Determining access to assisted reproductive technology: reactions of clinic directors to ethically complex case scenarios

J.E.Stern1,5, C.P.Cramer2, R.M.Green3, A.Garrod4 and K.O.DeVries3

1Department of Ob/Gyn Dartmouth-Hitchcock Medical Center, One Medical Center Drive, Lebanon, NH 03756, 2Department of Psychological and Brain Science, Dartmouth College, Hanover, NH, 03755, 3Ethics Institute, Dartmouth College, Hanover, NH 03755 and 4Department of Education, Dartmouth College, Hanover, NH 03755, USA

BACKGROUND: Our aim was to increase understanding of how patient selection is handled by assisted reproductive technology (ART) clinicians. METHODS: Ethically complex case scenarios were evaluated by the directors of USA ART clinics. Scenarios included using a son as sperm donor for his father, sex selection without associated disease, treatment of morally irresponsible couples, and a dispute over embryo disposition. Respondents reviewed eight scenarios and gave their opinions on whether to offer treatment. Reasons given for these decisions were placed into one of 13 categories. RESULTS: Survey response rate was 57%. Between 3 and 50% of respondents would treat in each case. Of reasons given, ‘conditional’ responses (requiring counselling, blood tests or agreement to other ‘conditions’) were common (31.4%). Non-maleficence (risk) accounted for 29.4% of responses, philosophy of medicine 18.9%, respect for patient autonomy 5.9% and legal concerns 4.6%. Discrimination and threats were each significant in one case. Reasons evoking absolutist beliefs, personal discomfort, commitment to justice, religion and ethical relativism were rare. CONCLUSIONS: Clinicians felt conflict between a desire to respect patient autonomy and their discomfort over the risk associated with the procedure. They raised concerns about misuse of medical technology. Attempts to resolve complex issues through negotiation and compromise were common.

Key words: ART/case scenarios/decision making/ethics/setting limits

Introduction

Practitioners in the field of assisted reproductive technology (ART) often encounter socially and ethically challenging cases. Such cases, though frequently encountered by the practitioner, have had surprisingly little discussion in the public forum. Cases that can be problematic include those related to patient attributes (marital status, age, sexual preference) and patient behaviours (substance abuse, psychiatric history, child abuse). Questions about the social or moral implications of the procedures offered, such as surrogacy or ART for HIV positive patients, also arise.

Many countries legislate the provision of ART services. In the UK the Human Fertilisation and Embryology Authority (HFEA) legislates which ART patients can be treated, use of donor gametes, and numbers of embryos transferred (Human Fertilisation and Embryology Authority, 2001). Unusual cases or cases that present exceptions to established guidelines may be reviewed individually by the HFEA before they can be treated. In many other countries specific laws have been enacted to cover some difficult questions of whom to treat and how the various technologies should be used (Jones and Cohen, 1998). Germany, for example, is fairly restrictive in the use of these technologies prohibiting embryo discard and surrogacy, regulating gamete donation, and controlling numbers of embryos to transfer. In the USA there are few laws that govern the way ART clinics may deal with ethically complex cases. Although guidelines on some issues are available from the American Society for Reproductive Medicine (ASRM), decisions on difficult cases are often made by individual clinicians who must rely on their own best judgement about what is both ethical and legal.

We have previously reported on a survey of ART clinic directors in which we asked respondents a variety of questions about complex and ethically challenging ‘access-to-services’ cases (Stern et al., 2001; 2002). Such a case was defined as ‘a dilemma caused by the presence of behaviours or conditions in the patient that the provider finds to be so problematic for ethical or other reasons that the provider is uncomfortable treating this individual’ (Stern et al., 2001). We found that clinic policy varies extensively throughout the USA (Stern et al., 2001). We also found that the opinions of clinic directors about whether or not to treat certain couples were generally more restrictive than is suggested by their clinic policies (Stern et al., 2002).
Little was known about the underlying principles or general considerations used by medical professionals when making decisions in these ethically problematic cases. Ethical principles that might be considered in dealing with such issues include patient autonomy, non-maleficence, beneficence, and justice. General considerations could include philosophy of the use of medical technologies, concerns about legal liability and religious convictions. One way to gain an understanding about the way in which clinicians make decisions on these subjects is to present them with a set of case scenarios and to ask them to describe the reasons for their decisions. This paper reports on the responses of clinic directors to a group of eight complex case scenarios that were included as part of our survey of ART clinic directors. Clinic director decisions on the cases, as well as their stated reasons for these decisions, are analysed.

Methods
A 20 min survey was sent to the directors of all 324 Society for Assisted Reproductive Technology (SART) associated ART programmes in the USA. An original mailing was sent followed by two additional mailings to non-respondents. The surveys included questions about clinic policy, opinions of directors and demographics. We also presented eight case-scenarios. These scenarios were developed from situations previously encountered at clinics known to us. Cases covered a range of diverse topic areas. They were also chosen to highlight a variety of ethical principles. Instructions for scenarios read: “For the following cases decide how you would proceed given the stated facts of the case and circle the appropriate answer. If you are unsure, make a best guess as to what you would do in the given situation”. Following the scenario we instructed participants to “List up to three ethical or other considerations that entered into your decision”. Some respondents listed no reasons for their treatment decision. Others listed anywhere between one and five reasons per scenario.

Responses to the scenarios were coded into 13 categories. These were derived from an initial list of 27 categories that we considered possible reasons on theoretical grounds. A pilot group of survey responses were read by four independent scorers, and the number of categories was compressed based on groupings of categories that achieved inter-rater reliabilities of ≥70%. The 13 categories are shown in Table I.

For the actual analyses, responses were categorized by three independent scorers. Of the original 1305 responses given by respondents, four were dropped because they were too illegible for any of the scorers to read, and 76 (5.8%) were dropped because the three scorers placed the response into three different categories. Of the remaining 1225 responses, 864 (70.5%) were given the same rating by all three scorers and 361 (29.5%) were given the same rating by two scorers. In the latter case, the score given by the aberrant scorer was not considered further.

Responses to scenarios were analysed for frequency within each scenario, as well as frequencies for respondents who would permit a procedure versus those who would deny treatment. Because the number of responses given by individual respondents and for individual scenarios was highly variable, statistical comparisons between groups were not appropriate.

Results
Our response rate to the survey of 324 clinic directors was 57%. As outlined in our previous publications (Stern et al., 2001; 2002), respondents were 86% MDs, 7% PhDs and 6% in other categories. They were 21% female and 79% male. All regions of the country were represented equally. Ethnic background was 87% Caucasian, 4% Hispanic/Latino, 4% Asian, 2% African American and 2% other designations. Religion was 45% Protestant, 24% Roman Catholic, 16% Jewish, and 13% Other. Both for-profit and not-for-profit ART programmes were represented and respondents had been with their clinics for an average of 8.7 years ± 5.4 years.

The set of eight case-scenarios was evaluated by the survey participants. Figure 1 shows the percentage of responses in each category from all cases combined. There are 13 categories. Of these, conditional, non-maleficence, autonomy, legal concerns and philosophy of medicine/clinic policy represent 91.2% of the answers. These five categories are presented in Figures 2 and 3, which depict responses to specific scenarios. Several categories were important in only one case; these included the categories of discrimination, relativism, threats and personal discomfort. These categories will only appear in relation to the case in which they constituted >1% of the answers. Religious, justice and absolutist categories represented very few answers and are not shown in the subsequent Figures.

Scenario A
A 48-year-old man who has had both testicles removed as a result of a rare testicular cancer would like to have a child with his newly-wed wife of 25. He would like your clinic to establish the pregnancy using donor insemination with the sperm of his 23 year old son.

Will you perform the inseminations?
In this case a couple is asking for a standard procedure, artificial insemination, but they are doing so under unusual circumstances. Some clinics will perform donor inseminations with the sperm of known donors while others will not (U.S. Congress, Office of Technology Assessment, 1988). This case is more complicated than most cases of known-donor insemination by the fact that the proposed inseminations are intra-familial and inter-generational which has implications for family dynamics and could impact the well-being of the child. The percentage of clinic directors who responded ‘yes’ to this scenario, indicating that they would treat this couple, was 44.3%. Those who responded ‘no’ constituted 55.7% of respondents. The breakdown of the reasons for these decisions is presented in Figure 2, Scenario A. The responses are distinguished by whether or not the decision was to permit or deny treatment. As can be seen, the prevailing reason for denying treatment is non-maleficence or concern about risk. The major risks cited were those to the donating son, the resulting child, or the family structure. Whether respondents were in favour of or opposed to providing this service, many mentioned the potential psychological problems for the 48-year-old husband, the son, the wife and the child.

When the respondent’s decision was to permit treatment the major comments were conditional. The category of ‘conditional’ covered those responses in which the respondent was willing to permit treatment provided specified conditions were met prior to or during treatment. In Scenario A the conditions
mentioned included requiring psychological counselling or screening of all parties and requiring testing of the son along with quarantine of his sperm to ensure that the donation was medically safe. Legal issues were addressed by many respondents, with a number of suggestions that special consents be drafted to clarify who would have legal responsibility for the child. The following comment is an example: “consent forms must be completed by all parties with the understanding that son is not responsible in any way for child”. Legal concerns about inheritance were also mentioned by some.

One prominent issue that surfaced in the answers was a concern about the genetic link between the 48-year-old and the resulting child. This was mentioned both by those who would treat the couple and those who would not. In some cases the decision on whether or not to treat seemed to hinge on the importance of this link to the respondent. Those who felt it was

Table I. Categories for survey responses

<table>
<thead>
<tr>
<th>Category</th>
<th>Possible criteria for inclusion in category*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conditional</td>
<td>Addition of conditions to make the case more amenable to resolution. These conditions could include increased knowledge about facts of the case, treatment alternatives (e.g., the possibility of preliminary counselling), or particular patient attributes. Evasions of the issue, seeking a way out of the dilemma, or anticipation that the problem would go away. Seeking a technical fix.</td>
</tr>
<tr>
<td>Non-maleficence</td>
<td>Concerned about possible harm caused to the patient or to a resulting child by the procedure. Concerned about risk of family tension, family conflict or incest concerns. Concern regarding any implicit or explicit harm.</td>
</tr>
<tr>
<td>Absolutist</td>
<td>Morally opposed to abortion or embryo destruction (under any circumstances).</td>
</tr>
<tr>
<td>Autonomy</td>
<td>Concerned about possible harm caused to the patient or to a resulting child by the procedure. Concerned about risk of family tension, family conflict or incest concerns. Concern regarding any implicit or explicit harm.</td>
</tr>
<tr>
<td>Discriminatory</td>
<td>Procedure would be wrong because it is discriminatory. Procedure might lead to discrimination.</td>
</tr>
<tr>
<td>Threat</td>
<td>Request harbours a threat. Desire not to capitulate to threats.</td>
</tr>
<tr>
<td>Personal Discomfort</td>
<td>Indicated desire to not perform the procedure but may believe that it would not be wrong for someone else to do it. Might refer the case to another clinic.</td>
</tr>
<tr>
<td>Justice</td>
<td>Justice-related, economic or allocative concerns.</td>
</tr>
<tr>
<td>Legal</td>
<td>Concerns about the lawfulness of a procedure. Concerns about the liability engendered.</td>
</tr>
<tr>
<td>Philosophy of Medicine</td>
<td>Concern that the procedure involved an improper use of medicine. Procedure violated (or conformed to) clinic policy or practice. Procedure violated the respondent’s personal views as a practitioner.</td>
</tr>
<tr>
<td>Relativism</td>
<td>Unsure about how to resolve the issue. Unsure that a resolution could exist. Unwilling to apply an ethical standard to others.</td>
</tr>
<tr>
<td>Religious</td>
<td>Religious or theological reason.</td>
</tr>
<tr>
<td>Other</td>
<td>Reason did not fit into any of the above categories.</td>
</tr>
</tbody>
</table>

*The answer was included in the category if it met any of the bulleted criteria.

Figure 1. Categorization of responses to all scenarios. Responses per category are shown as a percentage of the total number of comments received (n = 1400). Some cases elicited more comment than others and thus answers were not evenly distributed between the cases. There were also more responses from some respondents than from other respondents.
important would provide the service, those who felt that the desire for genetic continuity was overblown would not provide treatment.

Interesting answers that were generated by this question included one that read, "Have actually done this". Another response, "They do not need medical help for this procedure", opened the door for discussion of whether or not it would be better to keep medical personnel out of this situation altogether. Another respondent put their position this way: "Likely appropriate for some families but not others; thus, would not establish a firm policy against, but handle case-by-case with thorough psychological review of husband and son". Or, as another respondent put it: "difficult!"

**Scenario B**

Scenario B addresses an ethical issue that has been previously debated during formation of professional guidelines and in articles on new biomedical technologies (Ethics Committee of the American Society of Reproductive Medicine, 1999; American College of Obstetricians and Gynecologists, Committee on Ethics, 1996; Savulescu and Dahl, 2000; Sills et al., 1999).

A couple with two daughters would like to have a male child through the technology of preimplantation genetic diagnosis (PGD). Assume that you have the laboratory capability to perform this procedure to today's standards.

**Will you offer this procedure to this couple?**

Responses to this scenario were 21.4% 'yes' and 78.6% 'no'. As shown in Figure 2, Scenario B, those who believed in denying treatment did so largely on the basis of their philosophy of medicine. These considerations can include concerns over a general misuse of medical technology and the use of that technology for non-disease conditions. Some respondents simply stated that they felt that use of the technology for this purpose was unethical or was a slippery slope to greater misuse. The category of discrimination also appeared in responses to this case with many respondents concerned about the impact of sex selection on sex ratios, on society and on women's place in society. One response, "gives wrong message to existing daughters", summarizes this concern. A number of respondents also were unhappy with the couple’s apparent lack of responsibility over unnecessary discard of healthy embryos. In response to this consideration, one respondent who would perform the procedure said, "If couple willing to donate female embryos I would consider it". Others agreed that if the female embryos were to be donated to infertile couples or to research they might be willing to perform the procedure. Another source of discomfort about the

![Figure 2. Percentage of respondents who would permit treatment (stippled bars) or deny treatment (hatched bars) under the categories shown. Scenarios A, B, C and D are shown (n = 253, 158, 186, 160 respectively). Scenario B was the only one that elicited a significant number of responses in the category of ‘discrimination’. Scenario D was the only one that elicited a significant numbers of responses in the category of ‘threats’.](image-url)
procedure—reflecting a concern about non-maleficence—centred on exposing healthy, fertile women to the risks of IVF without clear medical indication.

Several of the answers reflected a negative attitude toward the request even by those who would honour the request for treatment. For example, one respondent said, “If we provide the service it is the couple’s choice, not mine”, while another pointed out that the “technology [is] available elsewhere anyway”. But others clearly believed strongly in the acceptability of using medical technology for this purpose as reflected in the statement, “There is nothing wrong with selecting gender of the child”.

**Scenario C**

In Scenario C a couple exercise their autonomy in a manner that many people might consider irresponsible or reckless. The scenario brings the desire of clinicians to respect patient autonomy into direct conflict with their own moral concerns regarding sanctity of human life and waste of professional resources.

A couple has undergone IVF at your clinic. They have conceived twins. You had discussed the risks of multiple pregnancy. They cannot find a physician willing to reduce this to a singleton pregnancy, so they decide to abort both fetuses. The couple returns to your clinic to undergo IVF again in hopes that they will have a singleton the next time.

**Will you perform IVF for this couple?**

The percentage of ‘yes’ responses in this case was 46.5%. The percentage of ‘no’ responses was 53.5%. Figure 2, Scenario C shows the breakdown of the reasons for these responses. Those who would deny treatment to the couple would do so largely over issues of philosophy of medicine or waste of professional resources. In addition there were concerns about the morality, or lack thereof, shown by the couple. Many directors referred to the couple as “callous”. Others were concerned about the couple’s ability to parent; for example, “the couple are too selfish to be good parents”. Others were simply offended by the previous action: “they are immoral and crazy”. Still others felt that the abortion represented the couple’s inability to understand the original consent to be treated: “couples unwilling to accept risks of IVF, i.e. multiple birth, should not undergo this procedure”.

Those who were willing to treat the couple did so largely with conditions. One oft-mentioned condition would be to require the couple to agree to transfer no more than one embryo, often one blastocyst (embryo at an advanced stage just prior to implantation). Others would treat only if the couple agreed to counselling. It was clear from the answers that even those directors willing to treat the couple wanted to do so only if they could decrease the odds of a similar abortion occurring in the future. Other respondents did not like the couple’s previous action but were so committed to the concept of autonomy that they were willing to provide services anyway: “while I think their actions despicable, they still have the right to make choices of this nature”. Others were not offended by the action, “[this is] not different from someone who has had a previous elective termination”. Still others appreciated the previous abortion as an attempt to take action against the risk of
multiple gestation: ‘we can’t deny treatment. They had the right to avoid risk’.

Scenario D

Scenario D presents an unusual situation in which the clinician is backed into a difficult ‘no win’ situation by the patient.

A couple comes to you for donor insemination. They are seeking donor insemination because the husband has a low sperm count as the result of taking Depo-Provera. Depo-Provera was prescribed to the husband by his psychiatrist to control his violent behaviour. The husband has a history of child molestation. The husband states that if you will not help them using donor insemination he will stop his medication to allow his sperm count to return to normal.

Will you perform the inseminations?

The percentage of clinic directors who were willing to treat the couple in Scenario D drops markedly compared with the percentage willing to treat the couples in cases A–C. Only 13.5% marked ‘yes’, they would treat, and 86.5% said ‘no’, they would not. Again in this case, those who would treat relied heavily on conditional responses (Figure 2, Scenario D). Directors often suggested psychiatric or social work consultations. In this case they also mentioned that these consultations needed to be demonstrated to have changed behaviours. Patient rights, patient autonomy and the man’s ‘strong desire for child’ were all cited as reasons to treat. As demonstrated in the following comment, concern for autonomy was also sometimes mixed with fear of the patient coming off the medication: ‘If the person feels he can be a good parent and remain under control on DMPA, it would be worse to un-medicate him’. Some of those who were willing to provide treatment considered the use of donor sperm a better option than the risk of the husband’s conceiving with his own sperm and potentially transmitting his psychiatric problems to his offspring.

Those denying treatment to this couple did so largely because of concerns about risk: risk to the prospective child, risk to the spouse and risk to society. Philosophy of medicine and clinic policy also entered into these decisions. This case was the only one in which a high percentage (22.8%) used the category of ‘threats’. The following comments were typical: ‘will not respond to threats’, ‘I will not be manipulated or blackmailed’, and ‘I would refuse to be blackmailed’ by the husband into offering donor inseminations’. Others explained that treating this couple violated their own personal ethics or personal comfort level: ‘personal conflict re helping couple to have a child to be brought up by this man’; ‘I choose not to enter into a physician–patient relationship’; ‘I do not have to help them and would choose not to do so’; ‘They can have copies of their records and can go wherever they want’. Physician responsibility to the future child and to society was also an issue: ‘responsibility of clinic to child’s environment’; ‘protection of children comes before childbearing’; ‘I am not responsible for what he does only for what I do’.

Several individuals found this case very difficult and could not give a definitive answer. One said, ‘You know these cases don’t lend themselves to yes and no answers. The cases are more complex than you list here.’ And another, ‘This case goes to ethics committee.’ Finally, one person who would deny treatment said only, ‘do I really need to enumerate the reasons?’

Scenario E

Case scenario E elaborates a situation in which a couple asks for transfer of numerous embryos. Please note as you read this that the guidelines for numbers of embryos to transfer have recently changed and numbers of embryos transferred have been slowly declining over the past few years (Practice Committee Report, 1999). Thus the percentage willing to transfer six embryos to this couple may be shifting over time. The reasons for the decisions are nevertheless still of interest and could be applied to a number that is lower than that in the scenario but higher than that which is recommended in the current guidelines.

A couple, in which the woman is 27, is undergoing IVF at your clinic. They state up front that they very much want to establish a pregnancy and that to do this they would like to have at least six embryos transferred in this cycle. After much discussion, the couple feel strongly that they would like this done even though they understand the risks of multiple pregnancy. They agree to sign a waiver absolving the clinic of any liability for the risks assumed.

Will you transfer six embryos to this couple?

The risk of multiple embryo transfer in a young patient is a high rate of multiple pregnancy (pregnancy with more than one intrauterine sac). Responses to this scenario were 34.3% ‘yes’ and 65.7% ‘no’. The categories of responses are shown in Figure 3, Scenario E. A large percentage of those prepared to treat the couple gave conditional responses to the case. Conditional responses included transferring only a single embryo next time, requiring counselling and requiring the signing of a legal waiver of responsibility. The reasons provided for denying treatment largely included concerns about the risk of the treatment and either philosophy of medicine or clinic policy such as following ASRM guidelines.

This case, more than many others, brings forth the stark difference between the respondents who will treat and those who will not treat the patient. The medical risks of multiple pregnancy are clear for young patients and ascertaining these risks is easily within the expertise of the reproductive specialist. Thus, there is little confusion about whether or not the intervention is risky; risk is clear. The difference in whether or not respondents will treat this couple lies in philosophy. Respondents who will transfer six embryos are primarily proponents of patient autonomy and the process of informed consent: ‘People should be able to have what they want within reason’; ‘Assuming we have established a coherent relationship this is the very definition of informed consent’; ‘It is their informed decision—I am not God.’ The respondents who would not transfer six embryos believe instead that it is their individual prerogative and responsibility to decide whether or not to apply their services in cases in which they believe the risk is excessively high: ‘I believe this is malpractice we would not agree to this even with a waiver’; ‘Physician must make the decision. Physician is ethically and legally responsible for the well-being of the child/children’; ‘Not obligated
to provide care I disagree with’’; ‘‘They do not know best.’’ As a middle ground, one respondent replied that the informed consent process should be able to be used to resolve the disagreement between his values and those of the patient: ‘‘This situation has happened to me: with counselling patient has agreed to not transfer six embryos; with good counselling this will not happen.’’ This response assumes the rationality of patients in a way that may not apply to all patients.

**Scenario F**

Scenario F deals with the question of whether or not to treat HIV discordant couples where the HIV positive spouse is the husband. Treatment of HIV discordant couples has been debated in the literature (Laurence, 1993; Rojansky and Schenker, 1995; Lyerly and Anderson, 2001). Recently the ASRM has recommended that HIV discordant couples be treated only at ART clinics ‘‘that can provide the most effective methods of sperm preparation as well as the rigorous testing and treatment necessary to minimize the chance of HIV transmission to partner and offspring…these centers should use strict study protocols with proper informed consent and thorough follow-up’’ (Ethics Committee of the American Society for Reproductive Medicine, 2002). However at the time this survey was mailed this recommendation was not in place. Protocols for processing of sperm samples for intruterine insemination (IUI) have been published (Semprini *et al.*, 1992), and at least one laboratory has made extensive use of these procedures for clinical cases (Marina *et al.*, 1998).

*A couple in which the husband is HIV positive and the wife HIV negative would like to conceive. They believe that their best chance of pregnancy with the lowest chance of HIV transmission is to use gonadotrophin IUI cycles. They would like your clinic to perform these procedures.*

**Will you offer IUI to this couple?**

Our responses to this scenario were 13.5% ‘‘yes’’ and 85.5% ‘‘no’’. Categories of responses are shown in Figure 3, Scenario F. Non-maleficence in the form of concern about transmitting HIV to the child, wife and clinic staff, constituted the major justification for denying treatment to this couple. Some respondents justified their concern about the risk of infection to the woman and child by pointing to the fact that data are not available to show conclusively that HIV is removed from semen by the sperm wash procedures presently used to prepare sperm for IUI (this is still a concern). Worries that the child would be left fatherless were also voiced. A number of respondents suggested that either donor insemination or adoption were adequate alternatives for this couple.

*Treatment would be offered by those who believe that patient autonomy should be the deciding factor when considered in conjunction with informed consent and adequate counselling. One respondent said, ‘‘I would need airtight legal documentation (protection, waivers, lawyer’s stuff) before doing so….’’ Whether there is such thing as ‘‘airtight legal documentation’’ is a separate question. Respondents from some states indicated that treating this couple would be illegal in their state. However, another respondent was worried about the legality of the decision to deny treatment: ‘‘Limitation of services based upon a medical problem which has been labelled a disability (HIV+) can be a medical-legal problem.’’*

**Scenario G**

Scenario G generated the most consistently negative responses to providing treatment. This scenario involved an unusual case of surrogacy for convenience.

*A man of 62 desires a biological child. He intends to raise the child with his girlfriend. The girlfriend does not wish to be pregnant, so he approaches your clinic to arrange for a surrogate.*

**Will you arrange a surrogate pregnancy for this man?**

Only 2.9% would treat the couple in this scenario; the other 97.1% would not. Figure 3, Scenario G presents categories of responses only for those who would deny treatment. Those who would permit treatment are omitted due to the insignificant number of responses. Although we did not define the type of surrogacy intended, traditional or gestational, it was clear from the comments that traditional surrogacy was assumed by most respondents. Responses of those who would deny treatment fell largely into the categories of non-maleficence and philosophy of medicine. Reasons for denial included the instability of the relationship, the age of the male partner, the likelihood that the male partner would not survive long, the lack of commitment on the part of the girlfriend, the poor prospects for the child, and the fact that there was no medical condition on which to base treatment. Comments included: ‘‘genetic continuity is not that important’’; ‘‘find another girlfriend’’; ‘‘get real—way too liberal for my personality.’’ Others who would not treat this couple reported that surrogacy is illegal in their state, although one indicated that if it were legal he/she would provide treatment. Several others would not arrange for a surrogate but would treat the couple if they brought their own surrogate with them. Of those few who checked ‘‘yes’’ (would treat), one indicated that counselling would be needed and another deemed this case ‘‘no different than adoption.’’

**Scenario H**

The final case was one that involved a disagreement between the partners over embryo freezing (cryopreservation).

*A couple is considering cryopreservation. They are unable to agree about a plan of action regarding frozen embryos in the eventuality that they divorce at some point in the future.*

**Will you perform an ART cycle for this couple?**

The responses to this case were evenly split, 50% ‘‘yes’’ and 50% ‘‘no’’. Categories of responses are shown in Figure 3, Scenario H. Central concerns of the respondents who marked ‘‘no’’ were legal issues for their clinic and for the couple as well as concerns about the potential stability of the relationship and the preparedness for parenting of a couple who cannot agree on embryo disposition. Of those who marked ‘‘yes’, 31% said that they would do an ART cycle but would not cryopreserve embryos. One respondent preferred to avoid the problem by believing that the embryos ‘‘probably won’t survive the thaw.’’ Additional comments from respondents centred mainly on prior unpredictability of courts with regard to their support (or lack of support) for the informed consent documents used in ART. Some respondents preferred to leave the legal issues to
the courts rather than to worry about these issues themselves. For example: ‘‘this is a legal not medical issue,’’ and ‘‘pre-
signed agreements are virtually worthless. If divorce occurs
everything is open to dispute. Having said that, the lab would
refuse to freeze.’’

Discussion
The case scenarios presented to ART clinic directors in this
study were diverse in their topics and in the ethical issues that
they raised. Directors showed little agreement on whether or
not patients in the scenarios should be treated. Numbers willing
to treat the couple ranged from 3–50% in the different
scenarios. Of 13 possible categories of responses, five
categories were used consistently in all cases: conditional,
non-maleficence, autonomy, legal conditions and philosophy
of medicine/clinic policy. The conflict that developed in most
instances was a juxtaposition between the autonomy of the
patient to choose to do something and either the risks of the
procedure for various parties involved or the director’s
philosophy of how medical technology should be used. The
other conflict that seemed apparent was a disagreement
between respondents on just how risky certain procedures
might be.

Respect for patient autonomy was an important determinant
in these cases, particularly for those who would treat the
couple. We have previously shown that director opinion on
whether or not to provide treatment in certain access-to-
services situations is generally more restrictive than clinic
policy at their respective clinics (Stern et al., 2002). This
finding suggests that respect for autonomy is a strong factor for
clinicians, who may permit patients to be treated even when
they believe that treatment should not occur. Reasonable
people have disagreed on the degree to which autonomy should
be respected in providing ART. John Robertson contends that
decisions about the use of reproductive technology should be
governed primarily by a respect for ‘‘reprocreative liberty’’
(Robertson, 1994). According to Robertson, ‘‘If reprocreative
liberty is taken seriously, a strong presumption in favor of
using technologies that centrally implicate reproductive inter-
ests should be recognized. Although reprocreative rights are not
absolute, those who would limit reprocreative choice should have
the burden of establishing substantial harm’’ (Robertson,
1994). Sherwin, by contrast, takes issue with the importance
of autonomy arguing that ‘‘actual people are not independent,
and their decision-making does not always meet the norms that
define rationality. They do not, for example always act in
accordance with their own best interests’’ (Sherwin, 1992).

According to this model patient requests may not accurately
reflect the underlying value system and true desires of the
patient.

Concern about the risk of the procedure to the couple and
prospective child was another very important factor in these
cases, particularly to those directors who did not want to treat a
couple. In some cases these risks were clear. Scenario E,
multiple embryo transfer to a young patient, carries medical
risks of multiple pregnancy that are well known (Schieve et al.,
1999). Nevertheless, 34% of the respondents chose to treat the
couple, clearly signalling the strength of their desire to honour
patient autonomy even in the face of risk. In other cases,
though, the risks themselves were far less clear. Particularly
challenging were cases in which the risk was primarily
psychological or social. Medical doctors usually do not receive
training in determining psychosocial risk and data may not be
readily available to enable such risk to be assessed. In these
cases it may be hard to differentiate assessment of risk from
simple opinion or prejudice. Scenario A, that of intra-familial,
inter-generational sperm donation, illustrates this point. After
over 50 years of use, we are just starting to understand the
psychological ramifications of anonymous donor insemination
(Baran and Panmor, 1993; Turner and Coyle, 2000) and there
are no scientific data about the effect of sperm donations of the
kind presented in the scenario. Thus, concerns that the
arrangement could be risky to the offspring are just that—
concerns, not true assessments of risk. Many other questions
that we consider ethical questions in this field bring up
situations that have little data to support one position or
another. For example, we know little about the psychological
or social impact of single parenting, lesbian parenting, egg
donation and surrogacy (Miller, 1992; Golombok and Tasker,
1994; Brewaeys, 1998; Golombok, 1998; Golombok et al.,
1999). The effects of parenting by ‘‘confused’’ and/or poten-
tially ‘‘irresponsible’’ people (i.e. those in Scenario C who
aborted twins, or those in Scenario H who could not make a
joint decision on embryo disposition) are equally unknown. We
know that children who are abused suffer serious consequences
(James, 1989; Herman, 1992), but the extent of harm that can
be caused by less concrete situations is unclear. Thus assessing
risk in these cases may depend on personal experience,
personal bias and the degree of one’s willingness to accept
uncertainty.

In general, clinicians have the right to deny treatment to
those seeking elective procedures and many respondents to our
survey chose to deny treatment for reasons related to their own
personal views on the uses and abuses of medical technologies.
Certain actions that a clinic might take, such as denying
treatment to an inter-racial couple for reason of race, are clearly
immoral and illegal. However, most instances of refusal to treat
are not clearly unethical or clearly covered under existing law.
Where laws do not exist there have been few cases to test these
issues in the courts. In a review of the legal and ethical aspects
of such issues, the New York State Task Force on Life and the
Law stated, ‘‘Physicians offering assisted reproduction are
under no legal or ethical obligation to treat every individual or
couple who requests their services’’ (The New York State Task
Force on Life and the Law, 1998). Refusals that reflect a basic
disagreement over misuse of technology include refusal to use
PGD for sex selection (Scenario B) and refusal to participate in
surrogacy arrangements (Scenario G). Clinics can translate
these concerns into policy, although only 40% of the clinics in
our survey had written policy on access-to-services issues
(Stern et al., 2001).

The ‘‘conditional’’ category of response was the category that
was most often used by respondents. This category often
contained practical suggestions to ensure safety (e.g. screen the
sperm donor and quarantine the donor sperm), to enforce
protocol (e.g. transfer fewer embryos), or to obtain additional information on the case. Use of this category, however, may also have been a way to delay or avoid making a concrete decision about the case. For example, sending a patient to counselling to resolve conflict may be an excellent idea, but the couple could return from counselling with their demands unchanged. This action in itself may not alter the underlying ethical problem. Some respondents also appeared to be trying to change the nature of the case by modifying treatment, such as by using special wash procedures to reduce HIV (Scenario F), transferring only one blastocyst (Scenario C), and having the couple arrange their own surrogate (Scenario G). Though clever, this sort of solution may not work. For example, offering only single blastocyst transfer in Scenario C, where the couple had undergone a previous elective termination of twins, could still result in identical twins, particularly if there is an increased identical twin rate for blastocyst transfer (Permano et al., 1999). The underlying ethical question, whether or not to provide services to a couple who could decide to abort again, may thus not be eliminated by this action. Further, the action fails to address the question of whether or not to provide services to a couple who had already aborted a pregnancy for the sole reason that the woman was carrying twins. Placing conditions on treatment is useful in a clinical setting, but it should not be expected that these conditions will control the situation or eliminate the ethical questions.

There were some respondent statements that made less useful contributions to the resolution of cases. Responses that demonstrated avoidance such as ‘who am I to decide what is ‘right’?’ (Scenario A), are examples. Statements of personal discomfort are also less helpful since they express the sentiment without providing specific reasons for the discomfort. A respondent, who would provide PGD for sex selection in Scenario B, clearly evaded the ethical conflict: ‘technology available elsewhere anyway.’ These sentiments, though understandable, are unhelpful in resolving the case. The risk in using reasoning of this sort in the face of an ethical conflict is that by failing to fully define the ethical concerns, the clinic may embark unknowingly on a course of action that is ethically problematic. They may treat patients who should not be treated or fail to treat patients who should be treated simply because they do not have the energy or resolve to refine their responses to the issues.

Reasonable people can disagree over whether allowing clinicians to make access-to-services decisions—as is done in the USA—is better than having legal oversight—as is the practice in many European countries. It is our belief that laws governing new technology tend to lag so far behind the technology itself that they are often in danger of being obsolete by the time the legislation is enacted. There is also the problem that laws may be unsuited to responding to the complex individual circumstances that often characterize this area. Nevertheless, the present persistent problem facing clinicians in the USA concerns what steps to take when encountering a complex access-to-services case. In resolving such a case there is often no single ‘correct’ course of action, however, some actions are clearly ‘wrong’ and need to be avoided. There are four specific suggestions for reviewing such cases that we can make based on the information that we have gathered on current practices at ART clinics. First, we believe that it is important for clinics to have written policies on access-to-services issues. Written policies may be helpful to ensure that all patients are being treated according to the same standards and to demonstrate to patients that a particular decision is not arbitrary.

Second, we suggest that caregivers spend adequate time finding out the ethically relevant facts of a case. Central to this is not being hurried by a patient’s sense of urgency. Finding out the facts may include having a physician ask more probing questions or asking a patient to undergo a more extensive mental health evaluation. It may involve seeking the advice of a lawyer. Some of the responses to our survey found in the ‘conditional’ category were in effect suggestions that clinicians acquire this sort of factual information. Finding out the facts could in some cases show that the original concerns were unfounded or it could aid in overcoming a tendency to prejudice or bias in determining a solution. Knowing the facts will help ensure that the decision is based on more than speculation and assumption.

Our third suggestion is to clearly define the ethical issues. It may be tempting to deny treatment because something sounds ‘weird’ or unusual but that sort of analysis will not explain the clinician’s reasoning to the patient, or to a court of law. A good guiding principle may be to define clear and concise reasons for denial of treatment. One clear reason for denial might be evidence of significant medical or psychological risk to the patients or their future child.

Our fourth suggestion is to solicit the opinions and perspectives of a variety of resources and individuals. If a multidisciplinary ethics committee is available this might be one source of advice. If an ethics committee is not available or if their deliberation process is too slow, then drawing from local ethics, mental health, legal and social science expertise should be considered. As an illustration, our institution has assembled an informal group of advisors comprising of an ethics professional, several physicians, a mental health worker, and an embryologist. Legal advice from our Risk Management department is sought when needed.

The data in this survey suggest that most clinicians practising ART are struggling with access issues. These data, along with our previous reports on this survey (Stern et al., 2001; 2002) indicate that further discussion of access-to-services issues as well as some training in systematic approaches to solving complex ethical problems could be very useful to clinicians in this field.

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References

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