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The moral difference between premature infants and neonates compared to older patients

par

Dr Annie Janvier

Département des études supérieures,
Faculté de Médecine

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The moral difference between premature infants and neonates compared to older patients

présentée par:
Dr Annie Janvier

A été supervisée par les personnes suivantes :

Président rapporteur – Daniel Lajeunesse
Directeur de recherche – Guy Bourgeault
Codirecteur de recherche – William Meadow
Membre du jury – Louis Beaumier
Examinatrice externe – Saroj Saigal
Représentant du doyen – Daniel Lajeunesse

RÉSUMÉ EN FRANÇAIS ET MOTS CLEFS

En ce qui concerne l'admission aux soins intensifs de patients avec handicaps sévères potentiels ou une survie prédite très diminuée, les attitudes et opinions divergent. Cette thèse confirme que les soignants ne sont pas bien informés sur le devenir des prématurés et ne considèrent pas les nouveau-nés de la même manière que les patients plus vieux.

Huit scénarios de patients critiques, incompétents, tous avec des séquelles neurologiques potentielles importantes, ont été présentés à des médecins et à des étudiants en médicine, droit, anthropologie et bioéthique. Les répondants devaient estimer pour chaque scénario si l'admission aux soins intensifs était dans le meilleur intérêt de chaque patient, s'ils interviendraient, puis s'ils accepteraient une requête familiale de ne pas intervenir. Les patients aux deux pôles de la vie avaient moins d'estimations de meilleur intérêt et plus d'acceptation de refus d'intervention. De plus, les estimations de meilleur intérêt n'étaient pas reliées à la survie ni au handicap potentiel. Les interventions pour le nouveau-né étaient désirées moins souvent que pour les individus plus vieux, même ceux avec un devenir beaucoup plus sombre. Afin de comparer directement la valeur de la vie des huit patients, les répondants devaient indiquer dans quel ordre ils soigneraient les patients s'ils arrivaient à l'urgence tous en même temps. Le prématuré fut placé au septième rang, le bébé à terme au cinquième. La survie, les années potentielles de vie gagnées et le handicap présent ou futur n'étaient pas associés au rang.

La valeur de la vie des nouveau-nés est moins que peut ne l'être prédite à l'aide de données médicales objectives. Des recommandations de sociétés académiques pédiatriques se penchent sur la prise de décision en ce qui concerne les prématurissimes. Celles-ci mettent l'emphase sur les choix parentaux et sur le devenir des patients. Ces recommandations officielles justifient l'intervention optionnelle pour ces patients par leur survie et le devenir à long terme. Des statistiques de devenir similaires ne justifieraient pas une telle approche chez des patients plus vieux. Pourquoi se sent-on moins obligé d'intervenir pour les nouveau-nés en difficulté? Met-on les nouveau-nés dans une catégorie morale différente, voire même inférieure? Cette question est explorée d'un angle légal et éthique et plusieurs avenues sont explorées: du statut de personne, au choix reproducteurs, aux enfants « précieux », et à des facteurs liés à l'anthropologie et l'évolution.

MOTS CLEFS

Nouveau-nés, prématurité, néonatologie, pédiatrie, soins intensifs néonatals, bioéthique, soins intensifs, valeur de la vie, principe du meilleur intérêt, qualité de vie, statut de personne, prédictions, incertitude, devenir à long terme, handicap, patients incompétents, énoncé de principe, allocation des ressources, opinions, perceptions, éthique substitutive, dévaluation, légalité de la naissance, opinions, perceptions, retrait d'intervention.

ENGLISH SUMMARY AND KEY WORDS

Opinions and attitudes diverge when it comes to admitting patients with potential severe neurological handicaps or extremely diminished lifespan to intensive care units. The thesis confirms that caregivers are not well informed of outcomes of preterm infants, and that they do not consider neonates in the same way as older patients.

Eight scenarios of critical incompetent patients, all with potential neurologic sequelae were presented to physicians and to students in law, medicine, bioethics, and anthropology. Assessments of whether intervention was in the best interests of a patient were not closely related to survival, nor to disability. Intervention for newborn infants was desired much less frequently than for older individuals, even some with much worse predicted outcomes. Accepting a family's refusal of intervention was much more common for the very old and the very young. Respondents were invited to directly compare the value of patients' lives by giving the order they would resuscitate the patients, were they to all arrive at the same time. The premature infant was ranked 7th, the term infant 5th. Survival, the potential life years gained, and / or impairment (or potential for) were not associated with decision-making. The value placed on the life of newborns is less than expected by any objective medical data. Specific policies regarding decision-making for extreme preterm infants exist in many countries and are often directive, focusing on parental choice and expected outcomes. Furthermore, the recommendations often state survival and disabilities as reasons for optional intervention, although such outcome statistics would not justify similar approaches in older populations. Why do we feel less obligated to treat imperilled neonates? Do we put newborns in a special and lesser moral category? This question is explored from a legal and ethical perspective and several hypotheses are offered, pertaining to personhood, reproductive choices, "precious children", and probable evolutionary and anthropological factor.

KEY WORDS

Neonates, Prematurity, Neonatology, Pediatrics, Neonatal intensive care units, bioethics, intensive care units, value of life, best interest principle, quality of life, personhood, predicting outcomes, survival, disabilities, uncertainty, incompetent patients, policy statements, resource allocation, opinions, perceptions, devaluation, legality of birth, withholding and withdrawal of intervention, substitutive ethics, "qualitative fieldwork".

SHORT SUMMARY

Opinions and attitudes diverge when it comes to admitting patients with potential severe neurological handicaps or extremely diminished lifespan to intensive care units. The thesis confirms that caregivers are not well informed of outcomes of preterm infants, and that they do not consider them like older patients.

Eight scenarios of critical incompetent patients, all with potential neurologic sequelae were presented to physicians and to students in different disciplines. Assessments of whether intervention was in the best interests of a patient were not closely related to survival, nor to disability. Interventions for newborns were desired much less frequently than for older individuals, even some with much worse predicted outcomes. Accepting a family's refusal of intervention was much more common for neonates. Respondents were asked to rank patients: the preterm was 7th, the term infant 5th. Survival, potential life years gained, and / or impairment (or potential for) were not associated with ranking. The value placed on the life of newborns is less than expected by any objective medical data. Specific policies regarding decision-making for extreme preterms state survival and disabilities as reasons for optional intervention, although such outcome statistics would not justify similar approaches in older populations. Why do we feel less obligated to treat imperilled neonates? Do we put newborns in a special and lesser moral category? This question is explored from a legal and ethical perspective and several hypotheses are offered, pertaining to personhood, reproductive choices, "precious children", and probable evolutionary and anthropological factors.

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LIST OF ABBREVIATIONS

AAP: American Academy of Pediatrics
ALL: Acute lymphoblastic leukemia
AML: Acute myeloblastic leukemia
BW: Birth Weight
CCQ: civil Code of Quebec
CNN: Canadian Neonatal Network
CNS: Central Nervous System
CPR: Cardio Pulmonary Resuscitation
CPS: Canadian Pediatric Society
ELBW: Extremely Low Birth Weight
ER: Emergency Room
GA: Gestational Age
GBM: Glioblastoma Multiformis
HMD: Hyaline Membrane Disease
ICU: Intensive care Unit
IQ: Intellectual Quotient
IRB: Institutional Review Boards
IVF: *In Vitro* Fertilization
MVA: Motor Vehicle Accidents
NICU: Neonatal Intensive Care Unit
NRP: Neonatal Resuscitation Program
PICU: Pediatric Intensive Care Unit
PVS: Persistent Vegetative State
QOL: Quality of life
QALY: Quality adjusted life years
RDS: Respiratory Distress Syndrome
SPR: Society for Paediatric Research
USA: United States of America

À la mémoire de mon père, Claude Janvier.
Sa curiosité, sa spontanéité, son originalité, son intolérance envers la médiocrité, sa perspicacité, son dépassement de soi et sa constante remise en question des normes et des « vérités non contestées» ont été et seront toujours une inspiration pour moi.

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LIST OF ARTICLES, FIGURES AND TABLES

The table below includes all the figure and tables included in the thesis. Because most of the figures are in published articles, the page of the article, and the corresponding page of the thesis are indicated in the table. The 5 articles are listed below this table.

LIST OF ARTICLES

Article 1: Annie Janvier, Sophie Nadeau, Marianne Deschênes, Elise Couture and Keith J Barrington. Moral distress in caregivers: an NICU experience. J Perinatology; 27: p 203-208.

Article 2: Annie Janvier, John Lantos, Marianne Deschênes, Elise Couture, Sophie Nadeau, Keith J Barrington. What if they knew? Acta Paediatrica (2008) 97: p276-79.

Article 3: Annie Janvier, Isabelle Leblanc and Keith J Barrington. The Best Interest standard is not applied for neonatal resuscitation decisions. Pediatrics, vol 121, Number 5, May 2008, p:1-7 (Galleys included in thesis).

Article 4: Annie Janvier, Isabelle Leblanc and Keith J Barrington. Nobody likes premies. Accepted by J Perinatology November 1st 2007, in press, to be published May 2008.

Article 5: Annie Janvier, Karen Bauer and John Lantos. Are newborns morally different from older children? Theoretical Medicine and Bioethics (2007) 28:413-425.

INTRODUCTION

At the moment of birth a foetus becomes a baby. This instantaneous transition from intrauterine to extrauterine life has enormous moral and legal implications. In Canada, the foetus has almost no rights in utero, maternal autonomy being paramount.[1] The foetuses only rights are to inherit, if born alive, or to sue for avoidable insults that may have been experienced during the pregnancy.[2] On the other hand, the foetus has no right to life. Indeed, abortion is not a crime in Canada *(R. v. Morgentaler)* and, moreover, a father cannot legally prevent the abortion of the foetus by the woman carrying his baby (*Tremblay v. Daigle*). If a foetus dies *in utero* from professional negligence (*Sullivan and LeMay v. The Queen*), or because of battery to the woman, the person causing the injury can be prosecuted for the injury to the woman, but cannot be charged with murder nor homicide, because the foetus (even past the expected delivery date) is not considered to be a person.[3] At the moment of birth, as soon as the shoulders have exited the birth canal, the baby becomes a full-fledged citizen, endowed with legal rights that should be no different from any other citizen. In the medical context, these rights are said to be identical to those of any other vulnerable incompetent patient who lacks decision-making capacity. Competent patients usually make life and death decisions for themselves (autonomy). For incompetent patients the surrogate (often the family) has to decide. If the patient had not previously expressed any preferences, they have to intervene according to their perception of the patient's best interest. Neonates are naturally incompetent and when they are sick, the decision-making in life and death situations can be difficult. One has to judge what is the preferable course of action for a baby, despite all the uncertainties involved. Responsibility for decision-making in this population is usually given to the baby's parents, who are generally considered to be the best to judge what is in their child's best interest, and what are acceptable risks and benefits of interventions.

The Neonatal Resuscitation Program (NRP) textbook, which is the standard neonatal resuscitation text used in North America and many other parts of the world, states: "The ethical principles regarding resuscitation of newborns should be no different from those followed in resuscitating an older child or adult."[4] This statement notwithstanding, current practice does not seem to be consistent with the idea that the principles are no different. There is clear evidence of categorical separation of the ethical assessments associated with treatment or non-treatment decisions for newborns from similar decisions for older children or adults. For example, the 1983 President's Commission on Bioethical Issues devoted a special section of its report to dilemmas surrounding the treatment of newborns, thus distinguishing these dilemmas from the more general dilemmas addressed in its discussion of withholding and withdrawing life-sustaining treatment in adults.[5] Such distinctions, though well intentioned, have reified the dichotomy that has isolated newborns from the rest of the population, kept them in a separate moral universe, and allowed decisions to be made upon a different basis than those made for any other age group.

This PhD deals with the moral difference between the neonate and older patients through articles in clinical ethics, more particularly in reflective bioethics. The introduction that precedes the articles will have three main sections: (1) the recent birth and evolution of bioethics, clinical ethics and reflective bioethics; (2) the birth and evolution of neonatology; (3) a brief overview of ethical issues and values in neonatology. This thesis will present five articles, all published or accepted for publication. In the four articles accepted or published in scientific journals, there is an abstract, an introduction with a literature review, methods used for the research, results, and a discussion. Therefore, there will not be an introduction and methodology preceding every article. Instead, a short review of the methods used will be presented.

This thesis has three parts, (1) the perception and opinions of caregivers about sick neonates; (2) the principle of best interest, the value of life of neonates and how they can influence decision-making; (3) the reasons behind the relative devaluation of neonates. Also, before each of the three parts, a short text will introduce the articles and place them in context.

The first part of the thesis will analyze the perceptions and opinions of caregivers regarding critically ill neonates. Are the caregivers, involved in obtaining informed consent for interventions for premature infants, themselves well informed? The prior literature suggested they were often misinformed and pessimistic regarding outcomes of premature infants. The study presented goes one step further to ask: what would caregivers do were they adequately informed, would their decision-making be different?

We also investigated how this misinformation was related to ethical confrontation, a form of moral distress experienced by caregivers in the Neonatal Intensive Care Unit (NICU).

The second part of the thesis has two articles presenting the results of another study. The first section of this study was designed to verify if the best interest principle was used for decision-making regarding neonates. The second section investigated what individuals would do in situations of scarcity. For health care decisions, a physician is expected to act in the conflicting roles of doing the best for individual patients, while also doing the best for society by using resources judiciously. The caregiver might be convinced that Intensive Care Unit (ICU) admission for a lung cancer patient is in his best interest, while at the same time realize that some might judge this money better used invested in smoking prevention programs. Patient selection for scarce resources demands that we place a relative value on human lives. Likelihood of survival, handicap, and age might all influence which patient will be given the highest priority. We studied how physicians and students (in medicine, anthropology, bioethics and law) took decisions of resource allocation for eight hypothetical patients, two of them being newborn infants.

The third part presents some of the hypotheses that could explain the devaluation of neonates: from personhood to the sense of duty, to reproductive decision-making, to familial distributive justice and the "replaceability factor" of neonates, or their possible interchangeability. Throughout the articles presented in this thesis, inconsistencies behind some of the principles we use will be pointed out. In turn, these inconsistencies eventually affect our decision-making. A general discussion and conclusion will explore the scientific and ethical validity of policies that specify which neonatal patients should receive or not receive resuscitation. Many professional societies and national commissions have developed policies or guidelines about the treatment of preterm infants. These blanket policies are generally based on gestational age. No other area of medicine has been as focused upon this or as specific in its delineation of treatment limitations. Instead, in other areas, guidelines for resuscitation are quite broad and general, with much room for clinical judgment and professional discretion. Why is neonatal bioethics different in this area? This thesis will come to a conclusion that neonates, and particularly premature infants are devalued compared to older individuals, and that they should perhaps be considered to be morally different.

Medical developments have changed the way we respond to diseases of neonates, to their illnesses, and to the pain and suffering of their parents; not only as physicians, but also as a society. We have to question if we are responding adequately to these new challenges. If we can recognize the biases we have and the true reasoning behind our decision-making, only then can we, and the people whom we train, be empowered to respond appropriately and consistently to the real needs of sick neonates and their families.

Bioethics, clinical ethics and reflective bioethics

Scientific research and the resulting discoveries have produced substantial social benefits, such as decreased infant mortality and increased longevity. Scientific research has also uncovered new dilemmas which pose troubling ethical questions. In the 1960s, revelations of abuses of human subjects in biomedical experiments were made public. These medical experiments had mostly occurred during the Second World War. During the Nuremberg Trials, the Nuremberg code was erected as a set of standards for clinicians and scientists to follow when enrolling patients in medical research. The Nuremberg code is often considered as the origin of modern bioethics. Modern bioethics was indeed initially mainly research ethics. Research ethics continued to evolve following public attention that was drawn to unethical research practices. Unethical research practices and the desire to regulate medical research led to the Belmont Report in 1979, the establishment of the National Human Investigation Board in the US, and the requirement for establishment of Institutional Review Boards (IRB) across North America. All of these institutions and reports identified basic ethical principles that should underlie the conduct of clinical studies involving human subjects, and also developed guidelines to be followed. For example, in the Belmont report, published in 1979, a statement of basic ethical principles to assist physicians in resolving the ethical problems surrounding research with human subjects is centred on the following three important principles: the respect for autonomy of individuals, beneficence, and justice. Modern bioethics was evolving.

With more and more scientific discoveries, and new challenges in public health and resource allocation, the needs for bioethics expanded. In addition to research ethics, which remained more normative, and ethics of health policy and clinical ethics developed. Since the early 1980s, many journals have been developed in the field of bioethics, in addition many degrees with a specialization in bioethics are now offered around the world. The current thesis is in the field of clinical ethics. At first, bioethics was mainly practiced and studied by theologians, philosophers and social scientists. Today, many bioethicists come from other backgrounds. The number of individuals with a professional background in health care has increased, and bioethics has become multidisciplinary. The epistemological question of the nature of bioethics remains under debate: is it a speciality of medicine, of philosophy, a field in itself? Who is an ethicist? Is an ethicist anybody who calculates the risk-benefit ratio and the consequences of his interventions for patients? Dr Lantos, a paediatrician and ethicist, summarizes the debate well: "The field of bioethics is defined; it is a fence-straddling field. Its very existence as an independent field suggests some deficiencies in the traditional systems of medical education. But it is not clear whether bioethics per se is an adequate response or whether studying philosophy, theology, sociology, anthropology or survey methodology can help us decide whether what a particular doctor does in a particular situation is right or wrong. It represents a first step."[6]

Clinical ethics is an applied field of bioethics, studying how judgments and moral values are applied to medical decisions. Mark Siegler is seen by many as being the father of clinical ethics. In 1984, the University of Chicago established the Centre for Clinical Medical Ethics devoted to this clinical specialty. This centre has trained more than 200 physicians and nurses, many of whom now direct programs all over North America. Now many universities and hospitals have bioethics degrees for the training of new clinical ethicists. As a discipline, medical ethics expresses its practical application in clinical settings. Clinical ethicists, generally caregivers who perform ethics consultations in clinical settings, have brought a more practical aspect to bioethics.

I was attracted to clinical ethics when I heard Dr Meadow, a neonatologist and also a clinical ethicist from The Center for Clinical Medical Ethics in Chicago give a talk at the Society for Pediatric Research (SPR) in 2002. For me, it was a revelation. Dr Meadow was doing exactly what I wanted to do: combining bioethics and medicine with an original approach to generate new insights into how physicians act, and how decisions should be made for vulnerable patients. In this thesis, the practice of medicine, paediatrics and neonatology were a source of questioning, and were fed in turn by my ethics curriculum throughout medical school, residency, neonatal fellowship and my research in bioethics. The bioethics I have aspired to do is in a field sometimes referred to as "reflective bioethics", which combines bioethics and medicine by pushing the analysis of clinical decisions further than with the application of moral theories. Dr Casarett and colleagues describe reflective bioethics as follows:

> *"(reflective bioethics is) Looking beyond narrowly circumscribed issues such as the distinction between ordinary and extraordinary means, right or wrong, or*

> *what constitutes informed consent, out to larger considerations of the cultural and medical contexts in which these individual discussions ought to be undertaken."*[7]

Clinical reflective bioethics, as pertaining to neonatology, does not study only dilemmas in this field, nor does it define decisions made by caregivers as being right or wrong, it analyzes how decisions are taken, in what context, and what influences these decisions. These analyses may unveil some biases caregivers have in the decision-making, and help describe where the difficulties are in taking those decisions.

The birth and evolution of neonatology

The birth of neonatology as a speciality paralleled in time that of modern bioethics. Even if human beings have been providing some medical care for newborn infants for centuries, neonatology is a recent speciality. The high infant mortality was recognized as a problem as early as the 1860s,[8] but improvements in the care of neonates and major decreases in mortality are rather recent. The first premature infant incubator was invented and marketed in 1898 by Dr. Joseph B. DeLee in Chicago, Illinois. In 1965, the first neonatal intensive care unit (NICU) was opened in New Haven, Connecticut, and in 1975, the subspecialty of neonatology was established by the American Board of Pediatrics.[8]

Before 1970s, babies that were even mildly premature would often die. Patrick Bouvier Kennedy, the son of the late US president John F Kennedy was born in 1963 at a gestational age (GA) of 35 weeks and died 2 days later. At that time, to be born 5 weeks early was a substantial risk. Patrick Kennedy's death from hyaline membrane disease (HMD) also called respiratory distress syndrome (RDS) was extremely publicized and helped spark new public awareness of prematurity and further research. This disease occurs when there is not enough surfactant in premature lungs. Our lungs produce surfactant. It helps to keep them open and prevents their collapse. Surfactant is usually produced by the lungs of neonates, but the amounts may be insufficient when they are premature. The 1960-80s brought a rapid evolution in neonatal care. Mechanical ventilators, also called respirators, allowed for survival of newborns that were more and more premature. Despite these advances many babies would die from HMD. HMD can be ameliorated and even prevented if mothers who are about to deliver prematurely receive betamethasone, a hormone that speeds the production of surfactant in the lungs of the baby before he is born. In the 1980s, the development of exogenous surfactant (from the lungs of cows or pigs), which can be instilled into the lungs of babies, drastically improved survival and decreased adverse outcomes. Since the 1990s, because of antenatal corticosteroids, mechanical ventilation and exogenous surfactant, babies born at 35 weeks almost never die, and long term outcomes are generally almost identical to term babies.

Neonatology is a subspecialty of paediatrics that focuses on the medical care of newborn infants who require intensive monitoring. Rather than focusing on a particular organ system, which is the case in most other specialities, neonatologists focus on the global care of newborns that require NICU admission. Many newborn babies are admitted to the NICU, the most common indication for admission being prematurity. In Canada, 7-8% of babies are born premature, with a gestational age (GA) of less than 37 weeks. Most premature babies in the NICU are only mildly premature, between 32 and 36 weeks gestation. The lower the GA, the fewer such infants there are. For example, in the NICU there are more infants born at 33-35 weeks than 30 weeks, fewer at 27 weeks, and still fewer at 24 weeks of GA. Extremely premature babies, with a gestation of less than 28 weeks or a weight of less than 1000 grams (also called Extremely Low Birth Weight babies, ELBW), comprise 0.8% of all deliveries and about 10% of NICU admissions. In modern NICUs, infants weighing 1000 grams or born at 27 weeks gestation have an approximately 90% chance of survival with the majority having normal neurological development.[9] Other babies admitted to the NICU can have congenital malformations requiring surgery, alternate modes of feeding or increased surveillance, yet others have birth asphyxia, suspected infections requiring antibiotics, or respiratory difficulties. Neonatology is a hospital-based speciality and NICU nurses are specifically trained to care for these vulnerable infants. The average length of stay of babies in one of our NICUs is 14 days, with some babies exceptionally staying for more than 4 months and other less than 24 hours.[10]

As in every academic speciality, some neonatologists pursue research to improve the care of neonates. Other neonatologists are specialized in the follow-up of babies that are particularly at risk. Neonatal follow-up is quite unique. There have until recently been no other specialities where patients at risk are systematically followed and assessed by the same department where they were admitted. Neonatal follow-up is a form of quality control: it better assesses the long term effects of health problems early and later in life and helps neonatologists understand the outcomes of the babies treated in the NICU. With the help of neonatal follow-up, neonatologists have found ways to improve outcomes, prevent some of the disabilities, and are better equipped to inform parents in the delivery room and the NICU.

Ethical issues in the NICU

As neonatal medicine has developed, clinical ethics has also become increasingly present in the healthcare environment. For more than 30 years, neonatal medicine has provided specialized and intensive care measures aimed at improving the health and survival of neonates. Because of many improvements in the way we care for these infants, a substantial reduction in infant mortality has occurred. Babies are more likely to survive and less likely to develop a handicap for each problem they encounter and at each GA. The rate of handicap or significant morbidity appears to have remained steady because, even if a lower proportion of babies survive with impairments, more babies survive. In fact, prematurity rates are continuing to increase. This is due to a constellation of factors: lower socio-economic status, increasing maternal age, pregnancies with multiple embryos created by artificial reproductive technologies, obesity, and many other factors that are increasing in our society. Although Canada has an increasing rate of preterm births, the United States of America (USA) retains the highest rate of industrialized countries with 12.5% in 2004.[11] One of the ethical issues in NICU is how to prevent babies from coming to the NICU in the first place. Global ethical issues, totally out of the scope of this thesis but extremely important, include the world wide infant mortality. While my thesis focuses on babies who are admitted to the NICU who are at elevated risk of later disabilities, many babies born in the world still die of benign infections, mild prematurity, and even malnutrition. This ongoing tragedy is beyond the scope of this thesis but merits considerable reflection and thought.

In countries in which medical technology is developing quickly, many ethical and moral questions arise at the same time as a new development is made or, all too often, afterwards. Knowledge regarding management of pregnancy and delivery has advanced such that the risks for the mothers and the infants are considerably reduced, but such knowledge brings about new questions. At what GA, birth weight (BW), or for what long-term outcomes should very sick newborn infants receive intervention? Do parents always have a choice when their newborn is at risk of handicap? Should they be entirely responsible for the decisions, or should others also be involved? What is the best way to take these critical decisions?

The rest of this introduction will present a brief overview of ethical issues and values in perinatal and neonatal care. It cannot be exhaustive and some areas might be only briefly covered. When a foetus or newborn infant is at high-risk the individuals involved in decision-making are the parents, the nurses, and the physicians: all are attempting to act in the best interests of the baby. Decision-making with regard to at-risk babies usually concerns three major categories of questions. Firstly, whether to intervene for a baby, whether the intervention should be stopped, and finally who should be primarily responsible for the decisions, and how. The health care workers are confronted with these decisions, which involve many values and principles. Decision making in neonatology is often complex, it does not simply consist of explaining the treatment options to a patient and then asking if they prefer one treatment to another. Frequently, in fact, the unborn patient is not even "present" at the moment these decisions are made.[12] At the moment of birth however, the foetus becomes a person and therefore a citizen with as much right to protection as other vulnerable patients. Even though the premature infant is endowed with these rights at birth, for some commentators such premature infants are still not considered to be entirely persons.[13,14] Legally, physicians need a patient's consent in order to care for them.[15] If the patient is incompetent a "legally authorized person" will take the decisions for them.[15] Babies, being naturally incompetent are generally in the care of their parents who take decisions for them, a process known as "substituted consent". Such substituted consent should be given in the best interest of incompetent patients. According to the standard of "best interests", the individual who is giving substituted consent must evaluate the different options in order to maximize the benefits of an intervention and minimize as much as possible the harm associated with it. The future quality of life of the patient will inevitably be evaluated in the decision-making process. It is assumed that parents are the best placed to know what is in the best interest of their children and will act accordingly. Except in an emergency situation, a court order is required in order to treat infants without parental consent. Ultimately, however, if the physician believes "that the designated surrogate threatens the patient's best interests, the decision should be overridden", such overriding of family decision-making has been supported in the courts.[16,17] Indeed if resuscitation is considered to be in any incompetent patient's best interest, and significant harm is caused by not intervening, refusal of care is generally not accepted, neither ethically nor legally.

A complicating factor for many of these decisions in neonatology is that failure to provide the medical care in question often leads to death. It is easier to make decisions or compromises about decisions which have less serious consequences compared to deciding between death on the one hand, or on the other hand, the risk of a life requiring multiple interventions and with potential long term disabilities, and furthermore, to make such a decision for an infant before or soon after it is born.

Values in NICU care

A. Vitalism: the value of life

The principle of personal integrity and the importance of the value of life require that life be respected for all human beings and that killing is not acceptable. One point of view regarding how these values impact on medical decision-making is that of the vitalists. For vitalists, life is the supreme value, and one cannot compare a life with handicap to an absence of life.[18] The principle of justice, related to the value of equality, is also extremely important for vitalists, in other words, all individuals have a right to life no matter what its nature, and must be protected against whosoever wishes to put that life in peril. Dr. Koop, Surgeon General of the United States during the Baby Doe period (see below), was a vitalist. For him, all human beings were created in the image of God and must be kept alive.[18] For vitalists, even individuals who are in a persistent vegetative state deserve to receive whatever treatment is required to keep them alive and even such a limited existence has value.

Paul Ramsay, in an article concerning the "slippery slope" was to some extent in favour of a vitalist vision for newborn infants, because, he stated, letting a baby die opened the door to horrible crimes. He compared the situation to the crimes of the Nazis, which started with little things and rapidly degenerated, "any boundaries preventing infanticide that can be fixed or preserved today are precious and should be cherished and strengthened, however non-rational they may be".[19] This argument can seem extreme, but other authors have evoked vitalist arguments that are more deserving of reflection. Burt felt that the population must have confidence in medicine and in physicians because they save lives and preserve health. The idea of leaving babies to die "because they are not normal" shook the population of the USA in the Baby Doe affair.[20] This baby, with Trisomy-21, died of malnutrition because the family refused a surgical intervention that was simple, commonplace and had few long-term complications. On the other hand, individuals with trisomy 21 have moderate to severe mental retardation, and this is what prompted the parent's request. The physicians accepted this request. Burt considered that it is essential to preserve the social image of physicians and as a result, it is in the best interests of the population as a whole to treat all newborn infants in order to preserve confidence and social peace.[20] Walter felt that judgments of value with regard to newborn infants who are at risk of long-term consequences in some way define our humanity.[21]

In their book Mixed Blessings: Intensive Care for Newborns, the sociologists Jeanne Guillemin and Lynn Holmstrom criticize intensive care nurseries because they are too vitalist.[22] According to them, decisions made are almost always in favour of life and are almost automatic. Parents are often similarly committed to the lives of their infants, which according to these authors, does not help, as they state: "parents' sheer determination coupled with their commitment to the survival of their infant also contributes to the aggressiveness of treatment in the NICU, it seems they also err on the side of over-treatment rather than under-treatment."[23] Dr Lantos, a world-renowned paediatrician and bioethicist, finds this lack of understanding of intensive care on the part of the sociologists bizarre; he writes in a criticism of the book "the authors don't explain why they think such a response by doctors and parents should be considered a bias rather than a moral commitment or a normal social response. This is a curious judgment for a social scientist to make, it is as if a social scientist would point out that parents are biased on the side of picking up their crying infants rather than letting them scream, or that lifeguards have a bias to rescue people who appear to be drowning".[24] The media also add to a vitalist image of the NICU, they are often sensationalist and biased. A good example of a sensationalist documentary is the film Médecine Sous Influence, where NICU physicians are painted as technology crazed vitalists and extremists who refuse to let go and experiment on neonatal victims. In fact, extreme vitalism is a feature neither of our health care system, nor of those working in intensive care. Evidence for this can be found in studies of the modes of death in NICUs, very few babies die during on-going cardiopulmonary resuscitation, the majority succumb because intensive care is withheld or withdrawn, which would not be allowed in a vitalist world-view.

Life is always sacred for vitalists, but what does it represent for them? With advances in medical technology issues have arisen which have forced a re-evaluation of what life is. With the advent of organ transplants, the concept of brain death emerged. An individual can thus be dead even if his heart continues to beat – at the time this was a new concept. But what about the human being with a persistent vegetative state able to survive without a respirator but with no ability to communicate? In the eyes of some, patients in persistent vegetative state are dead, even if they are not brain dead. For others, there is no obligation to treat if "there is inability to survive infancy, inability to survive without severe pain, and inability to participate, at least minimally, in human experience (capacity for interaction)".[25] For vitalists, the best interest of an infant is always to treat to extend life because even the most limited life is better than death.

B. Quality of life: the value of health

Healthcare workers in general promote the value of health with respect to the individual, which is to say they promote the quality of life and the relief of suffering. Quality of life judgments are based on an assessment of the value of the life of an individual, of its usefulness to them or others, and are essentially subjective.

Ramsay, a vitalist, writes that "a quality of life approach wrongly shifts the focus from whether the treatments are beneficial to patients to whether the patients' lives are beneficial to them", which opens the door to euthanasia which he condemns.[26] Beauchamp and Childress state that Down syndrome (Trisomy-21) is not a reason for letting a newborn die, even if the baby has malformations that put his life in danger.[27] As a result they come to the conclusion, that legally and morally "mental retardation is irrelevant in determining if treatment is in the patient's best interests. Proxies should not confuse quality of life with the value of the patient's life for others and they should not refuse treatment if it would be in conflict with a patient's best interests in order to avoid burdens to the family or costs to society".[28]

Several research studies have shown that parents of preterm infants, and the infants themselves when they are older, judge their quality of life to be much better than judgments made by health care workers.[29,30] Parents, both of full term infants, and of very premature babies, have a very different attitude to the treatment of extremely premature infants and a different judgement of the value of life with disabilities as opposed to death.[31] Healthcare workers in neonatal intensive care units are a group who are relatively homogeneous in terms of health and (lack of) disability and have a tendency to negatively judge disabilities and to undervalue the quality of life of preterm infants and their families.[31] Many studies have demonstrated that neonatologists underestimate the long-term outcome of premature infants and that nurses are even more pessimistic than physicians.[30,32,33] Dr. Saigal has performed numerous research projects on this subject and has demonstrated that healthcare workers are much less tolerant regarding the possibility of disability and its uncertainties. For them, for example, it is much more difficult to envision the life of an infant in a wheelchair or blind than it is for the parents.[34] In several studies, parents appear to be much more vitalist than healthcare workers.[29,30,31,34] Furthermore, parents of infants both premature and full term have very different perceptions to the health care workers; 64% of them were in agreement with the statement, "we should try to save all newborn infants independently of their birth weight", in comparison 6% of healthcare workers agreed with this statement.[30] Parents of premature infants, of handicapped preterm infants, and of infants born at term had identical responses.[30] In contrast, in one study, 71% of nurses and 36% of paediatricians considered that saving the lives of newborn babies with potential for severe disabilities was not ethical.[32]

If potential disability has limited influence for vitalists in terms of when to intervene, mortality should have some importance. On the other hand, mortality is not the only outcome considered in ethical decision-making for NICU physicians and parents. Also important are the burden of prolonged intensive care, and the risks of long-term disability, or of later death. 12-25% of babies born before 27 weeks gestational age will have major neurological or developmental disabilities: cerebral palsy (8-10%), deafness (3%), blindness (3%), and developmental retardation (10-20%); up to 50% will have behavioural or educational problems: hyperactivity, learning difficulties, dyslexia or behavioural problems.[35,36] Importantly, although survival increases drastically between 23 and 25 weeks, there is little independent effect of gestation on disability rate at these early gestations.[36,37,38,39]

We should also consider the severity of handicaps that are experienced by former preterm infants. Cognitive deficits are the most common, but are rarely severe - the mean Intellectual Quotient (IQ) of extremely premature infants being approximately 86, which is to say one standard deviation less than control infants. This can be compared to a mean IQ of 40.2 for adolescents who have Trisomy-21 and for whom consideration of their degree of handicap when making medical decisions is considered to be unethical (see the comment by Beauchamp and Childress above).[40] Motor dysfunction (cerebral palsy), although usually classified as a severe adverse outcome, may occur in up to 12% of very premature babies; however, the majority of babies with cerebral palsy are ambulant and have a good quality of life. Multiple disabilities, with a profound burden on an individual and their family, are devastating when they occur, but are infrequent and arise in less than 5-10% of babies born at less than 28 weeks.[36]

The principle of beneficence, that is, to do good to one's patients, is important for all healthcare workers, the rule of least harm is also important. Lantos has written on this subject, "The question is whether we can have the good without the bad, or if not, whether the current balance of benefits to burdens is worth it".[24] It is difficult to predict for those who take into account the quality of life, which is generally the case for those who work in neonatology: what life is worth being lived? How do we make a judgement of the value of future life of a baby in order to know if death would be in their best interests?

C. Autonomy

Autonomy is also a value that is important in our health care system. For Engelhardt, a philosopher, informed consent has become a legal formality, or even a ritual "grace before meals".[41] In our pluralist society, secular and post-modern, liberty, equality and security are important goals and only rare individuals are in disagreement with these objectives. On the other hand, there are many more disagreements about how to arrive at these objectives. There is a diversity of moral opinions and a multitude of ideas about what is the good. Beyond the limits of what is legal, imposed by society, there is for Engelhardt only one way to escape nihilism and to approach others in a manner which is not coercive, that is to respect the other and not to use their body without their consent, to respect their autonomy, their manner of thinking and of leading their lives, in all spheres and not only in the medical sphere. The respect of the other in their autonomy is also critical in order to establish a common secular ethics, "If we do not take this approach to grounding ethics then we will be lost in nihilism; there will be no way to ground a morality for moral strangers".[41] For Engelhardt, it is our human abilities that define us as humans and gives us the right to consider personhood as a moral status. For newborn infants, Engelhardt states they do not have the status of persons because they are not autonomous, thus substituted consent is vital for deciding treatments that they will receive.[14,42]

Thomasma, a physician and bioethicist, does not accept the autonomy model for patient-physician relationships, nor the contractual relationship that results from imposing this model, nor the fact that autonomy should be considered universal and supreme. Autonomy for Thomasma means self-determination.[43,44] There are important limits to self-determination for any sick person. According to him it is false to believe that sick persons are capable of exercising their autonomy as much as those who are in full health. According to him, caring for a patient implies attempting to return to them their autonomy. The vision of Thomasma is relevant to our discussions – parents of children in intensive care are also suffering and they often have difficulty in taking life and death decisions.[44]

According to feminist theories, autonomy is relational. Sherwin, a philosopher, described two different approaches, the facilitatory model and the adversarial model.[45] Facilitatory policies view the pregnant woman as wanting to give to her foetus or child the best possible environment, both having many common needs, with several obstacles which stand in the way of fulfilling them: poverty, dependence, and isolation. In contrast, the adversarial model seeks to control the pregnant woman or the newly delivered mother by viewing the foetus or child as an adversary who must be protected from his mother, with distinct interests.[46] Such policies act against the autonomy of the mother and will often question their competence, including attempting to force treatments on premature infants. As neonatologists, it is important to inform parents and help them come to the best decision for their children. On the other hand, as for any incompetent patient, it is also important for physicians to be the spokesperson for our "naturally incompetent" patients, and certain refusals of treatment are not acceptable, for example that of baby Doe.

The best interests of parents and the family might not always be identical with those of the child. The President's Commission, created in the U.S. to reflect the acceptable norms for ethical treatment of newborns, recognized the importance of families: "the impact of a decision on an incapacitated patient's loved ones may be taken into account in determining someone's best interests, for most people do have an important interest in the well-being of their families",[47] it seems that health care workers in neonatology do not only have the high-risk babies as patients, but also their parents. In reality, it is not rare to consider the best interests of the family; their suffering associated with intensive care is often considered. Parental suffering is included in the formula of debating the best interests of the baby, however, this has generally not been discussed in the literature regarding life and death decision making, but it seems to be that at times, parental suffering is more acute than that of the baby. This suffering is related to maternal guilt feelings, to the intolerable uncertainties encountered each day, to the threat of bad news, to the fear that the baby's life would have been meaningless if he or she should die, to the chronic sleep deprivation...etc. At times, the parents' emotional reserves and their resilience may be exhausted. Parents can become emotionally drained and when yet another crisis occurs, a request or acceptance for discontinuation of therapy may result from their suffering as much -or even at times more- as their baby's. The best interests of the patient and the best interests of their family may sometimes be confounded, indeed this may be unavoidable.

D. Value of equality (principle of justice)

The principle of distributive justice is also important for caregivers: in terms of costs there is a desire to do the most good for the largest number and to give medical care following principles of equality to all patients. When trying to do the best on a case-by-case basis posing questions, for example, about the resuscitation of an infant as if he or she were an isolated individual, we sometimes forget to regard the entirety of the patient's reality and our conclusions as a result can only be incomplete. Finding solutions to ethical issues must also on occasion require an analysis of health care policies and hospital facilities. Always trying to improve our efforts and do better than those who came before us, we now find it inconceivable that women and their foetuses died as a result of gestational diabetes not long ago, or that premature infants of 35 weeks of GA regularly died because there was so little to offer. But inequalities persist, even today premature infants born outside of tertiary care centres have a lower chance of surviving, in part because of the deficiencies of air transport. The absence of federal funding and legal or regulatory restrictions on assisted reproductive technologies are contributing to an epidemic of multiple gestations and are leading to an increase in the frequency of prematurity and disabilities. As mentioned above, many infants on this earth do not have the good fortune to be admitted to a neonatal intensive care unit and die of simple easily treatable illnesses or even hunger. These problems cry out for solutions.

Contradiction of values

It is clear that at times different values may be in conflict, for example, the supreme value of life in the sense of vitalism and the importance of a good quality of life can be in conflict. What quality of life is worse than death? Beneficence may be in conflict with parental autonomy or values of equality and justice. This "confrontation of values" can raise questions regarding the best interests for a child. For example it may be difficult for a caregiver to let a premature baby die because of the parents' wishes when another with a worse prognosis is admitted to the NICU for intensive support.

In our pluralist society, definitions of the best interests of a child are subjective. Walters describes four different possible positions which have been found in the literature regarding decision-making for sick neonates: respect for life, parental authority, best interests and personhood.[21] Some of these positions are limited, according to Walters, and when pushed to the extreme may not be consistent with the best interests of the infant.[7] A belief in the absolute value of life is in opposition to considerations of personhood: on one hand, an anencephalic infant may be considered to be a human being created in the image of God warranting all possible medical care, or on the other hand may be considered an acceptable case for infanticide. The principle of best interests is subjective. Walters developed another principle that of "proximate personhood" which according to him truly allows consideration of the best interests of the infant. He attempts to respond to the following question "what would I want if I were that baby?" that might appear to be a form of intellectual gymnastics - abstract and difficult - but it deserves to be further explored. Walters wrote "the issue is not essentially ambulation or whether or not the parent or the physician would want to live if inflicted with the anticipated handicap, but what the projected child/adult would desire (what would they want if they were the baby). Mature persons could make a projection of substitutive judgment".[21] This position appears to have some validity, especially in the context where a number of studies have shown that the quality of life of patients as determined by health professionals is clearly less than that as determined by patients themselves.[29,30,34] When different values and different conceptions of the best interests of an infant co-exist, it is often impossible to obtain any consensus regarding which is desirable or acceptable.

As health care workers we try as far as possible to respect the best interests of our small premature patients. It appears quite simple to make decisions for the most extreme cases: the baby who weighs 350 grams who has such a low chance of surviving and such a limited predicted existence that intensive care, even if it were technically possible, is generally not indicated. At the other extreme, the decision to admit an infant to the NICU who is mildly premature, but has a good chance of surviving with a good outcome, is easy to make. Between these two extremes, the light gray and the dark gray, we attempt to respect the best interests of families, which may not always be identical to those of their infants. By recognizing parental suffering and giving more support to families and health care workers we will be able to improve things for our families. It is also necessary to accept that uncertainty will always be an important aspect of neonatal intensive care, both for health care workers and for parents.

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METHODOLOGY

The research and scientific studies, presented as part of this PhD thesis, were performed using a questionnaire methodology. In the first four scientific articles presented in this thesis, the part entitled "Methods" is dedicated to explicitly describing how the questionnaire was distributed, filled, and statistically analyzed.

Below is an overview of how the research was performed using identified target groups. Also, the inherent limitations of questionnaire studies is discussed. When planning a questionnaire study, multiple questions need to be asked, in order to ensure that the methodology is adequate to address the hypotheses, and that there is no unnecessary replication of previous work. These questions relate to determining what is the precise goal of the study, whether this is a worthwhile goal, and has previous work already addressed the important issues? For example, the goal of the second questionnaire was to determine whether age, survival or risk of disability influence respondents as they make decisions regarding resuscitation. Opinions and attitudes towards resuscitation at different ages of life or for patients with potential brain injury or with very reduced lifespan diverge greatly. It is important to determine how these clinical decisions are made, and what influences them. The background to the questions and a relevant literature review will be covered in the introduction of the thesis and in each article. Good questionnaire studies need to be well planned in order to be valid, reliable and discriminating. I will take the second questionnaire and analyze how it was created, and how the selection of respondents, the data collection and the statistical evaluation were performed.

Creating the questionnaire study

This questionnaire study was created to examine what effect the age of the patient, potential for survival and predictions of disability had on resuscitation decisions. This could have been achieved by doing semi-structured interviews in an emergency room (ER). Because we wanted to compare a non-medical population, who do not take resuscitation decisions in ERs, to a medical population, we chose to do a questionnaire study, understanding the limitation of this approach. There were 2 small pilot studies to create this questionnaire. The first was done with 4 attending staff, 10 medical residents, 10 medical students, and 16 students in law, anthropology, bioethics and medicine.

We created 8 different scenarios of patients of different ages and asked the same questions following each patient:

1- Would you intubate, resuscitate and consult intensive care for admission?

2- If the parents ask you not to resuscitate, will you respect their decision?

3- Do you think intubating, resuscitating and consulting intensive care for admission is in the patient's best interest?

4- If it was your child and you had a few minutes to consider your decision, would you wish the physician to intubate, resuscitate and consult intensive care for admission?

5- If it was your sibling's child and you had time to think (not an emergency situation), and s/he asks for your opinion, would you recommend that the physician intubate, resuscitate and consult intensive care for admission?

1. Creating the 8 different patient scenarios

Five out of eight cases were paediatric, 3 cases were adults. All patients had different chronological ages. In the first pilot study, we had 12 cases, with 4 scenarios of patients with the same age and different outcomes (a neonate and an adult). Because we planned to administer the questionnaires during a group activity where a maximum number of respondents could be reached, and because most of these sessions are 1 to 2 hours, we wanted the questionnaire to take about 10-15 minutes to answer. We realized that the questionnaires were too long for the data collection we had planned after only 10 respondents (1st pilot study). In the context of questionnaire studies, it can be difficult to have an acceptable balance between how much information we want to find out, and how much sustained attention the respondent will have. We realized that we could not answer all the questions we had in mind in one questionnaire study. We therefore measured only one concept: that of patients all having different ages, and all needing immediate resuscitation. We also realized some students did not understand the patients' pathologies and modified them in order to make have 100% (n= 40) of individuals in the second pilot study have the desire / motivation to answer all questions in the questionnaire, and to understand 100% of the questions.

We created 8 patients of different ages, with 3 possible outcomes, all arriving in the ER incompetent, unstable, and in need of resuscitation. We planned to analyse answers from different scenarios and compared them to each other in order to investigate differences in answers from respondents. Ethical reasoning based on cases, often requiring the comparison of different cases is referred to as casuistry. In my opinion, if one takes a case and then compares it to another case identical in all aspects except one, casuistry can be pushed much further. I have called this form of casuistry "substitutive ethics" in every day clinical work. Indeed, by changing the patients' stories minimally, or by changing only one aspect of their presentation, one can find surprising answers and make caregivers realize their biases. It can thus be much easier to understand the way we make judgments, and the source of our own prejudices.

a. Patients with 50% survival and 50% normal outcome

In this study, I created 4 patients who had identical outcomes. The patients were a 24-week gestation premature who has just delivered, a baby just born at term with a known brain malformation, a 2 month-old with meningitis and a 50-y-old after a car accident. They all had 50% survival. If they survived, 50% would be without impairment, 25% mildly or moderately impaired, and 25% severely impaired. The outcomes were explicitly described after each case and before the series of questions were asked. The cases were designed to have realistic outcomes.

The survival rate, and the probabilities of long-term disability of the 24-week patient in our survey were designed to conservatively reflect the actual chances of an infant delivered at 24-weeks gestation in a Canadian tertiary care centre.[1,2,3,4,5,6,7] Indeed, in the Canadian Neonatal Network (CNN), in 2005, the survival rate of premature infants of 24 week gestational Age (GA) was 72% when they were born in tertiary care unit. On the other hand, most of these babies had prenatal steroids, which is never the case when a woman delivers rapidly in the ER. We opted for 50%, which was realistic and an even number. The outcome of babies born at 24 weeks of GA, when they survive, have been studied extensively in the neonatal follow-up literature, and are similar to those in our scenario.

The term infant initially was designed to have an AV malformation and have hemodynamic instability because of this. This case was long to describe and had clarity issues in out first pilot study, therefore, we used only the term (brain malformation) and used identical outcomes as the premature infant. Because there are less babies who have such malformations, it is usually hard to exactly pinpoint the outcomes they will have, but we thought those described were realistic, and so did the medical respondents.

We did a literature search to find other infants who could have outcomes who could be easily predicted. One of the cases we deleted was a child who had extensive trauma inflicted by his parents. This case, we realized, introduced several layers of decision making (police and judicial involvement for example) that we did not wish to address in this study. In contrast a purely "medical" problem such as septic meningitis in infancy was conceptually more similar to the previous cases, and in addition there are good studies about the outcomes of such infants. Unstable infants with group B streptococcal meningitis have similar outcomes to those described in the questionnaire. [8]

Because trauma and motor vehicle accidents (MVA) are frequent in older children and adults, there are many trauma scores used in the ER to predict patients' outcomes. The outcome for our 50 y old patient scenario was thus realistic[9].

b. **Patients with a 5% survival**

A second outcome category was created where patients had a very low survival. Two patients had 5% survival: a 14-y-old with acute myeloid leukemia with central nervous system (CNS) involvement with 20% risk of impairment and a 35-y-old with brain cancer with 100% risk of handicap with treatment. . We hypothesized a very low survival rate would influence respondents. Myeloid leukemias in general have a worse prognosis than Acute lymphoblastic leukemias (ALL), and there are many scientific follow-up studies about leukemias. Often there are cancerous cells in the cerebrospinal fluid (CSF) and patients need cranial irradiation, which can bring about some learning deficits. This scenario was scientifically plausible. Glioblastoma Multiformis (GBM) is a deadly brain cancer that has on average 5% survival. To survive, patients need to have a part of their brain removed and to undergo radiotherapy and chemotherapy. With such treatment, survival is 5% and intact survival is 0% because of the surgical procedure.

c. Patients with pre-existing disabilities

Two other patients were already disabled: a 7-y-old with multiple disabilities (cerebral palsy, deafness, learning disability, hyperactivity) with a new head trauma, an 80-y-old with dementia and a new stroke. Both were noted to have a 50% predicted survival and, if they survived, a 50% chance of having further impairment.

We created a scenario of a 7-year-old child who reflected some of the most severely impaired outcomes among ex premature infants. Withholding care or withdrawing care in neonatology is often done in order to avoid having survivors with such disabilities. Motor delay is the most common neurodevelopmental disability of ex premature infant, however, most children are ambulant, and the large majority have a good quality of life. Cognitive impairment is also common, but is rarely severe, with average levels being approximately one standard deviation below controls[10]. Multiple disabilities, with a profound burden on an individual and their family, are devastating when they occur, but are infrequent and arise in 5% of babies born at less than 28 weeks.[11] We created such a case -which would occur only in 5% of premature infants born at 24 week gestation, our other scenario- in order to investigate the relative importance of actual, real, proven, disability in comparison with the potential disability of the preterm infant. As specified in the MVA adult case, trauma score exist for children and adults, are frequently used, and the figures presented were scientifically plausible.

The geriatric case was a demented 80-y-old with a new stroke. In adults with a primary hemorrhagic stroke, the mortality is about 50% in the first 4 weeks, 56% of survivors have significant impairment, and more than 10% of the survivors require institutional care.[12] The case was created to reflect this.

2. Validation of the questionnaire

a. Pilot studies

Pilot studies were done with the same category of respondents that were chosen to answer the questionnaire. These respondents were: medical staff and residents, and students in medicine, anthropology, law, and bioethics. It was distributed and respondent were given 20 minutes to respond. The pilot study respondents were asked if they understood each scenario and questions, if they would answer all the questions, and if they thought the questionnaire needed to be changed, and if yes, how. The first version of the questionnaire had some clarity issues that were addressed, and was too long to keep the respondents interested.

The second pilot (n= 40) study, with fewer questions, showed that the questionnaire was clear, and that all respondents were motivated to answer it. We hypothesized that the neonates and the geriatric patient would have the smallest proportion of respondents estimating it was in their best interest to be resuscitated, that fewer respondents would be willing to intervene, and that conversely, more would be wiling to accept a family's request to withhold intensive care. The pilot studies suggested that this hypothesis may be correct. When we did the actual study, we were confident that the questions were clear to the respondents, and that they were likely to fill the questionnaire. The reliability of a questionnaire refers to the stability and repeatability of measures. The questionnaire produced consistent results under the same conditions in the 2 small pilot studies: the respondents of the 2 pilot studies (n=50) appeared to give fairly consistent results regarding the best interests of the geriatric patient and the neonates. By shortening the questionnaire, making it less multidimensional and focusing more on one concept, we made our questionnaire simpler to answer and more reliable.

b. Internal validity

The internal validity of a questionnaire concerns the validity of the results internal to the study and minimization of sources of bias. For laboratory experiments, internal validity is easy to achieve, but it is more difficult for questionnaire studies. In the case if this questionnaire for example, it would be internally valid if we measured what we claimed we wanted to measure: the respondents' estimated of best interests, the wish to intervene or not, and the willingness to let the family withhold care. We wanted to compare patients of different ages and similar outcomes, or different outcomes in order to see if age or outcomes (survival, disability or both) influenced resuscitation decisions.

The **internal validity** could have been influenced by multiple factors and these factors were absent or minimized. These will be elaborated in point form below:

Our scenarios did not have any socio-economic, nor familial / marital status information that could have influenced the respondents and not enabled us to measure what we wanted to (ie influence of age and / or outcomes). Indeed, if the adult in the MVA was under the influence of alcohol at the time, perhaps the respondents' willingness to intervene would have been lower, even with the same outcomes. In contrast, if the mother who delivered at 24 weeks was 40 years old, infertile, and had become pregnant with *in Vitro* Fertilization (IVF), the answers might have reflected other values in addition to those that we wished to measure. Although not explicit, we might not have totally eliminated all social information from our cases. We raised this in the discussion of the fourth article presented ("Nobody like Premies") in this thesis: age can at times be considered to be a surrogate for social status, especially for older patients. We understood this limitation when we started the study, and have indicated it in our publications. Perhaps premature infants are also inherently and unconsciously considered to be socially inferior? One of the respondents, after the results of the study was out, told me he did not even finish the cases after reading "24 weeks pregnant" and after "80 year-old…demented", he thought intervening for these patients was "not worth it", although he did read the other cases meticulously. If this attitude was widespread, the questionnaire would remain valid, as the goal was to determine the influence of age on opinions, but the details of the cases that we meticulously described would have had little influence on decisions.

Similarly, all cases were "accidents" and were described to respondents in neutral ways, such that there was no information about whether the patients' habits, smoking, reckless driving…etc could have participated in their health "accident". For example, the willingness of respondents' to intervene could have been lower if the patient who had a stroke was a hypertensive obese man who already had a cardiac surgery, was a non-compliant diabetic and refused to stop smoking.

There are limitations with our patients' outcomes. **Outcomes will never be identical** between two patients, even less between four. Although for some patients, the long-term outcomes are presented as identical, the hospital stay and therapy will not be. Indeed, a 24 week premature infant will need some respirator support for on average 5-6 weeks, a patient with meningitis will probably have more pain from headaches, whereas an MVA victim might need only 2 weeks of intubation, but many abdominal and limb surgeries and have more somatic pain than the other patients. This might influence how the respondents answer the questionnaire. We think it is unlikely that these factors would influence the non-medical respondents.

The cases were **presented in order**, from the youngest to the eldest. To eliminate this bias, which could have affected the internal validity of the study, we could have printed numerous versions of the questionnaire with the patients in random order. Because of the limited financial resources to do this questionnaire study (none!), it would have been much harder to copy the information of more than 800 paper questionnaires in excel or SPSS format for statistical analysis. Furthermore I am not aware of such a procedure having been previously attempted. In my next funded questionnaire research, I will consider doing the questionnaire in this fashion.

Some cases might have elicited more "sympathy" and elicited more emotions or imagination in our respondents. This was not recognized when doing the study, but only after it was finished, when some respondent gave us their feedback. For the 7-y-old child, several respondents speaking about him referred to the "kid who was crossing the street and got hit", although it was only mentioned in the questionnaire that he was "hit by a car". These respondents thought he got hit because he was limping, because he could not hear the car's horn. One even thought he had not tied his shoelaces properly because he was hyperactive! **Eliciting emotions with cases** is not new in medicine and bioethics, but it is possible some of my cases elicited more sympathy than others because of this.

Because of the limited financial means for doing this study, Dr Isabelle Leblanc and I were the ones distributing and collecting the questionnaire. I doubt this could have elicited some **"prestige" bias**, as some students might have wanted to answer what they thought we would like. Because the questionnaire was anonymous, it is unlikely it did. On the other hand, the fact that there were no financial means involved, and that actual attending staff went in to many classrooms and waited for questionnaires (completed or not) to be returned, and that this was done to obtain data for a PhD, probably increased our response rate!

Because of the way we distributed the questionnaires (see below), one could suspect there could have been some **diffusion bias**. This is unlikely as we administered the questionnaire in similar groups around the same time periods, and tried to get the most respondents on each occasion. It is unlikely anthropology students would speak about the different scenarios to attending staff in obstetrics.

During the administration of this questionnaire, I had a 24-week preterm daughter. Some of the medical residents and staff knew about this. One could think this might have influenced their answers. I compared the questionnaires that were completed "before and after" Violette, and the answers were not statistically different. Also, one would think respondents would tend to be more generous towards the premature infants (knowing my story) were there **time bias** in the answers, and it was not the case.

c. External validity

Because of our high response rate, we know the results accurately reflect the opinions of our target population. If we administered the questionnaire to a member of the similar group / culture, we would probably have similar answers. For example, if the McGill medical class would answer this questionnaire tomorrow, or the neonatal staff at McGill, it is likely the answers would be similar. As specified later on, this questionnaire was only intended to investigate the target population we identified. For example, we did not intend to reflect the opinion of all physicians in Canada, and therefore its external validity (for Canadian physicians, or of individuals around the world) is unknown.

3. Selection of samples, data collection methods and research design

Anonymous questionnaires were distributed to individuals involved directly or indirectly with resuscitation decisions: students, nurses, residents, and physicians in pediatrics, obstetrics and adult medicine. Anonymity was assured in order to ensure that the respondents would not have any fear of their ideas or opinions being publicly known, which should help to reduce selection bias in respondents. The first page of the questionnaire was an informed consent form, which, to ensure confidentiality, did not require a signature, but a check mark. To avoid the respondents feeling pressured or fearing discrimination if they did not answer the questionnaire, they were asked to return it face down at the end of the session. The questionnaire started with demographic information, including gender, profession, level of training or years of practice, having children or not.

There are multiple ways to do questionnaire studies: one uses random sampling techniques, where a random sample is taken to represent the group studied. For example, if one wishes to study the opinion of neurologists in Canada, one can randomly select neurologists from a list of all the Canadian neurologists, and try to have them answer the questionnaire. One can then apply statistical methods to extrapolate to the hundreds of neurologists in Canada, such studies are usually hampered by low response rates, and the statistical methods used have to assume that the responses of those who do not respond would be the same as those who do. Questionnaires sent by mail usually have only a 40-60% response rate in the literature, with only rare studies having higher rates[13,14,15,16,17,18,19,20,21].

However, the major bias known **as response bias** is clearly a serious deficiency of such studies. Individuals with strong opinions or a particular interest about the issue are more likely to respond to the questionnaire, and are thus likely to skew the results. We therefore did not use random sampling techniques. An alternate methodology for questionnaire studies is to identify a **target group** and administer the questionnaire to the individuals in the target group, attempting to obtain a very high response rate. When response rates are high, the studies are more reliable in terms of accurately reflecting the opinions of the target group. The results of studies such as this one can be extrapolated to a wider population if the sample is representative, the external validity of such studies is therefore always debatable. However internal validity can be assured. Studies without internal validity (such as a postal questionnaire -or any questionnaire- study with a low response rate) cannot have external validity. Rather than use random sampling techniques, our goal was to obtain close to 100% representation from our target groups. In fact, most questionnaire studies in the related field have proceeded this way.[22,23,24,25,26,27,28,29,30,31,32,33,34,35,36,37,38,39,40,41,42,43] This was the methodology used in a previous major study dealing with decision-making in NICUs.[28] We therefore proceeded to identify target groups, and were able to obtain more than 85% response rate in all our groups.

For example, in our second study, the "physician" target groups selected were physicians involved directly or indirectly with acute resuscitation decisions in Montreal, McGill university: residents, and physicians in pediatrics, obstetrics and adult medicine. We obtained a list of all the individuals identified to be in the target group, for example a list of all the residents in family medicine at McGill University was obtained from the family medicine training program office, a list of all the obstetricians at the MUHC was obtained from the hospital, etc.

All the target populations in the two questionnaire studies described in this thesis were administered the questionnaire in a similar fashion, from the obstetric resident in Quebec City in questionnaire #1, to the anthropology student in questionnaire #2. The target populations received the questionnaire and were free to fill it in the following manner: the questionnaire was distributed at the beginning or the end of a group activity with the prior authorization of the group leader. For example, it was given to residents at a teaching period when the program director and the chief resident had agreed, or for example at the beginning of a nurse staff meeting if the nurse in charge consented, or at the beginning, the middle, or the end of a class with the permission of the law professor. If it was not considered appropriate at the time, a more suitable time was arranged with the individuals. The questionnaire was anonymous and participation was voluntary. The questionnaire was available in French or English. The questionnaire had to be completed individually at that moment and could not be taken home.

4. Method of statistical evaluation

The questionnaire answers were entered on a Microsoft Excel spreadsheet. Descriptive and non-parametric statistics were used, and analyzed with SPSS software (Statistical Package for Social Sciences). The analyses were designed to answer the questions posed under the hypotheses for each of the studies. These were addressed with the use of Chi-square statistics and multivariate modeling using the SPSS logistic regression models. Because a large number of potential statistical comparisons were possible, we limited the number of comparisons in order to protect against type 1 errors, in addition when the sample sizes were very large and multiple subgroups were compared this was only done if the initial p was <0.01.

When performing logistic regression analysis we used backward stepwise conditional procedures, initially entering any independent variable which was found on univariate testing to be related to the dependent variable with a p-value of less than 0.1, elimination of a term from the final model was determined at a probability of 0.1. Results were presented as Odds Ratios and their 95% confidence intervals.

5. Limitations of questionnaire studies

All questionnaire studies have their inherent limitations: opinions may not actually translate into actions if the respondents were in the specific situation. Deciding on paper is very different than having to take a decision for an incompetent patient, but there is really no other way to know caregivers opinions without placing them in the actual situation. Questionnaire studies also raise many hypotheses. The studies presented in this thesis do not explain why caregivers think this way, and only allows us to develop hypotheses. For example, in our research, we can explore the actions that caregivers' state they would take, but did not explore the rationale behind some of these actions, and only hypotheses around these issues can be raised. As mentioned the internal validity of our studies is assured by rigorous methodology and a very high response rate, on the other hand, it is uncertain how generalizable these results are to other groups, particularly those from other countries or cultures.

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PART I

Perceptions and opinions of caregivers: from misinformation to moral distress

The first two articles presented are the following:

-Annie Janvier, Sophie Nadeau, Marianne Deschênes, Elise Couture and Keith Barrington. Moral distress in caregivers: an NICU experience. J Perinatology; 27: p:203-208.

- Annie Janvier, John Lantos, Marianne Deschênes, Elise Couture, Sophie Nadeau, Keith J Barrington. What if they knew? Acta Paediatrica (2008) 97: p276-79.

The research for the first two articles was performed at the beginning of my training in bioethics, which corresponded to the end of my neonatal fellowship. The neonatal intensive care unit is frequently the site of ethically challenging cases, many of which center around interventions for the extremely premature infant. The philosophy of caring for such infants differs between physicians, between hospital centers and between physicians working in different countries. During training, it was not rare to hear residents say that if they themselves were to be the parent of an extreme preterm, they would deliver in a primary care center to be sure the baby would not be treated, or would not survive. A fellow in clinical medicine probably hears many such harsh criticisms of decision-making that an attending physician no longer hears. A fellow is still considered a medical resident, he is also closer to nursing as he literally almost "lives" in the NICU for a couple of years, is very frequently on service and is the "first line of defense" for most interventions. It was also not rare for residents and nurses to question the ethical decisions staff neonatologists made, saying they would decide otherwise were they the ones with the ultimate power of decision. As attending physicians, we still hear similar comments, but less often, and often voiced differently. Are we going too far? Should we let parents decide? These are recurrent themes, but trainees and nurses, when asked to voice their opinions during rounds or teaching, are often hesitant. Prior to these studies, there were no data in the literature regarding the experiences of medical residents in the

NICU, or their opinions regarding resuscitation decisions for the extremely preterm, despite the fact that when a mother arrives at a tertiary hospital in premature labor, she will often initially see a nurse and a resident before the attending staff in obstetrics or neonatology. Residents and nurses are a very important link in neonatal care, and their experiences and their opinions deserved to be known.

For these reasons, we thought that investigating their opinions about extreme prematurity and resuscitation practices was therefore important, rather than focusing solely on the opinions of attending physicians. The aims of this study were to investigate residents and nurses opinions regarding acceptability of interventions for very preterm infants. We also wanted to determine whether ethical confrontation (related to moral distress) was frequent for residents and nurses caring for extremely preterm infants and to determine factors associated with it. I wrote the questionnaire and the research protocol. My collaborators, Sophie Nadeau, Marianne Deschênes and Elise Couture were fellows at the same time as me. They helped me identify the target groups and the methodology we would use for the questionnaire administration. They helped collect the questionnaires and are in great part responsible for the excellent answer rate. Keith Barrington, a neonatologist, chief of the NICU at the Royal Victoria Hospital, helped with the design, statistics and the data analysis. The results of these articles were originally presented in a single long article, which was hard to read. John Lantos, a clinical bioethicist and pediatrician who has a large experience in publishing articles related to bioethics, helped in separating the study in papers that would be more focused and likely to be published, and in reviewing the second article for clarity and conciseness.

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ORIGINAL ARTICLE

Moral distress in the neonatal intensive care unit: caregivers experience

A Janvier, S Nadeau, M Deschênes, E Couture and KJ Barrington

Department of Pediatrics, McGill University, Montreal, Quebec, Canada

Background: The Neonatal Intensive Care Unit (NICU) can be ethically charged, which can create challenges for health-care workers.

Objective: To determine the frequency with which nurses and residents have experienced ethical confrontations and what factors are associated with increased frequency.

Design/Methods: An anonymous questionnaire was distributed to nurses in a university center, a high-risk obstetric service, a maternity hospital NICU with 85% in-born patients and an outborn NICU, most of whose preterm admissions are those with surgical complications. Obstetric and pediatric residents in the four universities of the province also received the questionnaire, which included demographics, opinions regarding the gestational age threshold at which resuscitation of a premature infant with bradycardia was appropriate, knowledge of cerebral palsy (CP) outcomes (as an indicator of knowledge about long-term sequelae of prematurity) and questions about ethical confrontation in the NICU.

Results: Two hundred and seventy-nine caregivers participated (115 full time nurses and 164 residents). All the distributed questionnaires were completed. Frequent ethical confrontation was reported by 35% of the nurses and 19% of the residents. Among the nurses, moral distress differed significantly between work environments. Nurses working in an out-born NICU and obstetric nurses were more likely to overestimate CP prevalence ($P<0.05$). Nurses who overestimated CP rates had higher thresholds for resuscitation and were *more* likely to experience ethical confrontations. Of the residents, 60% were pediatric and 40% obstetric. All groups of residents frequently overestimated the prevalence of CP, and knowledge differed significantly by residency program ($P<0.05$). The residents who overestimated CP rates had higher thresholds for resuscitation, had more incorrect answers regarding prematurity outcomes and were *less* likely to have ethical confrontations.

Conclusions: A large proportion of nurses and residents report frequent ethical confrontations. Many residents and nurses have limited knowledge of outcomes and high threshold for resuscitation. Ethical confrontation is more common among nurses with poor knowledge about outcomes, and less common in residents with poor knowledge about outcomes.

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Keywords: extreme prematurity; neonatal resuscitation; moral distress

Introduction

Many caregivers have at times felt that they were caring for a patient when it may not have been in the patient's best interests to continue aggressive therapy, and have felt that their ethical and moral principles were confronted. In this study, we call this situation ethical confrontation, which has also been called moral distress in the literature.[1] Although attending physicians and parents are generally intimately involved in the decision-making process, residents and nurses may sometimes feel powerless, having to follow through with care plans and resuscitation decisions even when they do not agree that the best decision has been made.[1] We could find no literature describing the frequency of such ethical confrontations for residents and nurses involved in the care of extremely preterm infants, nor what influences the frequency of such confrontations.

The neonatal intensive care unit is often the site of ethically challenging cases, many of which center around the resuscitation and treatment of the extremely premature infant. The philosophy of caring for such infants differs between physicians, between hospital centers and between physicians working in different countries.[2,3] Both physicians and nurses routinely underestimate very preterm infants' survival and chances of a good long-term outcome, with nurses being more pessimistic than physicians.[4,5] The extent of resuscitation is known to be related to these estimates of outcomes.[6,7] We were unable to find data about residents' opinions on the subject in the literature. When a mother arrives at a tertiary hospital in premature labor, she will often initially see a nurse and a resident before the attending staff in obstetrics or neonatology. Investigating their opinions about extreme prematurity and resuscitation practices is therefore important,

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Correspondence: Dr KJ Barrington, Department of Pediatrics and Obstetrics and Gynaecology, cGill University, Royal Victoria Hospital, 687 Pine Avenue, West, Rm. C7.68, Montréal, Québec, Canada, H3A 1A1.
E-mai[redacted]

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rather than focusing solely on the opinions of attending physicians. Indeed, the accuracy of residents' and nurses' knowledge, their opinions regarding resuscitation for extremely premature infants and the frequency with which they experience ethical confrontations can all modify the interaction with the health-care team and the dynamics with the family.

The aims of this study were to determine whether ethical confrontation is frequent for residents and nurses caring for extremely preterm infants and to determine factors associated with ethical confrontation such as age, sex, the fact of having children, experience, religion, center where one works, knowledge of neurological long-term outcome and opinions regarding acceptability of resuscitations at the margins of viability.

We hypothesized that increased knowledge and experience would decrease the frequency of ethical confrontation. We further hypothesized that residents in the four programs of the province would have similar responses and that having children would modify opinions about extremely low birth weight (ELBW) resuscitation.

Methods

Between July and October 2002, an anonymous questionnaire regarding opinions and knowledge related to neonatal resuscitation and neurological outcome at and below 28 weeks was distributed to groups of residents and nurses. All residents in pediatrics and obstetrics in the province of Québec, Canada were surveyed. Four university centers in Québec have a residency program in Obstetrics and Pediatrics: Québec, Sherbrooke, Montréal (Université de Montréal and McGill University). Nurses of the McGill University Health Centre involved in perinatal and neonatal care were also questioned; the three groups being delivery room nurses, nurses working in a maternity hospital neonatal intensive care unit (NICU), NICU nurses working in a Children's hospital.

In Québec, 99% of mothers have prenatal care, over 80% of extremely premature infants are delivered in tertiary centers and receive prenatal betamethasone with approximately 80% of these having time to complete more than 24 h of antenatal steroids. Because of the high rate of early ultrasounds in the Canadian health care, we are generally fairly confident regarding gestational age. The questions in this study are asked in terms of gestational age. The 50th percentile for weight for a male at the following gestational ages are: 600 g at 23 weeks, 750 g at 24 weeks, 800 g at 25 weeks, 900 g at 26 weeks, 1000 g at 27 weeks and 1125 at 28 weeks. The Royal Victoria Hospital is a tertiary care center that has close to 4000 deliveries per year and has a maternity NICU with approximately 400 admissions per year of mostly inborn infants. The Montreal Children's Hospital NICU admits 400 out-born infants per year, with most of the preterm infants admitted being those who needed surgery or home oxygen: they tend to be sicker, have more complex problems and poorer predicted outcomes than at the maternity hospital.

Respondents filled the questionnaires individually during a group activity, for example, teaching for the residents or working shifts for nurses where a maximum number of caretakers could be reached. The first question was a request for consent, and if consent was refused the questionnaire was collected with the others at the end of the period. The first page of the questionnaire comprised demographic information with age, sex, religion, having children or not, residency years or nursing experience.

The questions asked were the following:

Ethical confrontation

During your practice, were you confronted with resuscitating/treating with important support/caring for extreme premature infants against your moral beliefs and values (having no choice to do it as a resident/nurse)?

The possible responses were as follows: always, generally, exceptionally, never.

For analysis, we grouped those who answered the question regarding ethical confrontation as 'always' or 'generally', this is referred to as 'frequent ethical confrontation'.

For the following two questions, we asked the caregivers to assume an AGA infant with average risk profiles.

Threshold of resuscitation for a preterm bradycardic infant

At what gestational age do you think it is reasonable to routinely resuscitate (in the delivery room) an apnoeic infant with bradycardia?

The possible responses were 22, 23, 24, 25, 26, 27 or 28 completed weeks of gestation.

CP prevalence

What is the prevalence of CP in infants born at less than 1000 g when examined at 5 to 8 years of age?

The possible responses were: 10, 15, 25 and 40%.

(CP ranges from 8 to 11% depending on the authors.[8–10] We accepted 10 and 15% as reasonable responses. Therefore, 50% of the answers were considered acceptable).

Center resuscitation practices

We questioned the neonatal directors of all four university centers in Quebec about their resuscitation practice in 2002 and asked their approval for publication.

Statistics

Descriptive statistics were used; χ^2 test was used to compare proportions between groups.

Results

Two hundred and seventy-nine questionnaires were completed; there were no refusals of consent.

Residents

One hundred and sixty-four residents completed the questionnaire. Depending on the residency program, 90 to 100% of the residents were available during the study period and 100% of those who received the questionnaire returned it completed. Seventy-five percent of the residents were female, 60% of the residents were in the age range of 25 to 29 years, 57% practiced the same religion and a further 31% were atheist. In center B, 36/37 (97%) of residents had the same primary language, and 87% practiced the same religion. In center C, 27/27 (100%) had the same primary language and 70% practiced the same religion (a further 22% were atheist). Center D was culturally more diverse: 15/43 (35%) had one primary language, 23% another and 77% spoke a variety of other languages, more than five religious groups (and atheist) were represented, none representing more than 40% of the respondents.

Nurses

One hundred and fifteen nurses completed the questionnaire. During the study period, 78 to 90% of the full time nurses were available, depending on the unit, and 100% of nurses who received the questionnaire returned it completed. The number of nurses per unit was as follows: obstetrics: $n=31$, inborn NICU: $n=38$, outborn NICU: $n=46$. The nurses working in the out-born NICU had fewer years in practice, fewer of them had children and they were younger than the other nurses ($P<0.05$).

Ethical confrontation

Thirty-five percent of nurses and 19% of the residents experienced frequent ethical confrontation. For both groups, ethical confrontation was not associated with religion, level of training or years of practice, sex, age and having children or not.

The proportion of residents who experienced frequent ethical confrontation differed substantially between centers (χ^2, $P<0.05$, Table 1). Thirty-six percent of the pediatric and obstetrics residents at center D frequently experienced ethical confrontation compared with, for example, obstetric residents at centers A, B and C, and pediatric residents at center C, where 0 to 6% of residents had frequent experience of ethical confrontation ($P<0.05$) (Table 1).

A higher proportion of the nurses in the outborn NICU reported frequent ethical confrontation (56%), more than the nurses in either the inborn NICU or the delivery room (22 and 24%) ($P<0.05$).

Center resuscitation practices and ethical confrontation

Center A: Twenty three- and 24-week gestation infants are resuscitated according to parental wishes. In 2002, 60 and 75% of infants were resuscitated in the delivery room at 23 and 24 weeks (data collected routinely by unit). Nineteen percent of residents had frequent ethical confrontations in this center.

Table 1

Center	*Frequent ethical confrontation*	*Estimate of CP prevalence*		
		40%	*25%*	*15% or 10%*
Nurses, out-born NICU (%)	56	39	30	29
Nurses, inborn NICU	24	8	29	64
Nurses, obstetrics	22	6	48	45
Pediatric residents, center A	28	4	44	52
Pediatric residents, center B	22	22	61	17
Pediatric residents, center C	0	38	31	31
Pediatric residents, center D	36	15	26	59
Obstetric residents, center A	6	6	44	50
Obstetric residents, center B	6	28	33	39
Obstetric residents, center C	0	7	57	36
Obstetric residents, center D	25	0	31	69

Abbreviations: CP, cerebral palsy; NICU, neonatal intensive care unit.

Center B: Twenty three-week infants are not offered resuscitation. Twenty-four-week infants are resuscitated according to parental wishes; a majority of the 24-week babies were resuscitated in 2002 according to the unit director (no data available). In this center, 13% of residents had frequent ethical confrontation.

Center C: Twenty three- and 24-week gestation infants are not offered resuscitation.

Center D: Twenty three- and 24-week gestation infants are resuscitated according to parental wishes. In 2002, 75 and 100% of 23- and 24-week infants were resuscitated (data collected by unit).

In center C, where 23- and 24-week infants were not offered resuscitation, 0% of residents reported they were frequently ethically confronted. Fifty-two percent of the residents answered they never were ethically confronted. The proportion of residents with ethical confrontations was significantly less than in all the other centers ($P<0.05$). In contrast, in center D where most of the 23- and 24-week infants are resuscitated, 31% of the residents experienced frequent ethical confrontation, significantly higher than all the other centers ($P<0.05$).

Among the nurses, 74 and 46% would not resuscitate a bradycardic premature infant at 24- and 25-week gestation, respectively. Thresholds for resuscitation were much higher for the nurses working in the out-born NICU than the nurses in either the inborn NICU or the delivery room ($P<0.05$). A higher proportion of nurses unwilling to resuscitate at 24 and 25 weeks reported frequent ethical confrontation ($P<0.05$).

The proportion of respondents who had experienced frequent ethical confrontation differed according to the gestational age that they reported as their threshold for resuscitation. Of residents reporting that they exceptionally or never experienced ethical confrontation, significantly fewer were willing to resuscitate; both at 24 and 25 weeks ($P<0.05$).

Overall, 75 and 44% of residents would not resuscitate a bradycardic premature infant at 24 and 25 weeks, respectively. The threshold for resuscitation differed markedly between centers. The proportion of residents willing to resuscitate a bradycardic infant at 24 weeks ranged from 0 to 43%; at 25 weeks 22 to 75%; at 26 weeks 46 to 88% and at 27 weeks 57 to 95% depending on where the resident was training ($P<0.05$). More residents believed resuscitation was appropriate at 24 and 25 weeks in center D, where the largest proportion of preterm infants (<25 weeks) were resuscitated ($P<0.05$). Fewer pediatric residents in center C (where resuscitation is not offered at 23 and 24 weeks) believed it appropriate to resuscitate a bradycardic premature infant at each gestational age ($P<0.01$).

The proportion of residents willing to resuscitate a bradycardic preterm infant at each week of gestation weeks did not significantly change with year of training, age, religion and having children or not. Twenty-seven percent of pediatric and 34% of obstetric residents expressed a resuscitation threshold of 27 weeks or later.

Residents who incorrectly thought CP rates were 25% or more were less likely to report frequent ethical confrontations ($P<0.05$) (Table 1). On the other hand, nurses who incorrectly thought CP rates were high were more likely to report frequent ethical confrontations ($P<0.05$) (Table 1).

Residents and nurses were not well informed about CP rates in ELBW infants (Table 1). Fifty-three percent of residents significantly overestimated the prevalence of CP in ELBW survivors. In one center, 38% of residents thought the CP rate was 40%; in another center only 17% of the pediatrics residents answered 10 or 15% (Table 1). The accuracy of the response did not increase with training, the only variable that was significantly different between those with accurate or inaccurate responses was center of training ($P<0.05$). Inaccurate beliefs about CP prognosis were correlated with higher thresholds for resuscitation ($P<0.05$).

Using multiple logistic regression to examine the responses of residents, and entering center of training as independent variables, incorrect answers regarding CP prevalence and threshold for resuscitation (by week of gestation), only center of training was a significant predictor of ethical confrontation ($P<0.001$). Further analysis within each center of training demonstrated that threshold for resuscitation (greater than or less than 25 weeks gestation) was associated with ethical confrontation ($P<0.05$) in centers A, B and D, but not in center C.

Among nurses, years of experience, work unit, incorrect answers regarding CP prevalence and threshold for resuscitation were also examined in a multiple logistic regression. Work unit and incorrect answers regarding CP prevalence were both independently associated with ethical confrontation, ($P<0.01$).

Conclusion

Although there are case studies[11] and published observations describing ethical confrontation[12,13] or moral distress in nurses in perinatal practice, there have been no previous studies describing the frequency or associated factors of ethical confrontation in residents and nurses treating high-risk preterm infants. We have demonstrated that a substantial proportion of these health-care providers frequently have such experiences. Furthermore, we have confirmed that a substantial number of residents and nurses caring for such infants are not well informed about their outcomes and many would not resuscitate infants even at 26 and 27 weeks gestation who have high potential for good outcomes.[14] Clearly, CP is not the only long-term disability of the former preterm infant. Developmental delay, learning disabilities, hearing loss, *etc.* occur with an elevated frequency among these children. The question focused on CP because it is consistently and clearly reported and is relatively stable among studies.[2–4] We felt that this made it a better indicator of knowledge than other, probably more important, aspects of impairment in these infants.

Residents with a threshold for resuscitation at a later gestational age were less well informed about the outcomes and have also experienced less frequent ethical confrontation. Also among residents, ethical confrontation differed substantially between residency programs. The centers that were less likely to offer intensive care to very preterm infants were the centers where residents were most likely to underestimate the likelihood of a good outcome and the same centers where there were less frequent reports of ethical confrontation. These centers were also more culturally homogeneous, with a much greater proportion of the residents speaking the same language at home and reporting the same religious affiliation. In Quebec, all the neonatologists are active academics and are presumably teaching the residents the same information regarding outcomes, but the residents' attitude toward the extremely immature infant appears to be affected by the culture of their training center. Residents who have not participated in caring for a 23- or a 24-week infant during their training may believe that the outcomes are so bad that resuscitation is not indicated. This is also consistent with the fact that residents who incorrectly thought that CP rates were 25% or more were less likely to have ethical confrontations. We hypothesize that the residents who have rarely seen extremely immature babies resuscitated are more likely to assume a bad outcome in all such infants; in not treating 23- or 24-week infants, or seeing fewer of them, a resident will experience fewer deaths in the NICU and less complications and thus may well experience moral distress less frequently. In center D, where 36% of residents experienced frequent ethical confrontation, there is also more cultural diversity. Because religion and cultural background can affect health decisions, values and resuscitation decisions, having more diversity, may increase tensions between health-care workers who may have differing opinions regarding the same case.

The situation seems to be different among nurses. Only nurses in one university health center answered the questionnaire: we therefore have no information about nurses from different university centers across the province of Quebec and cannot compare their opinions as we did with the resident population. On the other hand, we can compare the answers from nurses in obstetrics and neonatology in two different hospitals in the same university center. Nurses who are not well informed about CP rates will have a higher threshold for neonatal resuscitation, which is similar to the finding among the residents. In contrast, they report more frequent ethical confrontation. Fifty-six percent of the outborn NICU nurses reported frequent ethical confrontation, and 93% gave inaccurate answers to the question about CP rates. These nurses' experience of premature babies is very largely those needing surgery or specialized care in the children's hospital, therefore when they treat very immature infants they generally see more complications than the maternity hospital nurses. The incidence of complications seen by nurses probably has potent effects on their views on resuscitation of such infants, their knowledge of outcomes and their experience of ethical confrontation. We hypothesize that the more the major complications are seen, the more nurses have a false impression of bad outcomes in all extremely preterm infants, which leads to a higher threshold for neonatal resuscitation. Nurses who experience more complications and surgeries in extremely immature infants report more ethical confrontation, presumably because they are taking care of sicker babies where there are more frequently questions about the appropriateness of continuing care.

We did not ask the residents and nurses about the specific circumstances of their ethical confrontations. This should be further investigated. It would seem self-evident that improving the knowledge base of the residents and nurses with regard to long-term outcomes of the extremely preterm infant would likely reduce some unnecessary confrontations. However, among residents, this study does not suggest that improving knowledge will decrease overall ethical confrontations; in fact, the contrary appears to be the case. Explicit review of the likely outcome of the individual immature infant and review of reliable evidence regarding quality of life of survivors[15] should also help to put treatment options in perspective.

The manner in which we asked the question regarding ethical confrontation was based on our own experience that the majority of difficult issues in the NICU arose when the families wished to continue care, but members of the NICU team felt it was inappropriate. This experience is consistent with recent published data from a medical intensive care unit where nurses were far more likely to experience moral distress in situations of what they felt was 'over-aggressive' care rather than situations of under-treatment.[16] A recent study in a pediatric context[17] also found that about 20 times as many nurses, 15 times as many house officers and 10 times as many attending physicians agreed with the statement, 'Sometimes I feel we are saving children who should not be saved,' as agreed with the statement, 'Sometimes I feel we give up on children too soon'. However, if a respondent had frequent ethical concerns about failure to treat an infant in the NICU, they may not have responded that they had frequent confrontation. This is a limitation of this questionnaire and the contrary experience should be explored in future studies. In a questionnaire study, there will always be concerns about whether the respondents had understood the questions in the same way as the investigators. Preliminary drafts of this questionnaire had been felt to be easy to understand when tested on some local respondents.

Is it normal to feel ethically confronted, and should we try to reduce ethical confrontation? As noted above, there has been little prior investigation of the ethical stresses experienced by caretakers in perinatology. Studies examining ethics, prematurity and resuscitation have generally focused on parental decisions and physicians' knowledge, opinions and values, but not on ethical confrontation as such. In other fields also, the frequency with which health-care workers and trainees experience ethical confrontations are unclear.[16,18] Medical and nursing training and practice are often difficult, residents or nurses may also participate in procedures or resuscitations about which they have major reservations in other domains of practice. For example, ethical confrontations may be experienced by residents and nurses in the setting of performing liver transplantation in alcoholic patients, bariatric surgery, aesthetic surgery, prolonged and aggressive therapy after multiple relapses in oncology patients, intensive resuscitation of elderly patients with poor functioning, etc. In our health-care center, residents and nurses in obstetrics are not compelled to participate in pregnancy terminations if they do not wish to, but this limited right of non-participation is not extended to other areas of practice. The management of a health-care system would become impossible if every health-care trainee or practitioner was permitted to examine each case closely before deciding whether to participate in the care of the patient. Instead, we have to have a team approach, trusting that those most intimately involved are trying to make the best decisions based on the most complete understanding of the clinical situation and the desires of the patients (or their parents). This is essential in order that the system can function. This is bound to lead to situations where ethical confrontations occur, as part of a team providing care about which each member has their own ethical opinions regarding health, treatment options, autonomy and the value placed on life. Thus, eliminating ethical confrontations may be neither possible nor even desirable. Our data did not address whether nurses or residents would prefer to be able to withdraw from giving care in a greater proportion of cases. Ethical dilemmas such as these may lead to some of the symptoms of burn-out.[19]

We speculate that further investigation of these issues, and finding ways to support staff who are affected,[20] may help to reduce staff turnover and improve staff satisfaction even if ethical confrontation cannot be avoided.

Our data are consistent with an interpretation that ethical confrontations are more frequent in societies that are more pluralist and multicultural. Thus, populations that are more homogeneous in their beliefs may have more infrequent experience of ethical confrontation; our results showed that in centers B and C, with the least cultural variability as determined by the limited demographic information we collected, there were the least frequent reports of ethical confrontation. This may reflect less variability in value systems, but does not necessarily mean that the practices are more ethically appropriate.

Our study also showed that residents and nurses who are inaccurately pessimistic regarding outcomes rates had a higher threshold for resuscitation. This was also previously shown in a study examining the understandings and practices of pediatricians.[7] In contrast with previous work, we did not find the nurses to be less interventionist than physicians, although that previous study questioned attending staff rather than residents.[6] Although resuscitation and treatment of infants at extremely low gestational age is fraught with controversy and divergent opinions have been expressed, there has been little prior investigation of how groups of trainees and nurses are affected by the situation.

In summary, we wished to investigate the ethical experiences of nurses and residents involved in neonatal care because ethical confrontations can affect the morale of the health-care team and interfere with the provision of high-quality care. Further studies will be required to find ways to equip trainees and health-care workers with the tools to examine these confrontations, to learn from these difficult situations and thus to profit from them.

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REGULAR ARTICLE

Caregivers attitudes for very premature infants: what if they knew?

A Janvier[1], J Lantos[2,3], M Deschênes[4], E Couture[1], S Nadeau[1], K J Barrington[1] [redacted]

1.Department of Pediatrics, McGill University, Montreal, Quebec, Canada
2.University of Chicago, Chicago IL, USA
3.Center for Practical Bioethics, Kansas City, MO, USA
4.Department of Pediatrics, Laval University, Quebec City, Quebec, Canada

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Correspondence
KJ Barrington, Royal Victoria Hospital, 687 Pine Ave W, Montreal, Quebec, Canada H3A1A1.
E-mail [redacted]

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Abstract

Background: Decisions about resuscitation of extremely premature babies are controversial. Such decisions may reflect poor understanding of outcomes.

Objective: To compare caregivers' attitudes towards the resuscitation of a premature infant if they are only told the infant's gestational age or if they are only given prognostic information for infants at that gestational age.

Design/methods: Residents and nurses involved in perinatal care were asked whether they would resuscitate a depressed AGA 24-week gestation infant at birth. In another question they were asked whether they would resuscitate a depressed preterm infant with a 50% chance of survival, knowing that of those who survived, 50% would have a development 'within normal limits', 20–25% a serious handicap and 40% with behavioural and/or learning disability.

Results: Two hundred and seventy-nine caregivers responded (91% response rate). In the scenario that only presented gestational age, 21% of respondents would resuscitate. In the scenario that only presented prognostic statistics, 51% of respondents would resuscitate ($p < 0.05$).

Conclusions: Providers of perinatal health care respond to vignettes differently depending upon the format in which information is provided. The relative unwillingness to resuscitate a baby of 24-week gestation is surprising since outcomes for such babies are the same or better than those we described in the scenario that provided only outcome data without specifying gestational age. Two explanations are possible: (1) respondents have irrational negative associations with low gestational ages or (2) respondents are unaware of actual outcomes.

INTRODUCTION

Numerous opinions are expressed about the appropriateness of providing support for an extremely immature infant (1). The attitudes of health care providers regarding resuscitation of the extremely preterm infant affect intervention decisions (2,3), and these attitudes are often based on a poor understanding of outcomes (4). When a mother arrives at a tertiary hospital in premature labour, she may well see the nurse and the resident or fellow in the delivery room first, then frequently the attending obstetrician or maternal fetal medicine specialist, and then possibly the neonatal team if a consult to neonatology is requested. Little is known about the residents' knowledge and perceptions of ethical issues surrounding prematurity. Opinions of the 'first line' caregivers are important as these perceptions can directly influence who gets to see the neonatal team in order to consider resuscitation, and the 'tone' of the perinatal environment where parents are, which could also affect the parents' perceptions and informed consent. We wondered whether caregivers considered resuscitation of an extreme preterm reasonable at 24 weeks, and whether their opinion would change if they were presented with the actual outcomes.

THE AIM/QUESTIONS OF THIS STUDY WERE

1. What are caregivers' attitudes towards the resuscitation of a premature infant at 24-week gestation?
2. If they were given an accurate prediction of likely outcome: would a higher proportion resuscitate the same baby?

METHODS

Between July and October 2002, we surveyed residents and nurses about resuscitation decisions that they would make for premature babies, and their knowledge of outcomes. The following respondents received an anonymous questionnaire:

1. *Residents:* All 172 residents in paediatrics and obstetrics in the province of Quêbec, Canada.
2. *Nurses:* One hundred and thirty-six nurses of the McGill University Health Centre (MUHC, Montreal) involved in perinatal and neonatal care: delivery room nurses, nurses working in the maternity hospital and the Children's Hospital.

The questionnaire was filled individually by respondents during a group activity where a maximum number of caretakers could be reached, for example, residents' teaching or a nursing shift. The first question was a request for consent, and if consent was refused the questionnaire was collected with the others at the end of the period. The questions asked were the following.

Table 1 Description of respondents

	Nurses	Residents
n	115	165
Age 25–30 (%)	15	60
Age 31–40 (%)	38	17
Junior res (%)	X	47
Nurse < 5 years experience (%)	23	X
Nurse > 10 years experience (%)	47	X
Children, yes (%)	63	19

RESUSCITATION OF A 24-WEEK DEPRESSED INFANT

Do you think it is reasonable to resuscitate (in the delivery room) an AGA depressed infant at 24-week gestation?

The possible responses were: always, generally, exceptionally, never. 'Always and generally' were counted as positive answers.

HYPOTHETICAL INFANT

There is an impending delivery of a preterm infant with a 50% predicted survival and a long term outcome as follows if the baby survives:

1. 50% development 'within normal limits'
2. 20–25% serious handicap rate
3. 40% with behavioural and/or learning disability
4. Do you think such baby, if born depressed, should be aggressively resuscitated in the delivery room?

The possible responses were: always, generally, exceptionally, never. 'Always and generally' were counted as positive answers.

This question regarding a hypothetical newborn infant did not mention the gestational age in the scenario. The survival rate, and the probabilities of long-term disability were designed to conservatively reflect the actual chances of an infant delivered at 24-week gestation in a Canadian tertiary care centre (5–11).

RESULTS

Two hundred and seventy-nine questionnaires were completed; there were no refusals of consent. In total, the response rate, calculated as a percentage of all possible respondents in the target groups, was 91%.

One hundred and seventy-three residents were in training in pediatrics and obstetrics in 2002. Of these, 165 were received the questionnaire (95%) and 100% of these completed it. One hundred and thirty-six full-time nurses worked in perinatology at the MUHC in 2002. One hundred and fifteen nurses (85%) received the questionnaire of which 100% completed it. The demographic characteristics of the study population are shown in Table 1. (Gender, age, years of training/experience as a nurse, children of their own.) Residents were younger than nurses, fewer of them had children and fewer were female ($p < 0.05$).

Fifty-eight respondents (21%) would always or generally resuscitate a depressed preterm infant at 24 weeks. The proportion of nurses and residents who would resuscitate a 24-week infant was similar (17 and 23%, respectively). One hundred and forty-two (51%) of caregivers would always or generally resuscitate the infant in the scenario that only presented prognostic statistics, significantly more than the 24-week infant ($p < 0.01$, difference between groups 30%, 95% confidence intervals, 22–37%). Nurses would resuscitate the infant without a stated gestational age less than residents (38% versus 57%, $p < 0.05$, difference 13%, 95% CI 2–24%), but they would still resuscitate him/her significantly more than the 24-week infant (see Fig. 1, $p < 0.01$, difference 21% 95% CI 10–31%). Only 5% of respondents would resuscitate the 24-week infant and not the infant without a stated gestational age, 15% of respondents would resuscitate both infants.

Within the subgroups of residents from each university and the subgroups of nurses working in their different units, all groups were less likely to intervene for the infants with a known gestational age of 24 weeks than for the infants without a stated gestational age.

DISCUSSION

This questionnaire is one of many surveying opinions of caregivers surrounding neonatal resuscitation; it is unique because it includes the opinions of residents. When parents arrive in a university centre, they will usually see nurses and residents in obstetrics before the attending staff, and the same may be true for the neonatal consult. These caregivers may well 'set the tone' for treatment decisions in these difficult situations.

We were able to distribute the questionnaire to 95% of residents and 85% of nurses in our target groups, and 100% of those who received the questionnaire answered it: this is a high response rate for a questionnaire study which presumably reflects the interest of the topic to the residents and nurses working with this population and their desire to state their opinion.

Only 21% of respondents would resuscitate a preterm at 24-week gestation. This study showed that many of the respondents said they would not resuscitate, but did not investigate their reasoning. Is it because of the uncertain future of these babies, and a belief that withholding care is easier than withdrawing care? Is it because the respondent believes that many of the surviving infants have a life that is so limited that it is not worth living? Is it more of an emotional response to the foetus at 24 weeks that looks barely human? A decision to withhold resuscitation in this situation is generally considered to be ethically appropriate, and is in accordance with the current position statement of the CPS which does not mandate resuscitation of these babies. In contrast with previous work (12), we did not find the nurses to be less interventionist then physicians, although previous studies investigating this questioned attending staff rather than residents.

The residents and students were from four different universities in Quebec with different policies regarding resuscitation. Ranging from a more interventionist approach to very restrictive practices at 24 weeks. We have shown in another publication that the residents' attitudes and

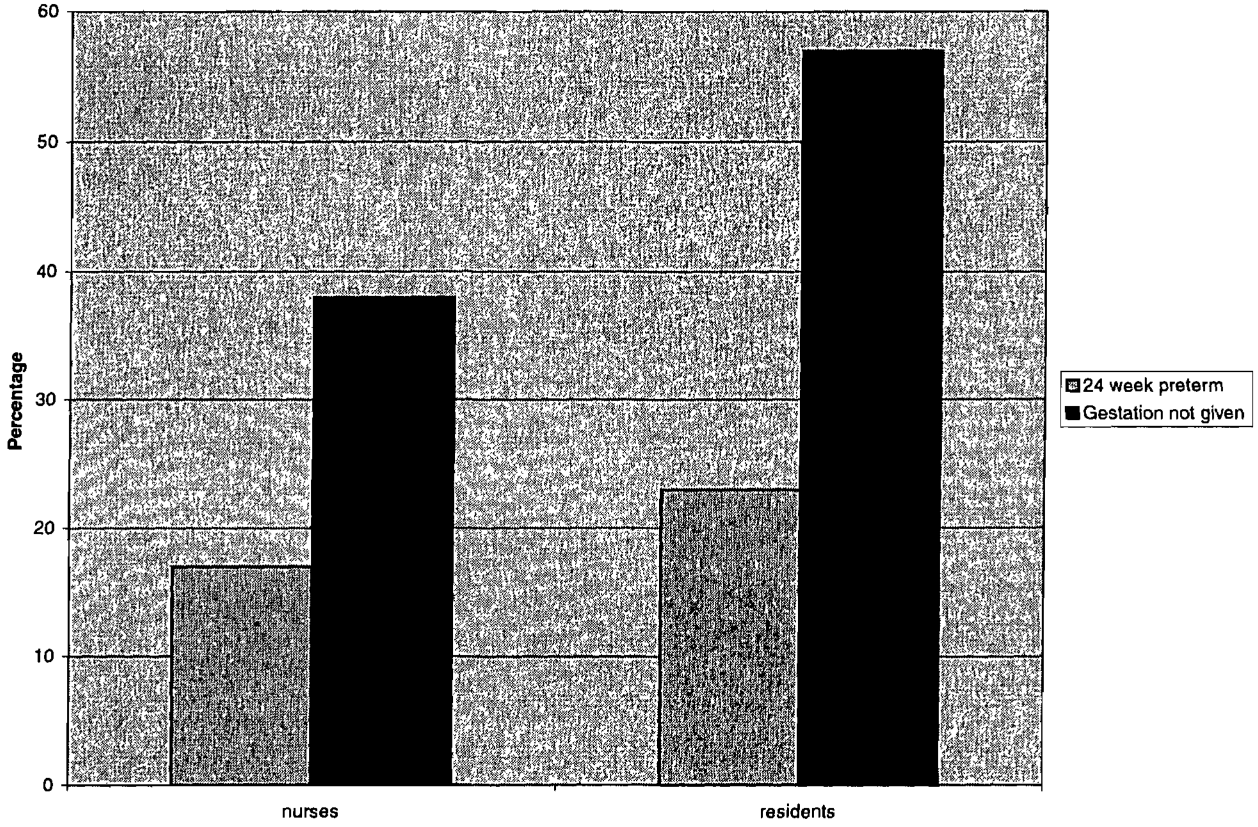

Figure 1 Percentage of respondents replying that they would always or generally resuscitate a preterm baby known to be a 24-week infant compared to an infant with outcomes described but no gestational age given.

knowledge regarding outcome varied according to where they were trained, those working in a centre which resuscitated most infants at 24 weeks thought their outcomes were better, and were accordingly more willing to resuscitate than the residents being trained where resuscitation was not offered at that gestation (13). The nurses' attitudes also reflect their personal experiences of very preterm infants; nurses working in an outborn, mostly surgical, NICU were much more negative about preterm infants, both in terms of their estimates of outcomes and their willingness to intervene, presumably as they see only those with complications. Nevertheless, in the current project, within the subgroups of residents from each university and the subgroups of nurses working in their different units, all groups were less likely to intervene for the infants with a known gestational age of 24 weeks than for the hypothetical case. This shows that, regardless of the underlying ethos of the centre, the very fact of being known to be very preterm is considered a negative characteristic, warranting a different approach.

There are clearly disagreements regarding how to make decisions for patients who need acute intervention and who are not capable of deciding for themselves. Whether age or disability among survivors or potential life years gained should be considered relevant is not universally agreed (14,15).

The opinions of caregivers about outcomes are a leading cause of mortality for infants born at <27 weeks. In some centres, resuscitation of the 24-week infant is not encouraged and their survival can be said to be 0%, others publish survival rates of 84% (16–18). Thus the survival rate may vary from 0 to 84% largely due to the opinions and attitudes of the decision makers. Respondents were more likely to want to resuscitate the hypothetical preterm but not the 24-week infant, even though in tertiary care centres in Canada the survival rate at 24 weeks is substantially better than that described in the hypothetical case, being currently 72% (11). Systematic review of large numbers of infants reported at extremely low gestational age also shows that our presented long term outcomes were also reasonable, not to say conservative (9). Many caregivers who would not resuscitate a 24-week infant believed it to be reasonable to resuscitate an infant having a 50% survival with 50% having an outcome 'within normal limits'. Differences in attitudes between the hypothetical case and the 24-week infant suggest respondents either have irrational negative associations with low gestational ages or that they are rational but unaware of actual outcomes. Even with the outcomes explicitly described, only half of respondents would resuscitate when the outcomes are stated to be a 50% survival and 50% 'normal' outcome. We wonder if our respondents would give the same answers if the hypothetical case had been an older child with other childhood pathologies with similar prognoses, such as a comatose child after penetrating head trauma, or severe bacterial meningitis in early infancy; research which we have published in preliminary form suggests that they would be much more likely to institute intensive care for the older child (19).

This is a questionnaire study that has multiple limitations. We do not know if opinions would translate into actions were the resident were in the specific situation, but the survey method is used to determine attitudes rather than predict actual actions. In any case the final decision regarding resuscitation is usually made by the staff physicians and families. However, it is important to know the opinions of the caregivers who often have the first contact with families in this situation. The wording of the two scenarios was slightly different, which complicates the interpretation of the results somewhat, however other questionnaires that we have performed also show a consistently negative approach to the very preterm infant, which is out of proportion to the prognosis; respondents are much more likely to wish to intervene for other infants with an identical prognosis who are more mature or slightly older (20). Those findings are consistent with the results presented herein: the unwillingness to intervene for extremely preterm infants is out of proportion to their prognosis.

This research project has demonstrated that if caregivers knew the outcomes of an infant, as opposed to only being told the gestational age, significantly more would wish to resuscitate infants at 24-week gestation. This reflects the need for more education about outcomes in neonatology. Reviewing outcomes of ELBW infants with good quality information could help to put treatment options in perspective. Discussions regarding individual cases in the neonatal intensive care unit using good quality relevant evidence may also help to improve knowledge and assist residents and nurses in providing the best care and the best information to families.

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PART II

The principle of best interest and the value of life of neonates

In an emergency situation, resuscitation of patients is often performed without obtaining explicit consent, which is assumed unless documentation of a previous decision is available. At other times, informed consent would be obtained because there is sufficient time to have a discussion with the patient or his representatives. Because of the constraints of time and the urgency of the situation, patients with potential brain injury may receive active resuscitation in circumstances that might otherwise be considered questionable. In such an emergency context, and even when time is limited, the risk-benefit ratio of the intervention has to be analyzed. Is it probably not always reasonable to resuscitate a patient, nor to proceed to starting intensive care. For the majority of individuals there are outcomes that would not justify Cardio Pulmonary Resuscitation (CPR). However, there are numerous opinions on where, and how, to draw the line. Some authors have written about futility of treatment, when a treatment does not work, or when the outcome does not justify a treatment.[1,2,3,4,5,6] There is some agreement that a physician does not have to initiate CPR when it is futile, but both the definition of futility, and the prediction of outcomes to determine if intervention would indeed be futile, are uncertain or subjective. In consequence CPR is often initiated in emergency situations.[7,8,9,10] For extremely premature infants, physicians will generally consult with the parents and obtain consent before intervening. In 1994, the Canadian Paediatric Society (CPS) recommended that resuscitation under a GA of 25 weeks be done only with informed consent of the parents. Physicians would inform parents and they would in turn, decide what is the best avenue of treatment for their children. Ideally, the decision-making process between the caregivers and the family of the incompetent patient goes smoothly. In reality, as in many areas of human endeavour, opinions are often divergent when is comes to resuscitation of patients with potential brain injury or with very reduced lifespan.

For incompetent patients with no advanced directives, surrogates are expected to use the patient's best interest as the guiding principle for decision-making.[11,12]

Treatments are considered to be in patients' best interests when the benefits of an intervention outweigh risks and burdens. In addition, however, if the caregivers believe "that the designated surrogate threatens the patient's best interests, the decision should be overridden"; such overriding of family decision-making has been supported in the courts.[11,13,14] If resuscitation is considered to be in an incompetent patient's best interest, and significant harm is caused by not intervening (such as when failure to intervene will lead to death), refusal of care is generally not accepted, neither according to many ethical thinkers, nor by the courts.

This study was designed to see if the best interest was respected for decision-making for incompetent patients of all ages. The medical literature abounds with articles of authors' opinions regarding futility, resuscitation decisions, and allocation of resources. There is a scarcity of knowledge when it comes to the comparison of opinions regarding resuscitation at different ages of life. The research and literature treat the geriatric population and the extreme premature infants as two separate groups. Should every individual be treated the same way if they have the same neurological outcome and the same survival?

The 2 articles presented in part II are the following. They are based on the same questionnaire study, with the same participants:

-Annie Janvier, Isabelle Leblanc and Keith J Barrington. The best interest standard is not applied for neonatal resuscitation decisions. Pediatrics, vol 121, Number 5, May 2008, p:1-7 (Galleys included in thesis).

-Annie Janvier, Isabelle Leblanc and Keith J Barrington. Nobody likes premies. Accepted by J Perinatology December 7th 2007, to be published in May 2008.

The objective of this questionnaire study was to determine opinions about resuscitation at different ages of life and resource allocation for resuscitation decisions and admission to the ICU. When do caregivers and students in both medical and non-medical fields judge it is reasonable to resuscitate patients at high risk of neurological sequelae? In terms of public health and resource expenditure, which patients should be prioritized? Resuscitation decisions and patient selection for scarce resources demand that we place a relative value on human lives. Likelihood of survival, likely outcomes, pre-existing handicap, and age can all influence which patient will be given the highest priority. Does age make a difference: are premature infants, newborn children, children, adults and an elderly viewed in a similar manner when it comes to resuscitation for life threatening and potentially handicapping events?

I designed this questionnaire study while I was a neonatal attending physician, in my early years of practice, and at the end of my course load in bioethics. I wrote the research protocol and the questionnaire study. Keith Barrington helped me do the numerous corrections for it to finally be accepted to the IRB, one year after its submission. Keith Barrington has also helped in the statistical analysis of the results and edited the articles. Isabelle Leblanc is a family physician with training in anthropology and literature. Medically, she has specialized in palliative care at the end of life and in neonatal and paediatric care. She helped me define the target groups, specially relating to students and residents. She is partly responsible for the high rate of response we had for this questionnaire.

The goal of this questionnaire was to determine whether we place a different value on the lives of neonates compared to older individuals. It seemed to me that neonates were not treated like older patients, and that they were perhaps morally different from older patients. Even though I have dedicated my professional career to the care of the newborn, the way I reacted to their deaths was different to my reactions to the death of an older child. Being a physician gives us an invaluable opportunity to do ongoing “qualitative fieldwork”. By speaking to hundreds of parents, some of them with disabled children, some of them with healthy babies or mourning their dead children, one can learn a lot even without transcribing, coding and categorizing information. Generally, the decision-making process for these families was different to the decision-making processes that I had experienced as a resident for older children with similar degrees of critical illness. While many physicians sense this as being true, it is not described in the literature, nor is there empirical evidence to support this perception. My published articles only present data from 524 respondents. Since then, we have proceeded to administer the questionnaire to many Quebec specialists (geriatricians, oncologists, neurosurgeons, etc…), to all Canadian neonatologists, and to students in their last year in medicine, anthropology, and law. We now have more than 1000 questionnaires, with a response rate over 85%. Interestingly, the results in the following 2 articles are very similar to the results we have subsequently generated from the other groups that are not part of these articles. This study has also started in other countries: Saudi Arabia, Ireland, Holland, Norway and the US. We will have to wait to see if the relative devaluation of neonates that we have found in our population is also present in other countries and cultures.

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ARTICLE

Best-Interest Standard Is Not Applied for Neonatal Resuscitation Decisions

Annie Janvier, MD[a], Isabelle Leblanc, MD[b], Keith James Barrington, MB, ChB[a]

Departments of [a]Pediatrics and [b]Family Medicine, McGill University, Montreal, Quebec, Canada

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What's Known on This Subject

If resuscitation is considered to be in an incompetent patient's best interest and significant harm would be caused by not intervening, then refusal of care is generally not accepted, either ethically or legally.

What This Study Adds

Whether resuscitation is considered in a patient's best interests is not closely related to survival rates or disability. Newborn infants and particularly preterm infants are systematically devalued, compared with older patients whose outcomes are the same or worse.

ABSTRACT

OBJECTIVE. Legal and ethical standards require resuscitation when it is considered to be in the patient's best interest. We hypothesized that newborn infants might be dealt with according to different standards, compared with older patients.

METHODS. An anonymous questionnaire describing 8 currently incompetent patients with potential neurologic sequelae who required resuscitation was administered to groups of physicians and students. Respondents were asked whether resuscitation was in the patient's best interest and whether they would comply with the families' wishes if resuscitation was refused.

RESULTS. There was an 85% response rate (*n* = 524). The largest proportions of respondents stated that it was in the best interests of the 2-month-old infant and the 7-year-old child to be resuscitated (97% and 94%, respectively), followed by the 50-year-old patient and the term infant (87%), the 2 patients with 5% chance of survival (76% and 80%), the premature infant (69%), and finally the 80-year-old patient (32%). Approximately one fifth of the respondents who thought that it was in a patient's best interests to be resuscitated would nevertheless accept the family's refusal of resuscitation for all scenarios except the 80-year-old patient (72% acceptance) and the preterm infant (54% acceptance).

CONCLUSIONS. Whether resuscitation is considered in a patient's best interests is not closely related to survival rates or disability. Newborn infants and particularly preterm infants are systematically devalued, in comparison with older patients whose outcomes are the same or worse. Accepting a family's refusal of resuscitation, even among respondents who thought that resuscitation was in the patient's best interest, was much more common for the newborns.

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Key Words

ethics, resuscitation, best-interest standard

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Address correspondence to Keith James Barrington, MB ChB, Department of Pediatrics, McGill University, Room C7.68, Royal Victoria Hospital, 687 Pine Ave W, Montreal, Quebec H3A 1A1, Canada. E-mail: [redacted] 1098-4275).

TECHNOLOGIC PROGRESS HAS increased the limits of medicine and enables many patients to survive or to prolong their lives. Some life-threatening events, for example, meningitis, trauma, and asphyxia, can lead to potentially serious neurologic sequelae and to complex decision-making involving withholding or withdrawal of care. For incompetent patients, these decisions are often made by a surrogate, most often a family member.

Ideally, the decision-making process involving the caregivers and the family of the incompetent patient proceeds smoothly. In reality, individual interpretations of risks, benefits, and outcomes can vary depending on religious beliefs, cultural factors, and ages. When controversies and disagreements exist and the patient has left neither advanced directives nor evidence of any preferences, the patient's surrogate, usually a family member, is consulted. Surrogates are expected to use the patient's best interest as the guiding principle for decision-making.[1,2] Treatments are considered to be in patients' best interests when the benefits of treatment outweigh the risks and burdens. Indirectly, the value of the life of the patient is judged during decision-making. If the caregivers think "that the designated surrogate threatens the patient's best interests, the decision should be overridden,"[1] and such overriding of family decision-making has been supported in the courts.[1,3,4] If resuscitation is considered to be in an incompetent patient's best interest and significant harm would be caused by not intervening, then refusal of care generally is not accepted, either ethically or legally. We wished to determine whether the same decision-making process would be followed for preterm and term infants as for older patients and whether decisions are made on the basis of outcomes or according to other criteria. The goals of this study were to describe how different groups of educated individuals valued patients' best interests, to determine whether survival, disability, poor neurologic prognosis, and age affected these estimates, and to determine whether the best-interest principle is generally followed (ie, if resuscitation is

TABLE 1 Probability of Outcomes for Each of the 8 Patient Scenarios

Age of Patient	Previous Disability	Probability, %		
		Survival	Normal Outcome Among Survivors	New Major Disability
24-wk preterm	NA	50	50	25
Term	NA	50	50	25
2 mo	NA	50	50	25
7 y	Yes	50	0	50
14 y	No	5	80	20
35 y	No	5	0	100
50 y	No	50	50	25
80 y	Yes	50	0	50

NA indicates not applicable.

considered to be in the best interest of an incompetent patient, then how often would family demands to withhold care be accepted?).

METHODS

Between February 2005 and January 2006, we administered an anonymous questionnaire to physicians at McGill University Health Center who were involved in resuscitation decisions. The same questionnaire was administered to university students in different disciplines, including law, anthropology, bioethics, and medicine. Students in law, medicine, and anthropology were first-year students at McGill University. The bioethics students were postgraduate students at the University of Montreal. For the target groups of respondents, our goal was to have >80% participation from the full-time physicians and from the students.

Questionnaires were administered during a group activity where a maximal number of respondents from each target group could be reached, such as a resident/student teaching session or a staff meeting for physicians. We obtained the authorization of the group leader before distributing the questionnaire, and we attended a group activity that was most convenient for all respondents. The first question was a request for consent; if consent was refused, then the questionnaire was collected blank with the others at the end of the period. The first page of the questionnaire contained demographic information (ie, gender, work environment, occupation, residency years, and having children or not). The questionnaires were completed individually and could not be taken home.

Eight scenarios of currently incompetent, critically ill patients with potential neurologic sequelae were presented. All arrived in the emergency department of a university health center when a family member cannot be immediately consulted. The patients were of different ages, and their outcomes were explicitly described; gender or other social information (such as marital status) was not provided (Table 1).

There were 4 patients with a 50% chance of survival, that is, a premature infant at 24 weeks of gestation who has just been delivered, an infant just born at term with a known brain malformation, a 2-month-old infant with bacterial meningitis, and a 50-year-old patient with severe trauma, including head injury, resulting from a car accident. If these patients survived, 50% would be without disability and 25% severely impaired. Two other patients were previously disabled, namely, a 7-year-old patient with multiple disabilities (cerebral palsy, deafness, learning disability, and hyperactivity) and new head trauma and an 80-year-old patient with substantial disability from dementia and a new stroke. Both patients were noted to have a 50% predicted chance of survival and, if they survived, a 50% chance of having additional disability. Two patients were described as having only a 5% chance of survival, that is, a 14-year-old patient with acute myeloid leukemia with central nervous system involvement, with a 20% risk of disability in case of survival, and a 35-year-old patient with brain cancer with a 100% risk of disability with treatment.

The patients were presented in order from the youngest to the oldest. After each patient description, the following questions were asked. (1) Do you think intubating, resuscitating, and consulting intensive care for admission is in the patient's best interest? (2) If the parents/family asked you not to resuscitate, would you respect their decision? (3) If the patient was your child/partner, would you wish the physician to intubate, to resuscitate, and to consult intensive care for admission? (4) If the patient was your sibling's or good friend's child/partner and he or she had a few minutes to consider the decision and asked for your opinion, would you recommend that the physician intubate, resuscitate, and consult intensive care for admission? (5) If the patient were you and you were able to decide, would you want the physician to intubate, to resuscitate, and to consult intensive care for admission? (The last question was asked only for scenarios in which the hypothetical patients were adults.) For each of these questions, respondents could respond on a Likert scale, with the following options: always, generally, exceptionally, or never. Always and generally were counted positive answers.

Proportions were compared by using the χ^2 test with Yates correction; P values of >.01 are reported as not significant. To limit the number of comparisons and to protect against type I errors, in addition to limiting the critical P value for each comparison to .01, the following analyses were performed. For each of the questions, we compared the proportions answering always or generally for the 8 patients with a single χ^2 test and examined comparisons between scenarios only when the overall χ^2 was significant at $P < .01$. Similarly, in comparisons of responses between groups of respondents for a particular question, the overall χ^2 had to be significant at $P < .01$ before individual groups were compared. This study was approved by the McGill University institutional review board.

RESULTS

Study Groups

A total of 615 individuals were in our target groups; 527 received the questionnaire, with 524 respondents (response rate: 85% of the target groups and 99% of participants) (Table 2). All groups had similar response

TABLE 2 Description of Respondents

	Total	Students	Physicians	Residents	Staff Members
Target group, *n*	615	417	198	86	112
No. reached	527	359	168	72	96
No. answered	524	357	167	72	95
Response rate, %	85	86	84	84	85
Female, %	53	52	55	61	51
Have children, %	22	9	50	28	67
Junior resident, %	NA	NA	NA	56	NA
<5 y of practice, %	NA	NA	NA	NA	30

Response rate describes those in the target group who filled in the questionnaire. Total respondents include both students and physicians. The physician group includes residents and staff members.

rates. Fewer students than physicians had children ($P <$ .0001). Of the 357 student respondents, 107 were in law, 88 in anthropology, 139 in medicine, and 23 in bioethics. Of the 95 attending staff members, 32 were in family medicine, 23 in obstetrics, 12 in neonatology, and 28 in emergency medicine (adult and pediatric). There were 86 residents, 20 in obstetrics, 33 in pediatrics, and 19 in family medicine.

Best Interests

The 2-month-old infant and the 7-year-old child with multiple disabilities had the largest proportions of respondents stating that it was always or generally in their best interest to be resuscitated (97% and 94%, respectively; not significant in comparison with each other; $P < .001$ in comparison with all other patients), followed by the 50-year-old patient and the term infant (both 87%; $P < .01$ in comparison with all other patients). For the 2 patients with a 5% chance of survival, 76% and 80% of responses were always or generally (not significant in comparison with each other; $P < .005$ in comparison with all other patients). For the preterm infant, 69% estimated that it was in the patient's best interests to be resuscitated ($P < .001$ in comparison with all other patients). Finally, the smallest proportion of respondents estimated that it was in the best interests of the 80-year-old patient to be resuscitated (32%; $P < .001$ in comparison with all other patients) (Fig 1).

If It Were Your Own Child, Partner, or Sibling

The proportions desiring resuscitation for their own child, partner, and sibling were almost identical and were not significantly different from the proportions thinking it to be in the patient's best interest to be resuscitated. Most groups of respondents wanted resuscitation for their preterm infant significantly less than for all other children, with neonatologists being exceptions (92%, same as for other infants). Ethics students wanted to resuscitate their own child, partner, or sibling less than all other groups for all scenarios ($P < .01$) except for the 80-year-old patient, for whom the responses were not significantly different.

If It Were You

The respondents wanted resuscitation for themselves in smaller proportions than for their partner or sibling for all 3 adult scenarios ($P < .01$ for all comparisons). For example, for the 80-year-old scenario, 36% would never want resuscitation for themselves, compared with 15% for a sibling or partner ($P < .001$). For these 3 questions, there was no significant difference between the students' answers and those given by physicians. The answers were not different between respondents who had children and those who did not.

Best Interests Versus Accepting Nonresuscitation

The 80-year-old patient was the patient with the most respondents accepting the family's wish not to resuscitate (88%; $P < .001$ in comparison with all other patients), followed by the preterm infant (66%; $P < .001$ in comparison with all other patients) and then by the 2

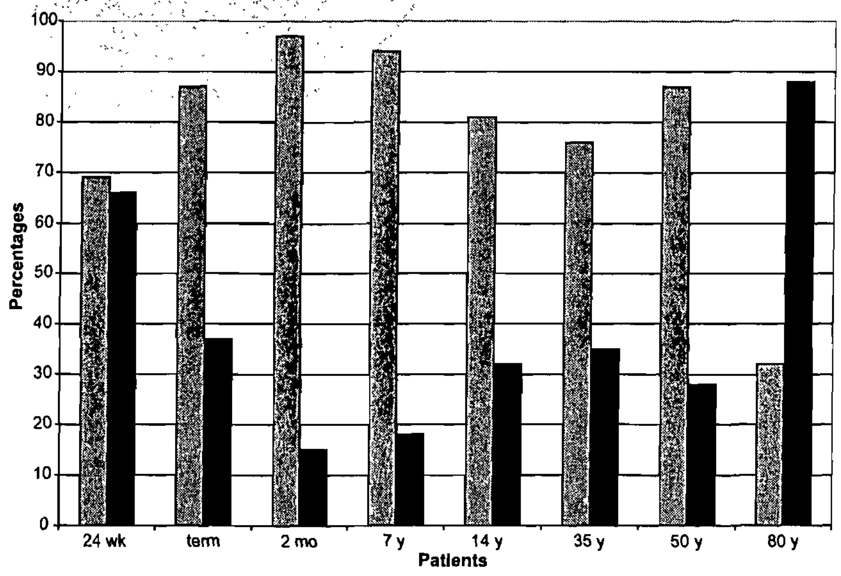

FIGURE 1
Percentage of respondents who thought it was in a patient's best interest to be resuscitated and transferred to intensive care (gray bars) and the percentage of those who would accept withholding care from the same patients (black bars).

TABLE 3 Proportion of Respondents Who Would Withhold Care at the Family's Request, Among Those Who Considered Resuscitation to Be Always or Generally in the Patient's Best Interest

Patient in Scenario	Respondents Who Stated That Resuscitation Was Always or Generally in Patient's Best Interest		Respondents Who Stated That Resuscitation Was Always in Patient's Best Interest	
	n	Proportion Who Would Withhold Resuscitation at Family's Request, %	*n*	Proportion Who Would Withhold Resuscitation at Family's Request, %
24-wk preterm neonate	364	53.6[a]	53	18.9[b]
Term neonate	459	29.6[a]	142	14.8
2-mo-old	509	15.3	202	5.4
7-y-old	490	16.3	205	7.8
13-y-old	420	22.6	152	11.2
35-y-old	397	22.4	73	12.3
50-y-old	458	21.4	65	10.8
80-y-old	169	71.6[a]	19	36.8[a]

[a] Significantly different from all other scenarios.

[b] Significantly different from the 2-month-old, 7-year-old, and 80-year-old scenarios.

patients with a 5% chance of survival (32% and 35%; $P < .01$ in comparison with the 50-year-old patient) and by the 50-year-old patient. In contrast, the 2-month-old infant and the 7-year-old child were the patients who had the largest proportions of respondents not accepting the withholding of resuscitation (15% and 18%, respectively; not significant in comparison with each other; $P < .005$ in comparison with all other patients).

Not surprisingly, the large majority of respondents who thought it was exceptionally or never in the patient's best interests to be resuscitated would accept family refusal of intervention for each of the scenarios (>95% would always or generally accept refusal, for all scenarios). Among those who stated that it was always or generally in the patient's best interest to be resuscitated, between 15% and 22% would accept family refusal of intervention for each of the scenarios except for the newborn infants and the 80-year-old patient; significantly more would accept withholding care for the newborns and the 80-year-old patient ($P < .0001$) (Table 3).

When findings were analyzed only among the smaller number of respondents who thought that resuscitation was always in the patient's best interest, there remained a statistically significant variation in the numbers of those who would accept the family's refusal to resuscitate ($P < .001$). The individual comparisons that were statistically significant were the 80-year-old patient in comparison with all other patients ($P < .0001$) and the preterm infant in comparison with the 2-month-old infant and the 7-year-old child ($P < .001$) (Table 3).

Among those who thought that it was in the patient's best interest to be resuscitated, physicians accepted refusal of care statistically more often than students for all patients ($P < .01$) except the 80-year-old patient, for whom there was no difference. Among the students, the bioethics students stood out; they were much more likely to accept family refusal for all cases, even when they thought that resuscitation was in the patient's best interests ($P < .01$) (Fig 2). The answers were not different between respondents who had children and those who did not.

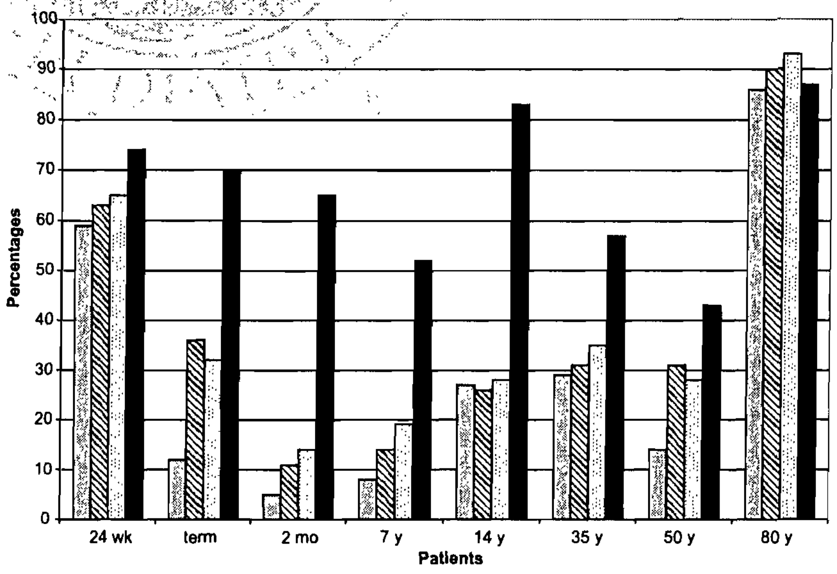

FIGURE 2
Percentage of student respondents who would accept family refusal of care. Bars indicate the difference between students in various disciplines. Gray: medicine; hatched: law; dotted: anthropology; black: ethics.

DISCUSSION

Decisions about initiating or withdrawing intensive care often are based on the best-interest principle, which takes risks and benefits in consideration. In this study, the majority (69%) thought that resuscitation was in the best interest of a 24-week preterm infant, but a significantly larger majority thought that resuscitation was in the best interests of a term infant and a 2-month-old infant with identical outcomes, an already seriously impaired child, an older child with 5% chance of survival, and even an adult with 5% chance of survival and 100% chance of permanent disability. The 80-year-old patient who already had moderately severe dementia was the only case with fewer respondents than for the preterm infant considering it in the patient's best interest to be resuscitated. Therefore, there seems to be a different value placed on life at its extremes, which, with the potential for many years of life to be gained, is particularly surprising for those just born. Survival rates seemed to have some influence on estimates of best interests but, for the 2 patients with 5% predicted chance of survival, including the patient with no chance of intact survival, significantly more respondents than for the premature infant thought it was in the patient's best interest to be resuscitated. Disability did not seem to influence respondents, because the 7-year-old child who already had multiple disabilities had the largest proportion of respondents estimating that it was in the patient's best interests to be resuscitated.

We found that a judgment of best interests was closely related to a desire to treat one's own child or partner; this may be a sign that what we want for our own families becomes the approach that we consider to be in the best interests of patients in general. It was also interesting that, for all of the adult scenarios, more respondents would want resuscitation for their partner or sibling than for themselves. Does this reflect a sense of duty to those to whom we are closest?

It is generally accepted that a treatment that is considered to be in a patients' best interest should be pursued.[1–4] Several authors contest this, however, especially in the field of incompetent or pediatric patients, and give more importance to minimizing harm.[5,6] For example, although vaccination is clearly in a child's best interests, one does not remove a child from his or her parents' custody solely because of refusal of basic vaccinations, because removing a child from the family may do much more harm.[5,6] For the patients in our scenarios, the harm risked through withholding care is death, and how respondents balance that potential harm with the "harm" of either intact survival or the possibility of lifelong handicap warrants additional investigation. Others have suggested that a standard of "reasonableness" would be preferable[7]; however, such a standard also would require a subjective assessment of whether it is reasonable to allow the infant to die, rather than having a chance of survival with an uncertain future.

Our results showed that, for all patients, ~1 of 5 respondents would be prepared to withhold resuscitation at the families' request, even when the respondents considered resuscitation to be in the best interests of the patient. We were surprised that the proportions were identical among all subgroups, including anthropology and law students, who had not received any formal training in this sort of decision-making, and staff physicians, who presumably had been exposed to bioethical reasoning. The exception was the bioethics students, who were prepared in a very large proportion to withhold a life-saving emergency intervention that they considered to be in an incompetent patient's best interest at the request of the family; this could point to the importance that autonomy has in the bioethics curriculum or the underlying values of those who self-select to enter the field of bioethics.

This abrogation of the best-interest principle was most marked for the 2 patients at the extremes of life, for whom more than one half of respondents who thought that resuscitation was in the patient's best interests would accept family refusal of intervention. The differences between patients were also significant even among those who were more definite and answered that it was always in the patient's best interest to be resuscitated; the 80-year-old patient and the preterm infant still elicited a greater willingness to withhold resuscitation than did the other patients. It seems that accepting withholding of resuscitation is somehow easier for the very old and the very young. Waring,[8] a philosopher and bioethicist, remarked that the value of persons is indicated by how we react to their deaths, "feelings of tragedy, evil, loss and sharp regret are supposedly more appropriate responses to the deaths of younger people." One might view the deaths of older people as tolerable. Indeed, it is not rare to hear that it is "better this way, nature took its course" or "he lived long enough" for an older individual.[8] Similar statements ("it is better this way, nature took its course" or "at least she didn't suffer") are also made for premature infants by staff members and by families. Perhaps the premature infant has not yet lived long enough?

For resuscitation decisions, some authors think that age should have in impact in decision-making and have proposed setting an upper age limit for resuscitation[9,10]; this is very controversial.[11–13] There seem to be no official policies or professional association guidelines that suggest an age limit for resuscitation, with the exception of premature infants.[14–18] At 24 weeks of gestation, many national associations deem prognosis to be so poor that life-saving interventions are considered optional and performed only with explicit family consent.[19] The survival chance and the probabilities of long-term disability for the 24-week patient in our survey were designed to reflect conservatively the actual chances of an infant delivered at 24 weeks of gestation in a Canadian tertiary care center.[20–26] We can find no other population in the literature for which a 50% survival rate and a 50% rate of normal outcomes among survivors would be seen as dismal enough to defer life and death decisions entirely to the family. Policy statements for preterm infants often state survival and disability rates as justification for optional intervention,[13–17] but our results suggest that underlying, widely held beliefs about the value of the life of

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a newborn may have a major influence on such recommendations.

The reduced value placed on the life of newborns, and particularly the preterm infant, by our respondents is less than expected on the basis of any objective medical data. In fact, this limitation of their value is probably not related to medical factors, because physicians and students had almost identical answers. What does explain these differences? It has been suggested that the proximity of gestational ages at which abortions are performed is relevant to resuscitation decisions.[27] This suggests that decisions regarding life and death for newborns, especially premature infants, may still be in the realm of reproductive choice and essentially considered a family decision. Perhaps there is a diminished sense of duty toward the premature infant. This would explain why so many respondents would be ready to accept withholding resuscitation even if they thought that resuscitation was in the patient's best interest. Several authors also suggested that newborns do not have the same status as older individuals, because they lack personhood.[26,28–32] Although there is no general agreement on this issue, our responses fit a general assessment that newborns were of less value. Even the respondents who had children and had personally experienced the gradual development of personhood in an infant had the same answers. Is the systematic devaluation of newborns attributable to more-deeply rooted anthropologic, cultural, social, and evolutionary factors? Until recently, most parents had experienced the death of a newborn or an infant, often several times; perhaps the necessary protective mechanisms to avoid continual grief over the loss of newborns have caused us to devalue them.

Because of our high response rate, we know that the results accurately reflect the opinions of our target population, but these cannot be directly extrapolated to other groups or cultures. Also, all questionnaire studies have their inherent limitations. We do not know whether opinions would translate into actions if the respondents were in the specific situations. In this study, the scenarios were variably unrealistic; very few preterm infants are delivered in an emergency department, for example. Even for this scenario, however, it does occasionally happen that a mother delivers in the emergency department and we must decide whether to initiate resuscitation without discussing the issue at length with the mother. More importantly, this was a conscious decision to make the scenarios as consistent as possible except for the ages and outcomes of the patients. Also, the order of presentation of the cases was the same for all respondents in this study. We considered trying to randomize the order, but this was not feasible logistically. We decided to present the scenarios in the order of the patient's age because this would seem logical and unbiased to the participants, but we cannot rule out the possibility that a different order of presentation might have produced some differences in the results.

The range of caregivers and students we approached reflected the groups for which we could use a method that has provided us with very high response rates in the past and therefore eliminates the common concern regarding response bias in questionnaire studies. We were able to obtain agreement from directors of programs and courses to approach their students, residents, or staff members. This led to the choices we made regarding groups of respondents, which we tried to make as varied as possible to obtain a wide representation. We recognize that some respondents are rarely or never involved in these decisions during their working lives. However, the remarkable consistency between most groups of physicians and students suggests that these attitudes have little to do with training or experience. The groups of physicians and students were very heterogeneous but, to avoid inflating the number of exploratory analyses, we did not search out differences between some of the possible subgroups, Therefore, it may be that important systematic differences in responses were masked. Additional research is needed to explore the underlying reasons for these responses. Neonatologists in particular might respond differently to some of these ethical dilemmas in very preterm infants, because they might have had frequent actual experiences with such decisions.[33] Our initial sample of neonatologists was too small to draw any conclusions. Estimating an individuals' best interest indirectly demands placing a value on his or her life; the results of our study show that the lives of newborn infants, particularly preterm infants, are systematically devalued in comparison with others, both by physicians and by a nonmedical educated population.

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Nobody likes Premies: The relative value of patients' lives

Annie Janvier MD[1], Isabelle Leblanc MD[2], Keith J Barrington MB ChB[1]

1. **Department of Pediatrics: McGill University, Montreal, Quebec, Canada**
2. **Department of Family Practice: McGill University, Montreal, Quebec, Canada**

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Corresponding author:

Keith J Barrington
Professor of Pediatrics and Obstetrics & Gynaecology
McGill University
Director NICU
Royal Victoria Hospital
687 Pine Ave W
Montréal
Québec
H3A 1A1
Canada
514 934 1934 #34876
Fax 514 843 1741
[redacted]

Abstract

Introduction: Patient selection requires placing a relative value on human lives.

Methods: An anonymous questionnaire, administered to groups of physicians and students, presented 8 currently incompetent patients with potential neurological sequelae requiring emergency care.

Predicted outcomes were explicit: four patients, preterm and term newborns, 2-month-old and 50-y-old: 50% survival, and 50% chance of impairment. Two disabled patients, 7-y-old and 80-y-old with 50% survival. A 14-y-old and a 35-y-old had 5% survival, but differing impairment. Respondents were asked if they would resuscitate, and in what order they would resuscitate if all needed it simultaneously.

Results: 85% response rate, n=524. The proportion stating they would always resuscitate was smallest for the 80-y-old (18% p<0.001), then the preterm (35%, p<0.001), then the term and the 50-y-old (53% and 58%, p<0.01). The 2-month-old and the 7-y-old would be resuscitated most frequently (74% and 77%, p<0.01), followed by the patients with 5% survival (64% and 68%, p<0.001). The median order of triage was first the 2 month-old, followed by the 7-y-old, the 14-y-old, the term newborn, the 50-y-old, the 35-y-old, the premature newborn and the 80-y-old.

Conclusion: Order of resuscitation was not closely related to the predicted survival, impairment, or potential life years gained. Age probably has the strongest influence, with children's lives being valued more than adults', except for the newborns. The value placed on the life of newborns, in particular the premature, is less than expected by any objective medical data and was not consistent with any ethical theory that we tested.

Introduction

Technological and medical progress has increased the demands for intensive care; admissions to ICUs create significant costs and may need to be prioritized when multiple eligible patients are waiting for an available bed. For an individual patient, whether a specific treatment is of any benefit, is an ethically charged question. When more than one patient is eligible for intervention and resources are scarce, these considerations become even more complex[1,2,3]. Many ethical theories have been used to analyze patient selection for scarce resources. The differing options for making decisions in such circumstances can be thought of as representing the 2 opposing views of best outcomes versus fair chances[1,4,5]. Utilitarians believe that patients with the best outcomes have priority while the egalitarians believe all patients have an equal claim to life and deserve a fair chance[1,6,7,8]. Some authors have refined this to include an initial minimal medical inclusion criterion and allocate resources to the remaining patients[9,10,11]. How age is weighted in these considerations is also problematic because it may influence medical utility, but may also insidiously introduce social utility into the decisions[2,6,12].

Aim of study: To determine how groups of physicians and university students in bioethical disciplines value hypothetical patients.

Hypothesis: Patients with a low survival will be valued less. Patients at the extreme of life will be valued less than other patients with similar outcomes.

Methods:

Between February 2005 and January 2006, we administered an anonymous questionnaire to physicians involved in resuscitation decisions and to university students in different disciplines during a group activity where a maximum number of respondents could be reached. Eight scenarios of currently incompetent critically ill patients with potential neurological sequelae were presented. All arrived in the Emergency Department of a university health center, when a family member cannot be consulted. Physician respondents were associated with McGill University. Students in law, medicine and anthropology were first year students from McGill University. The bioethics students were postgraduates from University of Montreal. We have previously published a manuscript using data derived from answers to a different group of questions from this study (addressing the issue of best interests), which were designed around the same patient scenarios described below.

The first question was a request for consent; all questionnaires were completed individually and were collected immediately. The first page comprised demographic information.

The patients were of different ages, their outcomes were explicitly described; gender or other social information such as marital status was not given. Four of the patients had a 50% chance of survival: a 24-week gestation premature who has just delivered, a baby just born at term with a known malformation, a 2 month-old with meningitis and a 50-y-old after a car accident. If they survived, 50% would be without impairment, 25% mildly or moderately impaired, and 25% severely impaired. Two other patients were already disabled: a 7-y-old with multiple disabilities (cerebral palsy, deafness, learning disability, hyperactivity) with a new head trauma, an 80-y-old with dementia and a new stroke. Both were noted to have a 50% predicted survival and, if they survived, a 50% chance of having further impairment. Two patients had 5% survival: a 14-y-old with acute myeloid leukemia (CNS involvement) with 20% risk of impairment and a 35-y-old with brain cancer with 100% risk of handicap with treatment. The patients were presented in order from the youngest to the oldest.

Resuscitation

After each patient, the following question was asked: "*Would you intubate, resuscitate and consult intensive care for admission?*" Respondents could respond on a Likert scale, with the following options: "always", "generally", "exceptionally" or "never".

Patient ranking

Participants were asked in what order they would resuscitate the patients if all needed intervention at the same time (ranking 1-8, with 1 being the first to be resuscitated). To evaluate the rankings we calculated the mean, the median and the sum of the rankings. The lower the sum, the earlier the patient would be resuscitated.

Ethical approaches to patient selection

The two polarized ethical positions are equal chances versus best outcomes[1,6,5]. A strict egalitarian would use random allocation to determine patient ranking[13,14,15]. Other authors initially determine minimal medical criteria for eligibility, and then decide for the remaining patients[9,10,11]. For example, the criterion could be a predicted survival of $\leq$ 5 years, which would exclude the 14, 35 and 80-y-old.

A utilitarian approach could be based on survival, or disability, or could combine both using QALYs. For each of these patients, we calculated the Quality Adjusted Life Years (QALYs) in the manner described by Doyle et al[16], this information was not given to the respondents. An age based ranking in favour of the young would rank younger candidate before older ones[17,18]. We evaluated whether patient ranking would fit any of these patterns of patient selection.

This study was approved by the McGill University institutional review board.

Statistics: Proportions were compared using the Chi-square with Yates correction. Because of the large group of respondents, the threshold for significance was set at $p < 0.01$.

Results:

615 individuals were in our target groups, 527 received the questionnaire with 524 respondents, table 1 (response rate: 85% of the target groups, 99% of participants). All groups had similar response rates. Students had fewer children than physicians ($p<0.0001$). Of the 357 student respondents, 107 were in law, 88 in anthropology, 139 in medicine and 23 in bioethics. Of the 95 attending staff, 32 were in family medicine, 23 in obstetrics, 12 in neonatology, 28 in emergency medicine (adult and pediatric). There were 86 residents: 20 in obstetrics, 33 in pediatrics and 19 in family medicine.

Intubation and consultation to intensive care

The 2 month-old and the 7-y-old multiply disabled child had the largest proportion wanting to always resuscitate (74% and 77%; $p<0.01$ compared to others), followed by the 2 patients with a 5 % survival (64% and 68%; $p<0.001$ compared to others, figure 1). Conversely, the 80-y-old was the least likely to be always resuscitated (18% $p<0.001$), followed by the premature infant (35%, $p<0.001$), followed by the term infant and the 50-y-old (53% and 58%; $p<0.01$ compared to others). Sex of the respondents or having children did not affect the answers.

When pooling the responses "always" and "generally", $\geq$ 96% of responses supported resuscitation for all patients except for the premature infant and the 80-y-old (79% and 70%, $p < 0.001$). For all patients, less than 1% of respondents answered they would *never* resuscitate, except for the premature infant and the 80-y-old (8% and 7%, $p < 0.01$).

Students' answers followed the same statistically significant pattern as those given by physicians.

Patient ranking

The median order of resuscitation for all respondents was: 1st: 2 month-old with meningitis, 2nd: 7-y-old impaired child, 3rd: 14-y-old with leukemia, 4th: term infant with malformation, 5th: 50-y-old in car accident 6th: 35-y-old with brain cancer, 7th: premature infant and last 80-y-old with a new stroke (Table 2). Physicians and students had very similar rankings (Table 2). All subgroups ranked the 2 month and 7-y-old in first positions, the 14-y-old in 3rd or 4th position, and the premature infant in 6th or 7th position. The patient with the most rankings in either 7th or 8 position was the 80-y-old (503 responses, $p<0.001$), followed by the premature either 7th or 8 position was the 80-y-old (503 responses, $p<0.001$), followed by the premature infant (242 responses, $p<0.001$), and then by the other 2 adults (Figure 3). All other children had less than 35 respondents ranking them 7th or 8th; no respondents ranked the 2 month old either 7th or 8th.

Ethical approaches to patient selection

Random allocation was not used to rank patients; if respondents followed this model for decision-making, all patients should have had a mean ranking of 4.5 (see Table 2). The significant differences in ranks is statistical evidence that random allocation was not used, otherwise there would have been no significant difference between average patient ranks.

Patients with a probable £ 5 year predicted survival were rarely ranked in the last positions, except for the 80-y-old. 58 respondents (11%) ranked these patients (14, 35 and 80-y-old) in the last three positions. 2.5% of respondents ranked the two patients with a described 5% survival in the last two positions.

Disability by itself did not influence ranking: Only 3 respondents (0.6%) ranked the two patients with pre-existing disabilities, and the 35-y-old with a 100% probability of disability in last three positions and 17% ranked the 35 and the 80-y-old in the last two positions.

Because the 24-week infant, term and 2 month infant have identical survival and outcomes, they have identical QALYs: 32. Calculated QALYs for the remaining patients are: 7-y-old: 17, 14-y-old: 3, 35-y-old: 1.2, 50-y-old: 12, 80-y-old: 1.2. Only two percent of respondents placed the 3 patients with the highest QALYs in the first 3 positions.17% placed the 2 patients with the lowest QALYs in the last two positions. Significantly more respondents ranked the 35 year old before the newborn infants than the other way around, which is statistical evidence that the QALY model was not used for patient selection.

There was preferential ranking in favour of the children, except for the newborns. For example, 75% ranked the 2 month-old before the 50-y-old (who had identical predicted outcomes), and 75% ranked the 14-y-old before the 50-y-old despite the older patient having much better outcomes. Newborns were the exception to this rule, only 19% of respondents infant (242 responses, $p<0.001$), and then by the other 2 adults (Figure 3). All other children had less than 35 respondents ranking them 7th or 8th; no respondents ranked the 2 month old either 7th or 8th (Figure 3).

Ethical approaches to patient selection

Random allocation was not used to rank patients; if respondents followed this model for decision-making, all patients should have a mean ranking of 4.5 (see Table 2). Furthermore, not all subgroups followed the same non-random pattern or ranking.

Patients with a probable ≤ 5 year predicted survival were rarely ranked in the last positions, except for the 80-y-old. 58 respondents (11%) ranked these patients (14, 35 and 80-y-old) in the last three positions. 2.5% of respondents ranked the two patients with a described 5% survival in the last two positions.

Disability by itself did not influence ranking: Only 3 respondents (0.6%) ranked the two patients with pre-existing disabilities, and the 35-y-old with a 100% probability of disability in last three positions and 17% ranked the 35 and the 80-y-old in the last two positions.

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There was preferential ranking in favour of the children, except for the newborns. For example, 75% ranked the 2 month-old before the 50-y-old (who had identical predicted outcomes), and 75% ranked the 14-y-old before the 50-y-old despite the older patient having better outcomes. Newborns were the exception to this rule, only 19% of respondents ranked all five children in the first 5 positions. 61% of respondents ranked the 35-y-old (with 5% survival and 100% disability) before the preterm who had much better outcomes. The extremes of life had a strong effect on ranking: 263 respondents (50%) ranked the premature infant and the 80-y-old in the two last positions. The responses did not fit any described theory of patient allocation.

Discussion

This questionnaire study examined the relative value given to patients' lives when all needed immediate life saving medical care. This is called triage by some authors and is different from resource allocation when all patients are stable[9].We believe this is the first attempt to develop empirical data regarding physician and "lay educated persons" attitudes toward triage decisions. The respondents were informed that the hypothetical patients needed intervention and intensive care to stay alive. Patient selection is described as a two-stage process by several authors[9,10,11]. The first step determines which patient is suitable for the intervention. For example, a patient dying of metastatic cancer will probably not be eligible to receive a liver transplant. Our first question: "*Would you intubate, resuscitate and consult intensive care for admission?*" selected patients to be in the candidate pool. The second step involves comparing the patients[9,10,11,19]. Our second question, asking how respondents would rank patients were they all to arrive at the same time, forced the respondents to directly compare patients.

The 80-y-old would be resuscitated by fewer respondents than all the other patients, presumably because of his age and dementia. At the other end of life, the preterm, despite having identical probabilities of various outcomes as the term infant, the 2 month-old with meningitis and the 50-y-old trauma victim, would be resuscitated by fewer respondents. Children in general would be resuscitated more frequently and before the adults, except for the preterm. Survival and disability (or potential for) did not seem to influence the frequency with which patients would be resuscitated. For example, the multiply handicapped 7-y-old was the patient most respondents would resuscitate. It appears that patients at the extremes of life are not always in the candidate pool.

Survival appeared to have some influence on ranking, with the 14-y-old ranked after 2 other children. Disability, in contrast, did not seem to influence respondents, the 7-y-old being resuscitated in second position by all subgroups. It does not appear that respondents ranked patients in an egalitarian way, using random allocation. A utilitarian approach uses ability to benefit from an intervention as measured in quality and quantity of life gained to compare patients. However, rankings did not reflect the potential quality adjusted life years gained. Several human rights codes prohibit discrimination on the basis of age[20]. But age, as well as influencing medical utility, can also indirectly suggest a certain social value.[2,6,12] With the exception of the newborns, the respondents overall favored the young over the old.

The relative value placed on the life of newborns, in particular the preterm, is less than expected by any objective medical data and did not reflect any ethical theory that we analyzed. Interestingly, the few weeks difference between the preterm, the term and the 2 month-old made a big difference. Several authors have suggested that newborns do not have the same status as older individuals, because they lack personhood.[21,22,23,24,25] If, as stated by some authors, the acquisition of personhood occurs at 2 months and that patients with cognitive limitations also have limited personhood; 50% of the respondents ranked the extremely young and the extremely old according to personhood.[23,24,26] Other reasons for the devaluation of the preterm infant could be a diminished sense of duty towards them, or even the fact that abortions are performed at similar gestational ages, suggesting that life is perhaps still optional. Are they victims of the media, where the focus is on miracles and disasters?[27,28] The disease process could also interfere, and when seeing the word "premature", maybe the respondent did not read further and assumed a bad outcome. Medical knowledge did not contribute as the physicians and the students had almost identical answers. Is the systematic devaluation of the newborn due to deeper-rooted anthropological, cultural, social and evolutionary factors? Until recently, most parents had experienced the death of a newborn or an infant, perhaps the necessary protective mechanisms to avoid continual grief over the loss of newborns has caused us to devalue them. Waring remarks that the value of a person is given by how we react to their death: "feelings of tragedy, evil, loss and sharp regret are supposedly more appropriate responses to the deaths of younger people. One might view the deaths of older people as tolerable. Indeed, it is not rare to hear that it is "better this way, nature took its course", that "he lived long enough" for an older individual[29]. Similar statements ("it is better this way, nature took its course", "at least she didn't suffer") are also said for premature babies; maybe the premature infant has not yet lived long enough?

Is it reasonable to want to fix an age limit for resuscitation purposes? Zweibel and colleagues found in a national survey that most of their respondents would accept withholding of life-prolonging medical care from critically ill older patients, but few would use age alone as a criterion[30]. Setting an upper age limit for resuscitation is not a new concept[31,32]. Some authors justify this with the "fair inning" argument: in order for all individuals to have a fair opportunity, everybody is entitled to live a proper lifespan.[17,29,33] The view that it is appropriate to include age in some decisions about resource allocation is clearly not unanimous[34,35,36], and we could find no policy or professional association guidelines suggesting an age limit for resuscitation decisions, except for premature infants.[37,38,39,40,41] At 24-week gestation, many national associations deem prognosis to be so poor that life-saving interventions are considered optional. The survival rate, and the probabilities of long-term disability of the 24-week patient in our survey were designed to conservatively reflect the actual chances of an infant delivered at 24 weeks gestation in a Canadian tertiary care centre[42,43,44,45,46,47,48]. We can find no other population in the literature in which a 50% survival rate and 50% "normal outcome" among survivors would be seen as too dismal to justify resuscitative efforts. Policy statements for preterm infants often state survival and handicap as justification for optional intervention,[37,38,39,40,41] but other factors, those which influenced our respondents, whatever they may be, appear to be more important.

Because of our high response rate, we know the results accurately reflect the opinions of our target population, but these cannot be directly extrapolated to other groups or cultures. Also, all questionnaire studies have their inherent limitations: we do not know if opinions would translate into actions were the respondents in the specific situation. This study does not explain why caregivers think this way, and only allows us to develop hypotheses. Further research is needed to continue exploring these avenues.

This research is the first of its kind. Patients such as the ones we describe would have all died 100 years ago, and decisions to rank them would have been irrelevant as it was "nature" that decided the outcomes. Policies, administrators and physicians now decide if a patient lives or dies, and which patient to admit to the last intensive care bed. Physicians are often caught in the conflicting role of doing the best for an individual patient, while at the same time trying to use society's resources judiciously.[49,50] When these two roles conflict value judgments are required. The results of our study are consistent and tell the same story. Some lives will systematically be devalued when compared to others. It is important we are aware of these biases as they will likely influence our decisions.

	Total	**Students**	**Physicians**	**Residents**	**Staff**
Target group: n	**615**	417	198	86	112
n reached	**527**	359	168	72	96
n answered	**524**	357	167	72	95
Response rate%	**85**	86	84	84	85
female (%)	**53**	52	55	61	51
children (%)	**22**	9	50	28	67
junior resident (%)	**NA**	NA	NA	56	NA
< 5 y of practice (%)	**NA**	NA	NA	NA	30

Table 1: description of respondents. Response rate describes who in the target group filled the questionnaire. Total respondents are students and physicians. The physician group comprises residents and staff.

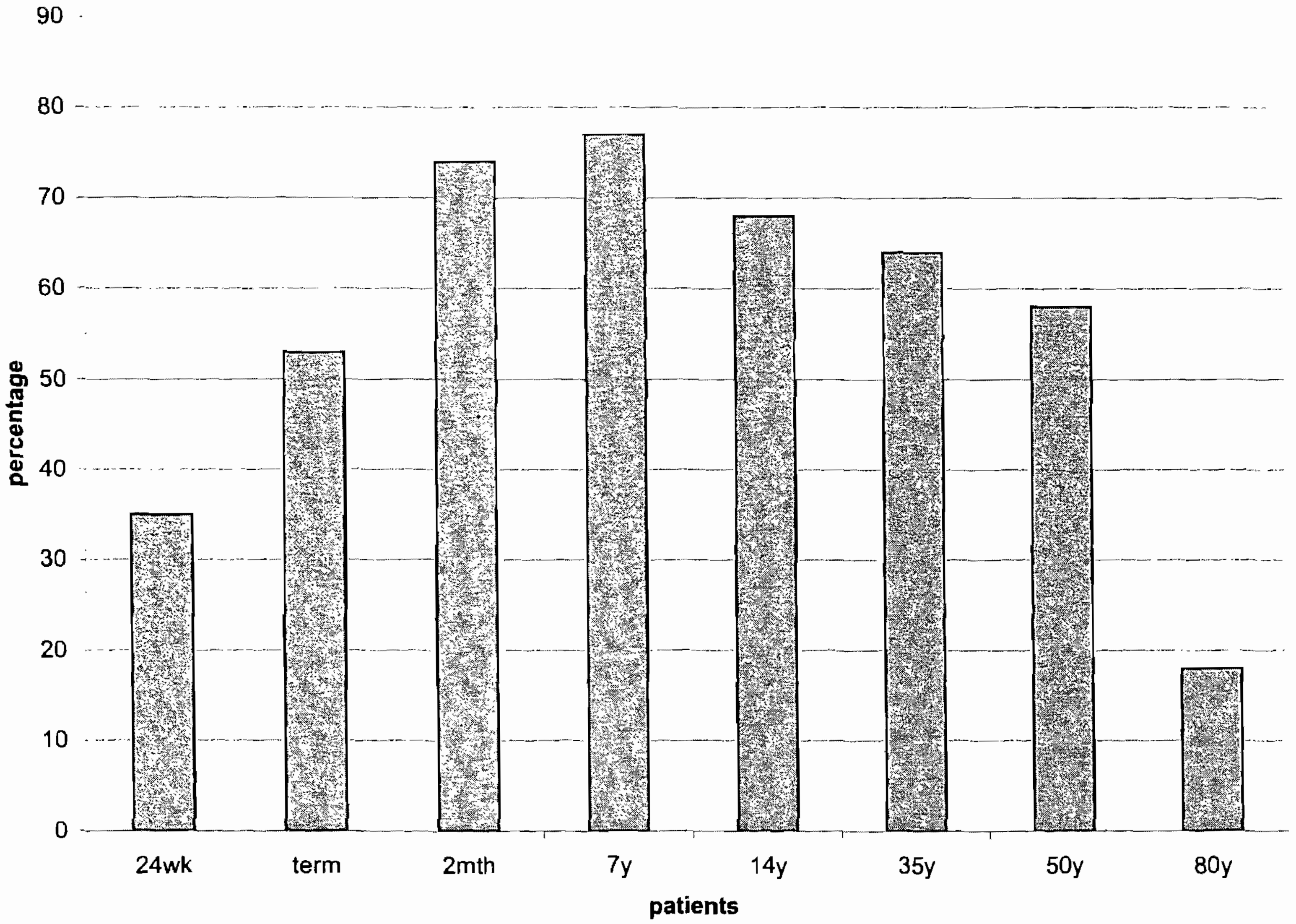
	Median ranking, all respondents (n=524)	Median ranking, Students (n=357)	Median ranking, physicians (n=167)	Total of the ranks	Mean Rank	Mode rank
24wk preterm	7	7	7	2960	5.7	7
Term	4	3	4	2027	3.9	4
2 month	1	1	1	1091	2	1
7y	2	2	2	1279	2.4	1
14y	3	4	3	1987	3.7	4
35y	6	6	6	2739	5.2	6
50y	5	5	5	2663	5.1	6
80y	8	8	8	4059	7.7	8

Table 2: Ranking of patients.

Legends for Figures

Figure1: Percentage of respondents who would always intubate and consult intensive care for the hypothetical patients

Figure 2: Number of 7th and last rankings given by respondents for each patient.


90
80
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percentage
24wk
term
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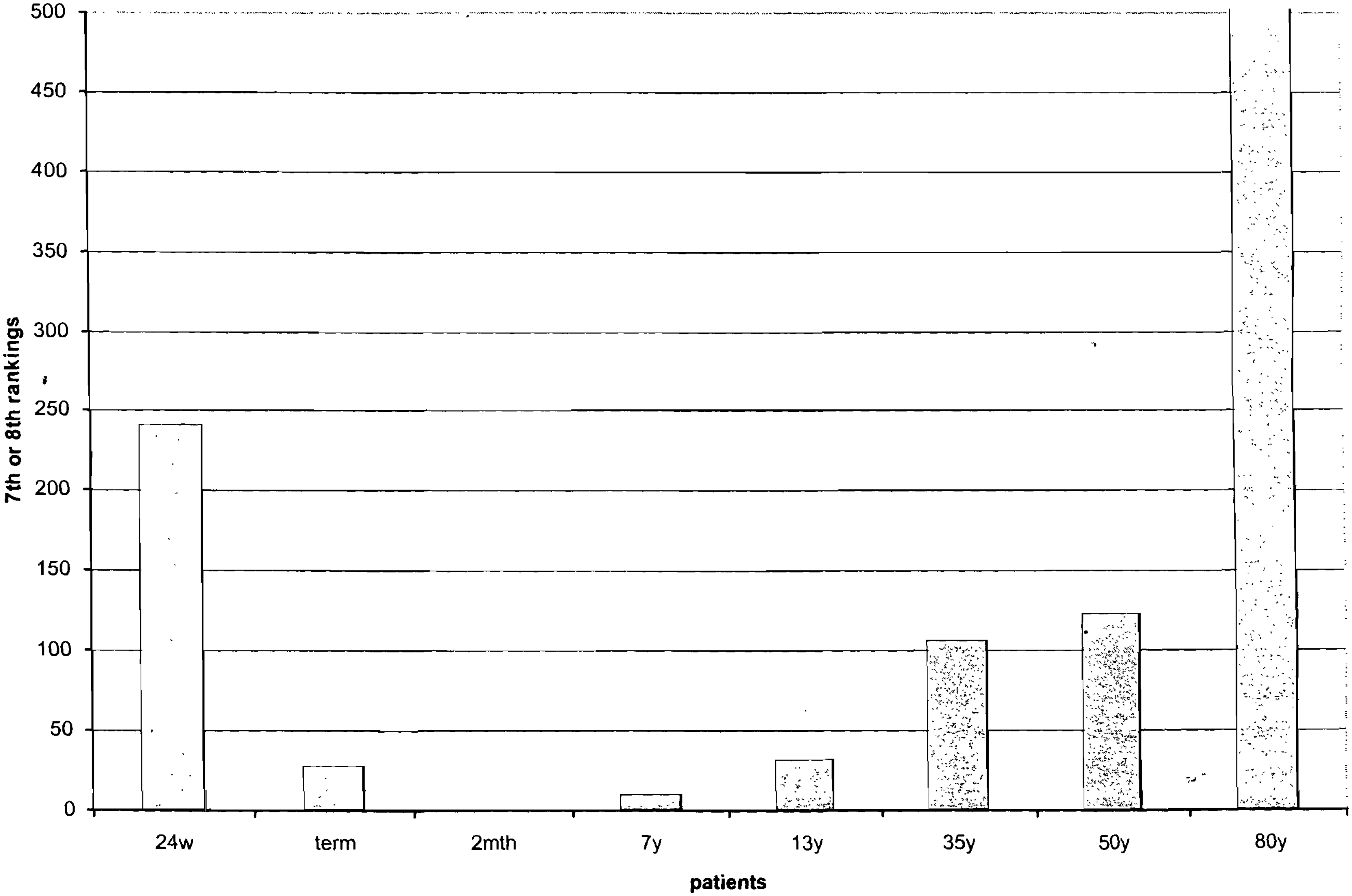
35y
50y
80y
patients



7th or 8th rankings
500
450
400
350
300
250
200
150
100
50
0
24w
term
2mth
7y
13y
35y
50y
80y
patients

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PART III

The moral difference between neonates and older patients

The last part of this PhD thesis explores why the neonate is perceived to be different to older patients. The following article is an opinion piece. Dr John Lantos, knowing my PhD thesis was on the subject, asked me if I was interested to write an article on this topic. I wrote the first draft of this paper. He and Karen Bauer, a medical student in Chicago with an interest in bioethics, have reviewed and edited the article, which I then finalized. Unlike the other 4 articles in this thesis, and most of my submitted and published articles, there is no hard data to support most of the hypotheses in this opinion piece. The limitations of the 2 previous questionnaire studies rest in the fact that we can conclude from them caregivers are not well informed, and that the neonate is relatively devaluated compared to older patients. On the other hand, we did not ask respondent why. It would have been possible to do a qualitative study on the subject, but it would not have necessarily been representative of the 1000 and more respondents who have thus far answered the questionnaires. Because abstracts from the last two papers were presented at many conferences and talks, I was able to hear hypotheses to explain / justify this devaluation from many individuals (from different backgrounds and different countries). This exposure and rich interaction -that I call “qualitative field work”- has no proven scientific methodology, but can be valuable to generate hypothesis and enrich reflexion. These hypotheses deserve to be investigated further to validate them in a quantitative study and describe better their relative importance.

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ANNIE JANVIER, KAREN LYNN BAUER, and JOHN D. LANTOS

ARE NEWBORNS MORALLY DIFFERENT FROM OLDER CHILDREN?

ABSTRACT: Policies and position statements regarding decision-making for extremely premature babies exist in many countries and are often directive, focusing on parental choice and expected outcomes. These recommendations often state survival and handicap as reasons for optional intervention. The fact that such outcome statistics would not justify such approaches in other populations suggests that some other powerful factors are at work. The value of neonatal intensive care has been scrutinized far more than intensive care for older patients and suggests that neonatal care is held to a higher standard of justification. The relative value placed on the life of newborns, in particular the preterm, is less than expected by any objective medical data or any prevailing moral frameworks about the value of individual lives. Why do we feel less obligated to treat the premature baby? Do we put newborns in a special and lesser moral category? We explore this question from a legal and ethical perspective and offer several hypotheses pertaining to personhood, reproductive choices, "precious children," and probable evolutionary and anthropological factors.

KEY WORDS: extreme prematurity, moral difference, best interest principle, risk benefit ration, resource allocation, policy statements

ARE NEWBORNS MORALLY DIFFERENT FROM OLDER CHILDREN?

Consider the following two cases:

Case #1: A previously healthy 2-month-old baby presents to the emergency room with fever, irritability, listlessness and respiratory pauses according to parents. He is very sick with neurological signs and a rapidly spreading rash. The lumbar puncture is purulent and confirms the diagnosis of bacterial meningitis. The prognosis is poor. If the baby survives, he will likely have severe neurological impairment.

Case #2: A baby is born at 24 weeks of gestation weighing 700 grams. In the delivery room, he is not breathing and has a poor muscle tone. He is intubated and given oxygen; his heart rate and color immediately improve. At this gestation, the average survival is

50%, and if the baby survives, he has a 50% chance of having a "normal" outcome.[1, 2, 3, 4, 5, 6, 7]

In many hospitals and in most countries today, the initiation of intensive care treatment would be considered obligatory for the baby in case #1, but optional in case #2.[8, 9, 10, 11, 12, 13, 14] This is in spite of the fact that the long-term prognosis for baby #2 is better than that for baby #1. Why do we feel less obligated to treat the premature baby? Do we put newborns in a special and lesser moral category?

The period immediately before and immediately after birth is a time during which a fetus becomes a baby. This transition from intrauterine to extrauterine life has enormous moral, and legal implications. The fetus has almost no rights in utero (mainly the right to inherit and to sue for in utero damages if born alive). At the moment of birth, however, it becomes a full-fledged citizen, endowed with rights that should be no different from any other citizen. In the medical context, these rights are identical to those of any other vulnerable incompetent patient who lacks decision-making capacity or autonomy. For competent patients, life and death decisions are usually driven by autonomy. For incompetent patients, the surrogate (often family) has to decide, and if the patient had not expressed any preferences, they have to intervene in the best interest of the patient. In newborns who were never competent, the guiding principle is the best interest, with a large and poorly defined zone in which parental wishes are decisive. The Neonatal Resuscitation Program textbook, which is the standard neonatal resuscitation text used in North America and many other parts of the world, states: "The ethical principles regarding resuscitation of newborns should be no different from those followed in resuscitating an older child or adult."[15] This statement notwithstanding, this is not the case in practice.

There is clear evidence of categorical separation of the ethical assessments associated with treatment or non-treatment decisions for newborns from similar decisions for older children or adults. For example, the 1983 President's Commission on Bioethical Issues devoted a special section of its report to dilemmas surrounding the treatment of newborns, thus distinguishing these dilemmas from the more general dilemmas addressed in its discussion of withholding and withdrawing life-sustaining treatment in adults.[16] Such distinctions, though well intentioned, have reified the dichotomy that has isolated newborns from the rest of the population, kept them in a separate moral universe, and allowed decisions to be made upon a different basis than those made for any other age group. The separation goes beyond clinical dilemmas.

The value of neonatal intensive care has been scrutinized far more than pediatric intensive care and adult intensive care. Such scrutiny suggests that neonatal care is held to a higher standard of justification. It has to prove itself in ways that other critical care units do not. Often the conclusions that are drawn reflect people's underlying biases, rather than the data. For example, Friedman and colleagues could write as late as 2002, "[t]he use of neonatal intensive care continued to rise rapidly in the 1990s despite the concerns of observers about its cost effectiveness."[17] Such a statement is astounding because there have been numerous studies showing that neonatal intensive care units (NICU) are far more cost effective than medical intensive care units (MICU).[18] In fact, neonatal intensive care is among the most cost efficient of acute medical intervention, with the costs per quality adjusted life year saved being about 1/100 of the cost of acute adult coronary care.[19] The majority of even the surviving extremely low birth weight infants achieve functional outcomes and economically productive lives.[20, 21] It is also noteworthy that major improvements in newborn survival have not resulted in proportionate increases in severe morbidity.[22]

Age-based assessments of the value of treatment, whether made at the bedside or in the context of cost-effectiveness analyses, can lead to differences in the treatment that patients receive. Newborns are not the only population subject to such differential treatment. There is evidence for the existence of age-based rationing for both the very young and the very old. Such evidence comes from descriptive epidemiologic studies of resource allocation at various ages. Dixon et al examined the total number of hospital admissions for people who died at various ages in England in 1999–2000. They reported that the number of hospital admissions steadily declined with increasing age. Decedents aged 25–64 had 3.7 hospital admissions in the last three years of life. Those over 65 years old averaged only 2.3 admissions.[23] A study in the United States showed similar results in that "patients who received intensive hospital and physician services were largely the 'young old,' aged 65 to 79 years with good functional status, while the frail 'older old,' aged 80 years and over, received largely supportive care."[24] In addition, bioethicists have defended age-based rationing of care for the elderly. Callahan's book, Setting Limits, explicitly argues for the appropriateness of age limits for life-prolonging treatment. He would have Congress restrict Medicare payments for such procedures as organ transplants, heart bypasses and kidney dialysis for the aged.[25] Such studies show that age-based rationing of hospital resources in adults, including intensive care, is a global reality.

Is it reasonable to want to fix an age limit for resuscitation purposes? Zweibel and colleagues found in a national survey that most of their respondents would accept withholding of life-prolonging medical care from critically ill older patients. Some authors justify this with the "fair inning" argument: everybody is entitled to a proper lifespan. Deciding on age would not be discrimination, as everybody gets older everyday, and could reach the "appropriate lifespan limit." In this case, this would not be similar to discriminating on sex or race, which most of us do not change during out life.[26, 27] The viewpoint that it is appropriate to include age in some decisions about resource allocation is clearly not unanimous.[28, 29] Furthermore, no policy or professional association guidelines in the United States suggest an age limit for resuscitation decisions. Instead, they consider age as one of a number of factors to be incorporated into an individualized decision making process.

The situation is quite different at the other end of the lifespan. There are multiple professional societies, both in the U.S. and abroad, which explicitly use gestational age alone as a criterion for initiating or withholding resuscitation.[30, 31, 32, 33, 34, 35, 36, 37]

Many national associations use 24 weeks of gestational age as a cut-off, below which prognosis is deemed so poor that resuscitation should be discouraged. In most tertiary care centers, babies born at 24 weeks have at least a 50% of survival with at least 50% of survivors having no chronic health problems or neurological sequelae. There is no other patient population for whom such detailed long-term outcome studies has been done. These is no other group of patients for whom resuscitation decisions are determined by the results of those studies. Since resuscitation is optional before 25 weeks and only done according to parental wishes, when a mother arrives in labor before that date, it may be considered easier to induce delivery before 25 weeks rather than wait for the baby to be delivered later, but still very prematurely, and be "stuck to do something." This could be called the "better luck next time approach." Even some tertiary care hospitals do not wish to resuscitate before 25 weeks and recommend this openly.[38] At other institutions, though, the same mother would be offered the opportunity of aggressive resuscitation by the neonatal team. A 2-month-old infant presenting with group B streptococcal meningitis,[39] or a 50-year-old pediatrician with an extensive hemorrhagic stroke,[40] would be likely to have immediate resuscitation and institution of care, despite broadly similar risks of death or disability when compared to the extremely preterm infant. Policy statements for preterm infants often state survival and handicap as justification for optional intervention.[41, 42, 43, 44, 45, 46, 47, 48] The fact that such outcome statistics would not justify such approaches in other populations suggests that some other powerful factors are at work.

We recently studied justice in resuscitation decisions, by comparing the attitudes of physicians and students in bioethics, medicine, law, and anthropology regarding active treatment of eight hypothetical incompetent patients needing intubation and intensive care at the same time. One patient was an extremely preterm infant and another was a 2-month-old infant with bacterial meningitis, both babies had the same outcomes. Another patient was a 35 year old with brain cancer with a 5% survival rate and a 100% handicap rate after surgery, radiation therapy, and chemotherapy. In the study, when we asked in what order should the patients be resuscitated if they all needed intervention at the same time, the 2 month old with meningitis was first, and the premature infant was resuscitated overall in seventh position, only before the hypothetical demented 80 year old with a stroke, despite having outcomes at least as good as, or in some cases dramatically better than the six preceding patients.[49, 50, 51]

Such hypothetical studies, along with the curious, differential and often peculiar use of cost-effectiveness analyses, as well as statements of principles from professional societies and national bioethics commissions, all suggest that newborns are treated as a special moral category. The relative value placed on the life of newborns, in particular the preterm, is less than expected by any objective medical data or any prevailing moral frameworks about the value of individual lives. The fetus, which has almost no rights in utero becomes a citizen endowed with rights as his shoulders come out of his mother. The rapidity of the transition from fetus to citizen may be one reason for the moral confusion felt by many doctors, parents, and judges, and may be the reason why professional bodies have felt the need to offer position statements regarding resuscitation that focus specifically on the newborn. The moral status of the newborn may also be influenced by the fact that terminations of pregnancy are sometimes performed even after fetal viability. In such cases, the disjunction between the moral status of the fetus in utero and the baby ex utero creates cognitive dissonance that may be resolved by either elevating the status of the fetus or denigrating that of the newborn.

There may be other reasons why newborns do not have the same status as older individuals. Some have suggested that they have not yet achieved some vague moral status labelled "personhood."[52, 53, 54, 55, 56] That is, they are human beings -like fetuses- but are not yet fully persons. Many who make this argument also apply it to human beings who lack certain key neurologic capacities, such as babies with anencephaly or adults with severe Alzheimer's disease. Some authors suggest that newborns do not acquire full personhood until about 2 months of age.[57, 58] This view has no basis in law and would be difficult to operationalize in a culture that seems to set high value on the lives of newborns in many contexts. Yet is seems personhood is important in decision-making for newborns.

Another hint as the special status of newborns comes from the widely recognized phenomenon that perinatologists and neonatologists are generally willing to intervene more aggressively and for a longer time when a mother is older or when she conceived by in vitro fertilization after many years of infertility.[59, 60] We often refer to these babies as "precious children." They are thought of as "irreplaceable." These concepts work, in a backhanded way, to denigrate the status or the preciousness of other babies. If these are the truly special ones, then perhaps the others are not so precious or are replaceable, maybe justifying the "better luck next time" approach. Such a phenomenon suggests that the value of a baby's life is determined, in part, by the family context into which he or she is born. After a perinatal loss, we are taught extensively *never* to tell a mother that she is still young, that she will have more kids, or that she has another twin (in some instances). We are taught not to say it because it is a natural tendency to say it after a neonatal loss—but probably not so natural after the death of an older child in the PICU.

Another instance of such influences—one that leads in the opposite direction—occurs when parents and families already have other children and view their current children as the "precious" ones who may need protection from the demands that a new baby might make. "Intrafamilial distributive justice" may be invoked, as when families say, "It won't be fair to our other children" to justify withholding or withdrawing care for a 50% survival with 50% normal outcome. This justification is routinely accepted by NICU physicians, but we doubt PICU physicians hear similar comments, and if they did, if they would be influenced by them the way neonatologists are. If one of the parents' older children suffered an accident, would they likely make the same decision to protect and devote attention to their two other healthy children or is this decision isolated to newborns?

The systematic devaluation of the newborn may also be due to deep-rooted anthropological, cultural, social and evolutionary factors. Until the late twentieth century, most parents experienced the death of at least one newborn or infant. Perhaps the commonness of infant death led to protective cultural and emotional mechanisms in the form of philosophic differentiation of the newborn from older people. Waring, a philosopher, remarks that the way we value a person is indicated by how we react to their death, "feelings of tragedy, evil, loss and sharp regret are supposedly more appropriate responses to the deaths of younger people. One might view the deaths of older people as tolerable. Indeed, it is not rare to hear that it is 'better this way, nature took its course,' that 'he/she lived long enough' for an older individual."[61] Similar statements of "it is better this way, nature took its course" and "at least he/she did not suffer" are also said for premature babies. Maybe the premature infant has not yet lived long enough to justify feelings of tragedy and regret secondary to instilled feelings of detachment that desensitize society from the loss of newborns?

Quality of life is often considered in decisions to withhold or withdraw care. This, too, may be assessed differently for a newborn than for an older child or adult. Babies who suffer intracranial hemorrhage are known to have a wide range of outcomes. Some may be neurocognitively devastated. Others will do quite well. The uncertainty of outcome, in a newborn, often justifies withdrawal of treatment. An older child with a traumatic brain injury may face a similarly uncertain prognosis. Generally, however, for older children, uncertainty and the possibility of a good outcome dictates that we continue treatment.

Fifty years ago, most patients who now survive treatment in intensive care units would have died, and "nature" would have determined outcome rather than nature along with medical intervention. Now, caregivers, hospitals, and families decide if incompetent patients die, and when resuscitation should be initiated and withheld. When deciding on the best interest of patients, the subjective interpretation of benefits, risks, and burdens comes into place. In order to make a judgment about the patient's best interests, we must place a relative value on his life.

Decisions to treat newborns differently suggest that we value their lives differently. Often, practitioners are unaware of their own implicit valuations. It is important that medical staff as well as families are aware of these biases and acknowledge them, as they will likely influence our decisions. In most cases, careful analysis of such implicit valuations will lead us away from treating newborns differently. Such analysis may often place us in conflict with prevailing social and professional norms.

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McGill University
Montreal, Quebec
Canada
E-mail: [redacted]

MS-2
The University of Chicago
Chicago
USA

John B. Francis Chair in Bioethics
Center for Practical Bioethics
Kansas City, MO
USA

Department of Pediatrics
The University of Chicago
Chicago, IL
USA

GENERAL DISCUSSION

This central question addressed in this thesis is whether there is a moral difference between premature infants and neonates compared to older patients. Empirically, several neonatal ethicists have suggested that there may be such a difference, with neonates not only being morally different, but also maybe inferior to "full fledged" persons.[1,2,3] Dr William Meadow, an innovative neonatologist and bioethicist, (also co-director of this thesis) once asked attendees at the beginning of one of his talks to imagine they were faced with the following dilemma. They are in a boat, and have 2 of their children with them: their 3 day old and their 3-year-old sons. The boat is sinking, they can only rescue one child, who do they choose? Because it was an artificial scenario, and unlikely to happen, attendees did not want to choose, but when convinced to do so, all the hands were raised for the 3-year-old. This was at a pediatric conference, many attendants were neonatologists. Multiple reasons were brought up: the neonate is not scared; he does not know what is or will be happening, nor what he will be missing, nor who he is yet. He only "existed" a very short time. His mother knows him, but not as much as her 3-year-old grabbing her skirt anxiously. The 3-year-old has more of a "story", the mother is more attached. The research presented in this thesis presents empirical research which supports the implications of those responses to this vignette. In my research, this devaluation of the neonate is global. Indeed, when only the physician group was presented at conferences in 2006,[4,5] the main hypothesis raised by attendants was that physicians knew what neonates had to endure in the NICU to survive: for some, the burden of treatment, witnessed by experienced physicians, was not worth the outcome. Interestingly, more than 400 respondents who are not in the medical field have answered the questionnaire and have almost identical answers to the physicians. The devaluation of the life of neonates, and to a larger degree the premature infant, is not acquired by working closely with them and witnessing their illness, nor by knowing what national policies recommend at what gestational age. It is also shared by a young educated population of future lawyers, anthropologists, and ethicists, regardless of their year of training.

1. SUBSTITUTIVE ETHICS

My research has been built around cases that have been compared to each other in order to investigate moral differences. Casuistry is an approach to ethical reasoning based on illustrative cases, often comparing different cases. Comparing cases which are artificially constructed to differ in only one detail is a form of casuistry which can be very illuminating. I have called this form of casuistry "substitutive ethics" in every day clinical work. Indeed, by changing the patients' stories minimally, one can find surprising answers and stimulate caregivers to examine their own biases. It can thus be much easier to understand the way we make judgments, and the source of our own prejudices. For example, delivery room nurses, NICU nurses, and physicians in perinatal medicine can be reluctant to offer intensive care to premature infants with a GA of 23 weeks. Lately, a mother came in contracting regularly, in active labour at 23-week gestation. She was young, pregnant with her third child and the couple, after our neonatal consult, had expressed they wanted intervention for their baby if she was to be born. The resident thought: "this is not the ethical thing to do, this is futile". This baby had a 30% predicted survival and intervention was not "physiologically futile", as the resident believed. He thought we should never offer resuscitation at that gestational age. I asked him to consider a 40-year-old mother, who had no children, but had been infertile for now 15 years, had 6 attempts of IVF and had a second mortgage on her house because of infertility treatments. The mother was a physiotherapist and treated children who had cerebral palsy. Would he consider intervening for that particular baby? He thought he would, that this was probably acceptable, but that "the case was different". By only changing the mother's demographic information, and keeping the baby's predicted outcome identical, an ethically unacceptable position became "probably acceptable" and it became in this "baby's best interest" to be treated. Many difficult cases are also encountered in critical care of older patients, adults and children. By comparing the responses to such patients with those to newborn infants interesting windows about the real foundations behind our beliefs can be opened. The empirical quantitative research presented in this PhD has been conceived using substitutive ethics. In the third article, for example, we used identical descriptions of the outcomes for 4 patients of different ages.

Neonatologists are frequently faced with paradoxes with regard to the babies they treat. For example, they might be asked to see mothers pregnant with a baby who has been diagnosed with Down's syndrome and a heart malformation which requires open heart surgery and cardio-respiratory bypass. They will generally convey the serious cognitive impairment that these children have, that they rarely have the ability to enter normal school, that the cardiac surgery is overall a big procedure, but that most children survive the procedure. Most important, what paediatricians will say to these parents, is that most of these children, even if handicapped, can have a good quality of life, and that families generally adapt to these difficult situations. Considerable amounts of money are invested in screening for Down syndrome, because this diagnosis brings about many families to terminate the pregnancy. When the baby is born, the situation is reversed. Neonatologists are compelled to treat in most cases. Cases may occasionally be reviewed by an ethics committee, and some cases in North America have gone to court. Although the court decisions have not all been consistent, the recent decisions have generally determined that if withholding treatment would not be accepted for a "normal" child then it is not acceptable for an infant with Down syndrome, otherwise the decision is discriminatory and unacceptable. We cannot discriminate on the basis of handicap. But when we medically analyse the situation, some babies with Down syndrome may appear to be over-treated: some of them have 4-5 surgeries, never eat by mouth, are never continent, and live in the hospital for years. While some babies with Down syndrome may be over-treated, the majority of potential Down syndrome babies are terminated following neonatal screening. On the other hand, many babies of 23-25 weeks are not actively treated in the developed world, even if they have potential outcomes that are much better than babies with Down's syndrome. These situations are paradoxical for the neonatologist and do not make rational sense: perhaps it is easier to discriminate against the possibility of handicap than confirmed handicap.

The same can be said about other babies. If we take the substitutive ethics approach we can create cases that have an outcome that would be considered a "severe handicap" for a premature baby, a handicap severe enough to consider, to offer, or even to recommend withholding care to families. For example, a baby is born with the following malformations: he has only one leg, and will be deaf. Scientifically, this could be due to amniotic bands that amputated his leg and an ear with the ear canal. The mother's labour is induced at 34 weeks because the amniotic band is circling the ear and might amputate one side of the face. Because he was born too early, he develops RDS and need to be placed on a respirator for respiratory failure. Before he was intubated, he also aspirated the milk he had been given to drink, and develops a severe pneumonia. He becomes unstable from his pneumonia, which will probably resolve, but which has 20%-30% risks of killing him. The baby will not be on a respirator for months. The parents object, they think this is unreasonable and do not want "a handicapped child". I have asked this question to many nurses, residents, and physicians, and am starting a questionnaire study with this vignette. Rare are the caregivers that would accept to relieve the baby's gasping with morphine and to keep him comfortable while he is dying. As a resident said: "Sure, he will limp, he might be deaf and might have problems at school with his deafness, but this baby's projected quality of life is "too good" and it is in his "best interest" to be treated". This NICU care of this infant is similar to some extent to that of preterm infants, but his future outcome is worse than most preterm infants: he is already and will definitely have multiple severe disabilities. Only 5% of premature infants < 28 weeks will be that affected (having multiple severe impairments).[37,38] Interestingly, premature infants with better outcomes will frequently have intensive care and NICU admissions withheld. As a clinician, I am confronted with these conflicting cases where justifications for actions seem to have no scientific nor moral basis: we often "make" the outcomes bad by the way we look at them, we can also "make" many conditions terminal for babies if we don't treat them.

2. POLICY STATEMENTS FOR NEONATES

Policy statements and recommendations about premature infants have not been discussed in this thesis and merit consideration.[6] The Neonatal Resuscitation Program (NRP) textbook, the standard neonatal resuscitation text used in many parts of the world, states: "The ethical principles regarding resuscitation of newborns should be no different from those followed in resuscitating an older child or adult".[7] Yet, the reality seems to be different. Many professional societies and national commissions have developed policies or guidelines about the treatment of preterm infants. For example, in 1994, the Canadian Paediatric Society and Society of Obstetricians and Gynaecologists of Canada published "Management of the woman with threatened birth of an infant of extremely low gestational age".[8] The Canadian position statement was directive, focusing on parental choice and expected outcomes at varying gestations. At 22 completed weeks of GA or less, a newborn was considered too premature to survive and palliative care was recommended; at 23 to 24 completed weeks, prognosis was deemed so poor that life-saving interventions were considered optional; and after 25 completed weeks life-saving therapies were generally indicated. Twelve years later, the Nuffield report, recently published in the UK,[9]examines the same issues and comes to very similar conclusions, which correspond to many other position statements of professional associations around the world.[10,11,12,13,14] In some countries, admitting a baby of 24 weeks gestation to the NICU is not recommended.[10,11,14]

These policies are generally based solely upon GA and fail to address, and even in some cases dismiss[9] the possibility that premature infants might be different from other incompetent patients. We will explore these factors and conclude by asking what the policy should be for these special patients.

A. Certainty in quicksand: gestational age assessment

Assessment of GA antenatally, based on menstrual timing, is known to be unreliable. Gestational age is only precisely known when the pregnancy results from in vitro fertilization (IVF) as the exact date -and even hour- of fertilisation is known. Pregnancies resulting from IVF have been used to analyze the accuracy of early (12 to 14 weeks gestation) ultrasound, and have demonstrated small *average* differences of up to 2.5 days, but the range of individual differences, more important for this discussion, is large, with the best performing formulas for GA calculation being inaccurate by up to -10 to +7 days.[15] Comparing early ultrasound to menstrual timing shows that the latter is still more inaccurate, by more than 14 days. GA dating based on second trimester ultrasound is also as unreliable as menstrual timing,[16] with differences of up to 14 days. Based on international recommendations, an intervention may be considered optional one day and become generally recommended the next (often at midnight!). Interestingly, this precise number of weeks at which this transition occurs is different from one country to another, and varies between 22 and 26 weeks in "developed" countries.[7,9,10,11,12,13,14]

These limitations should be explicitly recognized; apart from when the baby is a result of IVF, we can only know the gestational age within specified uncertainties. Instead of referring to a pregnancy as being 23 5/7, it would be more intellectually honest to refer to "a pregnancy with a best estimate of gestational age of 23 5/7 and a probable gestational age between 22-25 weeks (95% confidence intervals) according to 2nd term ultrasound, estimated foetal weight 650g, plus or minus 90 g, (95% confidence intervals)". The range of outcomes that would be described to the family for them to decide between comfort care versus intervention may be dramatically different, with no simple, if comforting, rules to apply.

B. Deciding on a single variable

Currently, counselling regarding survival is neither evidence-based nor individualized, and frequently fails to recognize that factors other than GA are also important. Some authors have tried to defend a simplistic universal application of "blanket rules" based on completed weeks of gestation, without consideration of the inaccuracy of gestational age assessment, nor consideration of other major influences on prognosis.[17,18] But birth weight, gender, place of birth (tertiary versus non-tertiary center) use of antenatal steroids, singleton vs. multiple gestation, socio-economic status and infection are all independent predictors of outcome – and adjusting for these factors will make prognostication much more relevant for an individual family than estimates made from GA alone. For example, a female infant at 23 weeks, born in a tertiary hospital after antenatal steroids weighing 750 g has far better predicted survival, than a male infant at 26 weeks weighing 550g who has not been exposed to steroids and is born in a community hospital.[19] Yet application of current blanket policies would allow or recommend no active intervention of the 23-week gestation infant, but would strongly recommend resuscitation of the infant at 26 weeks. Using completed weeks of gestation alone over-simplifies decision-making, and although being simple and user friendly, ignores a substantial body of evidence.

There is no other medical condition for which decisions regarding life and death are taken based on a single characteristic of the patient. A spokesman for Bliss, a premature baby charity in the UK, recently highlighted the lack of scientific rigor of such "blanket" policies by stating: "Decisions as to what course of treatment is appropriate should be based in the individual circumstances of each baby rather than a blanket policy of not treating patients born at less than a certain gestation... We might as well have a policy of not treating victims of car crashes which occur at over 50 miles an hour, or denying medical services to those over a certain age."[20]

C. Uncertainty in the delivery room

"Conditional" or "limited" resuscitation is also commonly offered, based upon an assessment of the newborn in the delivery room.[7], the Neonatal Resuscitation Program textbook states that: "If the baby's viability is thought to be marginal [...] You can assure the parents that you will make every effort to support their wishes, but it is also important to advise them that decisions made about neonatal management before birth may need to be modified in the delivery room depending on the baby's condition at birth and the postnatal GA assessment."[7] While this approach may be philosophically appealing and supported by leading ethicists,[21] as well as by policy statements,[22] epidemiologic studies suggest that there are no reliable predictors of outcome that can be obtained in the first minutes or hours of life.[23,24] Indeed, a premature infant may cry and appear vigorous at birth, and have a devastating cerebral haemorrhage the next day. Also, many neonates are born because their mother's sickness or instability, for example, when the placenta detaches and the haemorrhage threatens the mother's life. In some of these cases, an urgent caesarean section under general anaesthesia is done and the baby will also "be under general anaesthesia" at birth, as he will have received the anaesthetic that the mother just received. This neonate will often have marked respiratory depression and hypotonia at birth, but has no worse outcome as a result. Clinical assessment of gestational age, even after stabilization of the infant, when there is time to perform a careful standardized examination, is extremely unreliable with an uncertainty of greater than 4 weeks.[25] In a commentary, Mercurio illustrates this fact by recounting a fellow estimating the gestational age of 2 babies: one was assessed as less than 24 weeks with his transparent skin and fused eyelids, while the other was considered to be much older: in fact the babies were twins.[26]

The true importance of delivery room predictors of survival and intact outcome requires further investigation to determine if there are ways to make a "conditional" resuscitation a truly ethical option.[27] If for example a prolonged resuscitation of over 10 minutes were shown to discriminate adequately between infants who do well and those with devastatingly bad outcomes, the decision making process could then be explicit, such as "we will attempt to resuscitate for 10 minutes". Emotive and unhelpful phrases such as "if he's a fighter", "if she wants to live enough", "if he isn't too gelatinous and is strong"[28] imply an ability to clinically discriminate between infants who will do well and those with a poor outlook, they are therefore dishonest and should be avoided.

The birth process brings about something considerable: a new person having the same legal rights as any other incompetent patient in the hospital. On the other hand, before birth, the fetus was not a legal person and had only very limited rights. This legal difference, although valuable for lawyers, does not help neonatologists predict the outcome of a person with more certainty then they did for a human being or a fetus a few minutes before. Antenatal consultations are indeed quite unique: the neonatologist speaks to the parents about probabilities, before the baby is born. Unlike obstetricians or fetal interventionists, he does not perform ultrasounds, interventions, or examine the mother; he "just speaks about probabilities, about the future, a "crystal ball kind of medicine" as a student once stated.

3. ANALYSIS OF OUTCOMES: which study justifies my opinion?

In this "crystal ball" medicine of prenatal consultations, the neonatologist relies on scientific knowledge to be able to be more precise about his prognoses. The recent Nuffield report suggests that survival at 24 to 25 weeks gestation is 26%.[9] These figures are taken from the Epicure study, an important regional study incorporating all infants born at less than 26 weeks in the United Kingdom and Ireland.[29] However, in that study, a large proportion of the infants did not receive active care, and even among those who did, many were cared for in centres with little experience in caring for extreme preterm infants. Long term outcomes, expressed in terms of percentage of infants with intact survival, suggested that the chance of a baby surviving with a good outcome were much lower than previously described; however, babies who were not resuscitated, and babies who were not transferred for tertiary level care were included in this estimation. Such figures are of no relevance to counselling a mother with threatened preterm delivery in a tertiary care center. She needs to know the chances of a good outcome with active care (overall survival to discharge 72% at 24 weeks and 78% at 25 weeks from the Canadian Neonatal Network, 2005[30]), and the chances without active care (100% mortality). Of still more value to that individual mother would be a rational analysis of the likely outcomes that takes into account the other good and poor prognostic features for her particular baby.[31] Blanket policies that declare life optional at 23 and 24 weeks usually give great weight to the Epicure study[8,9,10,11,12,13], while those who are more interventionist focus on other data.[22,32] For example, the Australian and certain German outcomes are probably the best in the world at extremely low gestations, and are less frequently referenced in policy statements.[33,34] This picking and choosing of which data are given the most weight appears to be directed by the underlying ethos of the committee making the recommendations. A systematic evidence-based approach requires an honest assessment of all the data that are relevant to the particular family. Unfortunately, most articles do not report which infants actually received active care, complicating such a systematic approach. For future descriptions of outcomes of very immature infants such explicit descriptions are essential.

Mortality is not the only outcome considered in ethical decision-making. Also important are the burdens of prolonged intensive care (with or without survival), and the risks of long-term disability, or later death. 12-25% of babies born before 27 weeks, if they survive, will have major neurodevelopmental disabilities; and up to 50% will have behavioural or educational problems.[19,34,35,36,37,38,39,40,41] The severity of disability also requires consideration. Motor delay is the most common neurodevelopmental disability, and although cerebral palsy is usually classified as serious disability in the outcome literature, most affected children are ambulant with good quality of life.[42] Cognitive impairment, although common, is rarely severe, with average IQ levels being approximately one standard deviation below controls.[43] Indeed the IQ of very preterm infants at 8 years of age is more than 1 SD below the mean (less than 85) in only 38% of cases,[44,45] compared to a mean IQ of 40.2 for children with Down's syndrome,[46] who are, in contrast, judged to have a good quality of life by most physicians. On the other hand, some disabilities such as hyperactivity or schooling problems, classified as minor in the literature, can be more devastating to families than cerebral palsy. Multiple serious disabilities, with a profound burden on an individual and their family, are devastating when they occur, but are infrequent and arise in less than 5% of babies born at less than 28 weeks.[37,39] Unfortunately, such disabilities are very difficult to predict. Neonatal units have been leaders in developing outcomes surveillance and many infants having a moderate risk of neurodevelopmental sequelae are followed prospectively. Premature babies born before a GA of 29 weeks are usually followed prospectively, often in the neonatal department. This is quite different then for other areas of medicine where victims of head traumas, strokes, and other diseases at high risk of neurological sequelae are treated. Neonatal follow-up then helps neonatologists and parents take decisions.

Rather than numeric analysis of outcomes, the projected overall quality of life for the infant is a consideration that should influence parental choice. However, "quality of life" is largely a subjective construct: physicians and other healthcare providers routinely estimate the quality of life of patients to be worse than the patients and families do themselves. As a result, caregivers and parents differ substantially in their attitudes to the salvaging of potentially disabled newborns.[47,48] When extremely preterm infants were studied in adolescence and adulthood, they were found to adapt to adversity: even those with disability perceived themselves to have a good quality of life.[49,50,51] This valuable evidence should be taken into account during counselling, but is generally ignored in simplistic blanket policies, although similar research has rarely been done in survivors of other diseases. It seems that because of enormous reserves of resilience, human beings are able to cope with tragedies and adapt to most situations, this is also not usually discussed during neonatal consultations.

Even the word resuscitation is problematic, by asking parents if they want their baby resuscitated, they might imagine we do cardiac massage, give medications to start the heart, cut open their chests and defibrillate their arrhythmias. In fact, extremely premature infants usually need little support immediately after birth, often requiring only a tube in the nose to provide continuous positive pressure, or sometimes having a tube inserted into the trachea for assisted ventilation and administration of surfactant. It is rare that an extremely preterm infant delivered in a tertiary care centre, even when born unexpectedly in a "crash" delivery, receives cardiac massage.[52] Instead of asking families if they want resuscitation for their neonate, we should ask them if they want us to intervene –intubate, admit to the NICU- for their baby, a much less colourful but more accurate representation of what we do. If we again make the contrast with another acute clinical situation; we never ask parents of children who come in to emergency rooms with a respiratory arrest from sepsis if they want us to resuscitate their children.

A. Self-fulfilling prophecy

In an article describing the dialogue with parents in the delivery room, Desfrere et al state that parents should receive appropriate information of survival and risk,[53] but later state that "In France, a do not resuscitate order is appropriate for newborns weighing less than 500g and/or with a gestation of less than 24 weeks since the mortality is nearly 100%".[53] Although survival at 23-weeks is not the rule, it is by no means 0. In the NICHD neonatal network, the survival of a 23-week female weighing 620g is 40%.[54] Similarly, in another study, a group has decided to not recommend resuscitation below 25 weeks[17] to decrease the variability in neonatal consultation. As a result, the self-fulfilling prophecy will continue: more infants will die and a poor survival at 24 weeks will continue being used to justify non-intervention. When outcome data is given for the parents to decide, it should not be based on what the physicians and parents have decided *in the past*, but on the best assessment of what the survival would be if there was or was not an intervention for this particular baby.

4. JUSTIFICATIONS FOR NON-INTERVENTION, A DOUBLE STANDARD BETWEEN NEONATES AND OLDER PATIENTS?

A. Recommendations for older patients

Based on analysis of the literature, a number of professional bodies have determined that at less than 25 weeks of gestation, resuscitation is optional (or even not recommended) [8,9,10,11,12,13] These blanket policies justify this by referring to the poor outcomes of preterm infants and the burdens of the intensive care stay. These recommendations imply that it is ethically appropriate to offer palliation to an incompetent patient whose chance of survival is 50%-80%, when 25% of survivors face the possibility of survival with severe disability.[8,9,31,34,39]

I have reviewed all Canadian and American recommendations regarding withholding or withdrawing intensive care in acute situations. A review of cardiac arrest in older children following severe trauma noted that *none* of the children in this category who had a brain injury survived, but nevertheless recommended that "all children should receive aggressive resuscitation after injury".[55] In one large study of recovery in over 700 adults who were comatose following resuscitation from cardiac arrest, the mortality for the entire group was about 80%, and the long term functional outcomes among the survivors were in general extremely limited.[56] A related position statement of the American Academy of Neurology on the prediction of outcome of comatose survivors after cardiopulmonary resuscitation was recently published.[57] Despite an overall chance of less than 5% of having either a good long term recovery or being moderately disabled (substantially worse than the overall results at 23 weeks gestation), the recommendations suggested further prognostic information were required prior to consideration of withdrawal of care *in addition to* the clinical situation.[57] For incompetent adults, the reasons for withholding resuscitation when cardiac arrest is noted following trauma included decapitation or *rigor mortis*! One could reason that is only the neonatologists who have an ethically acceptable approach in these uncertain situations, and that we should have a comparable attitude to older patients. Indeed if that were true, and intervention was only offered to adults at the same predicted outcomes as are considered appropriate for premature infants, the frequency of intervention would be dramatically reduced.

B. Outcomes and paradoxes

Although the explicit justification within blanket guidelines for preterm infants is that outcomes are too poor to justify intervention, there are no other populations in which a 50-80% survival rate would be seen as too dismal to justify resuscitative efforts. A 2-month-old infant presenting with group B streptococcal meningitis,[58] a 50-year-old adult with an extensive haemorrhagic stroke,[59] or a 3-year-old with 75% full thickness burns would be likely to have immediate resuscitation and institution of care, despite broadly similar risks of death or disability. This was confirmed with the empirical research presented in this thesis. Similar outcomes in older populations would even be considered excellent!

C. Pain and suffering

Pain and suffering is also used as a justification for many blanket policies for not intervening in preterm infants. Although their hospitalization is by no means a pleasant experience in the first months, other children with much more pain are treated (for example patients with severe burns) without physicians considering the pain as a reason for not intervening. Victims of multiple traumas with fractures, burn victims, children with brain cancers or leukemia probably have more pain throughout their terrible illnesses. Although pain relief can always be better in the NICU, neonatologists are pioneers in pain research and management in paediatrics.[60,61,62] In many NICUs babies receive pain relief for installing IVs, for blood drawing and for vaccination; which is rarely the case in paediatric wards, emergency rooms or clinics. A child is expected to feel pain with his vaccination. A baby in the NICU is not. The extreme scrutiny of pain practices in the NICU, and about "pain and suffering of neonates" is not matched in other areas of paediatrics. What about suffering? Unlike a 3-year-old burned victim, the neonate will not be able to verbalise his anxiety and his fears. The psychological suffering will probably be experienced more by his parents and caregivers than by the neonate himself. Also, when babies die in the NICU, it is often very quickly: 70% of deaths occur in the first 5 days of life. Prolonged suffering with eventual death before leaving the hospital is less frequent, unlike some children treated for childhood cancers. Prolonged suffering because of disability can also occur, but not more than for many other diseases, from head trauma, to oncology patients, to strokes.

D. Costs

The costs of neonatal care and the principle of distributive justice have also been used as an argument for withholding or withdrawing care from premature infants, with the suggestion that enormous resources were being expended on very immature infants.[8] The costs for NICU care have been scrutinized extensively compared to those of adult ICUs. When babies die in the NICU, 70% do in their first 5 days of life.[63] Given this high mortality of extremely preterm babies in the first week of life,[64] the majority of the expenditure is on survivors who do well.[65] In addition, the tiniest infants utilize a small proportion of NICU resources: in one study, care of infants <25 weeks used 5.4% of the NICU resources.[66] Denying intensive care to infants born at <500g, and <600g would lead to a total NICU care savings of 0.8% and 3.2% respectively. One could object by stating that the babies with disabilities will need further care and resources. In fact, if one does a true economic analysis and uses the long-term rationale, NICUs become even more cost effective. Economical analyses are utilitarian; they place a value on lives and lives saved. Because most of the premature infants in the NICU survive without disabilities, and most can be economically productive even when living with limitations, neonatal intensive care is among the most cost efficient of acute medical endeavours. The majority of even the tiniest surviving infants achieve functional outcomes and economically productive lives.[67,68] The costs per quality adjusted life year (QALY) saved in the NICU being about 1/100 of the cost of acute adult coronary care.[69] It is also noteworthy that major improvements in newborn survival have not resulted in proportionate increases in severe morbidity.[70] Even with this intense scrutiny of NICU's cost effectiveness, some policy statements use distributive justice as a rational ethical argument for declaring life optional before 25 weeks.[8] Is this argument based on emotion or evidence?

But perhaps restricting intensive care to only patients with a better than 70% chance of survival is appropriate, and this reasoning should be applied for all individuals. This would mean a drastic decrease in PICU and adult ICU admissions, while leaving the NICU admissions largely unaffected (because of the small number of premature infants less than 26 weeks) and would save billions to health care systems; entire hospitals could probably be closed! We can think of no professional associations who would promote such an approach. If one was really to study justice in resuscitation of incompetent individuals, as I did in the fourth article presented, the reality would seem otherwise. Indeed as demonstrated in "Nobody likes premies", we compared caregivers preferences for active treatment of 8 hypothetical vulnerable incompetent patients needing intubation and immediate intensive care, one of whom was an extremely preterm infant. The preterm infant was resuscitated overall in seventh position, despite having outcomes at least as good as, or in some cases dramatically better than, the six higher-ranking patients.[71]

CONCLUSION

1. WHY ARE NEONATES TREATED DIFFERENTLY?

Despite their long-standing acceptance in the neonatal community, blanket policies are morally problematic: they implicitly treat neonates as a special and different moral category of patients without acknowledging that they might be different from older individuals, and sometimes even stating they are not. The Nuffield council report states "we find no difference in the moral status of the child of six days, months or years, we find no morally relevant differences between disabled and able-bodied children and adults".[9] Then why are there no analogous simplistic blanket policies for older patients?

The rapidity of the transition from having no legal rights *in utero* to being a "full fledged citizen" may be one reason for the moral confusion felt by many doctors, parents and even judges and may be the reason why professional bodies have felt the need to offer position statements regarding resuscitation. Is the micropremie still in the realm of reproductive decisions? Perinatologists and neonatologists are more willing to intervene for "precious babies",[72] born to older mothers or by artificial reproductive technologies. They are also less willing to intervene when families already have many children who are well and could potentially have their family affected with a disabled child. Such considerations are considered irrelevant when a child is admitted to the PICU. We are taught to not tell parents who have lost an extreme preterm that they can have another baby,[7] or that it might be for the best. Yet, this is what some parents themselves say after withholding care for their neonate or after a loss in the NICU. Physicians would be surprised if parents said the same for an older child. An extreme preterm is generally not considered to have a real disease per se. He is born too soon, he is not supposed to be there, and by choosing life, nature / physicians / medicine give him several diseases. If a neonate survives with disabilities, the caregivers often feel directly responsible for his disabilities. On the other hand, when a child, victim of a severe burn survives his PICU stay with disabilities, the PICU physician can always blame the fire or the smoke detector. Is this why physicians are expected to talk to parents about survival, disability, ROP, IVH, PDA, RDS, pain, PVL and obtain their full informed consent before treating premature infants? Is this why many neonatologists feel responsible to make parents understand every possible scenario that could happen to have the best informed consent possible? Perhaps it makes them feel less responsible if the baby survives with a disability.

Would The AAP recommend that we speak in that much detail about outcome –as is done for preterm infants-, stating infection rate, tremendous pain, opioid addiction, pneumonia, length of stay, rejection of skin grafts, contractures etc. in the ER to parents of a child victim of a house fire, and offer withholding of care? Would physicians even feel comfortable flooding parents in distress with that much information so soon after a catastrophic accident?

Do we have a diminished sense of duty towards these brand new persons with limited personhood; do they have less social standing? Is it because they haven't really lived yet, because we don't know them, because they are "interchangeable nonpersons"?[73] Because the premature baby seems barely human to some caregivers, it can cause moral distress to intervene, some can even not feel the imperative to protect them.[28] Is it because of this lack of personhood that micropremies are often seen as being "replaceable"? When we know our 3-year-old son, his personality, his favourite foods, his smell in the morning, his tantrums; when he has a head trauma, we know what we are missing. It might not be the case for neonates. Although difficult, it is easier for me, and for many other physicians I know, to see a premature baby die than an infant born at term, and easier to see a term baby die than a baby who has been in the NICU with us for many months, whom we have grown attached to. Older children are "not supposed to die". In the relative devaluation of neonates, the media, who mainly focus on disasters for premature infants and at times dubious miracles, never show the average family coping with everyday life, this would not be a best seller.[74,75,76]

A. Is this position ethically problematic, are there any alternatives?

Clearly, one cannot realistically demand the preservation of life at all costs, nor perseverance against overwhelming odds. One should then wonder if the neonate and preterm infant are morally different from older patients. Two positions exist: they are or they are not. If the same ethical reasoning is not being applied at all ages, the rationale should be made explicit. Justifications could be made according to personhood, sense of duty, or by suggesting that the value of life of a preterm baby is perhaps less, or at least not the same, as that of an older incompetent patient. Instead of these justifications, simplistic blanket statements based solely on GA are used for decision-making, using outcomes and cost justifications that would not be applied in older populations.

Finally, if the ethical principles regarding resuscitation of newborns are no different from those followed in resuscitating older incompetent patients, do we even need policy statements? It is traditionally stated that, for patients of all ages, when the burdens of disease or its therapy are excessive or disproportionate to expected benefits, non-initiation of intensive care or withdrawal of life-sustaining therapies should be considered. This way of formulating the issues may be intellectually appealing, but what does it mean in a practical sense? Would it be ethically and scientifically appropriate to recommend intervention for all patients according to a predicted range of outcomes, for example: "intervention is optional and should be done only according to family's wishes when survival is less than X% and severe handicap is Y% or more"? There are very few policy statements in the literature regarding resuscitation at any other age for life-threatening situations: whether it be for head traumas, near drowning, meningitis, stroke, or burns. The lack of policy statements in these domains may reflect the clear and universal understanding that X and Y are almost impossible to define for each individual patient, because such critical, life-saving decisions are extremely complex and should be individualized, taking into account the nuances of the literature, the condition of the patient, the desires of the family, and the expectations of society.

Is it ethically problematic to treat preterm infants and neonates differently to older patients? It makes me uneasy to read policy statements that are categorical in their refusal to intervene before 25 or 26 weeks.[10,11,13] In the same countries that originate these policies older individuals with much worse outcomes are given a chance, or at least their families are offered intervention. In many delivery rooms around the world, parents of babies of 23-26 weeks gestation are told "there is nothing to do", and given the "better luck next time" approach. Death is assumed in these cases to be better for that child and family than life after an NICU stay with a subsequent risk of disability. Interestingly, we often think we do a complete informed consent in the delivery room, but it is rare indeed to talk to the families about what complications they may encounter after their baby's death. Premature delivery often is a risk for future preterm deliveries. Will the parents experience guilt and depression, will they separate, have sexual dysfunction, experience an intensely stressful future pregnancy? No publications on these issues exist. Once the baby dies, the neonatologist is no longer involved, with the best of intentions, he saved the baby a difficult NICU course, but he also saved the caregivers a difficult admission and hospital stay. The NICU caregivers will not have to live with that baby's death all their lives, but the family will. Experiencing death of one of our children is a traumatic event, even if the baby is extremely premature. A true informed consent in the delivery room would completely inform parents about the possible outcomes for each treatment alternative, yet this is not done and there is only scarce scientific information on which to base such counselling. Further research is needed in that area. Are biases regarding extreme prematurity so ingrained that even knowledge and experience cannot overcome our prejudices? Maybe health professionals working in the NICU should receive more teaching about outcomes, as opposed to what is often the focus or neonatal training: randomized controlled trials, new modes of ventilation, and new technology. Even then, teaching on outcomes should focus on excellent research available on quality of life, on parental and family perception of health, on perceptions of health of individuals living with disabilities, as opposed to teaching about handicaps as seen by physicians and those who teach. At the bedside, "substitutive ethics" might also help change the ingrained devaluation of neonates, especially around cases where health care professionals are contemplating withholding or withdrawing intensive care.

Perhaps neonatologists are the only ones who have it right? One could postulate that restricting intensive care to only patients with a better than 70% chance of survival is appropriate, and that this reasoning should be applied for all individuals. This would mean a drastic decrease in ICU admissions at all ages, while leaving the NICU admissions largely unaffected (because of the small number of premature infants less than 26 weeks) and would save billions to health care systems, entire hospitals could even be closed down and many physicians would have to become palliative care specialists.

If babies of 23-26 weeks have similar outcomes when they survive, should all babies with more than 20% survival be admitted to the intensive care? This also does not seem to be particularity appealing. I don't consider the enormous reserves of resilience of human beings and families to be valid arguments to make the families cope with whatever physicians decide they can cope with. If this was the case, we could stop offering prenatal screening for Down's syndrome, and stop offering "social" abortions altogether. The extreme preterm lies in such close vicinity to accepted reproductive decisions that, if we were to make intervention at 22 weeks mandatory, abortions could become more problematic. There would also be repercussions on mother's health. Maybe some of them, if they were bleeding at 22 weeks gestation, would not visit a tertiary care hospital (or their obstetrician would not transfer them to a tertiary care facility) for fear their baby would be admitted to the NICU. These women would suffer consequences themselves, as a tertiary care hospital is better equipped in treating severe maternal haemorrhage, for example.

A reasonable option seems to tolerate the ambiguous status quo, where the lives of neonates, and more particularity extremely preterm infants, are relatively devalued. But if this status-quo is tolerated, we should have the intellectual honesty to say why, and not hide behind outcomes, costs, pain, or best interests arguments.

PERSPECTIVES

Is this position amenable to change?

Morality seems to change with time. Before baby Doe in the US, many babies with Down syndrome were left to die for want of minor surgeries. In the past, individuals with psychiatric illnesses were institutionalized and isolated from society. This is still the case in some countries, while other societies have evolved. To quote John Lantos, morality seems to be relative:

> *«It seems to me morality does change. The evidence is all around us. It used to be that one could smoke cigarettes in hotel rooms but had to go out into a dark alley to buy pornography. Now, we can lie in bed and choose among four dirty movies on Spectravision but have to sneak out into the alley for a smoke.»*[77]

In some countries, babies who don't breathe immediately after birth are left to die, many are full term babies who need only a few assisted breaths to survive intact. Five to ten percent of babies are born this way and need a little help to start breathing on their own. In some cultures, babies are not named until they are a couple of months old. While for example in Vietnam, babies are born at the age of 9 months, as though they clearly already existed and their chronological life started *in utero*. Our society has evolved and individuals with disabilities and psychiatric illness are integrated in society, although at times imperfectly. We can see wheelchair ramps, blind dogs are admitted in all public institutions, it is now possible for patients who live with deafness or with other limitations to find a job. Will our society evolve to find the death of premature infants less acceptable, the way we now find that the death of a 3-year-old "is not supposed to happen, a tragedy"?

Because neonatology is a rather new field, this might be true. On the other hand, it may also be that our evolutionary "wiring" has made us inherently tolerant of neonatal deaths, whether or not NICUs will exist for 100 or 300 years. The relative devaluation could be more nature than nurture. The systematic devaluation of the newborn may be primarily due to deep-rooted anthropological, cultural, social and evolutionary factors. Until the late twentieth century, most parents experienced the death of at least one newborn or infant. To survive the commonness of infant death, some protective cultural and emotional mechanisms in the form of moral (philosophic) differentiation of the newborn from older people might have been selected? Waring, a philosopher, remarks that the way we value a person is indicated by how we react to their death, "feelings of tragedy, evil, loss and sharp regret are supposedly more appropriate responses to the deaths of younger people. One might view the deaths of older people as tolerable. Indeed, "it is not rare to hear that it is "better this way, nature took its course," that "he/she lived long enough" for an older individual."[24] Similar statements such as "it is better this way, nature took its course" and "at least he/she did not suffer" are also said for the death of neonates. Maybe a premature infant has not yet lived long enough to justify feelings of tragedy and regret; do we have feelings of detachment that desensitize us to the loss of newborns? Considerations of personhood may well continue to be important for decision-making for newborns. Will morality of our society change in regards to the relative devaluation of neonates? Only time will tell.

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Ethics of resuscitation at different ages of life

(Dr Janvier, Leblanc and Barrington)

Informed Consent

We are conducting a survey of opinions and attitudes towards resuscitation at different ages of life. Opinions are divergent when is comes to resuscitation of patients with potential brain injury or with very reduced lifespan. It is important to determine how these decisions are made, and what influences them. An institutional review board approved this questionnaire.

This questionnaire is anonymous. It will be distributed to individuals involved directly or indirectly with resuscitation decisions in several specialities. The findings from these questionnaires will be published in a medical or bioethics journal, and the results and conclusions could also be presented in a conference. After the results have been established, the questionnaires will be destroyed. There are no risks in participating in this study, it takes 10-15 minutes to fill.

____ Check here to indicate that your have read the above informed consent, and that your participation in this research is voluntary

____ Check here if you choose not to participate in this study.

Ethics of resuscitation at different ages of life

(Dr Janvier, Dr Leblanc and Dr Barrington)

You are in a level 3 emergency. For the following scenarios, indicate your willingness to intubate + resuscitate the following incompetent patients and consult intensive care. This hospital has neonatal, paediatric and adult ICUs.

A mother arrives 24 weeks pregnant about to give birth. The baby has a 50% chance of survival. The prognosis for survivors is: 50% normal, 25% severe handicap (deafness, blindness, cerebral palsy, or psychomotor development significantly abnormal), and 40% mild handicap (hyperactivity, learning disorder). The baby delivers at 650g (compatible with 24 weeks) and does not breathe efficiently. You don't have time to consult with parents.

Would you intubate, resuscitate and consult intensive care for admission?
always generally exceptionally never

If the parents ask you not to resuscitate, will you respect their decision?
always generally exceptionally never

Do you think intubating, resuscitating and consulting intensive care for admission is in the patient's best interest?
always generally exceptionally never

If it was your child and you had a few minutes to consider your decision, would you wish the physician to intubate, resuscitate and consult intensive care for admission?
always generally exceptionally never

If it was your sibling's child and you had time to think (not an emergency situation), and s/he asks for your opinion, would you recommend that the physician intubate, resuscitate and consult intensive care for admission?
always generally exceptionally never

A term baby is born precipitously in the ER. He has a brain malformation diagnosed *in utero*. According to the prenatal consultations, the baby has 50% chance of survival. The prognosis for survivors is: 50% normal, 25% severe handicap, and 40% mild handicap. The baby is born and does not breathe efficiently. You don't have time to consult with parents.

Would you intubate, resuscitate and consult intensive care for admission?
always generally exceptionally never

If the parents ask you not to resuscitate, will you respect their decision?
always generally exceptionally never

Do you think intubating, resuscitating and consulting intensive care for admission is in the patient's best interest?
always generally exceptionally never

If it was your child and you had a few minutes to consider your decision, would you wish the physician to intubate, resuscitate and consult intensive care for admission?
always generally exceptionally never

If it was your sibling's child and you had time to think (not an emergency situation), and s/he asks for your opinion, would you recommend that the physician intubate, resuscitate and consult intensive care for admission?
always generally exceptionally never

A previously healthy 2-month-old baby presents to your ER with fever, irritability and respiratory pauses according to parents. He is very sick with neurological signs. The lumbar puncture is purulent and confirms the diagnosis of meningitis. The prognosis for this bacterial meningitis is 50% survival. The prognosis for survivors is: 50% normal, 25% severe handicap, and 40% mild handicap. The baby stops breathing. You don't have time to consult with parents.

Would you intubate, resuscitate and consult intensive care for admission?
always generally exceptionally never

If the parents asked you not to resuscitate, will you respect their decision?
always generally exceptionally never

Do you think intubating, resuscitating and consulting intensive care for admission is in the patient's best interest?
always generally exceptionally never

If it was your child and you had a few minutes to consider your decision, would you wish the physician to intubate, resuscitate and consult intensive care for admission?
always generally exceptionally never

If it was your sibling's child and you had time to think (not an emergency situation), and s/he asks for your opinion, would you recommend that the physician intubate, resuscitate and consult intensive care for admission?
always generally exceptionally never

A 7-year-old boy has cerebral palsy, he walks with a limp without any help and plays most sports. He will repeat his 1st grade because of a learning disorder and hyperactivity. He has a hearing deficit that requires aids entirely correcting his condition. He presents in ER with shallow breathing after being hit by a car. He has a brief seizure that stops with medication. His CT scan shows moderate to severe brain swelling. His prognosis is 50% survival with 50% chances to recover back to his baseline if he survives. He starts seizing again and the airway cannot be maintained.

Would you intubate, resuscitate and consult intensive care for admission?
always generally exceptionally never

If the parents asked you not to resuscitate, will you respect their decision?
always generally exceptionally never

Do you think intubating, resuscitating and consulting intensive care for admission is in the patient's best interest?
always generally exceptionally never

If it was your child and you had a few minutes to consider your decision, would you wish the physician to intubate, resuscitate and consult intensive care for admission?
always generally exceptionally never

If it was your sibling's child and you had time to think (not an emergency situation), and s/he asks for your opinion, would you recommend that the physician intubate, resuscitate and consult intensive care for admission?
always generally exceptionally never

A 13-year-old child has acute myeloblastic leukemia. She has brain involvement that will require radiation therapy. Staging predicts a 5% long-term survival, after bone marrow transplant. If she survives, the risk of long-term neurological sequelae is 20%, including major schooling problems. She arrives by ambulance in septic shock and needs intubation.

Would you intubate, resuscitate and consult intensive care for admission?
always generally exceptionally never

If the parents asked you not to resuscitate, will you respect their decision?
always generally exceptionally never

Do you think intubating, resuscitating and consulting intensive care for admission is in the patient's best interest?
always generally exceptionally never

If it was your child and you had a few minutes to consider your decision, would you wish the physician to intubate, resuscitate and consult intensive care for admission?
always generally exceptionally never

If it was your sibling's child and you had time to think (not an emergency situation), and s/he asks for your opinion, would you recommend that the physician intubate, resuscitate and consult intensive care for admission?
always generally exceptionally never

A 35 y old with no previous medical history comes to the ER with headaches increasing for the past month and difficulty with finding his words. His neurological exam is abnormal and he is disoriented. His CT scan shows a very large left-sided tumour consistent with *glioblastoma multiforme*, which has a 5% survival rate at 5 years. The surgery to remove this large mass will leave sequelae (variable, including paralysis, cognition and speech difficulty) and inability to work. You come back to speak with your patient and his family, but he has lost consciousness.

Would you intubate, resuscitate and consult intensive care for admission?
always generally exceptionally never

If the family asked you not to resuscitate, will you respect their decision?
always generally exceptionally never

Do you think intubating and resuscitating is in the best interest of the patient?
always generally exceptionally never

If this was your partner and you had to decide for them. Would you want the physician to intubate, resuscitate and consult intensive care for admission?
always generally exceptionally never

If this was your brother/sister and you had to decide for him/her. Would you want the physician to intubate, resuscitate and consult intensive care for admission?
always generally exceptionally never

If this was you and you were able to decide. Would you want the physician to intubate, resuscitate and consult intensive care for admission?
always generally exceptionally never

A 50-year-old trauma patient (car accident) arrives in the ER with multiple fractures and a cervical vertebra (C6) fracture (non-displaced). He needs fluid resuscitation and is semi conscious. His CT scan shows large areas of haemorrhages. His prognosis for survival is 50%. If he survives, the risk of normal outcome is 50%, and abnormal outcome is 50% with a significant probability of quadriplegia. The patient needs to be intubated, you don't have time to speak with the family.

Would you intubate, resuscitate and consult intensive care for admission?
always generally exceptionally never

If the family asked you not to resuscitate, will you respect their decision?
always generally exceptionally never

Do you think intubating and resuscitating is in the best interest of the patient?
always generally exceptionally never

If this was your partner and you had to decide for them. Would you want the physician to intubate, resuscitate and consult intensive care for admission?
always generally exceptionally never

If this was your brother/sister and you had to decide for him/her. Would you want the physician to intubate, resuscitate and consult intensive care for admission?
always generally exceptionally never

If this was you and you were able to decide. Would you want the physician to intubate, resuscitate and consult intensive care for admission?
always generally exceptionally never

An 80-year-old patient arrives by ambulance. According to his wife, he is acutely paralysed on his left side and cannot talk. He has moderate Alzheimer's disease, recognizes only his close family and keeps wandering off and needs help in his daily activities. His cerebral scan shows a massive stroke. The prognosis for survival is 50%. If he survives, the prognosis for recovery to his previous health state is about 50%. The patient stops breathing.

Would you intubate, resuscitate and consult intensive care for admission?
always generally exceptionally never

If the family asked you not to resuscitate, will you respect their decision?
always generally exceptionally never

Do you think intubating and resuscitating is in the best interest of the patient?
always generally exceptionally never

If this was your partner and you had to decide for them. Would you want the physician to intubate, resuscitate and consult intensive care for admission?
always generally exceptionally never

If this was your brother/sister and you had to decide for him/her. Would you want the physician to intubate, resuscitate and consult intensive care for admission?
always generally exceptionally never

If this was you and you were able to decide. Would you want the ER physician to intubate, resuscitate and consult intensive care for admission?
always generally exceptionally never

IF ALL OF THE PREVIOUS PATIENTS HAD TO BE RESUSCITATED AT THE SAME TIME, IN WHAT ORDER WOULD YOU RESUSCITATE THEM, INDICATE 1 TO 8. (1 = THE FIRST PATIENT TO BE RESUSCITATED)

Premature 24 weeks ____
Newborn with brain malformation ____
2 months old with meningitis ____
7-year-old in a car accident ____
13-year-old with leukemia ____
35-year-old with brain cancer ____
50-year-old in car accident ____
80-year-old with stroke ____

YOU ARE:

Male Female

ETHICS
Student

MEDICINE
Student

Resident, junior, senior
ER
Family medicine
Paediatrics
Obstetrics

Physician,
Adult: ER Family medicine
Paediatrics: ER NICU
Obstetrics

Do you have children? Yes No

less than 5 years experience, more than 5 years experience

Do you have children? Yes No