated for what it is, that is the state's intrusion into the determination of whether or not a person who makes no choice shall be allowed to procreate.[64]

Mr. Justice LaForest contended that, "the court...has the right and duty to protect those who are unable to take care of themselves, and in doing so it has a wide discretion to do what it considers to be in their best interests."[65] He further summarized:

> But this function must not, in my view, be transformed so as to create a duty obliging the court, at the behest of a third party, to make a choice between the two alleged constitutional rights - the right to procreate or not to procreate - simply because the individual is unable to make that choice. All the more so since, in the case of non-therapeutic sterilization as we saw, the choice is one the courts cannot safely exercise.[66]

iii) Case Definition of Health

When defining "health" in the "Eve" case, Mr. Justice LaForest stated, "and by health, I mean mental as well as physical health".[67] Mr. Justice LaForest had no doubt that the parens patriae jurisdiction "may be used to authorize the performance of a surgical operation that is necessary to the health of a person..."[68] Noteworthy is the fact that any medical intervention under this jurisdiction is to promote the physical and mental health of the individual "under the protection of the court". Simply stated, the discretion in the exercise of parens patriae "is to do what is necessary for the protection of the person for whose benefit it is exercised".[69] Moreover, "the discretion is to be exercised for the benefit of that person, not for that of others."[70]

In regard to hysterectomy, the medical procedure recommended in the case application, the court commented that "the implications of sterilization are always serious". The rationale given was that "it removes from a person the great privilege of giving birth, and is for practical purposes irreversible". Furthermore, "if achieved by means of a hysterectomy, the procedure approved by the Appeal Division, it is not only irreversible, it is major surgery". Recalling Lord Eldon's "admonition" in Wellesley v. Duke of Beaufort (1827) the court was reminded that "it has always been the principle of this Court, not to risk the incurring of damage to children...which it cannot repair, but rather to prevent the damage being done".[71]

Mr. Justice LaForest remarked,

> Though this comment was addressed to children, who were the subject matter of the application, it aptly describes the attitude that should always be present in exercising a right on behalf of a person who is unable to do so.[72]

Another consideration drawn to the court's attention was the fact that "unlike most surgical procedures, sterilization is not one that is ordinarily performed for the purpose of medical treatment". The Law Reform Commission of Canada's Working Paper 24 (1979) entitled "Sterilization: Implications for Mentally Retarded and Mentally Ill Persons" was then referred to for "providing a convenient summary of much of the work in the field".[73]

> Sterilization as a medical procedure is distinct, because except in rare cases, if the operation is not performed, the physical health of a person involved is not a danger, necessity or emergency not normally being factors in the decision to undertake the procedure. In addition to its being elective it is for all intents and purposes irreversible.[74]

Moreover, psychological values were evaluated. "There is considerable evidence that non-consensual sterilization has a significant negative psychological impact on the mentally handicapped."[75] Once again The Commission's Working Paper 24 was cited.

> It has been found that, like anyone else, the mentally handicapped have individually varying reactions to sterilization.
>
> Sex and parenthood hold the same significance for them as for other people and their misconceptions and misunderstandings are also similar. Rosen maintains that the removal of an individual's procreative powers is a matter of major importance and that no amount of reforming zeal can remove the significance of sterilization and its effect on the individual psyche.[76]
>
> In a study by Sabagh and Edgerton, it was found that sterilized mentally retarded persons tend to

> perceive sterilization as a symbol of reduced or degraded status. Their attempts to <u>pass for normal</u> were hindered by negative self perceptions and resulted in withdrawal and isolation rather than striving to conform...
>
> The psychological impact of sterilization is likely to be particularly damaging in cases where it is a result of coercion and when the mentally handicapped have no children.[77]

With regard to the case at hand, no evidence indicated "that failure to perform the operation would have any detrimental effect on Eve's physical and mental health". Furthermore, the court's interpretation of the application's purposes in sterilization, "as far as Eve's welfare is concerned, are to protect her from possible trauma in giving birth and from the assumed difficulties she would have in fulfilling her duties as a parent". It was also assumed "from the fact that hysterectomy was ordered, that the operation was intended to relieve her of the hygienic tasks associated with menstruation". One other purpose was "to relieve Mrs. E. of the anxiety that Eve might become pregnant, and give birth to a child, the responsibility for whom would probably fall on Mrs. E."[78]

In disposing of these arguments, Mr. Justice LaForest commenced by refuting the latter purpose. "One may sympthize with Mrs. E. ...it is easy to understand the natural feelings of a parent's heart. But the parens patriae jurisdiction cannot be used for her benefit."[79] Moreover,

> Its exercise is confined to doing what is necessary for the benefit and protection of persons under disability like Eve...So we are left to consider whether the purposes underlying the operation are necessarily for Eve's benefit and protection.[80]

The court was satisfied with the Law Reform Commission's dismissal of the argument concerning "the trauma of birth".[81]

> For this argument to be held valid would require that it could be demonstrated that the stress of delivery was greater in the case of mentally handicapped persons than it is for others. Considering the generally known wide range of postpartum response would likely render this a difficult case to prove.[82]

Regarding the argument "relating to fitness as a parent", the court referred to studies which indicated "that mentally incompetent parents show as much fondness and concern for their children as other people." Although acknowledging that "many may have difficulty in coping, particularly with the financial burdens involved, the court commented, "but this issue does not relate to the benefit of the incompetent; it is a social problem and one...that is not limited to incompetents".[83] In regard to judicial boundary LaForest argued:

> Above all it is not an issue that comes within the limited powers of the courts, under the parens patriae jurisdiction, to do what is necessary for the benefit of persons who are unable to care for themselves.[84]

It was further stated, "there are human rights considerations that should make a court extremely hesitant about attempting to solve a social problem like this" in this manner.[85]

In view of the concern regarding "hygienic problems", the court made reference yet another time, to the Law Reform Commission.

> If a person requires a great deal of assistance in managing their own menstruation, they are also likely to require assistance with urinary and fecal control, problems which are much more troublesome in terms of personal hygiene.[86]

The court remarked that "the drastic measure of subjecting a person to a hysterectomy for this purpose is clearly excessive."[87]

In summarizing, Mr. Justice LaForest submitted this disposition.

> The grave intrusion on a person's rights and the certain physical damage that ensues from non-therapeutic sterilization without consent, when compared to the highly questionable advantages that can result from it, have persuaded me that it can never safely be determined that such a procedure should never be authorized for non-therapeutic purposes under the parens patriae jurisdiction.[88]

The court found "it difficult to imagine a case in which non-therapeutic sterilization could possibly be of benefit" to an individual on behalf of whom the court is to act, "let alone one in which that procedure is necessary in his or her best interest". Doubtful as to how "to weigh the best interests of a person in this troublesome area" and mindful of the irreversibility of the procedure, the court however, recalled in certainty that "it has always been the principle of this Court, not to risk damage...which it cannot repair". Thus, it concluded "that non-therapeutic sterilization may not be authorized in the exercise of the parens patriae jurisdiction". In essence, the Court determined that there is "no authority or jurisdiction to grant the application".[89] Furthermore, "marginal justifications must be weighed against what is in every case a grave intrusion on the physical and mental integrity of the person."[90]

Summary

Underlying the Supreme Court of Canada's judgement in Eve v. "E." are the legal determinations made upon the key elements within the case. Some of those arguments have been synthesized out of the substance of Mr. Justice LaForest's case summary remarks. The above presentation has attempted to document the legal interpretations rendered on the three issues of concern for this paper: 1) proxy consent, 2) best interests - substituted judgement, and 3) the case definition of health.

NOTES TO CHAPTER II

1. "Proxy consent refers to the provision of consent (or refusal), particularly regarding research or treatment participation, by one person on behalf of another." Substitute consent is herein applied with the same definition force as proxy consent.
Melton, G.B., Koocher, G.P., and Saks, M.J. (eds.), Children's Competence to Consent, New York: Plenum Press, 1983, p. 255.

2. "The Eve Case and the Validity of Substitute Consent". The Newsletter of the Westminster Institute for Ethics and Human Values, London, Canada, February, 1987.

3. "The Eve Case and the Validity of Substitute Consent". The Newsletter of the Westminster Institute for Ethics and Human Values, February, 1987.

4. "Most codes distinguish between 'therapeutic' research (performed with the intent of treating a patient-subject) and 'non-therapeutic' research (performed primarily for the purpose of gaining new knowledge)..."
Medical Research Council of Canada, Ethical Considerations In Research Involving Human Subjects, Report No. 6, Ottawa: Minister of Supply and Services Canada, 1978, p. 6. See

also notes on p. 30-31 re "direct benefit" and "no direct benefit".

5. Dickens, B.M., "Case Comment Eve v. E." p. 115. See also Mr. Justice LaForest's remarks concerning therapeutic sterilization. [1986] 2 S.C.R. 437 (S.C.C.).

6. Medical Research Council of Canada, Guidelines on Research Involving Human Subjects, Ottawa: Minister of Supply and Services Canada, 1987, p. 31.

7. "The Eve Case and the Validity of Substitute Consent". _The Newsletter of the Westminster Institute for ethics and Human Values_, February, 1987.

8. Solomon, Robert, "Eve v. Mrs. 'E.'" _Westminster Affairs_, London. Canada, February, 1987.

9. Solomon, Robert, "Eve v. Mrs. 'E.'" _Westminster Affairs_.

10. "The Eve Case and the Validity of Substitute Consent". _Westminster Affairs_, February, 1987.

11. "The Eve Case and the Validity of Substitute Consent". _Westminster Affairs_, February, 1987.

12. "The Eve Case and the Validity of Substitute Consent". Westminster Affairs, London, Canada, February, 1987.

13. Freedman, Benjamin, "Eve v. Mrs. E.: What We Don't Know, And When We Don't Know It", Westminster Affairs, London, Canada, February, 1987.

14. [1986] 2 S.C.R. 388, at 427 (S.C.C.).

15. [1986] 2 S.C.R. 388, at 426 (S.C.C.).

16. [1986] 2 S.C.R. 388, at 434 (S.C.C.) Re D (a minor), [1976] 1 All E.R. 326.

17. "The question at issue there was whether an Indiana judge, who had ordered the sterilization of a 'somewhat' retarded child on her mother's petition, was immune from liability in a suit subsequently brought by the incompetent...The Supreme Court held that the judge was immune from liability on the basis of an Indiana statute which conferred upon the Indiana circuit court original jurisdiction 'in all cases at law and in equity whatsoever'".
[1986] 2 S.C.R. 388, at 420-421 (S.C.C.).

18. [1986] 2 S.C.R. 388, at 420-421 (S.C.C.) re Stump v. Sparkman (1978), 435 U.S. 349. [1986] 2 S.C.R. 421 (S.C.C.).

19. In the case "Matter of Sallmaier (1976), 378 N.Y.S. 2d 989 (Sup. Ct.), the Court, basing itself on expert testimony concerning the likelihood of a psychotic reaction to pregnancy, other evidence of psychological and hygienic difficulties, and the patient's proclivity for sexual encounters with men, authorized the sterilization of a severely retarded adult woman." This case somewhat reflective of the circumstances in Eve v. "E." contrasts sharply with the decision rendered by the Supreme Court of N.Y.S.
[1986] 2 S.C.R. 388, at 421 (S.C.C.).

20. [1986] 2 S.C.R. 388, at 422 (S.C.C.) re Matter of Sallmaier (1976) 378 N.Y.S. 2d 991 (Sup. Ct.).

21. [1986] 2 S.C.R. 388, at 427.

22. [1986] 2 S.C.R. 388, at 422 (S.C.C.) re Matter of Sallmaier at p. 991.

23. [1986] 2 S.C.R. 388, at 422 (S.C.C.).

24. [1986] 2 S.C.R. 388, at 422 (S.C.C.).

25. [1986] 2 S.C.R. 388, at 422-424 (S.C.C.) re Matter of Guardianship of Hayes (1980), 608P 2d 635, at p. 637 (Wash. S.C.).

> In five of the nine states in which equitable jurisdiction to authorize the non-consensual sterilization of a mentally incompetent person is recognized, that jurisdiction is based on the inherent equitable power of the courts to act in the best interests of the mentally incompetent person... p. 422.

26. [1986] 2 S.C.R. 388, at 432 (S.C.C.).

27. [1986] 2 S.C.R. 388, at 419 (S.C.C.) re Matter of Guardianship of Eberhardy (1981). 307 N.W. 2d. 881. (Wis. S.C.).

28. [1986] 2 S.C.R. 388, at 432-33 (S.C.C.) re Heffernan J. commenting in the case of Matter of Guardianship of Eberhardy, supra at p. 894.

29. [1986] 2 S.C.R. 388, at 433 (S.C.C.) re Heffernan J. in Matter of Guardianship of Eberhardy, supra at p. 894.

30. [1986] 2 S.C.R. 388, at 433 (S.C.C.) re Heffernan J. commenting in Matter of Guardianship of Eberhardy, supra at p. 894.

31. [1986] 2 S.C.R. 388, at 433 (S.C.C.) re Heffernan J. commenting in Matter of Guardianship of Eberhardy, supra at p. 894 as quoted by LaForest J.

32. [1986] 2 S.C.R. 388, at 433 (S.C.C.) re Mr. Justice LaForest's summary and disposition notes.

33. [1986] 2 S.C.R. 388, at 433 (S.C.C.) re commentary of Heffernan J. in Matter of Guardianship of Eberhardy supra.

34. [1986] 2 S.C.R. 388, at 433 (S.C.C.) re Heffernan J. commenting in Matter of Guardianship of Eberhardy supra p. 894.

35. Heffernan J., at p. 895.

36. Heffernan J., at p. 895.

37. [1986] 2 S.C.R. 388, at 433-4 (S.C.C.) re LaForest's J. summary and disposition notes.

38. [1986] 2 S.C.R. 388, at 431 (S.C.C.) re LaForest's J. summary and disposition notes for Lord Eldon's remarks re Wellesley v. Duke of Beaufort (1827), 2 Russ. 1, 38 E.R., p. 236 ff.

39. Mr. Justice Charles McQuaid, of the Prince Edward Island Supreme Court, Family Division rendered the original decision in the Eve v. "E." case.

40. [1986] 2 S.C.R. 388, at 431 (S.C.C.) re Mr. Justice LaForest's summary and disposition notes.

41. [1986] 2 S.C.R. 388, at 437.

42. Dickens, B.M. "Case Comment Eve v. E.", Canadian Family Law Quarterly, Vol. 2, No. 1, June 1987, p. 110.

43. Patterson Jr., Russell H., "Research With Those With Restricted Ability To Give Consent", Medical Research Council of Canada, Ottawa: Minister of Supply and Services Canada, Document 7, 1988, p. 6. Elsewhere in the following manner, "The second rule is that the court has the power to allow a proxy consent which corresponds with what the incompetent would have consented to had he been competent." p. 203 in Freedman, Benjamin, "On the Rights of the Voiceless", The Journal of Medicine and Philosophy, 1978, Vol. 3, No. 3, p. 196-225.

44. [1986] 2 S.C.R. 388, at 425 (S.C.C.).

45. [1986] 2 S.C.R. 388, at 425.

46. [1986] 2 S.C.R. 388, at 425.

47. [1986] 2 S.C.R. 388, at 434.

48. [1986] 2 S.C.R. 388, at 434-5.

49. [1986] 2 S.C.R. 388, at 435.

50. [1986] 2 S.C.R. 388, at 435. p. 435 re Matter of Guardianship of Eberhardy (1981) above at p. 893 commenting on re Grady (1981), 426 A2d 467 (N.J.S.C.).

51. [1986] 2 S.C.R. 388, at 435.

52. [1986] 2 S.C.R. 388, at 435.

53. [1986] 2 S.C.R. 388, at 435-36.

54. [1986] 2 S.C.R. 388, at 436.

55. [1986] 2 S.C.R. 388, at 436.

56. [1986] 2 S.C.R. 388, at 436.

57. [1986] 2 S.C.R. 388, at 436.

58. [1986] 2 S.C.R. 388, at 436.

59. [1986] 2 S.C.R. 388, at 437.

60. [1986] 2 S.C.R. 388, at 437.

61. [1986] 2 S.C.R. 388, at 437.

62. [1986] 2 S.C.R. 388, at 437.

63. [1986] 2 S.C.R. 388, at 435.

64. [1986] 2 S.C.R. 388, at 435.

65. [1986] 2 S.C.R. 388, at 437.

66. [1986] 2 S.C.R. 388, at 437.

67. [1986] 2 S.C.R. 388, at 427.

68. [1986] 2 S.C.R. 388, at 427.

69. [1986] 2 S.C.R. 388, at 427.

70. [1986] 2 S.C.R. 388, at 427.

71. [1986] 2 S.C.R. 388, at 428. For Lord Eldon's comments see Wellesley v. Duke of Beaufort (1827), 2 Russ. 1, 38 E.R. 236 at p. 242.

72. [1986] 2 S.C.R. 388, at 428.

73. [1986] 2 S.C.R. 388, at 428. Law Reform Commission of Canada Working Paper 24 "Sterilization: Implications for Mentally Retarded and Mentally Ill Persons", Ottawa: Minister of Supply and Services Canada, 1979, p. 3.

74. [1986] 2 S.C.R. 388, at 428.

75. [1986] 2 S.C.R. 388, at 429.

76. [1986] 2 S.C.R. 388, at 429 re Law Reform Commission of Canada, Working Paper 24 at p. 50.

77. [1986] 2 S.C.R. 388, at 429 re Law Reform Commission of Canada, Working Paper 24 at p. 50.

78. [1986] 2 S.C.R. 388, at 429.

79. [1986] 2 S.C.R. 388, at 429.

80. [1986] 2 S.C.R. 388, at 429-30.

81. [1986] 2 S.C.R. 388, at 430.

82. [1986] 2 S.C.R. 388, at 430 re Law Reform Commission Working Paper 24 at p. 60.

83. [1986] 2 S.C.R. 388, at 430.

84. [1986] 2 S.C.R. 388, at 430.

85. [1986] 2 S.C.R. 388, at 430.

86. [1986] 2 S.C.R. 388, at 431.

87. [1986] 2 S.C.R. 388, at 431.

88. [1986] 2 S.C.R. 388, at 431.

89. [1986] 2 S.C.R. 388, at 431.

90. [1986] 2 S.C.R. 388, at 434.

CHAPTER III

THE ETHICAL DILEMMAS

A review of the legal arguments in the "Eve" case in respect to the three issues under consideration that of 1) proxy consent, 2) best interests, 3) case definition of health, indicate from an ethical perspective in this writer's viewpoint, critical inadequacies and limitations. The deficiency in the legal determinations both in terms of the interpretations applied to these issues and their implications therefore, raises in respect to each of the above issues, an ethical dilemma!

The following chapter will attempt to elucidate these ethical dilemmas resulting from the legal determinations in the "Eve" case.

Dilemma i):

Proxy Consent

The Supreme Court of Canada's judgement that sterilization "should never be authorized for non-therapeutic purposes under the parens patriae jurisdiction"[1] is the legal determination pertinent to the discussion of proxy consent. Moreover, it is specifically the inadvertent effect of this decision that is of significant importance to the issue at hand.

> Nevertheless, the definitive statements of principle in 'Eve' would all but rule out any non-therapeutic intervention based on substitute consent. It is impossible to determine if this was the Supreme Court's intention or just the inadvertent result of the Court's strong reaction to the 'Eve' case...[2]

Concurring with Robert Solomon's legal analysis of the "Eve" case in respect to substitute consent in the above-mentioned, it is reasonable to maintain that no longer is it possible to assume that proxy or substitute consent in Canada is valid for any non-therapeutic interventions in the absence of statutory authorization. The Supreme Court of Canada had ruled that the Supreme Court of Prince Edward Island had "no authority or jurisdiction to grant the application"[3] for sterilization.

Furthermore, "the case law albeit limited, indicates that substitute consent must be exercised in the patient's best interests".[4]

In light of the above statement, it is apparent that only medical treatment that is deemed to be therapeutic and therefore, of direct benefit to an individual under the court's protection is now permissible by law under proxy or substitute consent in Canada. As the court stated,

> ...it is difficult to imagine a case in which non-therapeutic sterilization could possibly be of benefit to the person on behalf of whom a court purports to act, let alone one in which that procedure is necessary in his or her best interest...[5]

The "Eve" case, according to the court "leaves out of consideration therapeutic sterilization and where the line is to be drawn between therapeutic and non-therapeutic sterilization". However, it did assert that "utmost caution must be exercised commensurate with the seriousness of the procedure".[6] Further, "marginal justifications must be weighed against what is in every case a grave intrusion on the physical and mental integrity of the person."[7]

The subject of contraceptive sterilization on therapeutic grounds will be discussed further in this chapter under (iii) case definition of health.

Benjamin Freedman had this to say in discussing the best interests test which he referred to as a "misnomer". He added, "a better phrase might be consistent with the interests' of the incompetent, thereby excluding all forms of harmful treatment while expressly permitting a range of decisions on behalf of the incompetent."[8] He adds,

> And, decisions (by parent or court) to allow children to participate in non-therapeutic research representing minimal risk would be permitted as well, for such participation is consistent with the interests of the child.[9]

Although one may want to concur with Freedman's contentions, this is mere speculation on his part! Even though there is "substantial lattitude and uncertainty" in the unstated and yet to be defined aspects of the "best interests" standard, the above possibility is nothing more than a hopeful expectation on Freedman's part. Clearly he has been misinformed by the "Eve" case when he states, "...Nothing in the 'Eve' opinion is contrary to these points, which will only be settled by further litigation."[10] Firstly, it must be stated that the "Eve" case is not simply an "opinion" but a case law judgement. Secondly, if Freedman's suggestion clearly fell within the realm of possibilities in the court's decision, further litigation seems unnecessary!

Gilbert Sharpe on the other hand, has effectively summarized the Eve case judgement. He has also addressed its wide-ranging and critical implications.

> In brief, the Supreme Court of Canada, in reaffirming the decision of Mr. Justice McQuaid, has closed the door regarding substitute authorization for the contraceptive sterilization of persons unable, on account of mental incapacity, to make that choice for themselves. There are obvious implications for other non-therapeutic interventions, such as medical

> research, the removal of tissue such as bone marrow from a healthy child to help a sick one, and so on.[11]

He adds that, "Although the door does appear to have been left somewhat open for governments to enact enabling legislation regulating this area" that of (sterilization of the mentally incompetent) "by the court's careful examination of the history of the eugenic sterilization laws of Canada and of such reprehensible cases as Buck v. Bell (1927), 274 U.S. 200, it has created a climate that would make it very difficult for any government to proceed in this area".[12]

Thus, the legal analysis of the "Eve" case underlines the virtual elimination of substitute (proxy) consent for non-therapeutic medical interventions! "Nor has the law recognized any legitimate realm of family decision-making...in a benign research project that holds great promise of medical advances."[13] Moreover, "the current blanket prohibition against non-therapeutic interventions appears to be an inadvertent result of applying general principles of law to new situations."[14]

Underlying the inadvertent result of the "Eve" case decision is the virtual elimination of substitute or proxy consent for non-therapeutic interventions.

Pivotal in the court's determination of the exercise of its parens patriae jurisdiction ("for the care of the mentally incompetent"),[15] is that it has of necessity already implicity applied some presuppositions of the human person. "Personhood" has been defined as "the distinctive qualities that make up an individual".[16] Answers to questions regarding this key element of "personhood" are crucial to this issue of proxy consent. Responses from an ethical perspective to the questions: 1) What constitutes essential personhood? and 2) Can personhood be violated?, would be helpful to the discussion.

This writer is of the view that the Supreme Court of Canada has determined in the "Eve" case that "competency" is the limiting factor for essential personhood:

> competency, competence, capacity, and in the case of minors, maturity, are terms often used interchangeably to refer to one of the three conditions necessary for a treatment decision to be considered legally valid...voluntariness and knowledge are the other conditions. Used more generally, the term 'competency' refers to having certain skills, abilities, or a capacity to perform in a certain manner.[17]

It is evident from the case that the Court has adjudicated that since an "incompetent"[18] individual cannot give "informed consent [19] to a proposed medical procedure, it therefore cannot grant applications to others, in order to have a non-therapeutic intervention applied to the incompetent person.

In Eve's situation, sterilization was deemed to be a non-therapeutic procedure and henceforth beyond the court's jurisdictional boundary to grant such an application.

Moreover, the Supreme Court of Canada has asserted that its starting point under parens patriae, when acting on behalf of an individual unable to give informed consent (an incompetent subject), is solely by the "best interests" standard. The court has repeatedly stated "its exercise is confined to doing what is necessary for the benefit and protection of persons under disability like Eve".[20] The court has elsewhere commented, "the court undoubtedly has the right and duty to protect those who are unable to take care of themselves, and in doing so it has a wide discretion to do what it considers to be in their best interests."[21]

The court also appears to be contending that "personhood" is related essentially to "the free determining of one's own actions".[22] In other words, a "competent" individual is a person who is able as an autonomous being to determine his or her course of action, ie. to choose, to decide... Conversely, an "incompetent" person is one who is unable to exercise such "self-determination". Freedom apparently has been defined here by the court solely as the ability to self-determine. Wherein individuals are unable to freely exercise self-determination, the "incompetent" person or persons therefore, are cautiously dealt with under the protective and beneficial guise of the court's parens patriae authority. Thus, non-therapeutic interventions are not possible for the "incompetent" person who is unable to self-determine his or her own course of action.

Under its parens patriae jurisdiction and its underlying, operating principle of doing that which was considered in "Eve's" best interests, all constitutional rights guaranteed under the Canadian Charter Of Rights And Freedoms were interpreted or reviewed for Eve's protection and benefit.[23]

The Supreme Court had adjudicated that there is therefore, no legitimate grounds in this case for valid proxy (parental) consent to be applied wherein an incompetent is involved and the proposed medical procedure is deemed to be of non-therapeutic benefit!

Thus the ethical dilemma in regards to the issue of proxy consent can be deduced in the following manner. The dilemma here is rooted in the limited presupposition of "personhood" applied by the Supreme Court of Canada. It is believed that "competency" is the only criterion upon which this assessment of personhood has been determined. The difficulty emerges here!

When competency to self-determine one's course of action is not expressed, no intrusive form of intervention into one's personhood medical or otherwise is possible. According to the court, only interventions considered in the individual's "best interests" and protection are allowable, ie. therapeutic research.

Clearly competency is but one dimension of personhood (see Chapter IV regarding Self-integration: Proxy Consent). Personhood must also be considered with respect to its meaning in and with "community", and also in regard to the "contribution" of an individual. This the court did not do! Further, and because of this limitation, proxy-consent for non-therapeutic interventions with incompetent persons has been inadvertently invalidated! Secondly, this prohibition on non-therapeutic interventions including research of minimal risk invasions may indeed run contrary to what has been claimed for by the court. That is, it may not serve the best interests of the incompetent nor society in general. Persons who may greatly benefit from such research!

Dilemma ii):

The Best Interests Standard

The Supreme Court of Canada in review of the court's parens patriae power determined that this jurisdiction could only be applied with a very specific discretion. "...The discretion is to be exercised for the benefit of that person, not for that of others."[27]

Thus, the parens patriae power "is to be exercised in the 'best interests' of the protected person, or again, for his or her own 'benefit' or welfare".[28]

It is quite apparent that the "best interests" approach adopted by the Supreme Court of Canada is a highly exclusive interpretation of the standard. In the case at hand, it is applied solely for the benefit of the incompetent under the court's protection. Noteworthy is the fact that the court ruled that its jurisdictional power could never be extended to include the "best interests" of "others". Moreover, the interests of society and non-therapeutic possibilities and purposes were not able to be considered due to this limited interpretation of the "best interests" standard.

Mr. Justice LaForest of the Supreme Court of Canada commented:

> ...I cannot agree that a court can deprive a woman of that privilege (of giving life) for purely social or other non-therapeutic purposes without her consent. The fact that others may suffer inconvenience or hardship from failure to do so cannot be taken into account. The Crown's parens patriae jurisdiction exists for the benefit of those who cannot help themselves, not to relieve those who may have the burden of caring for them.[29]

As earlier noted there is a marked contrast evidenced between some of the United States courts' interpretation of the parens patriae jurisdiction and its exercise over against that of the Canadian courts'. (Note the case "Matter of Sallmaier (1976) in Chapter II.) The Supreme Court of Canada has ruled that the parens patriae jurisdiction can only be exercised in the estimate of the "best interests" of the protected person and not for that of others.[30] Whereas, the Supreme Court in the New York State case had taken a broader interpretation. Not only is the welfare of the person who is under the court's protection of primary concern and inherent in the parens patriae jurisdiction but also and significantly consideration is given to the "welfare of society"! "The decision to exercise the power of parens patriae must reflect the welfare of society, as a whole..."[31]

The Supreme Court of Canada has clearly determined that the "best interests" standard cannot include the concerns and interests of "others"; specifically the interests of family members and society. It is limitedly defined to the person or persons under the court's protection.

Further, Mr. Justice LaForest of the Supreme Court of Canada had fittingly juxtaposed a discussion on the social implications of "problem cases, ie. Eve v. "E"." The overall focus on the subject "alluded to the limited capacity of judges to deal adequately with a problem that had such general social overtones..."[32] (This has been recorded in Chapter II re Mr. Justice LaForest's reference to Heffernan J. in Matter of Guardianship of Eberhardy, 1981).

Two limiting factors of note were identified which have inhibited the courts from dealing adequately with such cases as Eve v. "E". Firstly, the courts lack in medical expertise and secondly and more importantly the courts are called upon to adjudicate such cases in the absence of "well thought-out policy determinations".[33]

The "Eve" case not only reflects a need for the development of policy guidelines in this area, but also offers a possible reason for the court's resistance and hesitation to include societal concerns under the "best interests" standard. Moreover, in the absence of public policy guidelines the court proceeded to discern the merits of the "Eve" case with great caution and solely, by means of its adopted approach, the "best interests" test.

A standard which allowed for a margin of error, according to the Supreme Court of Canada. Heffernan J. in matter of Guardianship of Eberhardy (1981) is cited:

> Importantly, however, most determinations made in the best interests of a child or of an incompetent person are not irreversible; and although a wrong decision may be damaging indeed, there is an opportunity for a certain amount of empiricism in the correction of errors of discretion. Errors of judgement or revisions of decisions by courts and social workers can, in part at least, be rectified...And of course, alleged errors of discretion in exercising the 'best interest' standard are subject to appellate review..."[35]

Elsewhere Mr. Justice LaForest has stated that it is difficult to weight the best interests of an individual in this troublesome area. The irreversibility in the proposed intervention draws the court to a more cautious decision.[36] (See Note 89 in Chapter II The Legal Argument.)

Thus, Mr. Justice LaForest concurred with Mr. Justice McQuaid of the P.E.I. Supreme Court, Family Division that he (McQuaid) was correct in concluding that "he had no authority or jurisdiction to grant the application" for sterilization.[37]

The Supreme Court of Canada refuted the applicability of the "substituted judgement" test in the "Eve" case. (Note the discussion and overview on "substituted judgement" in Chapter II.)

"What the incompetent would do if she or he could make the choice", according to Mr. Justice LaForest, "is simply a matter of speculation."[38] In concurring with Matter of Guardianship of Eberhardy (1981) Mr. Justice LaForest cited from that case:

> Any governmentally sanctioned (or ordered) procedure to sterilize a person who is incapable of giving consent must be denominated for what it is, that is the state's intrusion into the determination of whether or not a person who makes no choice shall be allowed to procreate.[39]

In the court's view "it is clearly not a personal choice".[40]

There were two Canadian Charter of Rights and Freedoms arguments raised by the counsel for the respondent. In one, counsel for the respondent contended that there is "a fundamental right to free procreative choice", so stated Mr. Justice LaForest. Counsel further submitted that "there is a fundamental right to bear children; there is as well a fundamental right to choose not to have children and to implement that choice by means of contraception".[41]

Mr. Justice LaForest responded:

> But assuming for the moment that liberty as used in S.7 protects rights of this kind...counsel's contention seems to go beyond the kind of protection S.7 was intended to afford. All S.7 does is to give a remedy to protect individuals against laws or other state action that deprive them of liberty. It has no application here.[42]

In the other argument presented by the respondent's counsel a contention was made based upon a "person's right to equality under S.15(1) of the Charter".[43]

> ...that the most appropriate method of ensuring the mentally incompetent their right to equal protection under S.15(1) is to provide the mentally incompetent with a means to obtain non-therapeutic sterilizations, which adequately protects their interests through appropriate judicial safeguards.[44]

Mr. Justice LaForest in review of this argument and one other similar contention by the counsel for the Public Trustee of Manitoba (see note 58 in Chapter II), concluded that "Section 15 of the Charter was not in force when these proceedings commenced, but, this aside, these arguments appear flawed".[45]

LaForest J. interpreted that these contentions were simply "raising in different form an issue already dealt with".[46] It appears that he perceived in these submissions a request for the application of the "substituted judgement" standard by the court to authorize the sterilization of an incompetent. In light of the court's previous determination that the "substituted judgement" test was sophistry and flawed, ie. "that the decision made by the court on an application to consent to the sterilization of an incompetent is somehow that of the incompetent",[47] these arguments were rejected.

The court then "...has the right and the duty to protect those who are unable to take care of themselves, and in doing so it has a wide discretion to do what it considers to be in their best interests".[48]

The Supreme Court of Canada in the exercise of its parens patriae power as evidenced in the "Eve" case, has determined what the underlying principle of this jurisdiction will be:

> ...namely the need to act for the protection of those who cannot care for themselves. The courts have frequently stated that it is to be exercised in the 'best interests' of the protected person, or again, for his or her 'benefit' or 'welfare'."[49]

Adopting the traditional interpretation of parens patriae power, the court has unequivocally stated that its protective powers are limited to "those who cannot care for themselves."[50] Moreover, the discretion of the parens patriae jurisdiction "is to be exercised for the benefit of that person (under protection), not for that of others."[51]

From an ethical perspective it is apparent that "the good" is limitedly defined by the court as that which is in that "best interests" of the one under protection, "for his or her benefit or welfare".[52] Consequently, best interests considerations under the court's parens patriae jurisdiction cannot balance the claims or concerns of "others" including those of society. Surely, this reflects an inherent flaw in the legal interpretation applied to this jurisdiction. This writer maintains that the above Supreme Court of Canada interpretation disenfranchises a competing party's interests, ie. Eve's mother. There is no equal representation of her claims and needs (her "best interests") afforded through due process. This oversight is underlined in light of the determination applied to this jurisdiction by some state courts in the U.S. The fact that some U.S. state courts take into account other "social" considerations in its interpretation of the best interests approach, appears to indicate an attempt to provide a more inclusive and balanced representation of the human condition, as Richard McCormick states, "one that is inextricable bound up with the well-being of others." (See note 21, Chapter V.) Not only is the welfare of the person under protection inherent in the parens patriae jurisdiction but also and importantly consideration is given to the "welfare of society"! "The decision to exercise the power of parens patriae must reflect the welfare of society, as a whole..."[53]

The parens patriae jurisdiction in the former situation appears to express a pre-judgement in favour of one of the contesting parties and it is therefore difficult to see how it can adjudicate competing interests fairly!

Further, the determination of the "best interests" of an individual, as if she or he was an isolated entity far removed from the social fabric and communal considerations severely undermines the relational and interactional aspect that is the human reality! Best interests here, is narrowly and inadequately defined! Surely the individual is tied together in the web of social interests and concerns. Ontology informs us that we are social beings who participate in a social reality and existence. Therefore, the socio-communal interests and considerations are valid and ought to be reflected in any standard of "best interests".

One can empathize with the Canadian ourt in its adoption of the "best interests" test. It was earlier noted that concerns were raised about the "insufficiency" of the "best interests" tool.[54] Notably, it is not an "objective test"[55] and coupled with the fact that the Supreme Court of Canada did not have the advantage of any lengthy case law experience with this standard, it is understandable why the court proceeded in the "Eve" case with caution, reservation and to a degree with uncertainty. However, there is a redeeming and thus attractive quality inherent in the "best interests" test which was described as its ability to be corrected. Heffernan J. contended that decisions rendered under this test "are not irreversible" and "errors of judgement or revisions of decisions" can be rectified.[56]

In addition to the above-mentioned, the court also "alluded to the limited capacity of judges to deal adequately with a problem that had such general social overtones..."[57] Not only was the court's lack in medical expertise identified as a limiting factor but also and more importantly the difficulty encountered from the lack of "well thought-out policy determinations".[58] Moreover, in the absence of public policy guidelines, the court had no way of knowing what the "interests of society" might be over against the interests of the person to be sterilized.[59] Thus, it proceeded to discern the merits of the case under the limited "best interests" considerations alone.

In respect to the "substituted judgement" standard noted previously, this test was outrightly rejected by the court. Mr. Justice LaForest contended, "what the incompetent would do if she or he could make the choice is a matter of speculation."[60]

In light of the court's determination that the "substituted judgement" standard was flawed, ie. "that the decision made by the court on an application to consent to the sterilization of an incompetent is somehow that of the incompetent,"[61] helped to further validate the "best interests" standard.

There is an ethical dilemma resulting from the court's limited definition of the "best interests" standard. Richard McCormick has stated "it patently equates 'best interests' with 'getting or keeping something for oneself' or, more generally, with 'deriving personal benefit'.[62] He further comments, "that equation, when unpacked, is a highly individualistic one and a subtle attack on the social dimension of our persons."[63]

Indeed as "social beings, our good, our fluorishing (therefore, our best interests) is inextricably bound up with the well-being of others".[64]

Although one may empathize with the Supreme Court of Canada's ready embrace of its "best interests" test for the reasons mentioned above, however, it is limitedly defined and contributes to a diminished view of "the good".

The fact that we are not merely isolated individuals or persons but as well social beings, compels us to understand and to struggle with the reality that each one of us is "inextricably bound up with the well-being of others".[65]

Thus the ethical dilemma in regard to the issue of the "best interests" standard can be deduced in the following manner.

The Supreme Court of Canada's limited interpretation of the "best interests" standard is the source of the ethical dilemma. This test in the court's determination is solely an exclusive standard extended to a person or persons under the court's protection. It does not include the interests of others nor the social well-being.

This standard as applied by the Supreme Court of Canada does not, therefore, validate the social dimension of which all persons are a part.

Moreover, ontology stands over and against the above notion. The nature of our existence clearly indicates that we are social beings and that our best interests "are inextricably bound with the well-being of others."

Furthermore, since this standard as applied by the Supreme Court of Canada does not reflect the socio-communal reality in its definition, the best interests test herein interpreted is an inadequate and limited instrument!

Dilemma iii):

Case Definition of Health

"Health" as defined by the Supreme Court of Canada in the "Eve" case was specified as "mental as well as physical health".[66] Noteworthy is the fact that the court had resolved that any medical intervention under its parens patriae jurisdiction is restricted to promoting the physical and mental health of the individual "under the protection of the court".[67] "The discretion is to be exercised for the benefit of that person, not for that of others."[68]

Summarized in Chapter II (iii) Case Definition of Health, are the serious concerns raised by the court in respect to hysterectomy, the recommended sterilization procedure in the case application. The exclusive focus of the court was directed to the physical and mental (psychological) health of Eve.

It was concluded that no evidence indicated, "that failure to perform the operation would have any detrimental effect on Eve's physical and mental health."[69]

Furthermore, the court's interpretation of the application's purposes in sterilization, "as far as Eve's welfare is concerned, are to protect her from possible trauma in giving birth and from the assumed difficulties she would have in fulfilling her duties as a parent". It was also assumed "from the fact that hysterectomy was ordered, that the operation was intended to relieve her of the hygienic tasks associated with menstruation". One other purpose was "to relieve Mrs. E. of the anxiety that Eve might become pregnant, and give birth to a child, the responsibility for whom would probably fall on Mrs. E".[70]

Mr. Justice LaForest disposed of these arguments by refuting the latter purpose initially. "One may sympathize with Mrs. E...it is easy to understand that natural feelings of a parent's heart. But the parens patriae jurisdiction cannot be used for her benefit"[71] Further he commented,

> Its exercise is confined to doing what is necessary for the benefit and protection of persons under disability like Eve...So we are left to consider whether the purposes underlying the operation are necessarily for Eve's benefit and protection.[72]

Previously, it has been demonstrated that the Supreme Court of Canada has clearly determined that the "best interests" standard cannot include the concerns and interests of family members and society. It is limitedly defined to have application for the person or persons under the Court's protection. (See Chapter III (ii) The Best Interests Standard.)

One result of this limited interpretation of the "best interests" test is the manner in which health is defined.

Health, as was noted, is defined solely in regard to two highly personalized categories of well-being, that of the physical and the mental health of the person or persons under court protection. Thus health as defined by the Supreme Court of Canada for the purposes of the "Eve" case does not have a social dimension or context! Thus Mrs. E's concerns or interests, due to the court's limited definition of health and best interests are rendered either non-existent or irrelevent to the case!

The court's reluctance to acknowledge any consideration of a "social" dimension in its definition of "health" or "best interests" underscores an inadequacy in the court's determination. Another illustration of the aforementioned lack in social considerations is evidenced in respect to the argument relating to Eve's fitness as a parent. The court stated that many mentally incompetent parents "may have difficulty in coping, particularly with the financial burdens involved". However, the court contended, "but this issue does not relate to the benefit of the incompetent; it is a social problem, and one...that is not limited to incompetents".[73]

> Above all it is not an issue that comes within the limited powers of the courts, under the parens patriae jurisdiction, to do what is necessary for the benefit of persons who are unable to care for themselves.[74]

The court's exclusion of any social considerations by definition and intent appears to be inherently flawed. This author, in agreement with Richard McCormick, concurs that each individual is as well a social being, and "as social beings, our good, our flourishing (therefore, our best interests) is inextricably bound up with the well-being of others".[75] That is, one cannot avoid the social issues and concerns when discussing an individual in any holistic manner. This appears to be what the court has done in the "Eve" case.

Mr. Justice LaForest summarily stated in his disposition remarks:

> The grave intrusion on a person's rights and the certain physical damage that ensues from non-therapeutic sterilization without consent, when compared to the highly questionable advantages that can result from it, have persuaded me, that it can never safely be determined that such a procedure should never be authorized for non-therapeutic purposes under the parens patriae jurisdiction.[76]

The court found "it difficult to imagine a case in which non-therapeutic sterilization could possibly be of benefit to an individual, let alone one in which that procedure is necessary in his or her best interest". On the other hand it recalled that "it has always been the principle of this Court, not to risk damage...which it cannot repair." Thus, it concluded "that non-therapeutic sterilization may not be authorized in the exercise of the parens patriae jurisdiction".[77]

The underlying principle of "best interest" was adopted by the Supreme Court of Canada in the exercise of its parens patriae jurisdiction. In respect to "health", best interests was defined as that which promotes the physical and mental health of the individual under court protection, in this case in respect to a mentally "incompetent" person named "Eve". Thus it appears that whatever is deemed to be a "therapeutic" intervention is both, that which is in the "best interests" of the individual and in respect to "health", that which promotes the physical and mental well-being of that person. Sterilization was determined by the court as not being in "Eve's" best interests. Thus, it was deemed to be a "non-therapeutic" procedure.

David Marshall in commenting on the "Eve" decision had this to say:

> The court did decide that sterilization 'should never be authorized for non-therapeutic purposes under the parens patriae jurisdiction', but it did not define what a therapeutic purpose might be. It would, it seems, include intervention to improve mental or physical health.[78]

This author is in complete agreement with David Marshall's analysis above. Earlier in his article, Marshall commented:

> The court, it seems, might also have decided that saving Eve herself from the seemingly impossible task of caring for and attempting to raise a child, when she was incapable of doing so, was a concern. In other words, the sterilization could have been seen as being both beneficial and therapeutic for Eve.[79]

Here, David Marshall contends that an argument could have been entertained to demonstrate that sterilization had indeed therapeutic and beneficial possibilities for Eve. Although this author is in agreement with Marshall's viewpoint, there is an important consideration that he has overlooked. The court in its discussion of Eve's fitness as a parent had already determined that such considerations "...do not relate to the benefit of the incompetent; it is a social problem...," thus these are issues that do not come "within the limited powers of the courts, under the parens patriae jurisdiction".80

In other words, what Marshall is suggesting would only have been possible if the court had determined that social considerations, ie. "parenting" were included under its jurisdiction. Clearly this is not the case. The present definitions of "best interests" and "health" are synonomous to that which constitutes therapeutic interventions and social concerns are interpreted as being within the non-therapeutic context.

However, Marshall has inadvertently raised the crucial issue in respect to the court's definition of health. This has been restated by the C.M.A. (Canadian Medical Association) Committee on Ethics.

> The Committee on Ethics of the C.M.A. regrets that the Supreme Court of Canada in its decision in the case re" 'Eve' found it difficult 'to imagine a situation where non-therapeutic sterilization

> could be of benefit' to an incompetent mentally retarded person.[81]

This is a direct result of the differing interpretations on the definition of health, one by the legal community and the other by the medical community. The Constitution of the World Health Organization declares that, "health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."[82]

The court's determination of health was limitedly defined as physical and mental health, whereas the benefits of sterilization for contraceptive purposes "may be primarily for the social and personal well-being of the mentally retarded person".[83] A consideration the court outrightly dismissed in its "best interests" standard and its definition of health. Bernard Dickens contends in defence of the court's position, "benefit to others or to society is not a ground for exercising a protective power in favour of non-therapeutic surgery."[84]

However, Dickens appears to have made a distinction between the individual's best interests and those of society and others. Moreover, "as social beings, our good, our fluorishing (therefore, our best interests) is inextricably bound up with the well-being of others".[85] If the individual is to be given consideration in a holistic manner the social issues must also be addressed'

The ethical dilemma in regard to the "case definition of health" can be deduced in the following manner.

At present, the "case definition of health" has been defined as physical and mental health. The legal community has determined that "health" as social well-being and any concerns of a social nature are not "best interests" considerations for an individual under the protection of the court. The above considerations would infer non-therapeutic interventions.

The World Health Organization defines health as "a state of complete physical, mental and social well-being..." Thus, the medical community has determined that "health" as social well-being and any concerns of a social nature are "best interests" considerations for an individual. The above considerations would infer non-therapeutic interventions.

Therefore, there is an ethical dilemma and a need to establish a norm for a more inclusive definition of health for the future.

Summary

By the means of an ethical analysis of each of the three key issues under consideration: 1) proxy consent, 2) best-interests, and 3) case definition of health, the foregoing has demonstrated inadequacies in the legal perspectives in respect to each of the aforementioned issues. Thus, in each case an ethical dilemma is reflected'

NOTES TO CHAPTER III

1. Eve v. Mrs. E. [1986] 2 S.C.R. 388, at 431.

2. Solomon, Robert, "Eve v Mrs. 'E'." Westminster Affairs.

3. [1986] 2 S.C.R. 388, at 431.

4. "The Eve Case and the Validity of Substitute Consent", Westminster Affairs, London, Canada, February, 1987.

5. [1986] 2 S.C.R. 388, at 431.

6. [1986] 2 S.C.R. 388, at 433-34.

7. [1986] 2 S.C.R. 388, at 434.

8. Freedman, Benjamin, "Eve v Mrs. E.: What We Don't Know, And When We Don't Know It," Westminster Affairs, London, Canada, February, 1987.

9. Freedman, Benjamin, Westminster Affairs, February, 1987.

10. Freedman, Benjamin, Westminster Affairs, February, 1987.

11. Sharpe, Gilbert, Health Law In Canada, Vol. 7, 1986: p. 91.

12. Sharpe, Gilbert, Health Law In Canada, Vol. 7, 1986 p. 91.

13. "The Eve Case and the Validity of Substitute Consent", Westminster Affairs, February, 1987.

14. "The Eve Case and the Validity of Substitute Consent", Westminster Affairs, February, 1987.

15. [1986] 2 S.C.R. 388, at 389.

16. The New Lexicon Webster's Dictionary of The English Language, New York: Lexicon Publications, Inc., 1988, p. 749.

17. Weithorn, Lois A., "Involving Children in Decisions", in Melton, G.B., Koocher, G.P., and Saks, M.J. (eds.), Children's Competence to Consent. New York: Plenum Press, 1983. p. 249.

18. "By definition, a legally incompetent subject is not autonomous, and cannot give a legally or ethically valid consent." Medical Research Council of Canada, "Guidelines on Research Involving Human Subjects", 1987. p. 28.

19. "In general, the rights of individuals to exercise personal control over their lives is recognized and protected, as in the example of the law of informed consent, which forbids unauthorized intrusions upon an individual's bodily integrity by health care professionals."
Weithorn, Lois A., "Involving Children in Decisions", Children's Competence to Consent, 1983. p. 238.

20. [1986] 2 S.C.R. 388, at 429.

21. [1986] 2 S.C.R. 388, at 437.

22. The New Lexicon Webster's Distionary of The English Language, 1988, p. 905.

23. "McQuaid J. was of the view that Eve, like other individuals, was entitled to the inviolability of her person, a right that superceded her right to be protected from pregnancy." p. 395.
"All S.7 (The Canadian Charter of Rights and Freedoms) does is to give a remedy to protect individuals against laws or other state action that deprive them of liberty. It has no application here." p. 436.
The above response was given by Mr. Justice LaForest in respect to the respondent's argument concerning what he called "a fundamental right to free procreative choice".

p. 435.

[1986] 2 S.C.R. 388, 395, 435, 436.

24. Freedman, Benjamin, "Eve v. Mrs. E"...Westminster Affairs, February, 1987.

25. Freedman, Benjamin, Westminster Affairs, February, 1987.

26. Freedman, Benjamin, Westminster Affairs, February, 1987.

27. [1986] 2 S.C.R. 388, at 427.

28. [1986] 2 S.C.R. 388, at 426.

29. [1986] 2 S.C.R. 388, at 426.

30. See note 24, 27, 28 in Chapter III.

31. [1986] 2 S.C.R. 388, at 422 re Matter of Sallmaier (1976) at p. 991.

32. [1986] 2 S.C.R. 388, at 433. See also notes 32 and 33 in Chapter II re Heffernan J. Commenting in Matter of Guardianship of Eberhardy (1981).

33. [1986] 2 S.C.R. 388, at 433 re Heffernan J. p. 895.

34 [1986] 2 S.C.R. 388, at 433 re Heffernan J. p. 895.

35. [1986] 2 S.C.R. 388, at 433 re Heffernan J. commenting in Matter of Guardianship of Eberhardy (1981) at p. 894.

36. [1986] 2 S.C.R. 388, at 431.

37. [1986] 2 S.C.R. 388, at 431.

38. [1986] 2 S.C.R. 388, at 435.

39. [1986] 2 S.C.R. 388, at 435 re Matter of Guardianship of Eberhardy (1981) at p. 893 commenting on re Grady (1981).

40. [1986] 2 S.C.R. 388, at 435 re Matter of Guardianship of Eberhardy (1981).

41. [1986] 2 S.C.R. 388, at 436.

42. [1986] 2 S.C.R. 388, at 436.

43. [1986] 2 S.C.R. 388, at 436.

44. [1986] 2 S.C.R. 388, at 436.

45. [1986] 2 S.C.R. 388, at 437.

46. [1986] 2 S.C.R. 388, at 437.

47. [1986] 2 S.C.R. 388, at 437.

48. [1986] 2 S.C.R. 388, at 437.

49. [1986] 2 S.C.R. 388, at 426.

50. [1986] 2 S.C.R. 388, at 426.

51. [1986] 2 S.C.R. 388, at 427.

52. [1986] 2 S.C.R. 388, at 426.

53. See note 31 in Chapter III.

54. See notes 26 and 27 in Chapter II.

55. See note 27 in Chapter II.

56. See notes 28 and 29 in Chapter II. See also note 35 and 36 in Chapter III.

57. See note 32 in Chapter III.

58. See note 33 in Chapter III.

59. See note 34 in Chapter III.

60. See note 41 in Chapter III.

61. See note 50 in Chapter III.

62. McCormick, Richard, "Freedom on the Rights of the Voiceless", The Journal of Medicine and Philosophy, 1978, Vol. 3, No. 3. p. 212.

63. McCormick, Richard, p. 212.

64. McCormick, Richard, p. 212.

65. McCormick, Richard, p. 212.

66. See note 67 Chapter II (iii) Case Definition of Health.

67. See note 68 and 69 Chapter II (iii).

68. See note 70 Chapter II (iii).

69. See note 78 Chapter II (iii).

70. See note 78 Chapter II (iii).

71. See note 79 Chapter II (iii).

72. See note 80 Chapter II (iii).

73. See note 83 Chapter II (iii).

74. See note 84 Chapter II (iii).

75. McCormick, Richard, "Freedom on the Rights of The Voiceless", The Journal of Medicine and Philosophy, 1978, Vol. 3, No. 3, p. 211-221 at p. 212.

76. See note 88 Chapter II (iii).

77. See note 89 Chapter II (iii).

78. Marshall, David, The "Eve" decision: "It may turn out to be a meek authority indeed", C.M.A.J., Vol. 136, March 15, 1987, p. 650-651 at p. 651.

79. Marshall, David, at p. 651.

80. See note 77 and 78 Chapter III (iii).

81. Marshall, David, at p. 650.

82. Dickens, Bernard, "No contraceptive sterilization of the mentally retarded: The dawn of 'Eve'", C.M.A.J., Vol. 137, July 1, 1987, p. 65-67, at . 65.

83. Marshall, David, at p. 650.

84. Dickens, Bernard, "No contraceptive sterilization of the mentally retarded: The dawn of 'Eve', at p. 66.

85. See note 79 Chapter III (iii).

CHAPTER IV

THE ETHICAL SOLUTIONS

Applying a developmental method of ethics, that is a methodology of ethics grounded in the nature of being (ontology) and in respect to the reality of human and social development, ethical solutions to the dilemmas emerging from the 3 issues i) proxy consent ii) best interests and iii) case definition of health will be presented.

The following presentation is indebted to and adapted from the theological and ontological perspectives of Paul Tillich et al. The attempt will be to draw from the insights and writings of Tillich primarily and others in order to resolve the ethical dilemmas at hand. This writer acknowledges responsibility for the interpretations made of this material.

What is of particular value to this presentation with regard to the 3 issues under consideration is Tillich's "three functions of life".

In the scheme of Paul Tillich's Systematic Theology he contends:

> Thus, within the process of actualization of the potential, which is called life, we distinguish the three functions of life: self-integration under the principle of centeredness, self-creation under the principle of growth, and self-transcendence under the principle of sublimity.[1]

Each of the three specific life functions identified by Tillich appears to co-relate directly to a particular case issue under focus. There is in other words, a one to one co-relation existent between life function and case issue. For instance the underlying issue of personhood discussed within the context of "proxy-consent", has a direct relation to Tillich's discussion of "self-integration". Likewise in regard to the "Eve" case issue of "best interests", Tillich's commentary on self-alteration (self-creation) has a co-relation. Further, the case issue regarding "case definition of health" is related to Tillich's discussion on "self-transcendence".

According to Tillich, life can be defined "as the actualization of potential being". Moreover, this potential being-ness "becomes actuality only through these three elements in the process we call life".[2] Thus, within the "structure of life processes" there are the three functions: self-integration, self-alteration and self-transcendence.

(i) Self-Integration: Proxy-Consent

Tillich informs us that the first function of life is "self-integration".

> In it the center of self-identity is established ...There is centeredness in all life, both as reality and as task. The movement in which centeredness is actualized shall be called the self-integration of life. The syllable 'self' indicates that it is life itself which drives toward centeredness in every process of self-integration. ...The nature of life itself expresses itself in the function of self-integration in every particular life process...[3]

Elsewhere he has described "centeredness" as "a quality of individualization, in so far as the indivisible is the centered thing."[4] Further, "a fully individualized being, therefore, is at the same time a fully centered being."[5]

However, and significantly this movement toward self-identity referred to as "centeredness" must be actualized in freedom and through destiny. "In man complete centeredness is essentially given, but it is not actually given until man actualizes it in freedom and through destiny."[6]

Further he states,

> Because man has a world which he faces as a totally centered self, he can ask questions and receive answers and commands. This possibility, which characterizes the dimension of spirit, is unique, because it implies both freedom from the merely given (environment) and norms which determine the moral act through freedom.[7]

According to Tillich, "personhood" is essentially "self-integration" wherein one actualizes one's essential centeredness which is the moral act,[8] within the context of

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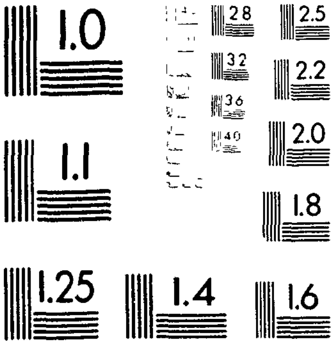

a community of others.

> A moral act, therefore, is not an act in which some divine or human law is obeyed but an act in which life integrates itself in the dimension of spirit, and this means as personality within a community. Morality is the function of life in which the centered self constitutes itself as a person...[9]

In reference to the previous chapter, this writer contended that pivotal to the issue of "proxy-consent" for non-therapeutic interventions has been the court's implicit presuppositions regarding the human person. The viewpoint expressed that the Supreme Court of Canada had determined in the "Eve" case that "competency" or the lack of, was the limiting factor for its estimate of essential personhood. It was further elaborated that the court interpreted "personhood" as essentially related to "the free determining of one's actions." That is a "competent" person is one who is able in his/her freedom as an autonomous being to determine her or his course of action (ie. having the ability to choose or to decide...). Conversely, an "incompetent" person is one who is unable to exercise "self-determination". Freedom, in the purvue of the court has been defined solely as the ability to self-determine. Wherein a person or persons are unable to freely exercise self-determination, the "incompetent" therefore, is cautiously dealt with under the protective and beneficial jurisdiction of parens patriae. Thus, non-therapeutic interventions are not possible for the "incompetent" who is unable to self-determine his/her own course of action. Moreover, the inadvertent effect of this case law decision is the apparent rejection of any valid proxy-consent for non-therapeutic interventions.

In respect to Paul Tillich's ontological reflections concerning the nature of being, there is agreement here with the Supreme Court of Canada's definition of freedom as "self-determination" and as an essential element of personhood (ie. the ability to give "consent"). Centeredness, individualization, self-identity, self-integration according to Tillich, are all actualized through the exercise of the freedom to self-determine. "In man complete centeredness is essentially given, but it is not actually given until man actualizes it in freedom and through destiny." 10

In the case of an "incompetent" person, wherein one cannot in freedom self-determine one's own course of action and thereby is unable to give "informed consent", is there indeed any other recourse available other than to act cautiously and carefully under the "best interest" considerations on behalf of the incompetent? This is the position that was taken by the court in the "Eve" case because of its limited definition of freedom applied as solely "self-determination".

Although it is believed that Paul Tillich would concur with the court's determination that one dimension of freedom is indeed self-determination (ie. the ability to consent), there is more to be said on the subject.

In his discussion of self-integration, Tillich claims that personhood is that which emerges in the encounter with others. Thus, he maintains personhood or personal life can only be intelligible as a relationship concept. To the notion of a person emerging within a community of persons, this author is in complete agreement with Tillich's ontology.

> Personal life emerges in the encounter of person with person and in no other way. If one can imagine a living being with the psychosomatic structure of man, completely outside any human community, such a being could not actualize its potential...Therefore, the self-integration of the person as a person occurs in a community, within which the continuous mutual encounter of, centered self is possible and actual.[11]

Thus self-integration or as elsewhere stated self-affirmation "has two sides which are distinguishable but not separable:"[12] "One is the affirmation of self as a self; that is of a separated, self-centred, individualized, incomparable, free, self-determining self."[13]

The other is in "the identity of participation which is an identity in the power of being".[14] Moreover, "in this sense the power of being of the individual self is partly identical with the power of being of his world, and conversely."[15]

Moreover, "being as a part" therefore "points to the fact that self-affirmation necessarily includes the affirmation of oneself as a participant".[16] According to Tillich, in order for a "self" to become a "person" (who is always a "person within a community of persons"), one's potential, created being must be actualized in freedom and through destiny. This is for him both the ontology in the nature of being and the moral imperative.[17]

Richard Crossman commenting upon Paul Tillich's concept of personhood stated:

> However, to show that a consideration of personhood necessarily involves a social dimension of morality does not thereby imply that the individual is the most important element in the historical dialectic between the individual and the group...Rather, the communal side of this dialectic is just as important and must be given equal consideration.[18]

Thus in agreement with Paul Tillich that personal life or personhood involves a social context or community in the ontology of being, Richard Crossman's statement is therefore, that much more emphatic and of critical importance. Crossman contends that "the communal side of this dialectic is just as important and must be given equal consideration".[19] Thus "social ethics as opposed to personal ethics"[20] is equally valid and must be given consideration in any context that involves a person in a community of persons! The validity of the above contention is born out of the reality of human life. There is indeed an "unconditional limit", for a person simply in the reality of the personhood of others and a need in such a context, to "treat others as persons".[21] This equitable balance of consideration is what this author understands Crossman to be stating. This writer is in complete agreement here with his contention!

In light of this analysis, firstly, the ability to self-determine and the freedom to give informed consent is indeed one aspect of personhood. Unfortunately, the Supreme Court of Canada limited its "Eve" case decision to this singular consideration of personhood. However, secondly, it is evident from the nature of being and reality as demonstrated in Paul Tillich's ontology that the full meaning of personhood cannot be discerned without a consideration of the person's participation within the "community" or social context of which that person is intrinsically a part. Moreover, personhood not only involves a consideration of the person's part within a community, it also involves the dialectic among the community of persons in respect to "that person". Thus, it would appear that the court is sensitive to only one aspect of the community in the "Eve" case. However, Mrs. E. represents another aspect of the community, whose interests and concerns cannot be dismissed or overlooked outrightly. The specific factors in the "Eve" case resulted in the court acting as proxy for Eve and inadvertently denied the parental (proxy) consent of Mrs. E. An apparent paradox indeed! The court ought to act to clarify that this proxy (parental) consent is valid beyond the particular determination in this case! Not to do otherwise would be inconsistent to the integrity of the aforementioned ethical analysis and the ontological reality indicated.

Furthermore, Richard Crossman's contention that communal or social considerations are as equally valid as the individual's and must be given the same consideration, demonstrates that Mrs. E.'s concerns and interests are valid considerations and proxy consent is valid consent even in the case of a proposed non-therapeutic intervention!

Paul Tillich describes self-integration as that which includes "sacrifice". But he comments that it is not an "unambiguous good".[22] He states, "...every sacrifice is a moral risk and that hidden motives may make a seemingly heroic sacrifice questionable."[23]

This however, "does not mean that there should not be sacrifice; the moral life demands it continuously but the risk must be taken with awareness" that it is clearly risk "and not something unambiguously good on which an easy conscience can rely".[24] He continues, "thus the ambiguity of sacrifice is a decisive and all permeating expression of the ambiguity in the function of self-integration"[25]

Also given is the further reality that one's "encounter with another person", according to Tillich, "implies the unconditional command to acknowledge him/her as a person", that is to respect the integrity and uniqueness of the encountered other. This then is for Tillich the "moral imperative" which is "experienced in the encounter of person with person". Furthermore, it is "the principle of agape" that expresses "the unconditional validity of the moral imperative", and it also "gives the ultimate norm for all ethical content". Moreover, "it is the source of moral motivation".[26]

Although human existence is void of an "unambiguous approach to the created nature of man and its dynamic potentialities", Tillich suggests that self-integration, in the moral[27] sense is possible by love. "For love includes the ultimate, though formal principle of justice, and love applies it in an ever changing way to the concrete situation."[28]

Tillich's discussion in respect to "sacrifice" has a direct relation to a third aspect of personhood under consideration which concerns the "contribution" made by an individual.

Given that sacrifice involves risk, that it is permeated by ambiguity; and the reality that sacrifices must be continuously made in this life, questions such as. "What is a worthy sacrifice?" and "What worthy purpose can it serve?" cannot be avoided. Further, can the "incompetent" person make a contribution, ie. the mentally incompetent adult or a neonate? Can there be any "violation of personhood" for the sake of the social well-being or social benefit and thus validating the support for non-therapeutic interventions?

Tillich maintains that "creative justice includes the possibility of sacrificing the other one in his existence, though not in his being as a person".[29] Although we are informed of our rights, this is understood to mean that agape, "for love shows what is just in the concrete situation",[30] on occasional circumstances may call upon us to surrender those rights, ie. personal inviolability in order to create a better world and society. Thus, it would appear that Tillich offers support for the possibility of a form of sacrificial love. However, safeguards must ensure that the integrity of persons are protected against abuse. There is to be "no sacrificing in one's being as a person".[31]

Support is given herein for the viewpoint that existence can be violated but "personhood" cannot be violated, if one can speak in this manner. In light of the above, sacrifices in love can be made for the well-being of the other. Moreover, since one is a part of the community and conversely, sacrifice is inevitable in order to maintain a "sense of balance and interrelation between a self and a participating responsibility in a community".[32] As previously stated, the communal or social considerations are equally as important as the individual's. Therefore, proxy consent could in theory validly serve justice. The possibility exists that an individual might legitimately and ethically be called upon to give permission to allow their charge to make a contribution or sacrifice in the cause of creative justice and the promoting of the social well-being. This writer's hope is that such sacrifice or contribution will be protected from potential misuse and abuse by rigid safeguards. Perhaps, a risk-benefit formula could be employed under the principle of minimum risk to contributing (subject) and maximum benefit to the community well-being.

The following is this writer's suggested outline of a minimal risk/maximum benefit ratio. The underlying principle originates from the D.H.E.W. guideline which states:

> When the risk of a proposed study is generally considered not significant, and the potential benefit is explicit, the ethical issues need not preclude the participation of children in biomedical research.[33]

There is considerable ambiguity in the medical literature on this subject of risk as it relates to research on children. Some contributors to this discussion include Franz J. Ingelfinger, D.E.W. Fisher, Henry Beecher and Alan M.W. Porter et al.[34] The proceeding framework therefore disclaims any notion that it is authoritative on this matter. However, the attempt has been to assist in furthering the process towards a meaningful teleology and guideline for research with children.

The Meaning of Minimal Risk

How then can we determine the meaning of minimal risk? Granted, terms such as negligible risk, discernible risk and minimal risk are slippery, difficult and to a degree relative. Admittedly, a value judgement is involved here and it has been suggested that it ought to remain within the domain of the medical profession. Richard McCormick comments on the meaning of "insignificant risk":

> For example, perhaps it can be debated whether venipuncture involves "discernible risks" or "undue discomfort" or not. But if it can be concluded that, in human terms, the risk involved or the discomfort is negligible or insignificant, then I believe there are sound reasons in moral analysis for saying that parental consent to this type of invasion can be justified.[35]

In Great Britain, it has been suggested that the standard of "minimal risk" is to be gauged by the child's capacity to mature to autonomy, unharmed by the exposure to such risk. The assessment of such risk is, of course, a matter of expert evidence to be assessed in good faith and includes both physical and psychological risk. If it can be shown without argument to be minimal, then the law at present would allow a parent to expose a child to it. This is only another way of saying that allowing a parent intentionally to expose a child to minimal risk will not endanger the child's capacity to mature to autonomy, unharmed by such exposure. And the need to safeguard this capacity must be the criterion of minimal risk.[36] Indeed Richard McCormick further clarifies that if we endorse a low risk/benefit ratio, we must be absolutely certain that "low risk" or "minimal risk" means "no realistic risk." He adds and this writer strongly concurs:

> If it is interpreted in any other way, it opens the door wide to a utilitarian subordination of the individual to the collectivity. It goes beyond what individuals would want because they ought to. For instance, in light of the above analysis, I find totally unacceptable the DHEW statement that "the investigator must also stipulate either that the risk to the subjects will be insignificant, or that <u>although some risk exists, the potential benefit is significant and far outweighs that risk</u>." This goes beyond what all of us, as members of the community, necessarily ought to do. Therefore it is an invalid basis for proxy consent. For analogous reasons, in light of the foregoing analysis I would conclude that parental consent for a kidney transplant from one noncompetent 3-year-old to another is without moral justification.[37]

This author argues that any greater invasion or intrusion beyond that stipulated as "minimal risk" would constitute a violation of the non-competent child's "personhood". A sacrifice, Paul Tillich would strictly forbid and consider impermissible conduct.

The following table denoting risk equivalents involved in research with human subjects has been included here for two reasons. Firstly, to commend such an attempt for it has tried to give some empirical basis to the task of determining risk levels. Secondly, to demonstrate that there is a lack of precision and ambiguity in such a calculus. For instance to what degree of accuracy can it be predicted that minimal risk of death in a specific research protocol will prove to be less than 1 per million? But it is a beginning and it is to be applauded, encouraged and hopefully refined as a workable and helpful instrument'

TABLE I

RISK EQUIVALENTS

	Minimal	Minor increase over minimal	Greater than minor increase over minimal
Risk of death	Less than 1 per million	1 to 100 per million	Greater than 100 per million
Risk of major Complication	Less than 10 per million	10 to 1000 per million	Greater than 1000 per million
Risk of minor Complication	Less than 1 per thousand	1 to 100 per thousand	Greater than 100 per thousand[1]

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[1] Table 1. The University of Western Ontario Review Board For Health Sciences Research Involving Human Subjects Guidelines. Revised November, 1988, p.8.

Maximum Benefit

There is the need for a method in determining "maximum benefit" to justify the undertaking of "minimal risk" non-therapeutic research with incompetent children. Recommendations made by the Law Reform Commission of Canada are believed to be helpful. Firstly, minimal risk non-therapeutic research ought to be attempted when the investigation is of major scientific importance and it is not possible to properly conduct it using adult subjects capable of giving consent. Secondly, minimal risk non-therapeutic research ought to be attempted when the research is in close, direct relation to infantile diseases or pathologies,[38] ie. infantile leukemia, cystic fibrosis, chorea, certain congenital deformities. (See also Chapter V, The Need for Non-Therapeutic Research With Children for other investigations of major scientific importance.) The potential benefits from the research might result in enhancing both the participant and society in general.

Minimum Risk/Maximum Benefit Ratio

The following is a suggestion for a minimum risk/maximum benefit ratio for non-therapeutic research involving non-competent children.

It is recognized that important studies would be impossible without using participants who are incapable of giving consent, particularly studies which are designed to benefit those very participants. In such circumstances, participants who are incapable of giving consent may be used provided that there is only minimal risk or discomfort to the participant.

In addition, the Ethics Review Board will take into account any potential for embarrassment and psychological risk as part of its evaluation. No research shall be attempted if the psychological risk is determined to be greater than minimal. The research must be of major scientific importance. This indicates that it has a potential maximum benefit value for the participant as well as society in general. Moreover, it must be demonstrated that it is not possible to properly conduct the research using adult subjects capable of giving consent. The research must indicate a close, direct relation to infantile diseases or pathologies.

Research protocols involving children will be subject to the same rigorous review as applies to competent adults. The consent of parent or guardian is required at all ages up to 18. Also, an independent third party (a judge or ombudsman) should give consent.

Investigators should as well, a) devote sufficient time to explaining their projects to parents, preferably in the presence of a non-involved professional colleague, for example, the child's nurse, and to listening to the anxieties that will often arise, b) monitor whether research procedures produce any disturbances in the child participant, c) deal promptly with any disturbance that does arise, either themselves or by appropriate referral and, d) devote sufficient time to explain their projects to nurses and other staff involved with the child participants and their parents, and to discussing any problems that may arise from research procedures. An Ethics Review Board representative is to monitor the research throughout.

In general, research procedures on neonates, infants and children should not be undertaken in such a way as to keep parent and child apart; where possible, parents should be encouraged to be present.

No financial or other inducement should be offered to parents or guardians to persuade them to enter their children into a research project; any reasonable expenses incurred however, should be paid.[39]

A standard which gives parents considerable discretion as to what they may consent to on behalf of a child should be established. Some check may be appropriate to ensure that a particular exercise of discretion is not against a particular child's interests, whether because of enthusiasm for the project, desire to participate or be seen to help, or just poor judgment. For this reason a proposal has been made that a child's advocate or guardian of the child's interests be involved before consent is given to involve a child in research. Perhaps, the best term to describe such a person is 'the child's friend'. This would capture the idea that his role is to speak for the child and to weigh all proposals in terms of the effect they may have, physically or psychologically, on the child.

First, ethics committees would be reminded of their obligation to consider the interests of children in research by the knowledge that the child's advocate or friend would be involved in any particular decisions to be made. Secondly, doctors, researchers, and parents, each time a child is considered as the possible subject of a research, would have to defend rationally the choice of this child and the validity of the exercise. This is not to say that they do not do so now, but rather that requiring them to do so to others can only enhance the protection of the child's interests. Thirdly, the existence of formal legal criteria for research interventions coupled with a procedure for ensuring compliance with them will serve to reassure the public and thereby create a climate in which appropriate research can be conducted in a climate of understanding and shared endeavour.[40]

Thus, "the incompetent" also may be asked to make such a sacrifice and contribution in the cause of "creative justice" wherein parental or proxy consent may be provided on their behalf for non-therapeutic interventions.

Given that "proxy consent" is contingent upon the understanding of "personhood" not only as the ability to give "consent"; but that it also entails one's participation in a "community" (and importantly and conversely the community's participation in that individual's reality); it as well concerns the "contribution" of the individual. Moreover, given the fact that the communal-social interests are equally as valid as the individual's and must be given the same consideration, it is therefore, ontologically unsound to maintain that the ability to give "consent" is the only consideration required for an estimate of personhood. The court had inferred this in its decision. The ethical solution, in view of all the dimensions contributing to "personhood" holds that there is no ontological ground for invalidating the integrity of "proxy consent". Although it has been repudiated in the "Eve" case it is still an ethically validated social instrument.

It is unfortunate that the validity of substitute (proxy) consent for non-therapeutic interventions has been called into question in Canada following the Eve v. "E." case. Prior to this case in Canada, the legitimacy of this substitute consent was favourably acknowledged and its proxy power was applied. Elsewhere notably in the United Kingdom and the United States, substitute consent for such interventions continues to be a valid form of authorization. This is a significant comparison which invites the legal community in Canada to reassess the implications of the "Eve" case in this regard.

In Canada, previous to the judgement rendered in the "Eve" case, some within the legal community addressed the issue of substitute (parental) consent with a degree of confidence as a valid proxy authorization. It is lamentable to observe the debilitating effects of one case law decision in turning back the commendable work put forth in support of substitute consent for non-therapeutic medical interventions in the pre-Eve era. It is a scenario that resembles trading clarity for obscurity, and progress for regression. Bernard M. Dickens is notably one who addressed the issue of parental consent as valid consent in those earlier days.

> The assertion of an absolute prohibition against the use of children with parental consent for the purposes of pure experimentation of minimal risk appears doubtful in legal concept, legal principle and legal authority.[41]

Elsewhere he has stated:

> A parent taking care to obtain proper information who is willing to submit his child to non-therapeutic medical procedures of negligible risk and pain, conducted under suitable conditions of attention to safety, may be confident that he is acting within his lawful authority.[42]

The Medical Research Council of Canada in its Report No. 6 of 1978 also included a discussion of parental/guardian/proxy consent as a valid form of substitute consent in regard to persons considered "incompetent" charges.

> The members of the Working Group were in agreement that consent on behalf of those unable to consent for themselves should often involve two stages. In the first, the parent or legal guardian of the child or the mentally incompetent person is asked to consent on behalf of the potential subject,... The second level of proxy consent is to be given by a subject advocate or ombudsman.[43]

The confidence that was expressed earlier in support of substitute consent for non-therapeutic interventions is no longer evidenced in the post "Eve" time frame. This is highly noticeable in the M.R.C. of Canada Guidelines 1987, section G.2, on "Research Involving Legally Incompetent Subjects".[44] Here, no mention of the terms "substitute" or "proxy" consent is made. Research involving incompetent subjects must be highly conscious of "the law of assault and the principles of common law preserving autonomy" on the one hand and the "hope of progress in prevention, diagnosis and treatment"[45] on the other. Furthermore, research involving children is also under scrutiny and legal purview. There is a degree of uncertainty and vagueness regarding the possibilities of these research subjects.

> The conditions under which children can volunteer for non-therapeutic interventions of no benefit to them are contentious; much centres upon the level of development of the individual child and the surrounding circumstances...[46]
>
> A concept has developed that a child incapable of giving legally and ethically acceptable consent may give an 'assent' which is significant in respecting a level of autonomy. Parental consent

> may be a necessary condition of engaging the child in research, but it is not necessarily a sufficient condition...[47]

Germane to the discussion concerning proxy-consent is the issue of children's rights. A focus will now be directed to this issue.

The Legal Perspective

Canada[48] as well as other countries, notably the United States[49] and Great Britain[50] have duly constituted laws and statutes which enhance the protective and welfare aspects of children's rights.

The general thrust of this body of legislation specifies the lawful claims afforded to children. Children have rights among others, to life, to security, to protection from harm and abuse, to care and to be supported in accordance with their best interests.[51]

Margaret Steinfils in assessing the status of children's rights in the U.S. comments, "Theirs is not an invention of rights, but an extension of well established rights to a new minority."[52] Correspondingly, in Canada an extension of rights to children is believed to have derived out of the Canadian Bill of Rights and the Charter of Rights and Freedoms as they have derived in the U.S. from the Bill of Rights and the Constitution of that nation.

Moreover, "The new dimension of the argument claims liberties for children that go beyond merely protective mechanisms that are exercised by the state to demand autonomous rights to be exercised by the child him or herself."[53] Children's rights advocates contend that "the child has individual interests and needs that must be given consideration and expression apart from those of parents or other definers of children's interests."[54] The emphasis is in support of the child's individual rights, to determine his or her own self-development and self-determination.

As the U.S. Department of Health, Education and Welfare study 1977 indicated:

> The legal trend toward enunciating and expansion of children's rights has caused considerable tension between emerging rights of children to exercise self-determination, on the one hand, and the traditionally-held rights of parents and the state, on the other hand, to protect children from their own judgment and to insist that their behavior conform to what is determined to be in their own best interests, in the best interest of the family unit, or in the best interest of the state.[55]

The common law as interpreted in the U.S. and not unlike the interpretation applied here in Canada, grants to parents the authority to direct their children in such matters as education, and generally in providing for their needs. The state reserves its right as parens patriae to intervene, only in instances when parents fail in their duty to protect and to provide for their children.[56] In the U.S., the fact that the rights of children may not always have been "properly represented by their parents or the state,"[57] has resulted in a:

> shift in the long lasting reluctance of the state and society to intervene in the parent-child relationship. This shift has been marked by a series of Supreme Court decisions establishing that in some areas, minors like adults have rights protected by the Constitution - rights that neither parents nor the state can override, and that the state must protect.[58]

Further, and of direct significance to this paper is the fact that in the U.S. in respect to matters of "consent to biomedical and behavioural research there has been little development of a judicial or statutory body of law"[59] in regard to children. In Canada, the "Eve" case has set the tenor on what is legally permissible in respect to biomedical research. As noted earlier, it inadvertently has set a case law precedent in restricting non-therapeutic research with incompetent subjects including children. Thus, it has also invalidated proxy (parental) consent to the aforementioned medical intervention.

"The primary issue with respect to the applicability of the doctrine of informed consent is the capacity of the child to comprehend and weigh the benefits and risks of proposed research."[60] This has been noted as a case to case evaluation with varying determinations resulting from U.S. court decisions.[61]

Thus children's rights advocates have raised this second issue of autonomous rights for children. The notion of empowering children to exercise their own autonomy is in principle a noble concept. However, the reality is that this autonomy at best can only be exercised by children who are capable of giving their legal consent or assent. Moreover, autonomous rights for the child would mean that the child has rights, over one's self, one's own body, one's property, and one's future. Anyone who would engage in alterations or intrusions in those areas must have that child's permission, that child's consent.[62] To do so otherwise would constitute an assault and criminal offense as stated earlier in this paper.

Only a child who is autonomous, that is free from coercion, deception and manipulation can give one's informed consent. Further, one must be competent to comprehend to choose and to decide what is in one's best interests in the exercise of one's right to self-determination. The problem here resides in the fact that only a few mature, emancipated adolescents would likely be capable of exercising the above! This clearly does not address the conditions of most children still under parental or guardian care, ie. infants and especially neonates! The further question then remains "who then can speak for the child, the neonate?" What bond, rights and duties exist that inform us of this relationship between parents and children? If the issue of children's rights had to stand solely upon the present interpretation of our laws, the position argued throughout this paper would be lost! The difficulty here is not in regards to therapeutic research with children, which is considered beneficial research, but, in respect to any proposal for non-therapeutic research with incompetent children. This type of intervention in all likelihood would be viewed as non-beneficial, not in the best-interests of the child, not in the interests of the child's care of protection. Furthermore, since the incompetent child is not autonomous and thereby cannot give his or her consent, any strict reading of the present laws would likely legally prohibit such research and its anticipated parental (proxy) consent!

At this time focus will be given to the issue of children's rights as reflected from an ethical perspective. Here, it is believed support can be derived to validate the argument of this thesis!

The Ethical Perspective

Willard Gaylin's helpful observation that, "there will be conditions where we will decide that someone is not competent to exercise his rights of self-determination",[63] accurately described our human condition. Further he notes:

> Similarly, we will inevitably decide that there is some age and some condition when even the reasonable child ought not be invested with the authority he will eventually acquire with age. We then are faced with the question of how and where

> to delegate that authority. To whom do we surrogate the responsibility? Who is to represent the interests of the child? Who is to be the decision maker? Traditionally, we have turned to the family and family members. We have selected the "next of kin." There has been a natural assumption that the family is the safest repository for these rights, that there is a primary congruence of interests between parent and child.[64]

Gaylin is aware that there are limitations and failures in the parent-child "paternalistic" relationship. "One need only think of the battered child to recognize the limitations of trust..."[65] These limitations in many instances where the family has failed the individual, have been the reasons for the emergence of so many human rights advocates, according to Gaylin, ie. those who defend the rights of the unborn, the rights of the infant.[66]

There is much advocation for the limiting of proxy, the decision-making privileges assigned to the family. But, Gaylin insists:

> In the end I expect that, with all its faults, we must be slow to abridge the power of the family. In a pluralistic society it is inevitable, and probably wise, that parents and guardians should continue to make choices for their offspring or charges. They are the child's primary teachers of values and so it is fitting that as guardians of those values they should also be responsible for determining whether medical treatment, for example, is reasonable or not. We must continue to presume that parents are acting in the best interests of their children, until proved otherwise. We must ask ourselves who - in general - best represents the will of him who cannot speak for himself: the family, or the courts.[67]

Gaylin is in full support of the notion that parental and guardian proxy should not be abridged unnecessarily and that parents should be the primary teachers of values and be responsible for determining matters such as whether medical treatment is reasonable or not for a child. He endorses the concept of paternalism and parentalism resolving that:

> inevitably we will end up with some population who are to be considered 'children', and as such may be assumed to be childish. Here such parentalism is not only necessary, but desirable. To be a parent, one must obviously behave parentalistically.[68]

It is "the interference with a person's liberty of action justified by reasons referring exclusively to the welfare, good, happiness, needs, interests or values of the person being coerced."[69]

This writer concurs with Gaylin that parents and guardians should continue to make choices for their children who are not competent, continue as the primary teachers of their children's values and continue to act in the best interests of their charges. Moreover, to act as proxy on their behalf, ie. notably in respect to medical interventions!

If it can be agreed upon that family autonomy including parental and guardian authority should be maintained and supported with the least amount of state intervention, then the question becomes, "To what medical treatments on behalf of their children can parents give their consent to?"

Firstly, it is clear that parents also have rights. These parental rights constitute a legal duty and responsibility to their children in Canada. This is "to provide the necessaries of life for a child under the age of sixteen years."70 Richard Nicholson in regard to the British context states,

> The present view of the law is that parents have duties toward their children, the principle one being to safeguard and care for them, and any rights they may have are only such as to enable them to perform these duties.71

Margaret Steinfels similarly comments in view of the situation in the U.S. (see footnote).72

Children as we have already noted have legal rights. But do children have the duty to be risk-bearers, ie. as subjects/participants in non-therapeutic research endeavours?

Here, there is considerable disagreement. Paul Ramsey adamently argues against such a proposal. Research which does not directly benefit children is absolutely, ethically impermissible for Ramsey. Further, since young children are incompetent to give their informed consent there cannot be any violation of persons. He argues that care and protection are the first order fudiciary duties of parents to children. A third-party permission to risk children in research of no benefit to them is a breach in that fudiciary duty.[73]

> A parent's decisive concern is for the care and protection of the child, to whom he owes the highest fiduciary loyalty, even when he also appreciates the benefits to come to others from the investigation and might submit his own person to experiment in order to obtain them. This is simply the minimum claim of childhood upon the adult community...[74]

Children who are not autonomous then for Ramsey have only rights. Rights to care and protection. They have no obligation or duty to others because they cannot give their consent. Therefore they cannot be risk-bearers!

This is the same line of argument submitted by Paul-A. Crapeau commenting on the non-therapeutic research possibilities with incompetent children in Canada.[75]

Benjamin Freedman has responded to Ramsey's argument. He contends that although children occupy a dependent and different status from that of adults, parents are not neglecting their duty in consenting to allow their children to participate in non-therapeutic research.[76] Even though children have some claims upon us for protection, participation in research does not seem to violate their rights unless such participation constitutes a harmful situation.[77] Indeed this writer supports the U.S. D.H.E.W.

position which states:

> In those cases where potentially great therapeutic benefits may well result from research and only minimal risk is involved, it may be reasonably argued that the calculus of morally right actions has shifted.[78]

Richard McCormick has also taken up the challenge in opposition to Paul Ramsey. His perspective that children have obligations to participate in non-therapeutic research reflects a conscious effort to assert the basic values of social justice and social responsibility and the reality of a social context. As the D.H.E.W. report states, "He maintains that a child ought to do something if that action is expressive of basic values of human nature or purposes of human life." The study further recounts:

> In the case of therapy, for example, it is a reasonable presumption that the child would consent because (in light of the normative ideal of health) the child ought to promote his own health. Similarly in the "non-therapeutic" case, according to McCormick, it is a reasonable presumption that the child would consent because (in light of the normative ideal of contributing to the health of others) the child ought to choose to participate in research.[79]

McCormick argues that:

> There is a general moral obligation to help others when there is little cost to oneself. Because children (like all individuals in society) ought to benefit others by their actions and would so act if they had a proper moral perspective, it is legitimate to involve them in research (provided

> it is no more than minimal risk)...Parental consent is said to be morally valid for both "therapeutic" and "non-therapeutic" contexts, because it is based on a reasonable presumption of the child's obligations.[80]

McCormick is quoted in the D.H.E.W. report:

> ...there are things we ought to do for others simply because we are members of the human community...If it can be argued that it is good for all of us to share in these experiments, and hence that we ought to do so (social justice), then a presumption of consent where children are involved is reasonable and proxy consent becomes legitimate.[81]

Firstly, McCormick disagrees with Ramsey. He affirms the notion that children like all members of the human community do have obligations to be risk-bearers in research including non-therapeutic research for the benefit of society. This writer believes that children and anyone else has a moral obligation to future generations. Moreover, as social beings everyone according to McCormick is able or can be enabled to contribute to the social well-being. Also McCormick acknowledges our human reality as an obligate social structure wherein social justice and social responsibility are essential elements to well-being. Secondly, McCormick advances the notion that parents give consent to involve their children in non-therapeutic research on the condition that the research is deemed to be minimal risk. Mr. Justice Jean-Luis Baudouin supportively comments in review of McCormick's minimal risk proposal:

> ...although consent remains an important and vital element, it should not necessarily be the one and only factor...the risk factor should thus be the major focus in any debate on the subject. In the name of what principle, it could then be asked, should there be a ban on an experiment of major scientific value and which involves no risk for the child?...the legality of experimentation on children must therefore be determined primarily in terms of the risk involved in the experiment. Consent in the form of parental permission should continue to be required. However, if the risks involved in an experiment are humanly acceptable, the impossibility of obtaining the subject's own consent should not be used to justify an absolute ban.[82]

The legality of non-therapeutic research on children has been contingent upon obtaining the child's own consent. The impossibility of obtaining such consent from non competent children has prohibited any non-therapeutic research on specific populations of children, ie. neonates. Should the minimum risk calculus be adopted as the new standard to determine the legality of experimentation, the informed consent impasse could possibly be overcome. nsent in the form of parental permission would continue and be validated once again!

The question then becomes, "Do parents have a right to risk their children?" Parents already risk their children every day, ie. allow them to go to school, play outdoors, play on sports teams, have surgery, visit the orthodontist,...If this is so, why cannot they allow their children to risk for a good purpose?

Children's rights advocates contend that this child before us is not to be placed at risk. However, others including the scientific community argue that neither do we want other and future generations of children to be at risk either! Perhaps, in order to balance the claims of children's rights and social justice, a minimal risk/maximum benefit calculus for non-therapeutic research with non-competent children holds promise.

Richard McCormick's contribution to the thorny issues of non-therapeutic research with non-competent children and the status of autonomous and protective rights, have been considered out of a socio-communal context. The treatment of these issues within this inclusive context is consistent with the ontological reality prescribed by Paul Tillich. This writer is in agreement with the notion that the rights of children must be respected however, a minimal risk/maximum benefit ratio for non-therapeutic research with non-competent children does not violate those rights and can be attempted! Further, proxy (parental) consent for such interventions would again be validated!

There is a notable contrast between the situation in Canada post "Eve" and the situation in the U.K. and the U.S. on the issue of substitute consent for non-therapeutic interventions. In Great Britain according to Roger J. Robinson "non-therapeutic research is justified only if the risks are minimal"[83] and the appropriate consents including parental consents are obtained.

> Children aged 7 or over should give their own assent to a procedure - in addition to the necessary consent of the parents. If the child is between 7 and 14 his unwillingness to take part in non-therapeutic research should be binding, but his parents could override his unwillingness to take part in therapeutic research. Over 14 the young person's view should be paramount, though parental consent is still legally required until 16 for therapeutic, and until 18 for non-therapeutic research.[84]

Substitute consent continues to be a valid form of authorization for non-therapeutic interventions in Great Britain.

Russell H. Patterson, Jr. acknowledges the continuing relevance of substitute consent exercised on behalf of "incompetent" patient-subjects as an acceptable practice in the U.S.:

> Since the determination of incompetence triggers substitute decision-making and decreases individualism and autonomy, it is important that the physician-scientist understand various tests of competency and the pitfalls of each.[85]

Elsewhere he states, "Once a substitute decision-maker is empowered to act on behalf of an incompetent, the question becomes: how will the decision-maker reach a decision?"[86]

In reference to the proxy decision-making of a family he comments:

> Proxy decision-making, for good reason has fallen for the most part on the family. This is not entirely satisfactory because it may be that the closest blood relative of the patient knows the least about the patient's preferences. .However, the practice of using family members as decision-makers is so well established it seems unlikely to change anytime soon."[87]

In the U.S. as it is in the U.K., the validity of substitute consent has not been repudiated or questioned as it has been in Canada following the "Eve" case.

Patterson, as one representative of the U.S. situation, raises many issues surrounding substitute (proxy) consent but at no point does he challenge the validity of proxy decision-making' "Proxy decision-making is founded firmly on many important principles, but the details of determining competence and determining who should serve as the decision-maker are large issues,..."[88]

In light of the above contrast between Canada and the situation both in the U.K. and the U.S., further ethical reflection into the inadvertent effects of the "Eve" case decision is being encouraged. Hopefully "substitute consent" will move from its status of vagueness to reassert its place of validity, a standing more consistent to that which is operative in the U.S. and in the U.K. In order that non-therapeutic medical interventions including research can once again proceed in Canada as elsewhere for the benefit of individuals and of society, this re-evaluation is necessary. Not to do otherwise would be inconsistent to the integrity of the aforementioned ethical analysis and the ontological reality indicated.

(ii) Self-Creativity: Best Interests

The second function of life, in the nature of being according to (Tillich's ontology) is called "self-creativity" and it is effective in the principle of growth.[89] "This process is the way in which life creates itself...life creates itself through the dynamics of growth."[90]

Thus, every new form of life "is made possible only by breaking through the limits of an old form". There is therefore continuity in the new with the old.[91]

This growth of life at every stage includes "conflicts with other life", which Tillich calls "a phenomenology of encounters".[92] He comments:

> One could point to the necessity for the individual to push ahead in trial, defeat and triumph in order to actualize himself, and to the inevitable clash with the attempts and experiences of other life. In push and counterpush life effects a preliminary balance in all dimensions, but there is not a priori certainty about the outcome of these conflicts.[93]

The reality of one's identity within a social context and one's communal encounters is discussed by

Tillich under the heading of "praxis".[94]

> Praxis is the whole of cultural acts of centered personalities who as members of social groups act upon each other and themselves. Praxis in this sense is the self-creation of life in the personal-communal realm.[95]

Praxis therefore, "includes the acts of persons on themselves and on other persons, on the groups to which they belong and through them on other groups, and indirectly on mankind as a whole".[96] Further, "...One can speak of social relations, of law, of administration, of politics, and one can speak of personal relations and personal development."[97]

Furthermore in respect to the "norms directing the cultural acts in all these modes of transformation, one could subsume the whole realm under the term 'ethics'."[98]

Tillich contends that there are "aims to the personal-communal realm" called praxis. The first is "the good", "and the good must be defined as the essential nature of a thing and the fulfillment of the potentialities implied in it". Moreover, one "good toward which praxis aspires", is "the concept of justice".[99] He maintains, "Justice is the aim of all cultural actions which are directed toward the transformation of society. The word can also be applied to the individual, in so far as he behaves in a just way."[100]

Justice here is essentially the term that is used to cover "the social good", whereas "humanity" is used to describe "the fulfillment of man's inner aim with respect to himself and his personal relations".[101] Thus the gap that exists between the present "social order" and "the state of universal justice" is for Tillich the "ethical problem". Likewise the gap between 'the human subject" and "a state of essential humanity" is also another "ethical problem".[102]

The reality that every cultural act involves a person or persons within the community context and who "participate in a culture's movement, growth and possible destruction", demonstrates that "everyone is subjected to the ambiguities of culture". Everyone is inseparable from the socio-cultural context and from "historical destiny".[103]

In review of the "Eve" case, the Supreme Court of Canada had adopted the traditional interpretation of the parens patriae power. The court unequivocally stated that its powers are protective powers and limited to those who cannot care for themselves. "The courts have frequently stated that it is to be exercised in the 'best interests' of the protected person, or again, for his or her 'benefit' or 'welfare'."[104]

Moreover, the discretion of the parens patriae jurisdiction "is to be exercised for the benefit of that person (under protection), not for that of others".[105] But might not the best interests of the protected person also be served by improving the community of which that person is part?

As argued in Chapter III, from an ethical perspective "the good" is limitedly defined by the court as merely that which is in the "best interests" of the one under protection. Consequently, "best interests" considerations under the court's parens patriae jurisdiction cannot balance the claims or concerns of "others", which include those of Mrs. E. and those of society. The reality of our being, not only as individuals but as social beings in light of Tillich's ontology demonstrates the inherent flaw in this legal interpretation applied to the "best interests" standard. The socio-cultural issues and concerns dismissed outrightly by the court must be given consideration and viewed as relevant to the case at hand. It would appear that witnout the wider view, a perspective that includes the social context, one's claims are meaningless. According to Charles Kammers, "Much of our development is a product of family experiences and socialization into cultural norms. Our development is strongly influenced by the groups and communities to which we belong."[106]

The court's dismissal of Mrs. E.'s concerns and interests as well as the social aspects in the case, in essence was a negation of what Tillich has coined "the phenomenology of encounters".[107] It dismissed, in other words, the communal-social reality whereby through the encounter and conflict with others growth is possible and creative justice can emerge through the process!

There is indication that the court was aware that it could indeed have benefited from knowing what the "interests of society" might have been in the case. However, in the absence of any public policy guidelines, the court felt it could only adjudicate the merits of the case from the limited "best interests" standard, which as noted reflected only the interests of the one under protection. The court is to be encouraged to ask for the development of such public policy guidelines which reflect also the interests of society!

In respect to the court's outright rejection of the "substituted judgement" test, the hope is that its validity as a tool may once again be reviewed and reinstated. There appears to be an indication that this standard at least is attempting to balance out the familial and social interests that inevitably accompanies every situation involving an "incompetent" individual and a proposed non-therapeutic medical intervention.

Russel H. Patterson maintains this position regarding the value of the "substituted judgement" test:

> The best interests standard requires the decision-maker to make only those choices that would benefit the incompetent individual. This has its shortcomings, since it may be difficult to determine the best interests of an incompetent

> patient in a given situation. It also affronts autonomy in that a competent individual has the right to make health care decisions that may or may not be in his or her own interest. If a substitute decision-maker applies a 'best interest' standard, he automatically denies the patient his right to choose a plan that might not be in his best interest by conventional standards. It might deny the subject the opportunity to participate in a research project.
>
> On the other hand, a 'substituted judgement" standard, which allows the proxy decision-maker to make a decision approximating that which the incompetent patient might have made if he were competent, advances the values of individual autonomy and self-determination.
>
> The 'substituted judgement' standard preserves to the extent possible the incompetent's right to self-determination. It preserves the patient's right to make a choice not necessarily in his own best interest, but a choice that is in the best interest of mankind.[108]

This standard appears that it would respect the social reality of our existence in accord with Tillich's ontology.

Whatever standard, ie. "best interests" or "substituted judgement", the court may adopt to adjudicate future cases involving "incompetent" individuals and a proposed non-therapeutic intervention, it is imperative that the interests of others: family members, and society be considered in the decision!

> ...the development of our humanity is a collective undertaking. We are largely formed by the communities of which we are a part, and through our actions, which shape our communities, we influence the development of ourselves and others. For better or for worse we are

> inescapably tied to each other and offer each other new possibilities for development...[109]

There needs to be the awareness that an individual is also a "part of a broader community"[110] whose interests are as equally valid as those of the individual and must be given equal consideration! Thus there is not only personal rights but social responsibility in the nature of our being and social reality!

Creative justice must encourage a vision for the future which is a "social vision", wherein there will be an equal consideration, balance and interplay between the interests of an individual and those of society!

Richard McCormick has meaningfully commented in support of the above contention.

> ...it patently equates 'best interests' with 'getting or keeping something for oneself' or, more generally, witn 'deriving personal benefit'. That equation, when unpacked, is a highly individualistic one and a subtle attack on the social dimension of our persons. As social beings, our good, our fluorishing (therefore, our best interests) is inextricably bound up with the well-being of others. That is one reason why, for instance, a long Christian (in this case Catholic) tradition has held it to be morally acceptable for an individual to forego expensive lifesaving medical treatment if such treatment would exhaust family savings, plunge the family into poverty, and deprive the other members of the family of (eg.) educational opportunity. In such an instance, it would be in the best interests of the ill individual because his best interests include his family.
> Something can be, therefore, in our best interests without we ourselves, precisely as isolated individuals, deriving any benefit or gain..

> Another modest example of this is the case where one individual (1) can provide considerable benefit to other(s) (2) at no cost to himself. I believe that if one considers our social being, it is legitimate to say that such provision is in the best interest of the individual. Indeed, that is exactly how I argued when attempting to justify non-therapeutic experimentation on those children incapable of consent...[111]

Willard Gaylin further applies the notion of social responsibility as grounds for validating proxy consent for non-therapeutic interventions.

> If a parent has no sense of moral obligation to the community at large, it may be to the good of the child as well as the community for the state to instruct the parent as well as the child as to social responsibility...[112]

Further, he writes in regard to a changed opinion of his longstanding opposition to the notion regarding the validity of proxy consent given for non-therapeutic experimentation.

> I myself, for years, felt that non-therapeutic experimentation should not be allowed via proxy consent. It was one of the few basic principles that I felt could be established in an unconditional way. My reasoning was that while it is a noble and generous act to offer oneself at risk for the good of the community or science, it is somewhat less generous, noble, or courageous for one person to offer another. I was forced to make one exception to that rule when I began to examine the problem of fetal experimentation. But another example described to me by a friend further shook my confidence in the sanctity of this principle. My friend described a scene in a doctor's office where he had taken his ten-year old son for a physical examination. The doctor,

> having completed the examination, turned to the child formally and asked permission to take a small sample of blood for epidemiological research that he was doing on a major childhood disease. As the father related the story, the doctor in a somewhat precious way explained to the child that this was not part of his examination but would help some "other little boys." Johnny asked the doctor, "Will it hurt?" The doctor answered, "A little like a pinprick." Johnny said, "I don't want it," whereupon the father said to his son, "Listen, young man, you just get your hand up on that table and let the doctor take the blood." Johnny, recognizing the note of authority in his father's voice, immediately complied, whereupon the doctor, forgetting the fomalism of his original consent proceedings, gladly took the sample.
>
> In explaining the situation to me, the father said that his reaction was not just an expression of authoritarianism or paternalism; he had a moral obligation to teach his child there are certain things one does, even if they cause a small amount of pain, to benefit others. "I was less concerned with the research involved than with the kind of boy I was raising. I'll be damned if I was going to allow my child to assume that he was entitled to be selfish and narcissistic because of some silly concept of children's rights.
>
> Paternalism by a parent in relationship to a young child is not, this father would argue, patronizing or "paternalistic". Instilling a set of values is a parent's moral responsibility. I tend to agree with the father, and while my approach might have been different from his, each parent has the right to a personal style within the limits of decency. I accept this as another category where proxy consent may be suitable in a non-therapeutic experimentation. The benefit to this child at this time is zero, but the cost is very low and the social gain may be very high. In such cases a parent may "volunteer" the child for a non-therapeutic experiment.[113]

Thus the "best interests" standard applied by the Supreme Court of Canada is limitedly defined and therefore contributes to a diminished perspective of "the good". A standard that could reflect the nature of our being and the social reality of our existence must include "the social good" and thus social interests. This was not attempted by the Court in the "Eve" case. It appears that for the reasons mentioned above, these considerations were dismissed. Thus, it is evident that on the basis of ethical analysis and the reality apparent in Tillich's ontology, the "best interests" standard employed in the "Eve" case is an inadequate and deficient standard!

The ethical solution in view of the social reality of human existence is that, by whatever standard is used, ie. "best interests", "substituted judgement..." in order to adjudicate or assess future cases involving "incompetent" individuals in non-therapeutic interventions, it is imperative that social concerns and interests be incorporated into the standard. Family members and societal considerations are essential to a responsible decision-making process!

(iii) Self-Transcendence: Case Definition of Health

The third element in the life process, according to Tillich is self-transcendence, the ability of those in the process of life "to stand outside their finitude in freedom".[114] "The polarity of freedom and destiny...creates the possibility and reality of life's transcending itself. Life, in degrees, is free from itself, from a total bondage to its own finitude."[115]

It is for Tillich a "striving in the vertical direction toward ultimate and infinite being". The vertical dimension "transcends both the circular line of centeredness and the horizontal line of growth".[116]

The focus here is upon "freedom as it embodies the ability to transcend the finitude and ambiguities of life...This freedom, however, is still a freedom within history". Thus, "it is only through that which is historical and finite that the infinite can be revealed. To be truly symbolic or bearers of transcendence elements or actions in history must participate in that which they point."[117] That is, the present reality can be transcended in freedom and at the same time there is a drive toward ultimate meaning and being for a more fulfilled future.

Self-transcendence in respect to the relation between an individual and the community in which and over against which one stands, "reflects a creativity, which...breaks through particular historical forms, transforming them and giving them significance that transcends their ambiguities". Thus one expression of creativity is through "the activity of decision-making which as a function of freedom creates and recreates the events in history". The other is expressed in the notion of fulfillment which "involves the relation of history to the unconditioned unity of meaning and being". 'This is only possible in the context of freedom which is realized in decision-making."[118]

Moreover, "in as much as historical change is an inherent part of decision-making" such fulfillment can never be final.[119]

Furthermore, "social change as transformation is necessarily linked to self-transcendence as the freedom for fulfillment." Decisions effecting changes "not only bear implications for cultural growth, they also test the adequacy or legitimacy of the cultural framework".[120] "That is, they test whether the values and meanings fostered by the culture can adequately deal with the full import of those exigencies."[121]

Such testing provides an opportunity for that cultural framework to be transcended, "an opportunity which if realized will foster change as the constitution of new horizons of expectation and legitimation."[122]

Paul Tillich identifies within human existence a drive toward reunion with others and the ground of being itself. A drive towards fulfillment in all of existence. Paul Tillich contends that this drive is none other than "love". "Love is the power in the ground of everything that is, driving it beyond itself toward reunion with the other one and ultimately with the ground itself from which it is separated."[123]

It is in "creative freedom" that this reunion is grounded, "for it is through the transcendence of freedom that the drive of history toward unity can be realized".[124]

Tillich comments:

> ...the eternal act of creation is driven by a love which finds fulfillment only through the other one who has freedom to reject and to accept love. God so to speak, drives toward the actualization and essentialization of everything that has being... Creation into time produces the possibility of self-realization, estrangement, and reconciliation of the creature, which, in eschatological terminology, is the way from essence through existence to essentialization.[125]

Therefore, Paul Tillich states:

> It seems appropriate to reserve the term 'self-transcendence' for the function of life in which...life drives beyond itself as finite life. It is self-transcendence because life is not transcended by something that is not life. Life, by its very nature as life, is both in itself and above itself, and this situation is manifest in the function of self-transcendence. For the way in which this elevation of life beyond itself becomes apparent, I suggest using the phrase 'driving toward the sublime'. The words 'sublime', 'sublimation', 'sublimity' point to a 'going beyond limits' toward the great, the solemn, the high.[126]

Thus self-transcendence for Tillich is a "striving in the vertical direction toward ultimate and infinite being".[127] And through freedom in life there is a drive toward fulfillment which "involves the relation of history to the unconditional unity of meaning and being".[128]

As previously noted, "health" as defined by the Supreme Court of Canada in the "Eve" case was specified as "mental as well as physical health".[129] Noteworthy is the fact that the court had resolved that any medical intervention under its parens patriae jurisdiction is restricted to promoting the physical and mental health of the individual "under the protection of the court".[130] As noted, "The discretion is to be exercised for the benefit of that person, not for that of others."[131]

The "Eve" case decision was rendered with reference to this above noted definition of health. (See Chapter II (iii) and Chapter III (iii) under Case Definition of Health.)

The court concluded that no evidence indicated "that failure to perform the operation would have any detrimental effect on Eve's physical and mental health".[132]

The case definition of health is directly related to the court's limited interpretation of the "best interests" standard which is applicable only for the benefit and protection of the person or persons under disability. Health as was noted, was defined solely in regard to two highly personalized categories of well-being, that of the physical and mental health of the person or persons under the court's protection. Thus, "health" as defined by the Supreme Court of Canada for the purposes of the "Eve" case does not have a social context or dimension! Thus Mrs. E.'s concerns or interests and those of society were deemed to be not relevent to the case. The court's reluctance to acknowledge any consideration of a social nature or regard due to its limited interpretation of "the best interests" standard and its "definition of health" underscores a pronounced inadequacy and inconsistency with regard to the human-social context of reality.

The court's exclusion of any social considerations by definition and intent is inherently flawed. This author in solid agreement with Richard McCormick concurs that our reality is such that "each individual" is as well a social being, and "as social beings, our good, our fluorishing (therefore, our best interests) is inextricably bound up with the well-being of others".[133] That is, with respect to an ethical perspective guided by the ontological reality, one cannot avoid the social issues and concerns when discussing an individual in any holistic manner! This is what the court has done in the "Eve" case. Therefore, the case law decision ought to be reviewed for it is based upon legal definitions that are limited and inadequate.

The Canadian Medical Association's Committee on Ethics issued the following statement in review of the Supreme Court of Canada's decision on the "Eve" case:

> The Committee on Ethics of the C.M.A. regrets that the Supreme Court of Canada in its decision in the case re: 'Eve' found it difficult 'to imagine a situation where non-therapeutic sterilization could be of benefit' to an incompetent mentally retarded person.[134]

This statement is the direct result of the differing interpretations on the "definition of health", one ascribed to by the legal community and the other by the medical.

The contrast is evident in the Constitution of the World Health Organization, wherein "health" has been given the following definition: "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."[135]

The court's determination of "health" was limitedly defined as "physical and mental" health whereas the benefits of sterilization for "contraceptive purposes" may be primarily for the social and personal well-being of the mentally retarded person.[136] A consideration the court outrightly dismissed in its "best interests" standard and its "definition of health".

Bernard Dickens in defence of the court's position contends, "Benefit to others or to society is not a ground for exercising a protective power in favour of non-therapeutic surgery."[137]

Bernard Dickens has, as did the Supreme Court of Canada made a clear distinction between what is considered in the "best interests" of an individual over against those of others and society. However, in light of Richard McCormick's analysis, "as social beings our good, our fluorishing (therefore, our best interests) is inextricably bound up with the well-being of others"[138] Indeed, if any one individual is to be given consideration in a holistic manner in respect to the nature of being and the reality of our existence, it is to affirm a personal existence in the context of community and of society! This social consideration must inevitably be dealt with.

Paul Tillich's ontology contends that through "creative freedom" one can transcend the finite, that is to (step beyond one's present reality figurtively, and evaluate, and decide anew) that which will move one closer toward "ultimate meaning and being". It is "love" that drives one in freedom towards fulfillment, which involves decisions effecting changes that "not only bear implications for cultural growth, they also test the adequacy or legitimacy of the cultural framework". Moreover, "they test whether the values and meanings fostered by the culture can adequately deal with the full import of those exigencies".[139]

Such testing provides an opportunity for the cultural framework to be transcended, "an opportunity which if realized will foster change as the constitution of new horizons of expectation and legitimation".[140] Thus through love, there is a drive toward reunion with others and with the ground of being itself. One is compelled towards fulfillment towards the ultimate meaning and being.

In light of the Supreme Court of Canada's "definition of health" as "physical and mental health" without a consideration of the social dimension as a part of the overall perspective, and in view of Paul Tillich's ontology, the press toward a more fulfilled definition of health would include the social dimension. Thus it is evident that the "definition of health" applied in the "Eve" case is deficient.

Furthermore, there is indication that the aforementioned definition is not universally supported nor agreed upon from within the legal community. N. Bala, H. Lilles and G. Thomson have stated, "In deciding on such intervention the Court must consider the best interests of the children in respect of their biological, social, emotional, cultural and intellectual development."[141]

Thus the ethical solution maintains that a more fulfilled definition of health must include a social dimension.

In the creative freedom exercised by this writer, there has been a press towards a more fulfilling definition of health, in the quest to discover its ultimate meaning. This process has revealed that the values and meaning presently ascribed to "health" by the Supreme Court of Canada does not adequately relate to its cultural framework. Health is more than the two highly personalized values, ie. the physical and mental health of an individual which has been applied by the court. This definition must include a social reality. Moreover, it ought to express the human-social context of reality. The present definition does not do that and therefore, reflects a severe limitation and inadequacy!

Summary

In light of "the nature of our being", and the reality in human existence as reflected in Paul Tillich's ontology et. al, each one of the three case issues investigated herein has demonstrated a deficiency within the legal arguments. Having stated at the outset of this paper that should this be proven, then, it of necessity calls into question the validity of the case law decision. A review of this case law is being asked for; as well as a review of its implications to non-therapeutic medical interventions including research!

The ethical solutions are herein stated in the body of this chapter.

NOTES TO CHAPTER IV

1. Tillich, Paul, Systematic Theology III, Chicago: University of Chicago Pres, 1963, p. 31-32.

2. Tillich, Paul, at p. 30.

3. Tillich, Paul, at p. 30.

4. Tillich, Paul, at p. 32.

5. Tillich, Paul, at p. 32.

6. Tillich, Paul, at p. 38.

7. Tillich, Paul, at p. 39.

8. Tillich, Paul, at p. 38.

9. Tillich, Paul, at p. 38.

10. Tillich, Paul, at p. 38.

11. Tillich, Paul, at p. 40.

12. Tillich, Paul, The Courage To Be. New Haven: Yale University Press, 1965, p. 86.

13. Tillich, Paul, The Courage To Be, p. 86.

14. Tillich, Paul, The Courage To Be, p. 89.

15. Tillich, Paul, The Courage To Be, p. 89.

16. Tillich, Paul, The Courage To Be, p. 89.

17. Tillich, Paul, Morality And Beyond. New York: Harper & Row Pub., 1963, p. 20.

18. Crossman, Richard, Ethics And The International Order Of Political Development: A Study Of Political Developmental Strategies In Latin America In The Light Of Social Change Theory And The Theology Of Paul Tillich (Ph.D. dissertation), U.P. Chicago: The Faculty Of The Divinity School, Dec. 1976, p. 185.

19. Crossman, Richard, at p. 185.

20. Crossman, Richard, at p. 185.

21. Crossman, Richard, at p. 185.

22. Sacrifice is "the act of depriving oneself of something for the sake of attaining some goal or for the sake of someone else...". The New Lexicon Webster's Dictionary, at p. 876.
Tillich, Paul, Systematic Theology III, at p. 43.

23. Tillich, Paul. Systematic Theology III, at p. 43.

24. Tillich, Paul, at p. 43.

25. Tillich, Paul, at p. 44.

26. Tillich, Paul, at p. 45, 48.

27. Tillich, Paul, at p. 48.

28. Tillich, Paul, at p. 48.

29. Tillich, Paul, Love, Power and Justice. Oxford: Oxford University Press, 1954, p. 86.

30. Tillich, Paul, Love, Power and Justice, at p. 82.

31. Tillich, Paul, at p. 86.

32. Allen, Joseph, A Covenental Model of Christian Ethics, Nashville: Abingdon Press, 1984, p. 118.

33. McCormich, Richard, "Proxy Consent in the Experimentation Situation," Biomedical Ethics. Mappes, T.A. and Zembaty, J.S. (eds.), New York: McGraw-Hill Book Co., 1986, p. 198.

34. McCormick, Richard, "Proxy Consent in the Experimentation Situation," p. 199.

35. McCormick, Richard, "Proxy Consent in the Experimentation Situation," p. 203.

36. Nicholson, R.H. (ed.), p. 137.

37. McCormick, Richard, "Proxy Consent in the Experimentation Situation," p. 203.

38. Baudoin, Mr. Justice Jean-Luis, Law Reform Commission of Canada, Biomedical Experimentation Involving Human Subjects, Working Paper 61, Ottawa: Law Reform Commission of Canada, 1989, p. 42 (a), (b). See all five recommendations that are being proposed for incorporation into a federal statute. This author most adamantly advises against the adoption of (c). Once again only "minimal risk" research is

possible on the ethical grounds argued in this paper! This position concurs with Paul Tillich and Richard McCormick et al.

39. Cited and adapted from The University of Western Ontario Review Board For Health Sciences Research Involving Human Subjects Guideline, Revised November, 1988, p 6-8. Also cited and adapted from Baudoin, Mr. Justice Jean-Luis, Law Reform Commission of Canada, 1989, p. 42.

40. Nicholson, R.H. (ed.), Medical Research with Children, p. 133-139.

41. Dickens, B.M., "The Use of Children in Medical Experimentation", Medico-Legal Journal, 1975, p. 167.

42. Ibid. Dickens, B.M. p. 169. See note 33.

43. Medical Research Council of Canada, Ethics in Human Experimentation, Report No. 6, 1978, p. 31.

44. Medical Research Council of Canada, p. 28. See note 43.

45. Medical Research Council of Canada, p. 29.

46. Medical Research Council of Canada, p. 29.

47. Medical Research Council of Canada, p. 29.

48. Rodrigues, G.P., Ouellet, J. (eds.), Canadian Bill of Rights and Constitution Act 1982, in Pocket Criminal Code 1989, Toronto: The Carswell Co. Ltd., 1988, p. 504-514

49. "...in 1967...the Supreme Court explicitly stated for the first time that "neither the Fourteenth Amendment nor the Bill of Rights is for adults alone." Further, "children are now considered to be entitled to fundamental constitutional rights."
Melton, G.B., Koocher, G.P., Saks, M.J. (eds.), Children's Competence to Consent, New York: Plenum Press, 1983, p. 2, p. 9.

50. "By having recourse to law, the State is indicating that it is not content to leave provisions for the protection and welfare of the child to less formal social regulation..."
Nicholson, R.H. (ed.), Medical Research with Children Ethics, Law and Practice, Oxford: Oxford University Press, 1986, p. 125.

51. Bill 77 (Chapter 55 Statutes of Ontario, 1984). An Act respecting the Protection and Well-being of Children and their Families, Legislative Assembly of Ontario, Toronto: Queen's Printer for Ontario, 1984, Sections 37-39, p. 32-38.

52. Steinfels, M.O., "Children's Rights, Parental Rights, Family Privacy, and Family Autonomy", Who Speaks For The Child, Gaylin, W. and Macklin, R. (eds.), New York: Plenum Press, 1982, p. 237.

53. Steinfels, M.O., Children's Rights, p. 237.

54. Steinfels, M.O., Children's Rights, p. 233.

55. The National Commission For The Protection Of Human Subjects Of Biomedical And Behavioral Research, Report And Recommendations Research Involving Children. D.H.E.W. Pub. No. (OS)77-004, Washington, D.C.: U.S. Govt Printing Office, 1977, p. 73.

56. The National Commission For The Protection Of Human Subjects, p. 73.

57. The National Commission For The Protection Of Human Subjects, p. 73-74.

58. Steinfels, M.O., Children's Rights, p. 225.

59. The National Commission For The Protection Of Human Subjects, p. 74.

60. The National Commission For The Protection Of Human Subjects, p. 74.

61. The National Commission For The Protection Of Human Subjects, p. 79-84. An overview of U.S. case law decisions regarding children's informed consent.

62. Gaylin, W., "Who Speaks for the Child?" Who Speaks For The Child The Problem Of Proxy Consent, Gaylin, W., and Macklin, R. (eds.), New York: Plenum Press, 1982, p. 13.

63. Gaylin, W., "Who Speaks for the Child?" p. 16.

64. Gaylin, W., "Who Speaks for the Child?" p. 16.

65. Gaylin, W., "Who Speaks for the Child?" p. 17.

66. Gaylin, W., "Who Speaks for the Child?" p. 17.

67. Gaylin, W., "Who Speaks for the Child?" p. 17.

68. Gaylin, W., "Who Speaks for the Child?" p. 22.

69. Gaylin, W., "Who Speaks for the Child?" p. 21.

70. Rodrigues, G.P., Ouellet, J. (eds.), Pocket Criminal Code 1989, Section 215 (1)(a), p. 127.

71. Nicholson, R.H. (ed.), Medical Research with Children, p. 132.

72. "...the judicious exercise of parental rights and authority fosters the development of children in order that they can maturely exercise their own rights and meet their own responsibilities."
Steinfels, M.O., Children's Rights, p. 241.

73. The National Commission For The Protection Of Human Subjects, p. 95-96.

74. Ramsey, Paul, The Patient as Person, Yale Univ. Press, New Haven, 1970, p. 25.

75. "...since consent cannot be obtained from the subject himself, it can only be given on his behalf by a person in authority, i.e., a parent, tutor or curator, or guardian. Such authority, however, carries with it a fudiciary duty to act in the interest and for the benefit of the beneficiary. Therefore, no one holding this

> position of trust may expose fetuses, children or the mentally incompetent to the potential risks of an experiment of no direct benefit to them."

Crapeau, Paul-A., Ethical Considerations In Research Involving Human Subjects, Medical Research Council, Report No. 6, Ottawa: Minister of Supply and Services, 1978, p. 30-31.

76. Freedman, Benjamin, A Moral Theory Of Informed Consent, Hastings Center Report 5, August 1975, p. 29-39.

77. The National Commission For The Protection Of Human Subjects, p. 99.

78. The National Commission For The Protection Of Human Subjects, p. 98.

79. The National Commission For The Protection Of Human Subjects, p. 100.

80. The National Commission For The Protection Of Human Subjects, p. 100.

81. The National Commission For The Protection Of Human Subjects, p. 101.

82. Baudouin, Mr. Justice Jean-Luis, Law Reform Commission of Canada, Biomedical Experimentation Involving Human Subjects, Working Paper 61, Ottawa: Law Reform Commission of Canada, 1989, p. 41.
In Great Britain this minimal risk criteria is present in the law to allow parents to give their appropriate proxy consent for their children to participate in non-therapeutic research. "It if can be shown without argument to be minimal, then the law at present would allow a parent to expose a child to it."
Nicholson, R.H. (ed.), Medical Research With Children, p. 137.

83. Robinson, Roger J., "Ethics committees and research in children", British Medical Journal, Vol. 294, No. 6582, London, Saturday, May 16, 1987, p. 1243.
Minimal risk is herein defined. In Great Britain Research Ethics Committees must be satisfied that

> the research project can be done only on children, is scientifically valid, and holds the possibility of considerable benefit to children. They should be sure that the benefits substantially outweight the risks.

These conditions need to be satisfied even before non-therapeutic research considerations are given. See also the recommendations made in "The Report Of An Institute Medical

Ethics Working Group On The Ethics Of Clinical Research Investigations On Children", in Nicholson, Richard H. (ed.), Medical Research With Children: Ethics, Law, And Practice, Oxford: Oxford University Press, 1986.

84. Ibid. Robinson, Roger J., p. 1244.

85. Patterson, Russel H., "Research With Those With Restricted Ability To Give Consent", International Summit Conference on Bioethics, Document 7, Session F, Medical Research Council of Canada, Ottawa: Minister of Supply and Services Canada, 1988, p. 5.

86. Patterson, Russel H., p. 6.

87. Patterson, Russel H., p. 7.

88. Patterson, Russel H., p. 8.
See also as an enclosed appendix in this article "some relevant guidelines developed for physicians in the United States by the American Medical Association's Council on Ethical and Judicial Affairs..." p. 10-14.
See as well "Report And Recommendations: Research Involving Children", The National Commission For Protection Of Human Subjects Of Biomedical And Behavioral Research, Washington: DHEW (Dept. of Health, Education & Welfare Pub.), 1977.

89. Tillich, Paul, Systematic Theology III, at p. 50.

90. Tillich, Paul, at p. 50.

91. Tillich, Paul, at p. 50.

92. Tillich, Paul, at p. 53.

93. Tillich, Paul, at p. 53.

94. Tillich, Paul, at p. 65.

95. Tillich, Paul, at p. 65.

96. Tillich, Paul, at p. 66.

97. Tillich, Paul, at p. 66.

98. Tillich, Paul, at p. 66.

99 Tillich, Paul. at p. 67.

100. Tillich, Paul, at p. 67.

101. "...Justice as the fulfillment of the inner aim of social groups and their mutual relations", at p. 67.

102. Tillich, Paul, at p. 68.

103. Tillich, Paul, at p. 68.

104. [1986] 2 S.C.R. 388, at 426.

105. [1986] 2 S.C.R. 388, at 427.

106. Kammer III, Charles, Ethics and Liberation an Introduction, New York: Orbis Books, 1988, p. 127.

107. Tillich, Paul, Systematic Theology III, at p. 53.

108. Patterson Jr., Russel, H., "Research With Those With Restricted Ability To Give Consent", International Summit Conference on Bioethics, Document 7, Session F, <u>Medical Research Council of Canada</u>, Ottawa: Minister of Supply and Services Canada, 1988, p. 6.

109. Kammer III, Charles L., at p. 141.

110. Kammer III, Charles L., at p. 143.

111. McCormick, Richard A., "Freedman on the Rights of the Voiceless", <u>The Journal of Medicine and Philosophy</u>, Vol. 3, No. 2, 1978, p. 212-13.

112. Gaylin, Willard, "The Competence of Children: No Longer All or None", The Hastings Center Report, April 1982, p. 33-38 at p. 37.

113. Gaylin, Willard, at p. 37-38.

114. Crossman, Richard, at p. 180.

115. Tillich, Paul, Systematic Theology III, at p. 86.

116. Tillich, Paul, at p. 86.

117. Crossman, Richard, at p. 180-181.

118. Crossman, Richard, at p. 187-188.

119. Crossman, Richard, at p. 188-189.

120. Crossman, Richard, at p. 196-7.

121. Crossman, Richard, at p. 196.

122. Crossman, Richard, at p. 197.

123. Tillich, Paul, Dynamics of Faith, New York: Harper & Row, 1957, p. 114.

124. Crossman, Richard, at p. 200.

125. Tillich, Paul, Systematic Theology III, at p. 422.

126. Tillich, Paul, at p. 31.

127. Tillich, Paul, at p. 86.

128. Crossman, Richard, at p. 188.

129. [1986] 2 S.C.R 388, at p. 427.

130. [1986] 2 S.C.R. 388, at p. 427.

131. [1986] 2 S.C.R. 388, at p. 427.

132. [1986] 2 S.C.R. 388, at p. 429.

133. McCormick, Richard, at p. 212.

134. Marshall, David, at p. 650.

135. In Dickens, Bernard, No contraceptive sterilization of the mentally retarded: The dawn of Eve. C.M.A.J., Vol. 1137, July 1, 1987, p. 65.

136. Marshall, David, at p. 650.

137. Dickens, Bernard, "No contraceptive sterilization of the mentally retarded: The dawn of Eve, at p. 66.

138. McCormick, Richard, at p. 212.

139. Crossman, Richard, at p. 196.

140. Crossman, Richard, at p. 197.

141. Bala, N., Lilles, H., and Thomson, G. (eds.), Canadian Children's Law Cases, Notes & Materials, Toronto: Butterworth & Co. (Canada) Ltd., 1982, p. 12.

CHAPTER V

THE IMPLICATIONS OF THE "EVE" CASE FOR NON-THERAPEUTIC RESEARCH WITH CHILDREN

The Need for Non-Therapeutic Research With Children

It is evident from the literature that "clinical research involving children is necessary for the continued betterment of children's welfare".[1] Further, John Pearn states, "Any research endeavour which will reduce the occupancy of child hospital beds will be ultimately cost-effective."[2] He contends:

> The underlying axiom of preventative research in the paediatric domain is that if a life can be saved or disability prevented then the benefits are there over a future lifetime...'Preventative reearch'...will benefit ourselves and our children..."[3]

Pearn also identifies research to establish norms and baselines as another "very important type of research which involves children". Since

> the core feature of childhood as a biological state is its constant change. Such change, both in terms of physical growth, and intellectual and social development, means that norms and baselines have to be established for each age and sex...[4]

under a number of socio-economic factors. Thus, "in this area, there remains an unfilfilled need for percentile charts of physiological and performance variables throughout childhood..."[5] Furthermore, he contends:

> One specialized area where this absence of normative data is particularly pertinent is in the field of antenatal diagnosis of congenital abnormalities...the patterns of such developmment for fetuses with genetic diseases and with congenital abnormalities are generally unknown. These data are urgently required..."[6]

In the many examples presented in his paper, John Pearn stresses the great need for paediatric research. He suggests that a new attitude needs to be shaped whereby research is no longer viewed simply as something in the realm of the medical field but that which "not only the researcher but also the paediatric patient are contributing to produce something new".[7] He is advocating for the realization of a medico-social vision wherein the well-being of all persons is considered and all persons contribute to this social well-being. This, he also applies to "non-therapeutic research, which can further be subdivided into the themes, ie. of preventative research, research to establish norms and baselines, and curiosity research".[8] He concludes his article with these words, "Sick children and potentially sick children of the future, need a research climate in which each of these five ongoing investigational themes are further encouraged."[9]

Robert B. Redmon in support of the above viewpoint, adds:

> If we assume that medicine as a whole, or paediatric medicine in particular, is a good, it becomes clear, I think, that minimal risk, non-therapeutic research with children is needed in a great many areas of paediatrics. From my own limited experience I know that the life-saving monitoring and regulating of blood gases in many distressed newborns could only be accomplished by knowing what the normal levels are, ie. by taking blood samples from normal infants. There are numerous examples like this,..."[10]

Further, in support of the essential need for paediatric research Graham Chance emphasizes:

> Findings resulting from research in adults cannot be reliably applied to children for the child cannot be regarded as a small version of the adult. The child's hormonal and metabolic milieu is different from that of an adult...Similarly, the newborn is not a small version of the child. Major differences exist in regard to metabolism, organ function and immune competence to mention but a few.[11]

Thus, "in order to promote their health, research on children is essential for without it they will be 'therapeutic orphans'..."[12] His example of "the history of the use of oxygen for treatment of sick newborns" clearly demonstrates "the adverse effects of lack of research in newborns".[13] One startling result of the withdrawal of oxygen therapy is reported. "It was calculated that between 1952 and 1962 for every instance of retrolental fibroplasia avoided, thirty infants had either been damaged or died."[14]

However, when the consequences of research findings are applied to therapy in children, the benefits to children abound.

> ...the marked reduction in mortality from leukemia, the dramatic reductions in mortality and morbidity in low birthweight infants, the virtual eradication of diptheria in developed countries, are all in major part a consequence...[15]

It is in this writer's perspective, from both a literature review on the subject of paediatric research and from his personal field-work experience with the Neonatal Intensive Care Unit of St. Joseph's Hospital, London, Ontario, that there is indeed a great and essential need for paediatric research and most significantly research that is not solely therapeutically inclined but also non-therapeutic in nature!

(i) The M.R.C. (Medical Research Council) of Canada Guidelines 1987: A Reflection of the "Eve" Decision In Respect to Proxy Consent

The restriction against non-therapeutic interventions is understood to be a direct effect of this case law being applied to other contexts, ie. paediatric research.

> ...the definitive statements of principle in 'Eve' would all but rule out any non-therapeutic intervention based on substitute consent. It is impossible to determine if this was the Supreme Court's intention or just an inadvertent result of the Court's strong reaction to the 'Eve' case..."[16]

As indicated earlier the Supreme Court of Canada determined in essence that non-therapeutic procedures are not possible in respect to an individual who is by legal definition "incompetent" and thus unable to give "informed consent". This was determined to be Eve's situation and therefore, no non-therapeutic intervention could be applied and thus "proxy consent" here was invalidated. It is inferred that the court's presupposition in regard to that which constitutes "personhood" was based solely upon one's ability to give consent. That, in Eve's case not being possible, the inadvertent result was the elimination of valid proxy (parental) consent.

It is evident that the 1987 M.R.C. Guidelines[17] are informed by the "Eve" case decision. Thus in paragraph 4 of section G 2(a) on page 29 it states: "The conditions under which children can volunteer for non-therapeutic interventions of no benefit to them are contentious..." The explanatory note at the bottom of the page simply reads, "Their existence is denied by some authorities. See M.R.C. Report #6, 1978, p. 30. See also Re Eve 1986, 2 S.C.R. page 327 (S.C.C.)." The latter is in reference to the "Eve" case. (This writer believes the reference is intended to state page 427 S.C.C.).[18]

The tenor of the presentation regarding non-therapeutic research is set by these qualifying statements. There is no mention made in respect to valid proxy (parental or guardian) consent for any non-therapeutic interventions that involve "incompetent" subjects. In paragraph 5, section 2(a) parental consent is addressed as valid but on a conditional basis alone. It is contingent upon a child's "assent" or consent to participate in research. It is moreover, not clear whether this is in reference to purely therapeutic research or non-therapeutic as well. The evasiveness and general tenor of the presentation may favour the former intervention. Thus here in the M.R.C. Guidelines as well as in the "Eve" case, valid proxy consent appears to be possible only for therapeutic purposes! This needs to be clarified in the document!

> Parental consent may be a necessary condition of engaging the child in research, but it is not necessarily a sufficient condition, the child's negative preferences in such cases should be respected.[19]

Medical research in Canada can only be considered for subjects who can at least give "assent" and thus a limited expression of their autonomy. Neonates (newborns) and intellectually disabled children are not even given "personhood" status in the M.R.C. Guidelines. In reality the text of the M.R.C. Guidelines implies that "personhood" commences with the ability to give "assent"! This is tantamount to denying to the most vulnerable persons in our society any dignity or respect. This is truly a lamentable situation! Once again, the above mentioned cannot be given consideration for non-therapeutic research purposes nor is there any indication that proxy consent in this context is valid.

Ontological Implications

The question needing to be asked is, "Can 'personhood' that of the incompetent person (ie. neonate) be violated?" Paul Tillich's ontology has demonstrated that sacrifice or contributions are a necessary fact of human existence. Thus, human existence, one's life can be intruded upon, but the dignity and integrity of one's personhood must be protected! Moreover, "personhood" is not defined ontologically by Tillich, merely on the basis of autonomy, but through one's participation within a community and the community or society's impact and relationship to that individual. In the affirming of human reality as innately a social reality, each one of us is acknowledged as an individual, but, as well a social-being, regardless of whatever competence standard is labelled against us. In that social context, social considerations are equally as valid as the individual's and according to Richard Crossman must be given the same consideration! Saying this, it informs us that ontologically speaking, the communal or social perspective or interests cannot be invalidated. That is, for instance, the principle of proxy consent is a valid concept beyond "Eve"! Parents, guardians, the courts, etc. are all aspects of the social-communal dimension, whose concerns and interests are significant, in the sense that outright dismissal without evaluating these considerations is irresponsible. Several suggestions of how this social context can be considered are as follows:

Robert Redmon contends that proxy (parental) consent applying a "substituted judgement" standard may be helpful in viewing non-therapeutic research as personally and socially beneficial and meaningful to others and to the child:

> It does make sense, however, to ask how a person with a particular moral outlook, particular values, virtues and vices, would act. Thus the prediction of how the child will later view his participation must be made by those in the child's family, in particular by his parents. Their consent should be based upon their own values and the expectation that the child will share,to some extent, in them. They might reasonably expect for example, that their child may later, as an adult, have an interest in the welfare of children whom the research may benefit...[20]

According to Richard McCormick because we are social beings, our best interests are intrinsically connected with the well-being of others. Thus, something can be in our best interests without ourselves deriving any benefit! There are instances in which an individual can provide considerable benefit to others with no cost to that person. In light of the social nature of our being it is legitimate to say that such a contribution is in the best interests of that person![21]

Furthermore, Willard Gaylin has addressed as previously noted, the need to create a sense of "social responsibility" as grounds for validating proxy consent for non-therapeutic interventions.

> If a parent has no sense of moral obligation to the community at large, it may be to the good of the child as well as the community for trhe state to instruct the parent as well as the child as to social responsibility...[22]

Stanley Hauerwas similarly to Willard Gaylin comments on the subject of non-therapeutic research:

> When confronted by questions of how to approach research on children we seem to be drawn to the language of rights...As an alternative to rights language I will try to show why the language of duties is more to the point.[23]

There is in Hauerwas a concern that personal rights be balanced out with social responsibility that is, emphasis upon self-determination be countered with a more responsible self-actualization thrust, which incorporates the interests and well-being of others! In essence he states "childhood is dependent on our understanding of family and community".[24] Furthermore, "...that children, even infants can have a moral role in a community even before they are agents" ...even when a child cannot choose that standing on his own.[25] Moreover, for Hauerwas those moral values within a community, should instill a social responsibility to participate in non-therapeutic research. He comments, "...we all have a responsibility to participate in non-therapeutic research..."[26]

Paul Tillich's ontological perspective validates both "community" considerations as well as personal "contributions". Acknowledging therefore, that both "proxy consent" and "non-therapeutic research" can be thus entertained as valid. Parents can speak on behalf of their "incompetent" charges and the social well-being of others can be one of those considerations in the decision to participate in non-therapeutic research. Hopefully, public policy guidelines will be developed to assist in the decision-making process with regard to the balancing of interests between the individual and society. (In this regard see the discussion on the minimal risk/maximum benefit ratio in Chapter IV.)

In respect to any subject participating in non-therapeutic research, and especially in regard to "incompetent" subjects, no one is to be used "as a means, and the question is always whether the end is commensurate with the person's good as a member of a morally, healthy community".[27]

Research, that is non-therapeutic, ought to be based upon a minimum risk/maximum benefit standard. Therefore, although "incompetent" subjects, ie. newborns may become research subjects, only minimal types of intrusions are possible. This satisfies Tillich's admonition that personhood in its dignity and integrity cannot be violated' It must be respected and reverenced! Thus within the sanctioning process of non-therapeutic research, safeguards are essential to block the possibility of abuse or misuse of persons! Ethics Review Boards need to carefully determine the ethical integrity in research proposals before approval and must also maintain a constant monitoring process throughout the study! Parents and family members should be encouraged to be "present during all stages of the research, and be involved in as much as possible."[28] (In this regard see Chapter IV concerning the minimum risk/maximum benefit ratio.)

(ii) The M.R.C. of Canada Guidelines 1987: A Reflection of the Eve Decision in Respect To The "Best Interests" Standard

The Supreme Court of Canada has adopted the traditional interpretation of the parens patriae power. The court unequivocally stated that its powers are protective powers and limited to those who cannot care for themselves. "The courts have frequently stated that it is to be exercised in the 'best interests' of the protected person, or again, for his or her 'benefit' or 'welfare'."[29]

The M.R.C. Guidelines reflect the Supreme Court of Canada's position with regard to the "best interests" standard. That is, if proposed research is deemed to be of no direct benefit to the child involved it is qualified as being "contentious".[30] Thus, some level of assent or consent is voluntarily required from the child in order to proceed with a non-therapeutic intervention. "...much centres upon the level of development of the individual child and the surrounding circumstances..."[31]

Moreover, the above statement does not refer to "incompetent" subjects who are children. In paragraph 5, section G 2(a) it states, "A concept has developed that a child incapable of giving legally and ethically acceptable consent may give an 'assent'..."[32]

In this illustration the reference is to what the M.R.C. guidelines have defined as a "legally" incompetent child. However, firstly, the language is so imprecise that it is indeterminable whether this is in regard to non-therapeutic research or therapeutic. Secondly, some expression of autonomy either by "assent" or "consent" is required before any intervention may be applied! What is abundantly clear by its marked absence in the guidelines, is the fact that non-therapeutic possibilities are not extended to children who are unable to either consent or assent. These children it would seem would more clearly reflect the "incompetent" status!

Graham Chance has commented:

> The Bioethics Committee of the Canadian Paediatric Society, in a statement to be published concerning ethical guidelines for research involving children, states that 'the Committee believes strongly that it is unethical to exclude children from the benefits of research by dint of their inability to give personal consent' and that 'such an extension (of Re Eve) would not be in the interest of children in general and should be strongly opposed'."[33]

The Ontological Implications

The questions requiring answers here are, "Whose interests are being served?" or "Whose interests ought to be served?" Let us begin to answer the above by reflecting on the nature of our human reality. Given that one's personal existence is always that of a person who participates within a community (that is, every person is a part of the social context in which he lives) and conversely, that the social context participates in the life of that individual, then it seems absurd to maintain that the "best interests" standard may not also reflect the interests of the social or cultural order. The inclusion of the interests of the "other", beyond the mere protective, exclusive application made by the court in the case of Eve and which was adopted into the M.R.C. of Canada guidelines, is ontologically more sound to maintain.

Paul Tillich states:

> In polarity within individualization, participation underlies the category of relation as a basic ontological element. Without individualization nothing would exist to be related. Without participation the category of relation would have no basis in reality.[34]

Further he contends that "no individual exists without participation".[35] Thus, "Whose interests are being served?" In light of the Supreme Court of Canada's determination of the "best interests" standard and the M.R.C. of Canada's adoption of that same standard (re Guidelines 1987), it appears that both of the above maintain that the "incompetent's" "best interests" are being served through the definitive force of the standard. Wherein the incompetent is protectively guarded from any non-therapeutic interventions. In reality. in light of an ontological perspective, it is evident that only the interests of a limited definition of "best interests" is being served.

"Whose interests ought to be served?" In response to the second query, and in respect to a broader social scope and reality revealed in Paul Tillich's ontology, clearly it is to see that "best interests" considerations need to be extended to include the wider social context as well! It is to support the position presented by the Canadian Paediatric Society that views negatively the exclusion of "children from the possible benefits of research on the basis of their inability to give personal consent".[36] As has been noted every person can make a contribution irrespective of any standard of competency. This opportunity should not be denied for incompetent children. Furthermore, not only will they obtain overall social benefit from such non-therapeutic research, but as noted by the C.P.S., the child (ie. neonate) may someday benefit from the experience! This sacrifice may help to instill a sense of altruistic values and assist in the development of a social responsibility in children and parents... Furthermore, to repudiate non-therapeutic research with incompetent children, ie. newborns would not be in the interests of "children in general".[37] As social beings, our well-being is inextricably bound with the well-being of others. This concern and care for the "other" is therefore, in all our "best interests". Specifically in reference to children, such non-therapeutic research would greatly advance the body of medical knowledge that could indeed advance the prevention, prognosis and care of children in general! This cannot be repudiated if we are socially responsible!

Clearly Tillich's ontology affirms the position taken by the Canadian Paediatric Society The need is for clearly stated public policy guidelines in this regard. Hopefully these guidelines once established may be implemented and applied by the courts and the M.R.C. of Canada to reflect a more ontologically realistic standard of "best interests" which includes social interests!

(iii) The M.R.C. Of Canada Guidelines 1987: A reflection Of The Eve Decision In Respect To "Case Definition Of Health"

As noted previously, "health" has been defined by the Supreme Court of Canada in the "Eve" case as "mental as well as physical health".[38] Significant is the fact that the court resolved that any medical intervention under its parens patriae jurisdiction is restricted to promoting the physical and mental health of the individual "under the protection of the court".[39] "The discretion is to be exercised for the benefit of that person, not for that of others."[40]

The "Eve" case judgement was rendered with reference to the above noted definition of health. The conclusion of the court found that no evidence indicated "that failure to perform the operation would have any detrimental effect on Eve's physical and mental health".[41]

The "case definition of health" is directly related to the court's limited interpretation of the "best interests" test, which was determined to be applicable only for the benefit and protection of the person or persons under disability. "Health" therefore, was defined solely in regard to the two highly personalized categories of well-being, that of the physical and mental health of the person or persons under the court's protection. Thus, "health" as defined by the Supreme Court of Canada for the purposes of the "Eve" case does not have a social context or dimension! It is apparent that the Supreme Court of Canada has ruled that "incompetency" precludes therefore, any consideration of non-therapeutic interventions! Therefore, a preclusion also of any benefit to society from this mode of intervention. The above condition is the direct result of the court's unequivocal position that considerations of a social nature were beyond its legal jurisdiction. This repudiation of the Supreme Court of Canada upon legal grounds, of any social considerations and social interests is also reflected within the Medical Research Council of Canada's Guidelines 1987.

One observes by its marked absence in the M.R.C. Guidelines, the fact that non-therapeutic possibilities do not extend to children who are unable to either give consent or assent. Thus children who clearly reflect the "incompetent" status have not been given consideration in the guidelines. This is unconscionably flawed! Since these persons are the most vulnerable in our society, some clarity or precision was and is needed in the documentation. The deliberate avoidance of the critical issues involved here does not lead to a resolution or amelioration in the benefit of all concerned! The hope is that further and immediate public policy guidelines will be developed and incorporated to amend this situation in regard to those persons unable to give consent or assent!

The Ontological Implications

The questions that need to be answered here are, "What constitutes health?" and "What ought to be the future norm of health?"

In light of the Supreme Court of Canada's definition of health limited to "physical and mental health", it is evident that the court at least for the purposes of the "Eve" case, has determined that health is constituted of two highly personalized categories of well-being, that of the physical and the mental dimensions of health. The court's exclusion of any social considerations by definition and intent is inherently flawed. That is, there is a social reality that cannot be denied, a human-social context of reality that must be given consideration.

The court's exclusion of any social considerations has failed to acknowledge that our reality is such that "each individual is as well a social being" and as "social beings", our good, our flourishing (therefore, our best interests) is inextricably bound up with the well-being of others".[42] That is, with respect to an ethical perspective guided by the ontological reality, one cannot avoid the social issues and concerns when considering the individual in any holistic manner! This is what the court has done in the "Eve" case. Therefore, the case law decision needs to be reviewed for it is founded upon legal definitions that are limited and inadequate.

Thus a more fulfilling vision of what the future norm of health ought to include and affirm is, the "social dimension" of health as well. It is to encourage the development of public policy guidelines on how the social well-being of persons and the society in general can be promoted and how social concerns and interests can be given consideration, as an ongoing part of the process towards actualizing a more fulfilling definition of health. As has been demonstrated in this paper, in regard to the ontology ascribed to by Paul Tillich, our human reality of necessity is also a social reality and therefore, the press toward a more meaningful definition of health must include the social dimension! Thus it is evident that the definition of "health" applied by the Supreme Court of Canada and adopted in the M.R.C. of Canada's Guidelines 1987, is deficient. The Medical Research Council of Canada did not challenge the implications of the "Eve" case upon its guidelines but absorbed its tenor into its document.

One means whereby consideration for the interests of society can be endorsed is through the support of non-therapeutic research. A research directed toward the development of medical knowledge and the betterment of society in general notwithstanding benefits to the subject as well in many cases. (See in this chapter, "The Needs for Non-Therapeutic Research with Children", also V(i) Ontological Implications.) The wellness of a society is not only attributed to the therapeutic (treatment) possibilities available and applied but also to the constant improvements in health care applied to the society in general. Much of this preventative, progressive health care can be attributed to research and in no small part of this research, is non-therapeutic interventions.

Children, not only the ones which can give consent or assent, but newborns (neonates) as well as the intellectually disabled are entitled to the benefit from improved health care as members of the social context! In converse, in order for this possibility to exist, these children identified as "incompetents" must be allowed to participate in non-therapeutic research! This, the designers of the M.R.C. Guidelines 1987, failed to do, no doubt having negatively and cautiously interpreted the implications of the "Eve" case for limited non-therapeutic research possibilities. It is lamentable that the legal community has weighed so heavily in setting forth guidelines that pertain to the ethics of medical research. It is a sincere hope that in the future the medical community will be better represented in forthcoming processes!

The need in the near future is for the public policy makers to set forth in clear statements based upon solid ethical foundations, a more inclusive M.R.C. of Canada Guidelines for research. Such guidelines must be ontologically sound, that is, able to reflect the nature of our being as of necessity a social reality and to encourage and instill the need for social responsibility. This will include a definition of health that at least includes a social dimension as well. As Graham Chance cautions, "the M.R.C. Guidelines could result in minimal opportunities for children to benefit from research, especially non-therapeutic research. The implications of such restrictions in research in children are serious".[43] Indeed the more fulfilled vision of medical research is to maximize and not minimize the benefits of research for children and this implies non-therapeutic research. Graham Chance suggests that the designers of the M.R.C. Guidelines make reference to the policy recommendations developed in the United Kingdom and the United States,[44] in order to more effectively ameliorate the present deficiencies in the Canadian research guidelines. This may indeed lead to an even further development of a more meaningful norm for the definition of health. One as we have stated should include the social dimension and this in turn will legitimate non-therapeutic research possibilities.

Summary

In order to maximize the benefits and the well-being of children in general, paediatric research is essential which includes non-therapeutic research.

Ontology informs us that we are social beings who participate in a social reality and existence. Thus, the socio-communal interests and considerations are valid. In this regard parental, guardian or proxy consent is valid consent. Further, public policy guidelines are needed to balance the interests of individuals and society. Moreover, in order that children may benefit from research, it is essential that children also participate in research including non-therapeutic investigations with "incompetent" subjects.

The implications of the "Eve" case for non-therapeutic research with children in respect to "proxy consent", conflicts with the ontological perspective. It is evident that the M.R.C. Guidelines therefore need some amending to come into line with these determinations.

Ontology also acknowledges that the present definition of the "best interests" standard, limited to the benefit of the ones under court protection is an excessively narrow perspective. One that misrepresents the social reality wherein social well-being and interests are to be served as well as the interests of individuals. A social existence not only affirms personal rights but also a social responsibility. Denying the incompetent the opportunities to participate in non-therapeutic research on the basis of the "best interests" standard is not therefore justifiable. If, as ontology makes vividly clear we are social beings and our well-being is inextricably bound to others because of this fact, then it is imperative that we begin to cultivate and instill a social responsibility! Indeed, this is essential if the general social well-being is to be promoted. Specifically the well-being of children in general will be enhanced by non-therapeutic research. This can only be possible when other children participate in research studies including non-therapeutic ones. "Best interests" considerations, therefore, must be a double-edged proposition. It must also allow "incompetent" subjects who are children to participate in order to enhance their present and future well-being!

The implications of the "Eve" case for non-therapeutic research with children in respect to the "best interests" standard, conflicts with the ontological perspective. It is evident that the M.R.C. Guidelines here also need some amending. That is, to state clearly that incompetent subjects who are children, must also be allowed to participate in non-therapeutic research to enhance the well-being of children, theirs and others.

Ontology further informs us that any holistic definition of health must include as well the social dimension. The social aspect of health is both in reference to enhancing the individual's as well as society's well-being. The ongoing process to more fully define a norm for health at this time includes the social dimension. Thus it entails support for non-therapeutic research to promote and enhance the general benefits to society and the well-being of others. This of necessity involves the participation of "incompetent" subjects who are children.

The implications of the "Eve" case for non-therapeutic research with children in respect to the "case definition of health", conflicts with the ontological perspective. Health, as defined by the Court simply stated "physical and mental health". It is apparent that the M.R.C. Guidelines here also adopted this limited definition of health, since it did not affirm the possibility of any non-therapeutic research with incompetent subjects, wherein social benefits are enhanced as well as benefits to the subjects in many cases. The M.R.C. Guidelines conflicts with the ontological perspective and is in need of some amending. That is to state clearly that the social dimension is an important aspect within the definition of health. This can be implicitly demonstrated by stating that incompetent subjects, who are children can participate in non-therapeutic research to enhance the well-being of children, their's and other's.

This paper is asking for the review of the "Eve" case and its implications for non-therapeutic research with incompetent children. The imprecision and deficiencies in the legal interpretations of the 3 key issues under consideration substantiate that request. This also will mean that amendments are necessary to the M.R.C. of Canada Guidelines 1987 in this regard. Moreover, there is a great need for public policy development to inform the above and instill a social responsibility!

Conclusion

The Supreme Court of Canada's decision in the Eve v. Mrs. "E." case was rendered on the basis of a number of key issues and the legal interpretations established upon them. Three issues from that case have been the focus of this paper (1) proxy consent (2) best interests and (3) the case definition of health.

This paper has rejected the legal arguments put forth with regard to each of the above-mentioned issues from an ethical perspective. This method has been described as a developmental method of ethics, since it is rooted within the ontology ascribed to by Paul Tillich et al.

Furthermore, this paper has suggested ethical solutions to the ethical dilemmas resulting from the legal determinations in respect to the above-mentioned 3 focus issues.

Re Eve also has wide ranging implications (a situation wherein the case law is applied to new contexts). One such context is in regard to the Medical Research Council of Canada's "Guidelines on Research Involving Human Subjects 1987". Specifically the guidelines in respect to the implications of Re Eve for non-therapeutic research with "incompetent" children. Here, it was noted the M.R.C. Guidelines adopted into its text, those legal determinations applied by the Supreme Court of Canada in re Eve. Once again, in light of the ontological perspectives contained herein, these arguments have been refuted as inadequate as well.

Thus in light of the above process and investigation contained within the bounds of this paper three recommendations are made:

1) This paper contends that it has rejected upon ethical grounds the legal arguments put forth by The Supreme Court of Canada in respect to the 3 focus issues under consideration herein: proxy consent, best interests standard and the case definition of health. Thus, it has of necessity called into question the validity of the case law itself and therefore, requests for its review.

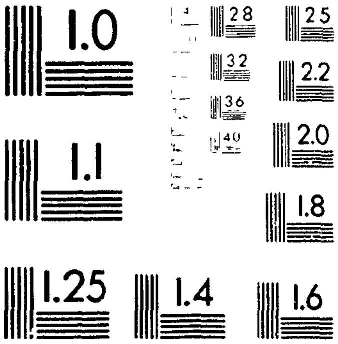
2) Amendments to the Medical Research Council of Canada Guidelines are also in order since the guidelines have respected the decision rendered in re Eve and had thus adjusted its text in accord with its tenor. Changes are being asked for here in regard to the G 2(a) "Research Involving Children" specifically as it

pertains to non-therapeutic research involving "incompetent" children. The amendments ought to include the participation of "incompetent" children in minimum risk non-therapeutic research through appropriate proxy consent.

3) This paper requests and encourages the process toward developing meaningful public policy guidelines that will be ontologically-sound (that is able to reflect the nature of our being as of necessity a social reality) and will instill a balance between personal rights and social responsibility.

Finally, from an ethical point of view, the present legal solution is unacceptable!

3 OF/DE 3



NOTES TO CHAPTER V

1. Pearn, John, "A classification of clinical paediatric research with analysis of related ethical themes," Journal of Medical Ethics, 1987, 13 26-30 at p. 26.

2. Pearn, John, at p. 26.

3. Pearn, John, at p. 26.

4. Pearn, John, at p. 28.

5. Pearn, John, at p. 28.

6. Pearn, John, at p. 28.

7. Pearn, John, at p. 29.

8. Pearn, John, at p. 29.

9. Pearn, John, at p. 30.
The five themes of research mentioned in Pearn's article are: 1) Preventative 2) Curative 3) Research to alleviate symptoms 4) Research to establish norms and baselines and 5) Curiosity research, p. 26-30

10. Redmon, Robert B., "How children can be respected as 'ends' yet still be used as subjects in non-therapeutic research," Journal of Medical Ethics, 1986, 12, 77-82, p. 79.

11. Chance, Graham, "M.R.C. Guidelines On Research Involving Human Subjects 1987: Comments In Regard To Research On Children," U.P. submitted to The University of Western Ontario Review Board For Health Sciences Research Involving Human Subjects Sub-committee, 1988, p. 1.

12. Chance, Graham, at p. 1.

13. Chance, Graham, at p. 1-2.

14. Chance, Graham, at p. 2.

15. Chance, Graham, at p. 2.

16. Solomon, Robert, "Eve v. Mrs. 'E.'", Westminster Affairs.

17. The M.R.C. (Medical Research Council of Canada) is a major research governing and funding body in Canada.

> The Medical Research Council holds that there are three levels of responsibility in the maintenance of ethical standards in human experimentation: the investigator himself, the institution in which he works and Council... Council has, in addition, an overriding responsibility that requires it to be assured that the responsibilities of the other two parties have been properly discharged. Council has no desire to dictate in detail mechanisms to be used and procedures to be followed by others but it must be content...that appropriate ethical assessments have been carried out. These circumstances require that Council set guidelines within which universities and investigators can discharge their responsibilities.

Medical Research Council of Canada, "Ethics in human experimentation," Report #6, Ottawa: Minister of Supply & Services Canada, 1978, introduction.

18. Guide M.R.C. of Canada, "Guidelines on Research Involving Human Subjects," Ottawa: Minister of Supply and Services Canada, 1987, p. 29.

19. M.R.C. Guidelines, 1987, at p. 29.

20. Redmon, Robert, at p. 81.

21 McCormick, Richard, at p. 212-13. See quote 68 Chapter IV.

22. Gaylin. Willard, at p. 37.

23. Hauerwas, Stanley, Suffering Presence, Theological Reflections on Medicine, the Mentally Handicapped and the Church, Notre Dame: University of Notre Dame Press, 1986, p. 125.

24. Hauerwas, Stanley, at p. 134.

25. Hauerwas, Stanley, at p. 137.

26. Hauerwas, Stanley, at p. 137.

27. Hauerwas, Stanley, at p. 137.

28. Redmon, Robert, at p. 81.

29. [1986] 2 S.C.R. 388, at 426.

30. M.R.C. of Canada, 1987, at p. 29.

31. M.R.C. of Canada, 1987, at p. 29.

32. M.R.C. of Canada, 1987, at p. 29.

33. Chance, Graham, at p. 3.

34. Tillich, Paul, Systematic Theology I, Reason and Revelation Being and God, Chicago: The University of Chicago Press, 1965, p. 177.

35. Tillich, Paul, Systematic Theology I, at p 176.

36. Chance, Graham. at p. 3.

37. Chance, Graham. at p. 3.

38. [1986] 2 S.C.R. 388, at 427.

39. [1986] 2 S.C.R. 388, at 427.

40. [1986] 2 S.C.R. 388, at 427.

41. [1986] 2 S.C.R. 388, at 427.

42. McCormick, Richard, at p. 212.

43. Chance, Graham, at p 3.

44. In the U.K. see the recommendations research involving children in Nicholson, Richard H. (ed.), Medical Research With Children: Ethics, Law and Practice: The Report of an Institute Medical Ethics Working Group on the Ethics of

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