EXCELENTÍSSIMO SR. DR . MINISTRO RELATOR DA ADPF 54 DO SUPREMO TRIBUNAL FEDERAL

Elizabeth Kipman Cerqueira, já qualificada nos autos do processo em epígrafe, na qualidade de técnica indicada pelo Ministério Público Federal que participou da Audiência Pública a convite do Sr Ministro Relator, vem, pessoalmente, expor e requerer o seguinte:

Quando da realização da Audiência Pública havida no dia 16-09-2008 , o ilustre advogado da parte Autora houve por questionar a peticionária a respeito de estatísticas e dados apresentados , colocando em dúvida a precisão das informações prestadas(vide video produzido pela TV Justiça).

No intuito de esclarecer a verdade real dos fatos a requerente apresenta com a presente o incluso relatório, de conteúdo autoexplicativo que demonstra a lisura de sua manifestação na Audiência Pública, para que nenhuma dúvida exista tanto da parte autoral quanto da parte de qualquer dos Ministros sobre a veracidade científica de suas afirmações.

Pelo exposto requer a V.Exa se digne determinar a juntada aos autos do incluso relatório sendo ouvida a parte argüente a respeito do mesmo.

N.Termos,

P.Deferimento

ELIZABETH KIPMAN CERQUEIRA

Gabinete do Ministro
MARCO AURELIO
Recebido em:

02 FEV 2009

ADPF 54

LIBERAÇÃO DO ABORTO EM GESTAÇÃO DE ANENCÉFALOS

A quem deve ser concedida primazia na atenção: à Mulher ou ao Feto?

Sobejamente durante esta Ação foi apresentada a situação do feto portador de anencefalia: seu desenvolvimento cerebral está seriamente comprometido, não há terapia possível no momento, talvez seja abortado espontaneamente, poderá acontecer o óbito intra-uterino ou logo após o parto.

Estes são fatos inquestionáveis, como também é fato que esta Ação se refere ao feto vivo; não o podemos igualmente negar. Se a questão tratasse de feto morto não caberia esta Ação, pois a prática médica é livre para atuar diante do óbito fetal intra-uterino conforme as normas éticas, técnicas e jurídicas.

É a verdade que não deve ser manipulada com argumentos sofismáticos ou manobras de raciocínio para levar à confusão: a Ação se baseia na suposição de que a previsão de curta vida justifica liberar as mães para apressar a morte de seus filhos em gestação. Não há dúvidas de que esta liberação agrediria um Preceito Fundamental: o do direito à vida independente do seu tempo de duração.

Para contornar a inovação legislativa pretendida, foram apresentados alguns pontos que justificariam a Ação:

1. O feto seria um morto cerebral e, portanto ao eliminá-lo não se incorreria em aborto provocado;
2. A mãe estaria correndo risco de morte durante esta gestação;
3. O Estado seria responsável pela tortura mental da mãe ao negar a possibilidade de escolha do aborto provocado (procurando estabelecer um paralelo com a gestação resultante de estupro);
4. A mulher teria direito de interromper a gravidez quando e por qual motivo quiser – argumento não tão explicitado pelos defensores desta Ação.

O FETO PORTADOR DE ANENCEFALIA ESTARIA EM ESTADO EQUIVALENTE À MORTE CEREBRAL

A apresentação da dra. Cinthia M. Specian provou sobejamente que esta afirmativa não está fundamentada cientificamente e, por este motivo, inclusive foi negada nos Estados Unidos a autorização para doação ou estudo dos órgãos de recém-nascidos vivos portadores desta anomalia. A avaliação neurológica destas crianças não conseguiu preencher as exigências do Protocolo para Morte Cerebral para esta idade. [1] Anexamos trabalho publicado no JAMA com destaque nas afirmações mais importantes (Anexo I).

Se não é possível diagnosticar a morte cerebral no recém-nascido vivo, muito menos é possível ter esta conclusão para o feto em gestação quando não se pode prever qual estrutura cerebral ainda irá se desenvolver até o momento do parto, embora, na ausência da calota óssea do crânio, os hemisférios cerebrais tenham sido definitivamente prejudicados em seu desenvolvimento além do que o preenchimento do Protocolo exige exames e testes possíveis após sete dias de vida extra-uterina.

Apenas ressaltamos que se trata de criança recém nascida portadora de anencefalia com respiração espontânea sem uso da assistência mecânica de aparelhos para respiração artificial, o que acontece nos casos diagnosticados como morte cerebral.

Esta pretensa *inovação legislativa* no Brasil deseja se basear em supostas afirmativas científicas já avaliadas e negadas em outros países?

DIAGNÓSTICO CLÍNICO DE MARCELA

A menor Marcela, portadora de anencefalia, que viveu 1 ano e 8 meses é um desafio que contradiz a afirmativa de igualar este quadro clínico com o de morte cerebral. Foi afirmado nesta Ação que em Marcela teria ocorrido um erro diagnóstico. Anexo três laudos de especialistas americanos que confirmam o laudo dos especialistas brasileiros: diagnóstico de anencefalia (Anexo II).

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[1] SHEWMON D. Alan e col. *The use of Anencephalic Infants as Organ Sources* JAMA, March 24/31, 1989-Vol 261, nº 12

RISCOS MATERNOS DURANTE A GESTAÇÃO DE FETOS PORTADORES DE ANENCEFALIA

1. RISCOS FÍSICOS MATERNOS NA GESTAÇÃO DE 2º/3º TRIMESTRE

Deve-se esclarecer que a medicina define como aborto, a interrupção da gestação até vinte semanas (para alguns até vinte e duas semanas) ou até o peso fetal de 500 g. Apenas se aplicaria o conceito de antecipação do parto após as vinte e duas semanas de gestação.

Estamos diante do confronto entre os riscos de manter a gravidez até a resolução espontânea e os riscos da aqui chamada *antecipação terapêutica do parto.*

O termo *terapêutico* se refere ao *tratamento de uma patologia.* Na situação em discussão, o feto corre risco de morte e o procedimento tem como evidente objetivo antecipá-la, portanto não há objetivo terapêutico para ele. Quanto à mãe, apresentamos a seguir uma discussão dentro dos conceitos estabelecidos da obstetrícia.

A – RISCOS DECORRENTES DA ANTECIPAÇÃO DO PARTO EM GESTAÇÃO DE 22 A 40 SEMANAS:

a) Trabalho de parto prolongado: não estando o útero preparado espontaneamente para o parto, a indução forçada exige muito tempo. Nos próprios relatos das mães que receberam autorização judicial para este procedimento, constata-se que o parto ocorre, em média, após 5 a 11 dias de internação, com o uso de medicamentos e de procedimentos indutores. Esta situação apresenta riscos médicos comprovados uma vez que afronta os processos estabelecidos no organismo feminino que orientam para a resolução natural da gestação;

b) Risco de ruptura uterina: os indutores do parto podem provocar a ruptura do útero colocando a vida da gestante em seriíssimo risco. Da mesma forma, podem levar ao descolamento da placenta com hemorragia súbita e fatal;

c) Infecção: O processo prolongado de parto e as manobras habitualmente aplicadas elevam o risco de infecção ginecológica que pode se generalizar;

d) Tempo de internação hospitalar: o período de internação supõe o isolamento familiar o que normalmente é considerado como fator de risco coadjuvante;

e) Aumento da resolução através da via cirúrgica (parto cesariano): a indução antecipada ao parto somada ao *stress* pela própria gestação, o processo demorado e

doloroso das contrações uterinas forçadas levam a um maior número de partos cesarianos motivados pelo fracasso da indução, pelas complicações provocadas, pela exaustão da mãe e da própria equipe de saúde além da pressão habitual dos familiares. Como se sabe esta não é a via melhor para o parto, sobretudo nestes casos. Um ato cirúrgico sempre acrescenta riscos para a mãe e compromete o seu futuro obstétrico como vem sendo defendido nos últimos anos pelo Ministério de Saúde.

Estes são os riscos principais do procedimento ressaltando que TODOS ELES SUPÕEM SEQÜELAS PERMANENTES conforme literatura mundial conhecida por todo obstetra. Acrescente-se a esta relação, as complicações que acompanham o aborto induzido relacionadas nesta apresentação.

B – RISCOS NA MANUTENÇÃO DA GESTAÇÃO APÓS 22 SEMANAS ATÉ A RESOLUÇÃO NATURAL DO PARTO:

a) Polidrâmnio: acúmulo do líquido amniótico além do volume considerado normal o que pode chegar a trazer desconforto e algum risco para a gestante. Existe o procedimento seguro de redução do líquido, realizado com o auxílio apenas de um exame de ultra-sonografia sempre que possível;

b) Hipertensão arterial: pode acontecer nesta gravidez como em qualquer outra gestação. É habitualmente controlável com medidas terapêuticas comuns e muito raramente exige uma intervenção mais radical onde o objetivo é manter a vida tanto da mãe como da criança.

Estes riscos, além de serem contornáveis, NÃO APRESENTAM SEQÜELAS APÓS O PARTO.

2. RISCOS FÍSICOS MATERNOS NA GESTAÇÃO DE 1º/2º TRIMESTRE

A – RISCOS DECORRENTES DO ABORTO PROVOCADO EM GESTAÇÃO ATÉ 22 SEMANAS:

a) Processo demorado que se prolonga por dias lembrando que o colo uterino se encontra fechado e resistente ao procedimento;

b) Riscos imediatos decorrentes do próprio procedimento como perfuração e laceração do útero, hemorragias, infecção; [2]

c) Complicações em futuras gestações provocando maior tempo de internação, de repouso, de acréscimo de risco como:

- sete vezes mais de probabilidade de placenta prévia; [3]
- maior freqüência de partos prematuros; [4]

d) Maior número de mortes por diferentes causas entre as mulheres que provocaram aborto por qualquer causa do que entre aquelas que levaram a gestação até o término natural, entre elas: doenças circulatórias, doenças cérebro-vasculares, complicações hepáticas; [5]

e) Maior incidência de câncer de mama para o que também concorre o maior número de partos prematuros cujo índice é maior após o aborto provocado.[6] (Anexo III e IV)

Os riscos de longo prazo são explicados, sobretudo pela ação dos hormônios: durante a gestação eles se organizam para mantê-la até a resolução natural do parto ou na eventualidade de um aborto espontâneo.

AS SEQÜELAS E COMPLICAÇÕES RELATIVAS A ESTES RISCOS SÃO EVIDENTES, com alto custo para as mães envolvidas, para as famílias e para o sistema social de atendimento à saúde.

B – RISCOS NA MANUTENÇÃO DA GESTAÇÃO ATÉ 22 SEMANAS:

[2] NEY Pie col *The Effects of Pregnancy Loss on Women Health* Social Science & Medicine 38(9);1193-1200 1994 * FRANK PI *Induced-Abortion Operations and Their Early Dequelae* Journal of the Royal College of General Practitioners 35(273):175-180 1985 * HALLBERG PE e col *Acute Pancreatitis Following Medical Abortion* BMC Women's Health 4(1) 2004

[3] BARRET JM e col *Induced abortion: a risk factor for placenta previa* American Journal of Obstetrics and Gynecology 1981 December 1;141(7):769-72 * TAYLOR VM e col *Placenta previa in relation to induced and spontaneous abortion: a population-based study* Obstetrics and Gynecology 1993 July;82(10:88-91);p.91

[4] ROONEY, B e col *Induced Abortion and Risk of Later Premature Births* Journal of American Physicians and Surgeons 8(2);46-49

[5] REARDON, DC e col *Deaths Associated with Pregnancy Outcome: A Record Linkage Study of Low Income Women* Southern Medical Journal Vol 95 nº8 Aug 2002

[6] BERAL V e col *Collaborative Group pn Hormonal Factors in Breast Câncer* Lancet 363:1007-1016 2004 * MALEC K *The Abortion-Breast Cancer Link: How Politics Trumped Science and Informed Consent* Journal of American Physician and Surgeons 8(2):41-45 2003

Iguais a qualquer outra gestação observando-se que a eventual morte fetal intra-uterina não apresenta risco maior para a gestante a não ser medidas simples de acompanhamento.

ASPECTO PSICOLÓGICO: TORTURA MENTAL PROVOCADA NA MÃE DECORRENTE DA IMPOSSIBILIDADE DE REALIZAR O ABORTO

"O fardo é quase sempre uma carga emocional, uma vez que, raramente, existe risco físico para a mãe em levar adiante uma gestação anencefálica, comparado ao risco da indução antecipada." [7]

Embora o risco físico nesta gestação seja praticamente igual ao risco de qualquer outra gestação, o aspecto afetivo-emocional deve ser considerado muito seriamente, porém o caminho da solução é justamente o oposto ao que vem sendo apresentado pelos promotores desta Ação.

O susto, a decepção, a preocupação consigo e com os outros filhos, o sentimento de culpa indevido - muitas vezes inconsciente, porém freqüente - causam grande dor psicológica e a mãe pode ser levada a seguir o impulso imediato de abreviar a solução da gestação esperando anular a tristeza. Em grande parte, isto depende de como a realidade lhe é apresentada; de como os profissionais e a família reagem ao "anormal" e ao imprevisto.

De toda forma, para a mãe, a esperança frustrada e a sensação de impotência são terríveis ao tomar ciência de que traz em si um filho que não sobreviverá. Entretanto, diversos trabalhos apontam os riscos psicológicos maiores para a mulher que provoca o aborto qualquer que seja a sua motivação.

Nos EUA, as estatísticas apontam para as mulheres que se submeteram ao aborto provocado:

- 250% mais de necessidade de hospitalização psiquiátrica; [8]
- 138% a mais de quadros depressivos; [9]
- 60% a mais quadros de *stress* pós trauma; [10]
- 7 vezes mais tendências suicidas; [11]

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[7] GOODWIN TM, M D Assistant Professor os Maternal-Fetal Medicine University of Southern California *Ethics & Medics* Vol 21, nº 3

[8] COUGLE JR e outros *Psychiatric admissions of low-income women following abortion and childbirth* Canadian Medical Association Journal 168(10):1253-1256 2003

[9] COUGLE JR e col *Depression associated with abortion and childbirth: A long-term analysis of the NLSY cohort* Medical Science Monitor 9(4):CR 105-112 2003

[10] COLEMAN PK e col *State-funded abortions versus deliveries: A comparison of outpatient mental health claims over 4 years* American Journal of Ortho psychiatry 72(1):141-152 2002

- 30 a 50% mais quadros de disfunção sexual; [12]

- 25% exigem acompanhamento psiquiátrico em longo prazo. [13]

Recentemente pode ser lida a notícia publicada no *British Journal of Psichiatry*, atualizada em *site* no dia 01 de dezembro de 2008: pesquisas realizadas em Nova Zelândia mostraram existir 30% mais problemas mentais em mulheres que fizeram aborto induzido, conforme expõe o coordenador do trabalho, dr. David Fergusson anteriormente totalmente favorável ao aborto por livre escolha.[14]

A que se deve este resultado estatístico que é comprovado tanto entre a população de baixa renda como na de alta renda?

As escolas de psicologia mostram que nenhum trauma é satisfatoriamente superado através de outro trauma. É o que acontece na gestação desde o início indesejada ou que se torna indesejada durante a sua evolução. O aborto provocado acrescenta outro trauma muito mais intenso sobre o anterior uma vez que toda mulher sente consciente ou inconscientemente que está determinando o fim da vida de um filho seu. [15]

Os dois depoimentos apresentados em audiência anterior nesta Ação como testemunhos de que o aborto permitido judicialmente teria sido a melhor opção anunciam este fato. A primeira mãe, afirma haver chorado todos os dias desde o aborto provocado até o nascimento de outro filho. A segunda afirmou logo que havia feito inseminação artificial e que não aceitava "filho defeituoso".

Portanto, além de ser extremamente questionável a "solução" do aborto nestes casos, o Estado não é o responsável pela existência da criança com anencefalia, embora deva tomar as medidas preventivas possíveis como a oferta do ácido fólico.

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[11] TISCHLER C *Adolescent suicide attempts following elective abortion* Pediatrics 68(5):670-671 1981 *CRISTOPHER LM e col *Suicides after pregnancy: Mental health may deteriorate as a direct effect of induced abortion* British Medical Journal 314:902 1997 * GISSLER M e col *Suicides after pregnancy in Finland 1987-1994: Register linkage study* British Medical Jouranl 313(7070):1431-1434 1996

[12] DOUVIER S e col *Interruption volontaire de grossesse: étude comparative entre 1982 et 1996 sur lê principal centre de cote d'or.Anelyse dês femmes ayant dês IVG itératives* Gynecol. Obstet. Fert. 29(3):200-210 2001 * BELSEY EM e col *Predictive Factors in Emotional Response to Abortion – Kings Termination Study* Social Science & Medicine 11(2):71-82 1977

[13] RUE VM e col *Induced abortion and traumatic stress: A preliminary comparison of American and Russian women* Medical Science Monitor 10(10) SR5-16 2004 * COUGLE JR e col *Generalized Anxiety Following Unintended Pregnancies Resolved Through Childbirth and Abortion: A cohort Study os the National Survey os Family Growth* Journal of Anxiety Disorders 19:137-142 2005

[14] http://www.bbc.co.uk:80/portuguese/reporterbbc/story/2008/12/081201_abortossaudementalrw.shtml *The British Journal of Psychiatry* (2008) 193: 444-451. doi: 10.1192/bjp.bp.108.056499 The Royal College of Psychiatrists *Abortion and mental health disorders: evidence from a 30-year longitudinal study* David M. Fergusson, PhD, L. John Horwood, MSc and Joseph M. Boden, PhD

[15] HENRIT L *Impacto f induced abortions on subsequent pregnancy outcome: the 1995 French national perinatal survey* British Jouranl of Obstetrics and Gynaecology 108(10):1036-1042 2001

Na situação da gestação de feto anencefálico, a mãe percebe o filho vivo embora irremediavelmente doente. Transforma-se o triste e doloroso em trágico ao não lhe permitir reconhecer e amar a criança como seu filho, apresentando-o como monstro ou como vida sem valor, como um "nada". Ela também pode se sentir um "nada" ou um monstro, chamada de "caixão ambulante" pelos próprios médicos. Além da dor de não ter um filho para si, a mãe precisa lutar contra o sentimento de haver gerado uma "anomalia". Todos os seus sentimentos se revoltam contra a associação inconsciente a si própria através de arcaicos sentimentos de fragilidade, de culpa e de temor.

Pode ser dificílimo viver o dia-a-dia desta gestação, porém a capacidade de intuir o valor e de captar o significado de cada situação é algo específica e exclusivamente humano e a mãe, tendo tempo, pode descobrir um *por que* e um *para que* pessoal e intransferível em seu sofrimento, sem agredir ainda mais a si mesma e àquele "ser que traz em seu ser". Não é sofrimento que faz crescer. Os filósofos e a sabedoria popular reconhecem que é a atitude que se toma diante do sofrimento não procurado e que nos atinge de forma inevitável que faz crescer como pessoa.

Quando a mãe interrompe a gravidez, abortando artificialmente, não pode assimilar e elaborar a dor que é obrigada a suportar ou a re-significar. Esta necessidade fica mais difícil de ser alcançada porque o aborto provocado expressa a negação de sentido de toda a vivência, até do próprio sofrimento. Não encontra resposta nem do "por que" nem do "para que".

Freud afirmou: *"Ficamos perplexos ao ver os inesperados resultados que sucedem a um aborto artificial, ao lado de matar uma criança ainda não nascida, mesmo a partir de uma decisão tomada sem remorso nem hesitação".* [16]

É MAIS FÁCIL UMA MÃE SE ARREPENDER DE HAVER PROVOCADO O ABORTO DO QUE DE HAVER ESPERADO ATÉ A SOLUÇÃO NATURAL DE SUA GESTAÇÃO.

Concluímos que:

1. A consideração de morte encefálica não se aplica ao feto e ao recém-nascido portador de anencefalia conforme os protocolos aprovados;
2. A expressão "antecipação terapêutica do parto" não se aplica;

[16] FREUD S *Obras Completas* Imago S E, 18:206 RJ 1974

3. A gestação não oferece risco de vida importante para a mãe;
4. O risco do aborto provocado e do parto provocado é maior do que na espera pela resolução espontânea da gestação;
5. Embora nem sempre seja inicialmente identificado, o aborto provocado pode trazer maior tortura psicológica à mãe.

Resta a questão:

MESMO COM O CONHECIMENTO DE TODOS ESTES FATOS, TEM A MÃE O DIREITO DE RESOLVER PELO ABORTO SE ESTA FOR A SUA VONTADE?

A resposta é negativa porque:

1. Não é permitido pela legislação brasileira; está se tentando criar uma inovação legislativa de forma indireta e disfarçada;
2. Não traz benefício real à mãe; embora possa aparentar um alívio imediato aumenta os riscos para ela tanto a curto como em médio e longo prazo;
3. Socialmente, apresenta um contra-valor: a anulação do "anormal";
4. É uma negação ao direito à vida transformando a Declaração Universal dos Direitos Humanos em *direitos individuais* daqueles que conseguem ter voz dentro de uma determinada cultura;
5. Sobretudo é o uso da dor destas mães, por parte de alguns, como ESTRATÉGIA DELIBERADA PARA INTRODUZIR NO BRASIL, O CHAMADO "DIREITO AO ABORTO", sem restrições, por livre demanda; a intenção não é a de descriminalizar o aborto em uma situação de forte conflito emocional, mas de relativizar o respeito à vida e à dignidade de toda pessoa humana. Fato este registrado em publicações como aquelas que aqui anexamos:

1. *Selective Abortion in Brazil: the Anencephaly Case,* Débora Diniz (**ANEXO V**). Este trabalho afirma em sua última coluna que, finalmente, nesta Ação, o aborto está sendo discutido em termos de direitos humanos e não como uma confrontação de credos religiosos.

Esta é uma tentativa de desmerecer os argumentos apresentados por aqueles que se opõem à liberação do aborto nos casos de gestação com anencefalia. Nesta apresentação escrita e na defesa oral, em nenhum momento fiz referência a bases religiosas, mas apenas foram apresentadas fundamentações científicas.

2. *Higroma Cístico em Feto 45,X – Diagnóstico Precoce por Ultra-sonografia e Amostra de Vilo Corial,* Thomaz R. Gollop e col (**ANEXO VI**). Numa afirmativa coerente com a sua habitual defesa da liberação total do aborto, o autor apresenta afirmativa final sobre o fato deste aborto se referir as crianças sem retardo mental e perfeitamente viáveis defendendo a "facilitação do processo" quando feito o diagnóstico precoce e "explicado minuciosamente o problema" aos pais.

Foi afirmado na Audiência Pública que, pelo fato de eu haver defendido os embriões em Ação anterior referente às pesquisas com Células-Tronco Embrionárias e por defender **os fetos e as mães** na presente Ação, poder-se-ia concluir que eu sou contra o controle de natalidade.

Pergunto: pode-se então concluir que aqueles que defenderam as pesquisas com Células-Tronco Embrionárias e defendem atualmente o aborto na presente Ação **também defendem o controle da natalidade**? Seria este o objetivo oculto do uso político da dor e do infortúnio das mães e pais dos bebês portadores de anencefalia?

Agradeço a oportunidade de haver participado desta Ação e a possibilidade de apresentar a documentação científica de minha exposição colocando-me à inteira disposição para qualquer complementação.

Jacareí, 17 de dezembro de 2008.

Elizabeth Kipman Cerqueira

ANEXO I

The Use of Anencephalic Infants as Organ Sources

A Critique

D. Alan Shewmon, MD; Alexander M. Capron, LLB; Warwick J. Peacock, MD; Barbara L. Schulman, RN

The recent abandonment of the only active US protocol for harvesting organs from anencephalic "donors" indicates both the practical and the ethical problems inherent in such an effort. Various data suggest that surprisingly few such organs would actually end up benefiting other children. Attempts to revise either the Uniform Anatomical Gift Act or the Uniform Determination of Death Act to allow organ removal from spontaneously breathing anencephalic infants face major ethical objections. Even if this posed no ethical problem in theory, the ultimate harm to society would not be offset by the good of the few surviving recipients of these organs. Furthermore, providing anencephalic infants with intensive care would tend to preserve the brain stem as effectively as the other organs, predictably rendering the occurrence of brain death unlikely. Thus, despite the great need for newborn organs, anencephalic infants are not as attractive a source as some had hoped.

(*JAMA*. 1989;261:1773-1781)

IN JULY 1988, Loma Linda (Calif) University Medical Center suspended the controversial protocol under which it had been the only center in the United States with an active program for harvesting organs from anencephalic infants for transplantation (*Los Angeles Times*. August 19, 1988:[pt I]3; *Los Angeles Times*. August 24, 1988:[pt I]25).[1] In reaching this decision (following 13 failed attempts to obtain organs from such babies during the preceding 7 months), the protocol's principal author acknowledged that critics had been justified in worrying about such issues as the consequences for the anencephalic infant and the expansion of the category of potential donors to infants with less severe defects. The experience of the Loma Linda program clearly indicates that substantial ethical as well as practical issues remain to be resolved before any further effort is made to employ anencephalic infants as organ "donors."

The attempt to harvest organs from anencephalics itself reflects the difficulties physicians have faced in responding to the growing demand for suitable donors generated by recent progress in pediatric organ transplantation. The first difficulty is that death in organ donors is usually diagnosed through the use of brain-based criteria (typically referred to as "brain death").[2,3] Yet, the sorts of injuries (such as highway accidents) that can destroy the brain, while leaving the other organs intact for transplantation, are much rarer in infants than in adults and older children. Aside from use of contrast angiography, diagnostic criteria for infant brain death have not been validated, and certainty of diagnosis is much less easily attained than in older patients,[4,5] recent guidelines[6-8] notwithstanding.

The difficulties in obtaining adequate numbers of infant cadavers with artificially supported vital functions have led some physicians to search for alternative sources of organs, such as other animal species, human fetuses, and even dying—but still living—human infants. Anencephalic infants are the main group so far proposed. Objections to using them as organ sources before death has been diagnosed and declared, which we discuss, led to the Loma Linda protocol under which organs were to be harvested only after death had been declared in infants receiving ventilatory support. In this article, we also discuss the issues raised by this now-suspended approach to obtaining infant organs.

HISTORICAL REVIEW

During the past 25 years, there have been a number of reports of heart[9-11] and kidney[12-23] transplants using anencephalic donors, with varying results. In most of the US cases of kidney transplants, the donors were declared dead prior to removal of organs; although the basis for determining death was not always stated, when reported it was the cessation of heart beat and respiration. In the few cases of heart transplants, death was putatively declared on the basis of neurological criteria.

These previous reports of the use of anencephalic infants raise several serious issues, the first of which is the physicians' lack of clarity about the status of these patients. For example, Lawson et al,[17] describing kidney harvesting from an infant of 37 weeks' gestation, stated that "the anencephalic fetus was delivered by cesarean section and was kept on a sterile field while the nephrectomies were performed. No attempt was made to resuscitate the fetus during the nephrectomies." Plainly, the source of the kidneys was a live-born infant, no longer a fetus; had the infant been stillborn, the kidneys would have been unusable.

Second, without announcing that a less demanding standard was employed, in some cases determinations of death appear to have been made that would have been unacceptable in nonanencephalic patients. For example, Iitaka and colleagues[11] regarded the anencephalic as a cadaver "once assisted ventilation is required," apparently not because this is the usual criterion for death but because "thereafter the condition of the donor deteriorates rapidly." The deviation from usual standards was particularly notable in two anencephalic heart transplant cases in the late 1960s.[9,10] It seems dubious that the cited criteria of a flat electroencephalogram and absence of all neurological functions would have applied to the anencephalic infants, because it is unclear how even to perform an electroencephalogram on these patients and because there is no reason for the neural tissue of an anencephalic to cease functioning prior to somatic death. Instead, the timing of the cardiac excision appears to have been based on the moment when the heart stopped beating spontaneously, albeit not irreversibly. That the cessation of heart beat in one case[9] happened to take place conveniently in the operating room after heparinization and cooling to −2.8°C in preparation for the transplant raises further questions as to whether the "donor's" death was entirely spontaneous.

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CURRENT DEVELOPMENTS

The problems that lay below the surface in these earlier attempts to transplant organs from anencephalic infants are receiving attention again because of the increased interest in obtaining neonatal organs. Several new arguments have been advanced for the use of these infants as organ sources. First, some have suggested that the inevitability of the rapid demise of anencephalics justifies their use ante mortem.[29,30] This was the rationale for bill 3367 introduced in New Jersey in October 1986 by Assemblyman Walter Kern, Jr, which would have amended the Uniform Anatomical Gift Act (UAGA) to permit parents of an anencephalic infant to donate its organs before death. Second, it has been argued that anencephalics are "brain absent" and therefore should be regarded as equivalent to being "brain dead."[29,30] On this basis, California Senator Milton Marks in 1986 promoted SB 2018, which, as originally formulated, would have expanded the Uniform Determination of Death Act (UDDA) to include anencephaly as a basis for diagnosing death, in addition to irreversible cessation of circulatory and respiratory functions or irreversible cessation of all functions of the entire brain.[31] Various groups, including the California Medical Association, opposed the use of live anencephalic infants as organ sources and these bills failed to be adopted. Subsequently, other professional groups, such as the California Nurses Association[32] and the United Network for Organ Sharing,[33] have expressed similar opposition to the application of special standards to anencephalic infants.

Alternatively, some physicians believe that organs can be harvested from these infants without having to change medical and legal standards. Loma Linda University Medical Center, for example, adopted a protocol in December 1987 under which anencephalic infants would receive ventilatory support at birth and then be monitored for up to 7 days or until all brain functions had ceased.[1] Hoping to increase the likelihood that brain death would occur within the 7-day limit, Loma Linda modified the protocol in April 1988 to delay ventilatory support until the infant began to manifest major respiratory or circulatory difficulties. The program was finally discontinued in July 1988 because few of these infants actually became brain dead under such circumstances (*Los Angeles Times*. August 19, 1988:[pt I]3).[1] In light of the heavy reliance on apnea as the major criterion in determining death in this approach, Ohio State Representative Tom Watkins proposed Substitute HB 718 to establish a special legal category of "respiratory brain death," under which anencephalic infants could be declared dead based only on apnea.

These various approaches, which have also been seriously considered at several other medical centers across the country though not implemented,[1,34] raise several important issues. First, should anencephalics be carried to term and then used as organ donors while still alive though dying? Second, can death be reliably determined in artificially supported anencephalic infants, and if so, should they be so maintained to enhance their utility as organ sources? An affirmative response to one or both questions is given by those who favor allowing parents of anencephalics to "salvage something positive" out of the tragedy by donating their child's organs to save the life of another child. Plainly, this argument has a great deal of appeal, and multiple popular accounts of these situations, as well as the experience of donor referral centers, make it apparent that this wish is strongly felt by some of the parents of anencephalics (*San Francisco Chronicle*. May 5, 1986:1; *New York Times*. September 9, 1986:C1). From a utilitarian standpoint, providing legal sanction for the harvesting of organs from anencephalics might seem a way to maximize net utility for society as a whole. Such a conclusion may be shortsighted, however, because either legalizing organ removal from live anencephalics or applying unvalidated criteria for death might undermine the very goal of promoting infant organ transplantation and endanger society in the process, while actually producing surprisingly few usable organs.

MEDICAL UTILITY

It is possible to calculate the approximate number of patients who would benefit from anencephalic organs if no ethical or legal barriers to their retrieval existed. (A fuller explanation of these figures and a more complete set of references are provided in a recent article by one of us [D.A.S.].[35]) The prevalence rate of anencephaly has been declining steadily over the past several decades almost everywhere in the world.[35-42] In the United States in the late 1980s, a conservative estimate is around 0.3 per 1000 total births.[35] Given a national birth rate of 3.75 million per year,[43] this yields an estimate of 1125 anencephalic infants potentially born each year in this country. Probably around 20% of pregnancies nationwide are screened for neural tube defects during the second trimester by means of either ultrasound or maternal serum alpha-fetoprotein testing and 95% of the detected anencephalic fetuses are electively aborted (Linda Dobbs, RN, Southern California regional coordinator for the alpha-fetoprotein screening program, UCLA Medical Center, Los Angeles, Calif, oral communication, July 1988), making the number of anencephalic births per year around 911. Some two thirds of anencephalics are stillborn,[39(pp58,73-76,84,109),41,44] reducing the annual number of *live-born* anencephalics to 304.

Slightly more than half of anencephalic births are premature (less than 37 weeks' gestation)[39(pp55-60),45] and some 50% to 80% have birth weights less than 2500 g.[45,46] Taking 60% as the proportion of anencephalics too small to provide transplantable organs, the annual number of useful anencephalics is 122. If as many as two thirds of the parents of these infants would be willing to donate their child's organs while still living, the number of donated, useful anencephalics decreases to 81.

But not all transplantable organs are actually used. In particular, the experience with grafting infant kidneys has been disappointing relative to the success rate with older donors; moreover, the technique of chronic peritoneal dialysis in infancy has improved enough that pediatric nephrologists generally prefer to treat infants with renal failure by means of dialysis until they reach several years of age, when the likelihood of a successful transplant is much higher.[47,48] For this reason, the kidneys from infant liver or heart donors are typically not salvaged. Around 15% of anencephalic hearts will be unusable on account of associated malformation or excessive hypoplasia.[49-53] Size-matching between donor and recipient organs is much more important for liver transplants than for hearts[48,54] and an estimated 25% of the livers will be unusable on the basis of malformation or hypoplasia.[40,51(pp79-80),52,53] Thus, the estimated annual number of usable anencephalic kidneys, hearts, and livers reduces to 0, 69, and 61, respectively.

For various reasons, around 25% of referrals of vital organs (all ages combined) are found acceptable by established organ-sharing networks, and the figure for hearts is even less. Some reasons for the nonuse of organs are the desirability of blood-type compatibility for hearts and livers, the need for temporal coincidence of potential donors and compatible potential recipients, and difficulties in transporting organs or sick patients across great distances. Infants with biliary atresia almost always receive first a Kasai procedure and then are placed on the national transplant waiting list at 4 or 5 months of age, by which time many are no longer size-compatible with a newborn donor.[55]

Such problems are illustrated by the

experience to date at Loma Linda University Medical Center. By the time of discontinuation of their protocol (and including the first case, referred from Canada prior to formal initiation of the protocol), 14 anencephalic infants had been referred for possible organ donation; 3 of those were declared brain dead within the specified 7-day limit, yet only a single vital organ, a heart, ended up being transplanted (*Los Angeles Times*. August 19, 1988:[pt I]3).[1]

It would seem that protocols respecting existing standards of brain death are simply not going to yield a sufficient number of usable organs to be worthwhile. Even if laws were relaxed so as to allow the harvesting of organs from live anencephalics soon after birth, it is doubtful that any more than 25% and 15% of otherwise suitable hearts and livers, respectively, would actually be used, bringing the yearly number of transplanted anencephalic kidneys, hearts, and livers to 0, 17, and 9, respectively, at most.

Finally, the net benefit to the infant recipients of these organs is unclear, as the experience with transplantation at this age is still so limited. A long-term survival rate of 50% and 20% for hearts and livers, respectively, is reasonable, given the current state of the art, reducing the yearly number of children nationwide who would actually benefit from anencephalic kidneys, hearts, and livers to 0, 9, and 2, respectively. These figures will undoubtedly increase as transplantation techniques improve. On the other hand, the magnitude of that increase will be offset by the decrease in the natural prevalence of anencephaly and the increase in prenatal screening. An optimistic projection of the annual number of patients benefiting from anencephalic kidneys, hearts, and livers nationwide 10 years from now is 25, 12, and 7, respectively.[26]

When enthusiasts begin to realize that the number of usable organs from anencephalics will fall far short of the demand, even if present laws requiring donor death were to be relaxed, various steps might be taken to increase the supply, even though current proponents would not endorse such extensions of their proposals. The number of donors could be increased, for example, by encouraging the parents of prenatally diagnosed anencephalics not to abort. Although proponents typically advise against allowing financial incentives in this area,[26] the power of human ingenuity to circumvent formal restrictions on economic transactions is well known.

It is even possible that an unlimited supply of anencephalics could be purposefully created by means of in vitro fertilization under the influence of an appropriate teratogen, with hired surrogate mothers to carry the organ sources to term. This may seem farfetched at present, but it is a logical development in the evolving trend of increasing interest in fetuses as "organ farms"[55-58] and an increasing desire to dominate human reproduction technologically.[60] Recently, some women have seriously proposed conceiving in order to abort for the sake of fetal tissue for transplantation, either for themselves or for a relative (*Seattle Times*. March 7, 1988:F1). Although their wishes were not carried out, the mere proposal of such a thing would have been unthinkable only a few years ago. If the present direction of evolution of societal attitudes continues, the day can be foreseen in which "anencephalic factories" are a standard source of transplantable organs, yet it requires little imagination to see that the good of the surviving organ recipients would hardly offset the global harm to society of an approving attitude toward such crass manipulation of human life.

ETHICOLEGAL CONSIDERATIONS

The natural cause of death in anencephaly is ultimately hypoventilation, which renders the vital organs unsuitable for transplantation by the time death could be declared. To make it legal to harvest these organs while still usable would thus require either (1) a revision of the UAGA to allow removal of vital organs from live patients (as proposed in New Jersey), (2) a legal definition of anencephalics as non–human beings or nonpersons or lacking any "interests" (as is frequently stated in the literature) and therefore outside the scope of laws protecting innocent human life, (3) an expansion of the UDDA to include anencephaly as a variant of "brain death" (as proposed in California), or (4) an attempt to accommodate such transplantations to existing laws by giving the anencephalic infant ventilatory support and waiting for traditional brain death to occur (as was attempted at Loma Linda).

Revision of the UAGA to Include Live Anencephalics as Acceptable Donors

The first alternative opens up possibilities for abuse that are only too obvious. The principle behind excepting some human organ donors from being dead ultimately reduces to one of the following: either homicide should be lawful if it is motivated by saving the life of another whose life is not threatened by the person killed, or homicide should be lawful if the victim is about to die anyway. But if these are valid principles for anencephalics, then they are also valid for a whole host of other patients, when, in fact, the law makes no such exceptions. This logical inconsistency might then be used to justify subsequent expansion of the exceptions to include incompetent patients in the final stages of a terminal illness or even prisoners on death row, whose organs would be much more suitable for transplantation than those of anencephalics and whose execution could be timed according to the availability of an optimally matched recipient.

Specifically, using this kind of logic, half of all the infants who die of congenital kidney, heart, and liver disease would better be used as organ sources to preserve the lives of the other half, rather than letting them all die along with their transplantable organs. Even though this sounds preposterous, the experience at transplantation referral centers indicates that the enthusiasm for using anencephalics does indeed quickly extend to other categories of dying infants. As a result of the national interest in Loma Linda's protocol, for example, that institution received from "good" physicians several referrals of infants with less severe anomalies for organ donation, such as "babies born with an abnormal amount of fluid around the brain or those born without kidneys but with a normal brain." Moreover, the referring physicians "'couldn't understand the difference' between such newborns and anencephalics." Joyce Peabody, MD, chief of neonatology there and primary drafter of the protocol, deserves much credit for her courageously candid statement: "I have become educated by the experience. . . . The slippery slope is real" (*Los Angeles Times*. August 19, 1988:[pt I]3).

Legal Definition of Anencephalics as Nonpersons

The second approach would be based on the philosophical tenet that anencephalics are not human beings, or at least not "persons," thereby eliminating the main ethical problem in killing them.* This could be argued on the basis of either their age or their neurological lesion. There are indeed ethicists who maintain that even neurologically normal human infants are not persons, that they therefore have no right to life, and that their killing would not be murder.[61,62] Such philosophers differ on the age at which they believe that postnatal infants become persons, ranging from a few days to several months. Clearly, if one's goal is to increase public enthusiasm for infant organ donation, this is not the best principle to invoke.

A greater number of philosophers, however, maintain that severe neu-

rological impairment is incompatible with personhood. For example, Joseph Fletcher[65] has argued that:

> Any individual of the species *homo sapiens* who falls below the I.Q. 40-mark in a standard Stanford-Binet test, amplified if you like by other tests, is questionably a person; below the 20-mark, not a person. . . . This has bearing, obviously, on decision making in gynecology, obstetrics and pediatrics, as well as in general surgery and medicine.

Singer[61] maintains that:

> If we compare a severely defective human infant with a nonhuman animal, a dog or a pig, for example, we will often find the nonhuman to have superior capacities, both actual and potential, for rationality, self-consciousness, communication, and anything else that can plausibly be considered morally significant. Only the fact that the defective infant is a member of the species *Homo sapiens* leads it to be treated differently from the dog or pig. Species membership alone, however, is not morally relevant.

The potential for diagnostic confusion that can invade attempts to draw lines of "personhood" based on neurological deficit is illustrated in the use of the unqualified term *hydrocephalic* by Lachs[65] in an argument that these children are not persons and that in comparison "pigeons have more personality [and] the indigo bunting more intellect." The fact that anencephaly is one of the few conditions that has been argued as an indication for even third-trimester abortions (partly on the basis of "total or virtual absence of cognitive function")[66] is often cited as a rationale for the legitimacy of killing the same beings a few weeks later, postnatally, for their organs.[67]

Even if it were possible in theory to know with certainty that a particular degree of neurological deficit was incompatible with personhood, it is extremely doubtful that in practice very many would be capable of applying such knowledge to individual cases without risk of error. And even if they, in good conscience, believed they were killing nonpersons for the sake of persons, the majority of the rest of the world—in their inevitable unsophistication—would fail to perceive any distinction between that and murder justified by utilitarian principles, and the general impression that the latter had become legitimate would have disastrous consequences for society.[68] Moreover, it would be presumptuous for anyone to maintain that he or she was certain enough that an anencephalic infant was not a person to be willing to risk committing murder by killing it for its organs, given that a large number of equally intelligent people do regard it as a person, albeit with a severe disability.

Were it conceded, for the sake of argument, that some categories of congenital brain malformations are so extreme as to be clearly incompatible with personhood, there is the obvious problem of knowing where to draw the line along the continuum of severity. In addition to the difficulties in defining anencephaly precisely (see below), infants with other severe congenital neurological anomalies and older children and adults in a persistent vegetative state are functionally similar to anencephalics (insofar as they operate on a brain stem alone) and would also fail to qualify as persons on the same basis. It would be inconsistent to legitimize the removal of organs from anencephalics on the basis that they are nonpersons, while proscribing the use of hydranencephalic, atelencephalic, lissencephalic, and persistently vegetative patients, those with end-stage degenerative brain diseases, and so forth.[69] All of these patients would equally fail to qualify as persons, and their organs would actually be both more usable and more plentiful than those of anencephalics. The impossibility of defining a logically consistent neurological boundary between persons and nonpersons is why even people who ascribe privately to the nonpersonhood theory mostly do not advocate its practical application in law.

Differentiating Anencephalic Infants by Lack of Consciousness

Short of labeling anencephalics nonpersons, many commentators have suggested that these infants can be treated differently from others because they are incapable of experiencing consciousness or pain, and therefore have no interests and cannot be harmed. Although this is undoubtedly true for those with complete craniorachischisis, such infants are of little interest vis-à-vis their organs, because they are almost invariably stillborn. Whether those with relatively intact brain stems have any subjective awareness associated with their responsiveness to the environment is inherently unverifiable, but what is known about the functional capabilities of the brain stem, particularly in newborns, suggests at least keeping an open mind.

In experimental animals, brain stem structures have been shown to mediate complex behaviors, sometimes traditionally assumed to be cortical, including binocular depth perception,[70] habituation, learning, and discriminative conditioning.[71-75] Similarly, decerebrate (anencephalic or hydranencephalic) human newborns with relatively intact brain stems can manifest a surprising repertory of complex behaviors, including distinguishing their mothers from others, consolability, conditioning, and associative learning,[76-80] although irritability and decreased ability to habituate are also common.[76,81] Lorber[82] described a remarkable case of a boy with hydranencephaly, diagnosed by pneumoencephalography, who had developed normally as of 21 months of age. Although the author suspected the existence of a cerebral cortex somewhere in the head, he was unable to find even a thin mantle between the injected air and the inner table of the skull. Even in normal human newborns, the cerebral cortex, though grossly present, is much less developed microscopically than the brain stem[83(p56-84,297-298)] and is relatively nonfunctional, as revealed by positron emission tomography.[84] Thus, it is possible, for example, that parents of hydranencephalic infants often fail to realize during the first month or two that anything is wrong with their baby.

Without question, decerebrate infants are neurologically much more similar to normal infants than they are to decerebrate adults, and it simply begs the question to apply adult-derived neurophysiological principles to this age group in support of the claim that a functioning cortex is necessary for consciousness or pain perception in newborns. Moreover, the phenomenon of developmental neuroplasticity could, in principle, allow brain-stem structures in the congenital absence of cerebral hemispheres to assume somewhat more complex integrative activity than would ordinarily be the case, as has been suggested in some animal studies.[85-87] Thus, it neither logically nor physiologically follows that anencephalic infants "by definition . . . can neither feel nor experience pain."[88] The main difference between decerebrate and normal newborns lies not so much in their actual functional abilities as in their potential for future cognitive development. Therefore, both prudence and logical consistency demand that we attribute to anencephalic infants at least as much consciousness and capacity for suffering as we attribute to laboratory animals with even smaller brains, which everyone seems to feel obliged to treat "humanely."

Revision of the UDDA to Define Anencephalics as Dead

Suggestions to include anencephaly within the definition of "death" pose many problems, including further expansion to other categories of patients with severe neurological impairments, damage to public confidence in death determinations (and thus a decline in the total number of organs offered for transplantation), and adverse impact on families that do not wish to regard their anencephalic child as dead.

At the heart of the proposals to amend the UDDA or comparable statutes is the assumption that there is no possibility of misdiagnosis or entry onto a "slippery slope" of expanding exceptions.[28-30] Nevertheless, serious misdiagnosis is possible; for example, in an epidemiologic study, Baird and Sadovnick[29] came across a case of amniotic band syndrome that was mistaken for anencephaly. Elsewhere, amniotic band syndrome has been reported as an actual *cause* of anencephaly, obviously implying a wide spectrum of severity compatible with that diagnosis.[60,61] Some cases of anencephaly are associated with the facial features of holoprosencephaly, introducing another direction for possible diagnostic confusion.[61(p422),62,96]

More fundamentally, the contention that "brain absence can be clearly defined"[120] and "cannot be expanded to include individuals with less severe anomalies or injuries"[29] is not confirmed by those most experienced in fetal neuropathology. Literally, *anencephaly* means absence of the brain, but the term has been and continues to be used to describe a developmental anomaly in which only the cerebral hemispheres are missing or extremely rudimentary, while the brain stem and varying portions of the diencephalon are present. A major textbook on anencephaly[51(p5)] states: "An almost incomprehensible array of synonyms and classifications of anencephaly exists in the literature; many include entities now considered to be pathogenetically unrelated to the anencephaly spectrum." Another expert on congenital malformations has written: "[Anencephaly] exemplifies the problems and difficulties of teratologic research in man. The terminology is confusing. . . ."[94(p185)] Current usage also implies partial or complete absence of the cranial vault, but one anatomist has stated that "the [calvarial] defect is so widely variable that a rigid classification is almost impossible."[95] (See, for example, the relatively small skull and scalp defect in specimen AN-61 in Figs 1a and 1b of Siebert et al[96] and in Fig 4-12 of Lemire et al.[28(p62)])

Indeed, anencephaly is not an all-or-none phenomenon, but constitutes an imprecisely defined range of conditions toward one end of a spectrum of congenital malformations related to failure of closure of the neural tube or to its later reopening.[51,96-98] The supratentorial brain tissue in preterm anencephalic fetuses, prior to involution in utero, may surprisingly resemble cerebral hemispheres with a midline fissure present.[95] Clearly, variability in both gestational age and degree of involution for age will result in variability in the amount of supratentorial tissue encountered in "anencephaly" and the consequent impossibility of providing an unequivocal operational definition of the condition based on degree of brain absence. For example, while most anencephalic brains weigh less than 60 g or so, one case of Melnick and Myrianthopoulos[50] (case 1-66) had a normal term brain weight of 391 g. Careful study of the cerebrovasculosa in third-trimester anencephalic fetuses led Bell and Green[99] to conclude that "in many anencephalics parts of both the forebrain and hindbrain are present, although incompletely developed," and to reject "the widely accepted view that the area cerebrovasculosa is totally disorganized, and that anencephaly is characterized by absence of the forebrain." They stressed the variability in degree of neural differentiation in the wall of the forebrain from one case to the next. Others[100,101] have also pointed out that some, even most, anencephalics have rudimentary cerebral hemispheres.

More importantly, the least severe cases of meroanencephaly (meroacrania), in which the forebrain and overlying tissues are only partially absent, are indistinguishable from the most severe cases of microcephaly with encephalocele. The literature is replete with both photographs and descriptions exemplifying the potential for confusion surrounding these two diagnoses.[35] One case in Dallas was diagnosed at the time of birth by the obstetrician as having microcephaly with encephalocele, but was later rediagnosed by a pediatric neurologist and a geneticist as having anencephaly. The parents were told that the infant would die within a few hours, but they eventually took her home and she lived for 14 months (Joni Burchett, Garland, Tex, oral communication, June 1988).[102] Judging from the published photographs, the "anencephalic" infants reported by Brackbill[91] and by Nielsen and Sedgwick[103] would probably have been diagnosed by many as having microcephaly with encephalocele. That amniotic bands can cause both anencephaly[92,93] and encephalocele[104] highlights the vagueness of the boundary between these two conditions. Because microcephaly with encephalocele constitutes a spectrum of its own, at the other end of which are quite functional individuals, the danger of misapplication of a revised UDDA to living, nonvoluntary organ sources other than anencephalics is far from hypothetical.

Definitional problems aside, the rationales for expanding the statutory definition of death to include "anencephaly" are broad enough to define other categories of dying, neurologically impaired patients as equally "dead," and subsequent expansions of the law would be likely once it became apparent that there are too few usable anencephalic organs to meet transplantation demands. Although present proponents caution against such a development, there is no reason to believe, in the context of today's rapidly changing bioethical mores, that inclusion of anencephaly would be the final such legislative revision.

Indeed, confusion about differences between dying, comatose patients on the one hand and dead bodies on the other emerges repeatedly in the writings of those who would proclaim anencephalics dead. For example, Harrison[25] labels anencephalics as "brain absent" to emphasize their supposed equivalence with "brain-dead" bodies. Yet his language—that one should "not detract from the dignity of [their] dying or abridge [their] right to die"—along with his injunction that the removal of organs should be carried out "in a way that would not conceivably cause suffering" reveal an implicit realization that the anencephalic infant is not dead.

Furthermore, atelencephaly[105,106] hydranencephaly,[83(pp251-255)] and extreme postnatal forebrain destruction resulting in a persistent vegetative state all involve just as much "brain absence" as anencephaly, underneath an intact scalp and skull. Proposals have in fact been made to define patients in a persistent vegetative state as legally dead,[107,108] and the removal of organs from persistently vegetative patients is starting to receive serious discussion in the medical literature.[109] In a recent radio talk show ("Point-Counterpoint." February 20, 1988 [KABC, 790 AM, Los Angeles, Calif]) about organ harvesting from anencephalic infants, the mother of a 12-year-old vegetative child called in to say that she would have no qualms about offering her child's organs to benefit another child, if only it were legal. Cranford[110,111] has also stressed the logical connection between the use of anencephalic and persistently vegetative patients as organ donors, forecasting that present trends will soon bring society to the point of considering both as equally legitimate. A physician in France was recently censured for using persistently vegetative patients for nonvoluntary, nonbeneficial, and potentially harmful medical experimentation (*Le Figaro*. February 25, 1988:40). Although such activity horrifies most people today, it will cease to elicit that reaction in a society that has become accustomed to defining patients without a cerebral cortex as "dead" in order to use their bodies for the benefit of others. Revisions in the law that would allow the use of anencephalics, on the basis of their absence

of potential for future cognitive functioning, could thereby render novels such as Robin Cook's *Coma* more prophetic than fictional.

Another rationale frequently offered for amending the UDDA to include anencephalics along with other "brain-dead" patients is the supposedly uniform imminence of their death. First of all, this is factually incorrect. In one series,[82] 5% lived between 1 and 2 weeks. Another study found that, of those with a birth weight greater than 2500 g (and therefore of greatest interest vis-a-vis organs), 8% survived between 1 week and 1 month and 1% lived up to 3 months.[46,112] In addition, there are documented cases of anencephalic infants surviving 16 days,[94(p199)] "several weeks,"[82(p58)] 32 days,[118] 51 days,[80] 2 months (*Los Angeles Times*, August 19, 1988:[pt I]3), 85 days,[102] 5½ months,[81] 7 months (personal experience of one of us [W.J.P.]), and 14 months.[102]

More importantly, the appeal to this logical contradiction—that an anencephalic should be considered legally "dead" on the basis of being about to die—reveals an underlying belief that other "brain-dead" patients are also not *really* dead, but merely near death, and that this somehow renders organ removal appropriate. This position treats brain death as a legal fiction by which to procure organs from still-living patients.

Plainly, reasoning of this or the previous sort erects no barriers to later expansions of the definition of death to other patients near death and/or without neocortical functions, whenever demand for transplantable organs increases. In our desire to increase the number of organ donations, however, it is crucial to keep completely separate the issue of defining death from that of transplantation needs. Manipulating the definition of death—by including anencephalic infants, whose spontaneous breathing, sucking, crying, and the like separate them from the dead bodies that society is usually willing to label cadavers and bury—may undermine the public's already tenuous confidence in brain-based determinations of death. The predictable result will be a decline in the donation of organs from all categories of potential donors, as occurred in England following a highly publicized television program that called into doubt the accuracy of brain-death diagnoses.[114] Interestingly, organ-procurement organizations nationwide noticed a drop-off in referrals as of the beginning of 1988, which happened to correspond to the widespread publicity of Loma Linda's anencephalic protocol, although the extent of causal connection between the two cannot be determined. If the UDDA were revised and the general public therefore concluded that statutory definitions of death were being invented based not on objective biologic properties of the "corpses" but on other patients' need for organs, any temporary increase in the number of organs for tiny infants would have been purchased at the cost of great harm to transplantation generally, which is just now—21 years after the first human-to-human heart transplant—beginning to build a solid base of public acceptance.

Expanding the statutory definition of death to include anencephalics would also cause problems for the parents of such infants who wish to sustain them with nutrition and comfort during the dying process. For the law to proclaim that anencephalics are "dead" would not only contradict the manifest reality of the families' efforts to care for them but might well pose financial barriers for the payment of days (or perhaps weeks) of medical or nursing services for the alleged corpses.

Providing Intensive Care While Awaiting Brain Death

In the hope of obtaining organs from anencephalic infants within the framework of existing statutory definitions of death and requirements that donors of vital organs be dead, some have advocated providing the infant with ventilatory assistance and intensive care while awaiting the occurrence of brain death. This approach is based on three assumptions: (1) that brain death is likely to occur under these circumstances, (2) that brain death in anencephalics can be diagnosed as reliably as in other potential organ donors, and (3) that the provision of intensive care, in the interests not of the infant in question but of someone else, is ethically appropriate.

Concerning the first assumption, the precise cause of death of these infants has never been systematically studied. As the condition involves a spectrum of maldevelopment of brain-stem structures, it is likely that those anencephalic infants who die within the first few hours after birth succumb to hypoventilation due to dysplasia of the respiratory control centers in the lower brain stem. Pressure on and mechanical distortion of the exposed brain stem during the birth process could also result in fatal, though potentially transient, respiratory dysfunction. The minority with better formed brain stems would be susceptible to dying after several days or weeks from multiple endocrine abnormalities, particularly pituitary and adrenal failure,[50,51(p266-72),116-118] which could render them much less able to withstand the physiological stresses of birth. Hypoventilation would still appear to be the proximate cause of death, if a fatal cardiac arrhythmia did not supervene. The small minority of long-surviving anencephalic infants probably die of aspiration or sepsis.

The important point is that there is no known progressive destruction of the nervous system, as in the vicious cycle of brain ischemia and swelling within a rigid skull that leads to brain death in patients who, for example, have suffered head trauma. A squamous epithelial membrane typically covers the exposed neural tissue (as also occurs with spina bifida),[94(p197),95] protecting it from both infection and exposure to air. Neither does the in utero involution of the cerebrovasculosa, which has no neurological function anyway, affect any other brain structures, particularly the relatively well-formed brain stem.[94(pp191-193),98,99,120] Thus, there is no basis for positing an intrinsic neurological cause of death, and the only anticipated effect of providing mechanical ventilation and intensive care would be to maintain the viability of the brain stem as effectively as that of the other organs, thereby merely postponing an essentially nonneurological death. A fortiori, cooling of the newly delivered anencephalic, as proposed by some,[88] far from hastening brain death, would only serve to protect the integrity of the brain even more, in addition to invalidating the clinical testing for brain death.

The scanty experience to date with intensive care of anencephalic infants supports this theoretical prediction. The infant with the longest survival (14 days) in Baird and Sadovnick's[80] series was given life support.[121] Ten out of the 12 live-born anencephalic infants entered into Loma Linda's protocol did not meet that institution's criteria for brain death within the specified 7-day limit, at which point the infants were disconnected from the ventilator and allowed to die.[1] Even modifying the protocol, so that resuscitation and ventilatory assistance not be provided until the infant was near death, did not improve the yield over the original procedure of intubation and ventilation immediately after birth. One of those babies survived at home for 2 months following discharge (*Los Angeles Times*, August 19, 1988:[pt I]3).

But the diagnosis of brain death is problematic even in those few anencephalics who do cease to manifest spontaneous respirations and brain-stem reflexes while receiving assisted ventilation. In nonanencephalic patients, the UDDA requires certainty of both the irreversibility and the totality of brain nonfunction. Certainty of the former ordinarily derives either from a

knowledge of the pathophysiological process responsible for the nonfunction or from a demonstration of absence of intracranial blood flow. But the likely causes of death in anencephaly are nonneurological and are therefore in principle potentially reversible. Hypoventilation and apnea could be caused by electrolyte or endocrine disturbances or by transient edema due to birth trauma to the exposed brain stem, none of which imply intrinsic irreversibility. Moreover, if a vertebral angiogram were performed, there would be no reason to expect it to show absent blood flow to the brain stem.

Establishment of the totality of brain nonfunction is both easier and more difficult in anencephalics. It is easier insofar as the absence of cortical function is self-evident. It is more difficult insofar as there are more peripheral factors that can create a false impression of brain-stem nonfunction. Associated malformations of the retina and optic nerves are common,[51(pp82-83),94(p182),122] so that pupillary nonreactivity should not be interpreted as supportive of a diagnosis of brain death. Similarly, maldevelopment of the middle and/or inner ears[123] could result in absence of reactivity to sound and absence of oculovestibular and perhaps oculocephalic reflexes, invalidating these, too, as evidence for brain death. Some protocols call for meperidine (Demerol) hydrochloride to be administered if the intubated infant shows signs of discomfort and for naloxone hydrochloride (Narcan) to be given at the time of neurological examinations. Even if it is assumed that the naloxone completely cancels the respiratory and general depressant effects of the meperidine, its duration of action is only 10 or 15 minutes, so that neurologically valid observation of the infant would be possible only during around 1% of the entire day. If spontaneous respiration or responsiveness to noxious stimuli were present intermittently, it could easily go unrecognized under these circumstances.

For all these reasons, diagnosing brain death in an anencephalic infant at the moment of loss of a small set of clinically testable brain-stem functions, or even after some arbitrary observation period, would not conform to existing diagnostic standards. Some might say that this is being too punctilious in the case of an infant who is about to die soon anyway. On the other hand, inevitability of somatic death is also the case with many nonanencephalic patients who are almost, but not quite, brain dead, yet that does not justify diagnostic corner cutting or proceeding with organ harvesting before actual death in those patients.

Obviously, inaccuracies in the declaration of brain death make no difference whatsoever from the point of view of dying, comatose patients themselves. The importance lies rather with the larger impact on society of establishing a tolerance toward sloppiness in either the conceptualization or implementation of standards for determining death, particularly when this is motivated both by pressure to obtain organs and by an implicit depreciation of a being whose humanity is at least possible, if not probable.

The medical profession and society have always demanded high standards in the diagnosis of death of donors of vital organs, and rightly so. The following are just a few examples of the extreme importance given to the issue of certainty of death, when physicians were trying to formulate reliable diagnostic guidelines for brain death in adults and older children during the 1970s and early 1980s:

"A hopeless prognosis may be an adequate criterion for termination of artificial resuscitation, but the bioethical issue involved is one of 'passive' euthanasia and not brain death. A hopeless prognosis without a pronouncement of death itself would seem inadequate grounds to remove viable organs for transplantation."[124]

"The criteria that physicians use in determining that death has occurred should: (1) Eliminate errors in classifying a living individual as dead, (2) Allow as few errors as possible in classifying a dead body as alive."[30(p161)] (Note the contrast in degree of certainty required against the two types of error.)

"It is particularly important that the most up-to-date and precise assessment of the dying patient's state be made, even if this means that organs must be sacrificed because the techniques for an absolute diagnosis of death are not available."[125]

"A diagnosis of brain death must never be confused with concerns about the quality of residual life in vegetative states. Moreover, a shortage of transplant organs should not be met by changing criteria for diagnosing death, or by the adoption of more lenient or flexible standards."[126]

Even if a particular anencephalic protocol does not purport to go against present laws, a selective lowering of diagnostic standards amounts to the same thing, even if it were to remain hidden from the general public and much of the nonneurological medical profession. It is simply disingenuous to present such approaches as perfectly consistent with existing diagnostic standards. It would be wiser in the long run for advocates to argue straightforwardly for the use of live anencephalics than to force this practice into appearing compatible with existing legal structures by loosening both the concept and the diagnostic standards of death.

Finally, even if some anencephalic infants receiving ventilatory assistance could reliably be determined to be dead by neurological criteria, the difficult ethical issue remains of subjecting one person to invasive, potentially burdensome treatments and prolongation of the dying process, solely for the benefit of another. Although a pure utilitarian calculus might favor just that, current ethical standards still regard respect for the inherent dignity and inviolability of persons as a moral good that outweighs the material evil of someone else's death due to natural causes. In the Loma Linda protocol, the precedents of resuscitation and intensive care solely for the sake of transplantation that were cited as ethical justification all involved already dead bodies, and hence are inapposite for the nonvoluntary prolongation of a dying process for the sake of another. It is certainly true that the care of potential donors near the moment of death may be influenced by plans for transplantation—but this follows concerted efforts aimed at saving the donor's own life, in stark contrast to the conflict of interest inherent from the outset in providing life-prolonging treatment to anencephalic infants. Walters and Ashwal[1] and Fost[127] offer a few arguably acceptable precedents for the nonvoluntary imposition of a burdensome procedure on a minor child for the sake of someone else. The practice of sibling-to-sibling bone marrow transplantation might be cited as a more generally sanctioned example. The main difference between this and the provision of intensive care to anencephalic infants, however, lies in the greater obligation toward the recipient by virtue of the family tie as well as the greater probability of benefit to the recipient, which in the case of awaiting brain death of an anencephalic receiving mechanical ventilation is very low indeed. In particular, it seems that the vast majority of anencephalics receiving ventilatory support will survive the experience, only to have their lives needlessly prolonged without actually benefiting any other child.

PARENTAL COUNSELING

How should one counsel the parents of an anencephalic infant who want to donate their child's organs in order to experience some sense of fulfillment? We do not understand why the proponents of legislative revision consider this to be a major psychiatric problem. Up until the time that certain legislators

and surgeons began to promote the idea that organ donation from live anencephalics ought to be an option, the thought never arose more than in passing; parents coped with their grieving process in just the same way that all other parents of terminally ill children do, and health care professionals comforted them just as they comfort all other parents of terminally ill children.

To encourage parents to donate organs from their still-living infant would do nothing more for most parents than to cause them agony over a decision between two options, only one of which is both presently realistic and also wise for society to permit in the future. Although some parents around the time of birth of their anencephalic infant desperately want to add "meaning" to their infant's life and death by giving life to another child, it should be remembered that this noble desire will most often end in further disappointment due to nonuse of the organs. And, if laws were revised to permit organ harvesting from live anencephalics, in the relatively few cases in which "the gift of life" would actually be realized, no one knows the degree to which the donating parents, once over their acute grieving process, might begin to suffer from doubts about the legitimacy of their authorizing what was, in the final analysis, the killing of their own child—a situation potentially analogous to the parental guilt syndrome that can occur years following an elective abortion.[125,129]

On the other hand, parents can be offered the opportunity to donate their child's nonvital organs, such as corneas and heart valves, for transplantation after death and otherwise to cooperate with postmortem investigations aimed at learning more about this condition and its prevention. This may seem to many like a negligible compensation at the moment, but in the long run it may be that what is emotionally better for the parents coincides with what is also better for society.

CONCLUSION

Although the proposal for donation of organs from anencephalics is well intended, it is shortsighted. Attempts to operate within existing laws by waiting for brain death simply do not work, and even if the laws were revised to permit organ harvesting from live anencephalics, the number of children who die each year from congenital kidney, heart, and liver disease would still be insignificantly reduced. Moreover, such radical revisions in the law would ironically undermine the very goal of promoting organ transplantation, and the moral confusion unwittingly introduced into society would constitute a far greater evil than the good done to the relatively few surviving recipients of these organs.

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ANEXO II

Paul A. Byrne, M.D.
577 Bridgewater Drive
Oregon, Ohio 43616
(419) 698-8844
e-mail:pbyrne@toast.net

September 10, 2008

To Whom It May Concern:

I was asked to evaluate the Computed Tomography (CT) and Magnetic Resonance Imaging (MRI) of the head of patient Marcela de Jesus Galante Ferreira, who had been diagnosed with anencephaly. Marcela de Jesus Galante Ferreira does have anencephaly as approved in the United States by major neurological organizations: The scalp is absent, and the skull is open from the vertex to the foramen magnum. The brain is present but abnormally developed. The orbits are shallow, and the eyes protrude. This is based on my evaluation of the CT of the brain performed on November 21, 2006 at the Fundacao Civil Casa de Misericordia de Franca Centro Diagnostico por Imagem and the MRI of the brain performed on November 13 2007 at the Hospital Sao Joaquim.

I have been certified multiple times as an expert in United States of America Courts to evaluate infants with abnormalities of the brain and skull, including Baby K, who had anencephaly. She lived beyond 2 years. The case was appealed to the United States Supreme Court. The Supreme Court upheld the Ruling of the District Court that ruled if Baby K should require a life supporting ventilator, Baby K was not to be denied this. The ruling in Baby K is the legal standard in District 4 of the United States District Courts.

Please contact me if you have questions.

Sincerely,

Paul A. Byrne, M.D., F.A.A.P.
Clinical Professor of Pediatrics,
University of Toledo, College of Medicine
Toledo, OH, and
Director of Neonatology and Pediatrics,
St. Charles Mercy Hospital,

UNIVERSITY OF CALIFORNIA, LOS ANGELES

UCLA

BERKELEY • DAVIS • IRVINE • LOS ANGELES • RIVERSIDE • SAN DIEGO • SAN FRANCISCO

SANTA BARBARA • SANTA CRUZ

D. ALAN SHEWMON, M.D.
Professor of Neurology and Pediatrics
Chief, Neurology Department
Olive-View/UCLA Medical Center

OLIVE VIEW-UCLA MEDICAL CENTER
14445 Olive View Drive, Room 2C136
Sylmar, CA 91342-1437
TEL: (818) 364-3104
FAX: (818) 364-3286
ashewmon@mednet.ucla.edu

September 10, 2008

To Whom It May Concern:

I have examined the CT scan dated November 20, 2006 and the MRI scan dated November 13, 2007 on baby Marcela de Jesus Galante Ferreira. I agree that they show absence of the calvarium and overlying soft tissues. Posterior fossa contents are present as well as some exposed, poorly differentiated supratentorial brain tissue. This is a classical case of anencephaly. Although most anencephalic infants die within the first week or so, a minority can live much longer, such as baby Marcela. A review of the literature on anencephaly, regarding both the diagnostic and life-span aspects, can be found the following two articles.

Shewmon DA: Anencephaly: Selected medical aspects. Hastings Center Report 18(5):11-19, 1988.
Shewmon DA, Capron AM, Peacock WJ, Schulman BL: The use of anencephalic infants as organ sources: A critique. JAMA 261(12):1773-1781, 1989.

If I can be of further assistance, please feel free to contact me.

Sincerely,

D. Alan Shewmon

D. Alan Shewmon, MD
Chief, Department of Neurology
Olive View-UCLA Medical Center
Clinical Professor of Neurology and Pediatrics
Vice Chair of Neurology
David Geffen School of Medicine at UCLA

Joliet Headache & Neuro Center

Thomas Zabiega, M.D.

To Whomever it may concern,

I was asked to evaluate the Computed Tomography (CT) and Magnetic Resonance Imaging (MRI) of the head of patient Marcela de Jesus Galante Ferreira, who had been diagnosed with anencephaly. I am basing my assessment on the standard definition of anencephaly as approved in the United States by all the major neurological organizations: "The scalp is absent, and the skull is open from the vertex to the foramen magnum. The brain, appearing hemorrhagic and fibrotic, is exposed to view. It consists mainly of the hindbrain and parts of the diencephalon; the forebrain is completely lacking. The orbits are shallow, and the eyes protrude." This is exactly what is seen in the imaging study of patient Marcela de Jesus Galante Ferreira. She only had the presence of the medulla oblongata, pons, midbrain, and cerebellum. The rest of her brain is absent. This is based on my evaluation of the CT of the brain performed on November 21, 2006 at the Fundaçao Civil Casa de Misericordia de Franca Centro Diagnostico por Imagem and the MRI of the brain performed on November 13 2007 at the Hospital Sao Joaquim. Please feel free to contact me with any questions or concerns.

Sincerely,

Thomas Zabiega, M.D.
Diplomate of the American Board of Psychiatry and Neurology

Affiliated with Provena Saint Joseph Medical Center and Silver Cross Hospital in Joliet, Illinois.

801 N. Larkin Avenue • Joliet, IL 60435 • (815) 744 - 6460

ANEXO III

Breast Cancer

Risks and Prevention

This booklet is written to help women understand what their risk factors are for the development of breast cancer and how they can reduce their risk

BREAST CANCER PREVENTION INSTITUTE

15 Factors Which Increase and Decrease Breast Cancer Risk

Factors Which INCREASE Breast Cancer Risk

Factor	Mechanism
Alcohol	Increases estrogen exposure by impairing liver function
Benign proliferative breast disease	Result of increased estrogen exposure
Birth control pills (contraceptive steroids in pill, patch or injectable form)	Increases estrogen exposure
BRCA genes	Inherited defects in cancer defense genes
Cigarette smoking	Benzopyrenes damage DNA
Early menarche	Increases estrogen exposure
Female sex	Increased estrogen exposure
High socio-economic group	Delayed childbearing
Higher education	Delayed childbearing
Hormone replacement therapy (HRT)	Increases estrogen exposure
Increasing age	Premenopausal: Increases estrogen exposure Postmenopausal: Impairs immune function
Induced abortion	Leaves increased number of immature breast lobules and increases risk of premature births Increases estrogen exposure
Late childbirth (over 30 years old)	Increases exposure of immature Type 1 & 2 lobules to estrogen before first birth
Late menopause	Increases estrogen exposure
Nulliparity (never bearing children)	Maturity of breast lobules does not occur
Premature birth before 32 weeks	Leaves increased number of immature breast lobules Increases estrogen exposure
Postmenopausal obesity	Increases estrogen exposure
Radiation	Damages DNA
2nd trimester miscarriage	Leaves increased number of immature breast lobules

 (Underlined words can be found in the Glossary)

Angela Lanfranchi, M.D., F.A.C.S.
Clinical Assistant Professor of Surgery
Robert Wood Johnson Medical School
Piscataway, NJ

Joel Brind, Ph.D.
Professor of Endocrinology
Baruch College, City University of New York
New York, NY

For more information regarding the risk and prevention of breast cancer, call toll-free

BREAST CANCER PREVENTION INSTITUTE

1-866-622-6237

(1-86 NO CANCER)

or visit our website at

www.bcpinstitute.org

BREAST CANCER Prevention INSTITUTE

THE BREAST CANCER PREVENTION INSTITUTE
is a research and educational
501(c)(3) public charity with headquarters at
9 Vassar Street
Poughkeepsie, NY 12601 USA

ANEXO IV

Uma vez que uma mulher se torna mãe, ela será sempre mãe, tenha ou não nascido o seu filho. O filho morto fará parte da sua vida por mais longa que ela seja. O aborto não é definitivamente uma "solução fácil" para um grave problema, mas um acto agressivo que terá repercussões continuas na vida da mulher.

Relação entre aborto e cancro da mama

Estas informações foram produzidas num esforço conjunto do Endeavour Forum, Inc., 12 Denham Place, Toorak, Victoria 3142, Austrália; telefone: +613-9822-5218; faxe: +613-9822-3069, Prof.ª Doutora Babette Francis, Coordenadora Nacional e Internacional e também da Revista *Abortion-Breast Cancer Quarterly Update*, P.O. Box 3127, Poughkeepsic, NY, 12603 EUA; telefone & faxe: 914-463-3728.

e-mail: **jbrind@abortioncancer.com**, Prof. Doutor Joel Brind, Director e Editor.

(Traduzido por Joana Godinho, da Associação Mulheres em Acção, que teve a gentileza de me enviar esta colaboração)

Em 1970, a Organização Mundial de Saúde – World Health Organization (W.H.O.) – publicou os resultados da sua investigação sobre a experiência reprodutiva em relação à incidência do cancro da mama. O estudo, no qual tomaram parte mais de 17 mil mulheres em sete lugares de quatro continentes, obteve informações que são indiscutíveis ainda trinta anos depois.

As mulheres que começam a ter filhos sendo ainda jovens têm menos probabilidade de sofrer de cancro da mama que aquelas que têm filhos numa idade mais avançada, ou que aquelas que não os têm.

Que protecção adquirem contra o cancro? Baseando-se nos seus resultados, os cientistas da W.H.O. concluiram:

"Estima-se que as mulheres que têm o seu primeiro filho antes dos 18 anos têm só cerca de um terço do risco de sofrer de cancro da mama que aquelas cuja primeira gravidez aconteceu aos 35 anos ou depois."

Significa isto que uma mulher jovem que fique grávida diminui o risco de ter cancro da mama, mesmo que ela tenha um aborto? Em relação ao aborto, os cientistas da W.H.O. afirmaram que os seus resultados:

"sugerem um aumento de risco associado ao aborto – contrariamente à redução do risco associado com as gravidezes levadas a termo, ao dar à luz."

Estudos de investigação, publicados em respeitáveis publicações médicas, confirmaram estas conclusões [2] e a sua causa hormonal:

Vinte e cinco de trinta e um estudos epidemiológicos [3-33] mundiais – estudos em mulheres de ascendência Africana, Asiática e Europeia – concluíram que mesmo um único aborto aumenta o risco de adquirir mais tarde cancro da mama.

Um dado importante é que a este aumento do risco por causa do aborto se acrescenta um risco maior, por se atrasar a primeira gravidez levada a termo, portanto, *o aborto aumenta o risco de sofrer de cancro da mama de duas maneiras!*

Já se perguntou porque é que, em menos de meio século, enquanto que o aborto se legalizou e se tornou numa prática comum, a incidência de cancro da mama no mundo industrializado aumentou *mais do dobro* ? [34,35]

Tem perguntas sobre o verdadeiro impacto que terá nas mulheres do seu país a importação dos "direitos reprodutivos" dos países industrializados?

O sistema de saúde pública do seu país está preparado para uma epidemia de cancro da mama?

A Ligação Estrogéneo:

Porque é que os abortos induzidos fazem aumentar o risco de ter cancro da mama, o que não acontece na maioria dos abortos espontâneos?

O estrogéneo é a hormona – o mensageiro químico – que, na puberdade, converte o corpo de uma menina no corpo de uma mulher. Na verdade, há uma série de esteróides, estrogéneos, que podem estimular o desenvolvimento da mama e de outros tecidos femininos. O estrogéneo mais abundante e importante que os ovários femininos segregam chama-se estradiol. O estradiol é tão potente que a sua concentração no corpo de uma mulher se mede em partes por triliões. O estradiol - uma décima parte – também se produz no corpo do homem e tanto homens como mulheres precisam de estradiol para o crescimento normal e para a manutenção dos ossos.

Depois da puberdade, os níveis de estrogéneo sobem e baixam duas vezes em cada ciclo menstrual. Sobre a influência da hormona folículo-estimulante da hipófise, novos folículos com óvulos crescem nos ovários durante a primeira metade (chamada fase folicular) do ciclo menstrual. As células foliculares que segregam o estradiol e que rodeiam os óvulos proliferam e por isso os ovários produzem quantidades cada vez maiores de estradiol, alcançando o pico no dia anterior à ovulação. Normalmente, este pico pré--ovulatório é o nível mais elevado de estradiol no sangue que uma mulher não–grávida experimenta. Serve de estímulo à hipófise, de modo a que esta segregue outra hormona, a hormona luteinizante (LH) que despoleta a ovulação.

Depois da ovulação, o folículo que expulsou o óvulo enche-se com um novo tipo de células chamadas células lúteas. Estas células lúteas proliferam sobre a influência da LH pituitária e, por sua vez, fazem segregar quantidades ainda maiores tanto de estradiol como da hormona progesterona da gravidez, da qual o estradiol se forma.

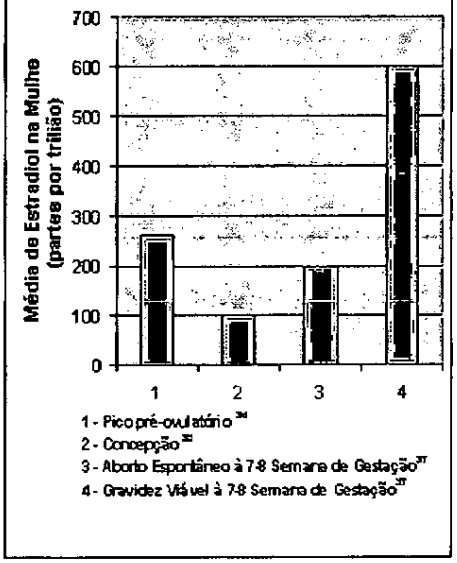
Como a secreção pituitária de LH baixa drasticamente depois da ovulação, o corpo amarelo (como se chama agora o folículo anterior) começa a diminuir uma semana depois da ovulação, a não ser que se tenha dado a fertilização do óvulo (concepção). Se ocorreu a concepção, o embrião começa a segregar outro mensageiro químico quase imediatamente: a gonadotrofina coriónica humana (HCG) que actua como a LH para "salvar" o corpo amarelo. Se não houve concepção, o corpo amarelo morre. Como o estrogéneo e a progesterona são respectivamente necessários para o crescimento e a maturidade do endométrio (o epitélio do útero na qual se implanta o embrião), este descama na menstruação.

(* Embora o HCG seja usualmente referido como uma hormona, na verdade, não é. Como é uma mensagem química entre dois indivíduos de uma espécie (neste caso, mãe e filho) é mais apropriadamente descrito como sendo uma feromona. Como normalmente não é segregado pelo corpo feminino, o detectar específico da sua presença é a base de todo o teste de gravidez.)

Se, pelo contrário, houve concepção e se salvou o corpo amarelo, este começa a gerar concentrações enormes de progesterona (necessárias para permitir a implantação do embrião e a manutenção da gravidez) e de estradiol. Níveis de estradiol significativamente elevados (comparados com os níveis em mulheres não-grávidas na mesma fase do ciclo menstrual) podem ser detectados cedo, nos 5 dias posteriores à concepção. [36] Como se mostra na *Figura 1* , pelas 7 a 8 semanas de gestação (depois do último período menstrual, o UPM), o sangue de uma mulher grávida já contém seis vezes mais estradiol (i.e., 500% mais) que no momento da concepção, mais do dobro que o nível mais alto obtido durante o estado de não-gravidez (o pico pré-ovulatório). [37]

Em notável contraste, as gravidezes destinadas a abortar espontaneamente (i.e., que acabam num desmancho) durante o primeiro semestre não geram, normalmente, estradiol em quantidades que excedam os níveis do estado de não-gravidez37,38 (Figura 1). Já em 1976, uma equipa de obstetras suiços foi capaz de prever abortos espontâneos com uma exactidão de 92% com só uma medida de estradiol!38 Teoricamente, isto faz sentido: a causa do aborto espontâneo é o nível inadequado de progesterona da qual se forma o estradiol.

Figura 1 - Nível de Estradiol no Sangue em Mulheres Grávidas e Não-Grávidas



A relação entre o estradiol ou os estrogéneos, em geral, com o risco do cancro da mama, deve-se ao papel que têm no crescimento do tecido da mama. O estradiol faz com que a mama cresça para um tamanho maduro durante a puberdade e que cresça uma vez mais durante a gravidez (pelo menos durante os dois primeiros trimestres). As células da mama que são sensíveis ao estímulo do estradiol são as primitivas ou indiferenciadas. Uma vez terminalmente diferenciadas e constituídas em células produtoras de leite, o que sucede sobre a influência de outros factores (ainda bastante desconhecidos), as células da mama deixam de responder a estímulos de reprodução.

São as células indiferenciadas que são também vulneráveis aos efeitos dos carcinogéneos (como a radiação, os produtos químicos, etc.) as que podem produzir tumores cancerígenos um dia mais tarde. Portanto, se uma mulher já passou por algumas semanas de uma gravidez normal e logo aborta essa gravidez, retém mais dessas células vulneráveis ao cancro do que as que tinha antes de ficar grávida. Além disso, qualquer célula anormal, com a potencialidade de formar o cancro, já existente no seu peito (e tais células estão presentes em alguma medida em todas as pessoas) foi estimulada a multiplicar-se. Tudo isto significa uma maior probabilidade estatística do que o aparecimento eventual de um tumor cancerígeno.

Diferentemente, uma gravidez levada a termo produz a plena diferenciação dos tecidos da mama com o fim da produção de leite, o que deixa na mesma menos células vulneráveis ao cancro das que lá estavam antes do começo da gravidez. Isto significa a bem conhecida redução do risco de cancro da mama como consequência de uma gravidez levada a termo.

Também é bem sabido que as mulheres que começam a ter filhos ainda jovens, diminuem o risco de ter cancro da mama mais tarde [1]. Quanto mais cedo o peito se torne maduro com o fim de produzir leite, menos provável é a presença de células anormais, vulneráveis ao cancro proveniente de abusos carcinogéneos (e o que quer que estes sejam é ainda bastante desconhecido). Sustentando esta teoria, um estudo experimental sobre o efeito de gravidezes e abortos induzidos na incidência de cancro da mama em ratas jovens tratadas com carcinogéneos químicos foi publicado em 1980 [39]. A mesma equipa de investigação publicou também um estudo excelente sobre a diferenciação dos tecidos da mama humana como função da gravidez e da idade [40].

Além disso, como há sempre células indiferenciadas (e inclusive algumas células anormais) na mama das mulheres, o excesso de exposição aos efeitos promotores do crescimento do estradiol ou outros estrogéneos, contribui para o risco de cancro da mama cada vez que ocorra essa exposição.

Não é de surpreender, portanto, que os factores de risco de cancro da mama mais conhecidos envolvam alguma forma de excesso de exposição aos estrogéneos. Por exemplo, mulheres que atingem a puberdade muito cedo ou que entrem na menopausa tardiamente, ou que tenham poucos filhos ou nenhum, estão mais expostas aos aumentos de estradiol que ocorrem com os ciclos menstruais. As mulheres que dão de mamar aos seus filhos também experimentam menos ciclos

menstruais e por isso, reduzem o risco de ter cancro da mama.

Mesmo os factores de risco não relacionados com a reprodução parece que operam através de mecanismos mediados pelo estrogéneo. Por exemplo, a obesidade pós-menopáusica eleva o risco supostamente porque as células adiposas (gordas) sintetizam os estrogéneos, do aumento dos niveis de estrogéneos no sangue dessas mulheres. Até mesmo o consumo crónico de álcool parece aumentar o risco de cancro da mama através do aumento dos niveis de estrogéneos no sangue da mulher. Isto também sucede em dietas altas em gorduras animais comparadas com dietas vegetarianas. Pelo contrário, certos vegetais reconhecidos como protectores contra o cancro, por exemplo, os da família dos brócolos e da couve, ajudam o corpo feminino a eliminar estrogéneos mais rapidamente.

Como o efeito dos estrogéneos no risco do cancro da mama foi reconhecido desde há muitos anos, os médicos são cautelosos ao receitar alguns medicamentos, como a terapia para substituição de estrogéneos na pós–menopausa de mulheres mais velhas, especialmente naquelas com histórias médicas de cancro da mama na família. Segundo parece, estes medicamentos elevam ligeiramente o risco de cancro da mama, se se utilizam por vários anos.

Deduz-se por isso que os médicos deveriam ter-se preocupado desde há muito com o possível aumento do risco de cancro da mama atribuivel aos abortos induzidos, dado o nivel extremamente alto de estradiol que experimentam as mulheres, mesmo nas primeiras semanas de uma gravidez normal.

Finalmente, há outro aspecto crucial dos abortos espontâneos em relação ao risco de cancro da mama que deverá ser realçado, isto é, o efeito de desmanchos espontâneos no segundo trimestre. O maior número de perdas de gravidez ocorre no primeiro trimestre e mais de 90% destas caracterizam-se pelos niveis anormalmente baixos38 de estradiol na mãe. Contudo, há motivos para crer que as gravidezes que sobrevivem no primeiro trimestre (o que não sucederia sem um nivel suficientemente alto de progesteronas, que são paralelas ao estradiol) provavelmente aumentam o risco de cancro da mama se terminam em desmancho.

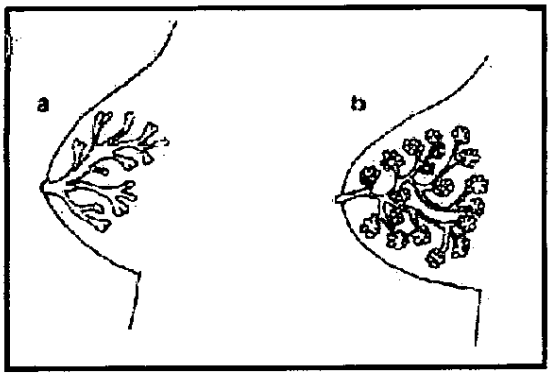


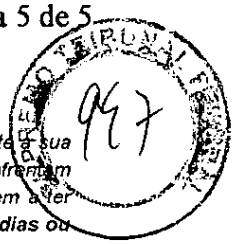
Figura 2 – Representação esquemática da mama: a) de uma mulher que nunca esteve grávida e b) no final de uma gravidez levada a termo. A mama de uma mulher que nunca esteve grávida consiste em canais e lobos terminais primitivos, vulneráveis a carcinogéneos, enquanto as mamas lactantes consistem, na sua maior parte, de lobos maduros – aglomerado de alvéolos que segregam leite – os quais são resistentes aos carcinógeneos. *(Adaptado das referências #39 e 40)*

A Conferência Mundial sobre o Cancro da Mama reconhece a ligação entre o aborto e o cancro da mama

A primeira Conferência Mundial sobre o Cancro da Mama teve lugar em Julho de 1997 em Kingston, Ontario, Canadá. A conferência foi co-empreendida pela Organização Feminina do Ambiente e Desenvolvimento (*Women's Environment and Development Organization*) que na altura era presidida por Bella Abzug.

Na conferência, o Dr. Joel Brind, Professor de Endocrinologia na Universidade de Baruch, da Cidade Universitária de Nova Iorque e Director da Revista Trimestral Actualizada sobre o Aborto e Cancro da mama (*Abortion-Breast Cancer Quarterly Update*), dirigiu um seminário sobre a ligação entre o aborto e o cancro da mama. O discurso do Dr. Brind incluía uma actualização da *"revisão compreensiva e meta-análise"* [2] deste problema, publicado originariamente no *Jornal de Epidemiologia e Saúde Comunitária (Journal of Epidemiology and Community Health)* da Associação Médica da Grã-Bretanha. Bella Abzug assistiu ao seminário do Dr. Brind e participou numa discussão cordial e animada sobre a ligação entre o aborto e o cancro da mama.

Um ano depois, no Outono de 1998, a Conferência Mundial publicou o seu *Relatório do Plano de Acção Global (Global Action Plan Report)* [41], no qual a organização expunha a sua agenda para a erradicação definitiva do cancro da mama. Sob o título de factores de risco relacionados com as hormonas, o *Relatório* diz em parte pertinente:



"Hoje em dia, as mulheres em geral estão mais expostas a níveis altos de estrogéneo durante a sua vida que o que era costume nas gerações anteriores. Acredita-se que agora as mulheres enfrentam níveis excessivos de estrogéneo tanto naturais como sintéticos, aumentando o risco de virem a ter cancro da mama. O uso prolongado de pílulas de controlo da natalidade, gravidezes tardias ou falta delas e o não dar de mamar, ABORTOS INDUZIDOS, uma dieta alta em gorduras, em carne ou em produtos lácteos e a terapia de substituição de hormonas depois da menopausa, todos são citados como factores de risco que aumentam os estrogéneos e o cancro da mama ."

LEMBRE-SE: Os direitos reprodutivos não têm significado sem o direito da mulher a saber todas as consequências das opções que faça!

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«Caimos tão fundo que atrever-se a proclamar aquilo que é óbvio se transformou em dever de todo o ser inteligente». (Georges Orwell)

ANEXO V

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SELECTIVE ABORTION IN BRAZIL: THE ANENCEPHALY CASE

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Keywords
abortion,
selective abortion,
anencephaly

ABSTRACT
This paper discusses the Brazilian Supreme Court ruling on the case of anencephaly. In Brazil, abortion is a crime against the life of a fetus, and selective abortion of non-viable fetuses is prohibited. Following a paradigmatic case discussed by the Brazilian Supreme Court in 2004, the use of abortion was authorized in the case of a fetus with anencephaly. The objective of this paper is to analyze the ethical arguments of the case, in particular the strategy of avoiding the moral status of the fetus, the cornerstone thesis of the Catholic Church.

The moral debate on selective abortion crossed the borders of the clinics and hospitals and reached the courts and Parliament following the popularization of ultrasound in public health care in Brazil in the 1990s. The negotiations regarding the best decisions were no longer restricted to bedside ethics, as they were during previous years when abortion cases were restricted to private health physicians. In public health care, the moral negotiation regarding abortion of non-viable fetuses included legal negotiation, since abortion is a crime in Brazil. A moral solidarity between private health care physicians and women was not common in public hospitals, where selective abortion was considered a crime. It was not rare for cases to be published in newspapers with nationwide circulation, where women seeking termination put forth their personal dramas in the hope that this would help to solve their dilemmas more quickly.

The debate surrounding the right to selective abortion has intensified in Brazilian medical and judicial circles in the last decade. In contrast to other countries, where the diagnosis of fetal malformation occurred in a context of abortion as a reproductive right, abortion in Brazil is a crime against the potential life of the fetus.[1] There are two cases when abortion is not penalized: in the case of rape or to save the woman's life. The Brazilian Penal Code does not include fetal malformation as an acceptable case; however, it is estimated that since 1989, 3000 law suits have resulted in the authorization of the interruption of pregnancies in the case of anomalies that are incompatible with life outside the womb.[2] The majority of these suits come from poor women, users of the public health system.

The first bill in the National Congress proposing to regulate selective abortion dates from 1972. Since then, there have been intense discussions among medical, legal and social movements on this matter. This first bill had a strong eugenic

[1] D. Diniz. Aborto en Brasil. *Cadernos de Saúde Pública (Public Health Reports)* 2005; 21: 675–682.
[2] T. Gollop & S. Pimentel. O STF e Anomalia Fetal Grave: Justiça. (The Supreme Court and Serious Fetal Anomaly: A Claim for Justice). *Jornal da FEBRASGO* 2004; 9: 10–11.

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inspiration, the intent of which was to avoid disabilities in the population and to restrict reproductive rights for specific groups.[3] However, in most cases, the bills were pro-choice and from a non-eugenic perspective, but to support the right to abort they had to face eugenic arguments. Only one bill from the 1990s proposed the criminalization of selective abortion of non-viable fetuses, qualifying it as 'eugenic abortion'.[4] During the last five years, the period of the greatest concentration of the debate in the courts, there has been no such bill suggesting the criminalization of selective abortion.

The selective abortion discussion had three public arenas for debate in Brazil. The Legislative branch was the first, with the presentation of bills that intended to regulate the right to abort in the case of a non-viable fetus. From 1972 to 2004, 12 bills were proposed regarding selective abortion in such a case. Of the 12 proposals, 6 were presented in 2004, after the anencephaly case went through the Brazilian Supreme Court, legalizing the interruption of pregnancy in a case of anencephaly. Most of the recent bills aim to recognize the right to selective abortion in the case of fetal anencephaly. A characteristic of the recent legislative debate is the strong participation of the Federal Senate in three proposals, since abortion was traditionally discussed in the Chamber of Deputies. Moreover, there are other bills, which propose the authorization or the total prohibition of abortion in the country, which would result in legislation regarding fetal malformation.

The second arena of negotiation was the courts, where the first cases of selective abortion were authorized. The first judicial authorization for selective abortion dates from 1989.[5] Recent analysis regarding the content of the first Brazilian judicial decisions show that most of the suits were favorable to the woman's right to decide and the denied cases were commonly due to religious rather than to legal arguments.[6]

The third arena for public discussion was the Supreme Court, who ruled in favor of the constitutional appeal regarding the anencephaly case presented by social movements in 2004. The case proposed to guarantee the right to selective abortion in cases of anencephaly and to protect the health care team in charge.[7] The Supreme Court case was a benchmark for the reproductive rights movement in Brazil, as the case opened a wide political discussion about Brazilian abortion legislation. For the first time, the Federal Government made a commitment to confront and revise the punitive character of the abortion legislation.[8]

The case of anencephaly became the paradigm for a wider debate about human rights and reproductive rights in Brazil. The 15 years of Brazilian jurisprudence regarding selective abortion was not restricted to anencephaly;[9] however, the Supreme Court case was exclusively about anencephaly, basically due to two reasons. First, the prognosis for babies born with anencephaly is extremely poor. There is a consensus in the international medical literature regarding the diagnosis of fetal non-viability: if the baby is not stillborn, he or she will die within hours or days after birth. The medical diagnosis is simple and largely offered by the public health care system in Brazil. The most common diagnostic technique is carried out by ultrasound. The image of an anencephalic fetus is clear even for the layperson, which facilitates the comprehension of the diagnosis and the decision making. The second reason, which is also medical, was the estimation that anencephaly accounted for 50% of the cases already decided by Brazilian judges.

[3] Câmara dos Deputados. (Chamber of Deputies). Brasil. 1972: PL 632/1972.

[4] Câmara dos Deputados. (Chamber of Deputies). Brasil. 2004: PL 1.459/2003.

[5] A. Biancarelli. 2004. STF Libera Aborto em Caso de Anencefalia. (The Supreme Court Allows Abortion in the Case of Anencephaly). *Folha de São Paulo* 2 July.

[6] Diniz, *op. cit.* note 1; M. Frigério et al. Aspectos Bioéticos e Jurídicos do Abortamento Seletivo no Brasil. (Bioethical and Legal Aspects of Selective Abortion in Brazil) *Revista da Sociedade Brasileira de Medicina Fetal (Journal of the Brazilian Society of Fetal Medicine)* 2001; 7: 12–18.

[7] Consejo Regional de Medicina de Bahia (CREMEB). 2004. *Anencefalia e o STF.* (Anencephaly and the Supreme Court). Brasilia: LetrasLivres.

[8] Secretaria Especial de Politicas para as Mulheres. (Special Policy Ministry for Women). Brasil. 2004. *Plano Nacional de Politicas para as Mulheres (National Policy Plan for Women).*

[9] Frigério et al., *op. cit.* note 6.

Even though the correlation between anencephaly and folic acid deficiency is well known in the medical literature, not all of the cases of anencephaly are the result of this deficiency:[10] genetic and unknown causes correspond to at least 60% of the cases.[11] According to the World Health Organization, Brazil is the fourth ranking country in the world in terms of the numbers of anencephalic newborns, after Mexico, Chile and Paraguay.[12] The explanation for this high incidence is the prohibitive legislation on selective abortion in these countries, rather than a higher incidence of anencephaly for genetic or other medical reasons.

In countries with a strong Catholic tradition, as is the case in Brazil and in all Latin American countries, the dilemma regarding abortion is paralyzed by the conflict between the right to life of the fetus and women's autonomy. The principle of the right to life of the fetus was brought to penal legislation by the prohibition of abortion, even in the early stages of pregnancy. The theory of fetal potentiality supports the criminalization of abortion as an act of crime against a potential person.[13] The clinical condition of anencephaly was decisive in supporting a new argument regarding abortion morality, facilitating the avoidance of the discussion of the moral status of the fetus.

According to the United States Institute of Neurological Disorders and Stroke:

> anencephaly is a defect in the closure of the neural tube during fetal development . . . Anencephaly occurs when the 'cephalic' or head end of the neural tube fails to close, resulting in the absence of a major portion of the brain, skull, and scalp.[14]

The certainty of the early death of the fetus, in the uterus or shortly after birth, was the moral foundation for the thesis proposed to the Supreme Court, that the interruption of the pregnancy of an anencephalic fetus does not fit into the penal definition of abortion. According to the Brazilian Penal Code, abortion is a crime against life and against a potential person. A fetus with anencephaly is a fetus without the capacity to live a life outside the womb. The consequence is that it is a fetus for which it is not possible to impute the principle of the right to life since the founding statement is absent: the capacity to survive outside the womb.[15]

This change of perspective moved the moral debate of the beginning of life and fetal status to the end of life and women's rights to be free from torture. A moral agreement on fetal status or when life begins would not be necessary to confront the judicial demand. The case was related to the definition of death, and how to protect women's rights by avoiding unnecessary suffering. According to Brazilian legislation on organ transplantation, a person is considered dead when there is no longer cerebral activity.[16] An anencephalic fetus does not have cerebral activity due to the absence of the major part of the brain, skull and scalp: the Brazilian Federal Council of Medicine defines it as a 'cerebral stillborn'.[17] The concept of a cerebral stillborn was proposed to simplify the analogy between anencephaly and a person who is brain dead: the first has no

[10] K. Swaiman & S. Ashwal. 2003. Anencephaly. In *Pediatric Neurology: Principles and Practice. Vol 1.* K. Swaiman & S. Ashwal, eds. Boston. Mosby: 250–251.

[11] D. Horovitz. 2004. Um Caixão Ambulante. (A Walking Coffin). In *Anencefalia: O Pensamento Brasileiro em sua Pluralidade.* (Anencephaly: Brazilian Debate in its Diversity). ANIS, Brasília: LetrasLivres: 29–30.

[12] M. Medeiros. Anencefalia no Brasil: O que os Dados Mundiais Revelam? (Anencephaly in Brazil: What do the World Data Reveal?). In *Anencefalia: O Pensamento Brasileiro em sua Pluralidade.* (Anencephaly: Brazilian Debate in its Diversity). ANIS. Brasília: LetrasLivres: 21–22; World Health Organization (WHO). 2003. International Clearing House for Birth Defects Monitoring Systems. International Centre for Birth Defects. In *World Atlas of Birth Defects.* 2nd edn. WHO/ICBDMS/EUROCAT. Geneva: WHO.

[13] D. Boonin. 2003. *A Defense of Abortion.* Cambridge. Cambridge University Press.

[14] National Institute of Neurological Disorders and Stroke (NINDS). *NINDS Anencephaly Information Page.* Bethesda, MD: NINDS Available at http://www.ninds.nih.gov/disorders/anencephaly/anencephaly.htm [Accessed 25 May 2007].

[15] Diniz, *op. cit.* note 1.

[16] Ministério da Saúde (Ministry of Health). Brasil. 1997. Lei 9.434. Remoção de Órgãos, Tecidos e Partes do Corpo Humano para fins de Transplante e Tratamento. (Brazilian Organ Transplantation and Donation Act). Brasília. Governo Federal.

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cerebral activity because it does not have the major portion of the brain, and the second, even though it does have a brain, has no brain function. Fetuses with anencephaly and people without cerebral activity are, therefore, considered dead, allowing medical procedures such as abortion and organ transplantation.

The legal definition of a fetus with anencephaly, as potentially dead after the delivery, allowed a redesign of the debate on selective abortion. The first step was to legally demonstrate that the case of anencephaly was not covered by Brazilian legislation on abortion: abortion is a crime when it interrupts the potentiality of the fetus.

In the case of an anencephalic fetus, the potentiality argument was not strong enough to confront the woman's right to decide, because the fetus will not survive after the delivery. The next step was to redefine the medical procedure as a 'therapeutic anticipation of birth'. If abortion is a crime against life or against a potential life, this legal definition would not apply to the clinical situation of anencephaly, since there is no potential life. In this sense, the Supreme Court case did not mention 'abortion', but 'therapeutic anticipation of the birth'. This was a legal and moral strategy to avoid the paralyzing dilemma of the right to life of the fetus versus the right to the woman's reproductive autonomy.

The Supreme Court stated that, in the absence of the penal crime of abortion, it would be an infraction of the constitutional principles to prohibit a woman from interrupting her pregnancy. Obliging a woman to carry out a pregnancy with an anencephalic fetus might be considered an act of torture and a violation of fundamental principles, such as the right to health, autonomy and dignity. This change of perspective represented a swerve in the Brazilian public debate, since, for the first time, abortion was discussed in human rights terms and not as a confrontation of religious beliefs.

Considering the wider political arena of abortion in Brazil, the anencephaly case was not an isolated case. It opened a succession of public debates around key questions in the legal framework, such as the role of the secular State and the punitive character of the abortion legislation. Besides this, the ethical principles evoked to support selective abortion in cases of fetal anencephaly are also valid in supporting the right to abortion in different situations.

Anencephaly allowed a broadening of the understanding of the social and moral phenomena involved in an abortion decision, after the paralyzing dilemma surrounding fetal status and women's autonomy was overcome. For the first time in Brazil, the Supreme Court called a public hearing, a clear indication of the political importance of this question. Only after the public hearing will the plenary session of the Supreme Court meet to judge the case. This will be a historical judgment, not only for the political and ethical challenges that involve the secular identity of the country, but mainly because it will be the first time that Brazil has seriously confronted reproductive rights as a human rights issue.

ANEXO VI

RELATO DE CASO

Higroma Cístico em Feto 45, X
Diagnóstico Precoce por Ultra-sonografia e Amostra de Vilo Corial

Cystic hygroma in a 45,X fetus
Early detection by ultrasound and chorionic villus sampling a case report

RESUMO

Paciente primigesta sem antecedentes de doença familial ou hereditária é submetida à ultra-sonografia de rotina na décima semana de gestação, constatando-se higroma cístico. Encaminhada ao nosso Instituto, é repetida a ultra-sonografia por via vaginal com 11 4/7 semanas, encontrando-se edema subcutâneo de tronco e confirmando-se o higroma cístico. Optou-se, pela facilidade de acesso, por amostra de vilo corial, por via transcervical, cuja análise citogenética revelou constituição cromossômica 45,X. Esse trabalho assinala a importância da ultra-sonografia precoce e da amostra de vilo corial na detecção precoce de anomalias fetais.

Palavras-Chave: higroma cístico; biópsia de vilo.

Rev Bras Ginec Obstet, 17:185, 1995

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Introdução

O higroma cístico (HC) constitui-se em massa líquida visível a ultra-sonografia já em períodos precoces da gestação, envolvendo a região póstero-lateral do pescoço e mais raramente a região superior do tronco. Ele pode apresentar-se simples ou septado. É clássica a distinção à ultra-sonografia entre o HC e os erros de fechamento do tubo neural,pois nesses últimos o canal raquimedular apresenta-se aberto e com freqüência malformado.

Em termos fisiopatológicos, o HC decorre de uma anomalia de comunicação entre o sistema venoso e a drenagem linfática superior. Na dependência da extensão dessa anomalia, poderá ocorrer hidropsia fetal seguida com freqüência da morte do concepto.

Em 80% dos casos, o HC está associado a anomalias cromossômicas (Pijers e col,1988; Cohen e col, 1989 e Watson e col, 1990). A anomalia cromossômica mais freqüentemente observada é a síndrome de Turner, caracterizada por cariótipo 45,X. O presente relato apresenta diagnóstico precoce por ultra-sonografia e amostra de vilo corial de paciente primigesta grávida de 11 semanas, portadora de HC cervical extenso.

Relato de Caso

Paciente de 28 anos casada com marido não consangüíneo de 35 anos. Negam-se antecedentes de malformações congênitas, retardo mental ou aborto habitual nas famílias do casal. A consulente realizou a primeira ultra-sonografia em outro serviço com dez semanas de gravidez e foi por este encaminhada ao Instituto de Medicina Fetal por haver suspeita de HC.

A ultra-sonografia realizada com 11 4/7 semanas sob nossa orientação revelou: comprimento céfalo-nádegas 49mm, edema acentuado no subcutâ-

neo de tronco e massacística na região posterior do pescoço (Figura 1). A avaliação ultra-sonográfica revelou inserção posterior da placenta com acesso fácil e, em função disto, optamos pela amostra de vilo corial por via transcervical. O estudo citogenético revelou constituição cromossômica 45,X em 25 metáfases analisadas através de bandas G.

Discutimos com o casal, em minucioso aconselhamento genético, quais as implicações da síndrome de Turner em todas as fases do desenvolvimento de um ser humano. O casal decidiu interromper a gravidez. O estudo anatomopatológico confirmou a presença do HC cervical.

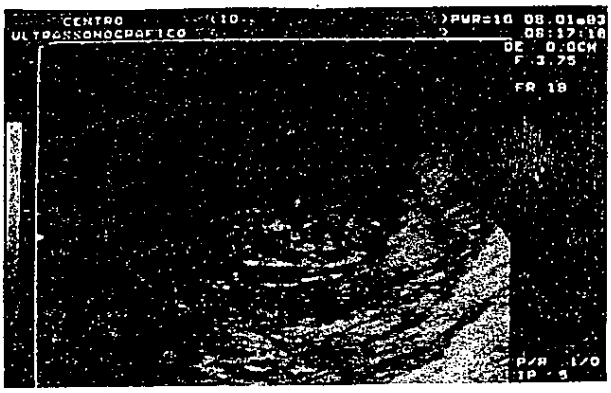

Figura 1 - Imagem ultra-sonográfica em gestação de 11 4/7 semanas mostrando o higroma cístico e o edema de parede torácica.

Discussão

A ultra-sonografia precoce por via abdominal e/ou vaginal é uma aquisição relativamente recente da propedêutica em Medicina Fetal. Entre patologias que são diagnosticáveis por esse método estão os HCs. O grande diagnóstico diferencial será feito com as meningoceles e meningoencefaloceles. Nessas últimas, com grande freqüência, a coluna não está íntegra.

Segundo trabalho recente de Johnson e col (1993) é fundamental ser cuidadoso na orientação dos casos diagnosticados com HC durante a gestação, pois, do total de casos diagnosticados, 33,8% regridem sem deixar seqüelas, sendo que, nos casos com cariótipo normal, a taxa de regressão é de 85,2%. Por outro lado, nossa orientação tem sido indicar estudo citogenético fetal em todas as gestações comprometidas por anomalias fetais observadas à ultra-sonografia, uma vez que anomalias cromossômicas estão presentes em 30% desses casos, conforme os achados de Eydoux e col (1989).

O caso aqui relatado reveste-se de aspectos interessantes. Em primeiro lugar, não é comum diagnóstico precoce de HC. Em segundo lugar, merece consideração o fato de a amostra de vilo corial por via transcervical ter sido um método de eleição excelente pois tratava-se de gestação de 11 4/7 semanas com placenta posterior, e qualquer outro método (via transabdominal ou amniocentese precoce) seria tecnicamente mais difícil de ser realizado. Finalmente vale assinalar que o aconselhamento genético no pré-natal das aneuploidias de cromossomos sexuais é uma tarefa sempre árdua e deve ressaltar o fato de estar envolvido risco baixo de recorrência em futuras gestações, da ordem de 1%. A dificuldade prende-se ao fato dessas crianças não terem retardo mental e serem perfeitamente viáveis, estando a maior limitação, restrita ao desenvolvimento estatural, aos órgãos genitais internos e externos e à incapacidade reprodutiva. Devido a esses aspectos, o diagnóstico pré-natal precoce tem uma grande contribuição na facilitação do processo de decisão dos casais envolvidos nessas situações.

SUMMARY

A primigravida without any congenital or hereditary disease in the family was submitted to a routine ultrasound in the 10th week of pregnancy in which a cystic hygroma of the neck was identified. She was referred to our Institute and in the 11th 4/7 week of the pregnancy, another ultrasound identified subcutaneous trunk oedema and confirmed the cystic hygroma. Due to posterior implantation of the placenta, transcervical chorionic villus has been performed and revealed a 45,X chromosomal constitution. This report underlines the value of early prenatal diagnosis in means of ultrasound and chorionic villus sampling.

Key-Words: Cystic Hygroma; villus sampling.