

Canadian Fertility and Andrology Society Counselling Special Interest Group (CSIG)

Assisted Human Reproduction Counselling Practice Guidelines

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Canadian Fertility and Andrology Society

Counselling Special Interest Group

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PREFACE

The Counselling Special Interest Group (CSIG) was inaugurated at the joint Canadian Fertility and Andrology Society (CFAS) and American Society of Reproduction Medicine (ASRM) Annual Meeting in 2005. The mission of CSIG is to:

- a) promote opportunities for communication and networking among Canadian counsellors;
- b) provide professional development through education and training;
- c) support counsellors' involvement in research activities;
- d) encourage multi-disciplinary collaboration and exchange;
- e) develop standards of practice for counselling within the scope and context of the Assisted Human Reproduction Act of Canada;
- f) encourage counsellors working in the field to become members of CFAS.

The Counselling Practice Guidelines Committee was established in January 2008 to fulfill the mandate of developing standards of practice for Canadian counsellors. Committee members included Susan Bermingham MPs, Judith Daniluk PhD, Christopher Newton PhD, Janet Takefman PhD, and Samantha Yee MSW. Contributions by Sherry Dale MSW, Jean Haase MSW from Assisted Human Reproduction Canada, and Valerie Wilkie RN from Nursing Special Interest Group are acknowledged.

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SECTION A

ASSISTED HUMAN REPRODUCTION (AHR) COUNSELLING

1. Definition

The services provided by mental health professionals trained to help individuals and couples cope with the psychosocial challenges and implications of involuntary childlessness and Assisted Human Reproduction (AHR) interventions, and to assist them in making informed lifestyle, treatment, and parenting decisions, consistent with their own values and goals.

2. Purpose

- Provision of counselling and psychosocial support to individuals and couples experiencing fertility challenges prior to, during, and/or following AHR intervention
- Helping individuals and couples to examine the emotional, psychosocial, relationship, and ethical implications of various treatment and parenting options
- Assisting in ensuring informed consent and decision-making
- Assisting patients to set realistic goals and prepare for, and cope with, various treatments and their outcomes
- Assisting participants in third-party arrangements to set appropriate boundaries and expectations, negotiate their short- and long-term relationships, and consider the potential implications and ramifications for themselves and their offspring
- Provision of support, consultation, and education to members of the AHR team

3. Common Psychosocial Challenges

a. Intrapersonal

- Experience of grief and loss
- Ongoing and prolonged stress and uncertainty
- Self esteem and identity issues
- Fear of not achieving family goals
- Negative thoughts, feelings, and beliefs
- Mental health issues such as depression, anxiety, psychosomatic complaints, adjustment

b. Interpersonal

- Expectations and boundaries for self and others
- Relationship issues such as communication, sexual and intimacy concerns
- Familial, social and workplace relationships

c. Ethical/Cultural

 Ethical, cultural, moral, religious and spiritual dilemmas related to involuntary childlessness and treatment options

d. Treatment

- Coping with diagnostic procedures and treatment interventions
- Decision-making challenges such as treatment options and termination, parenting options, disclosure, fertility preservation, embryo storage and disposition
- Managing donor and surrogacy arrangements
- Dealing with treatment failure, treatment termination and reproductive losses
- Coping with pregnancy and parenting post-treatment

4. Roles of the AHR Counsellor

- Psychosocial support, education, counselling, crisis and/or therapeutic interventions
- Patient advocacy
- Liaison with the patient's multi-disciplinary treatment team regarding
 psychosocial issues
- Referrals complementary alternative medicine (CAM), legal, mental health
- Addressing ethical issues/concerns
- Development of counselling protocols/interventions
- Documentation (record-keeping, report-writing)
- Training and supervision of mental health professionals
- Research and writing

5. Qualifications of AHR Counsellors

- a. Holds a Master's degree in a mental health field from an accredited university. Acceptable disciplines would include clinical or counselling psychology, social work, psychiatry, and marriage and family counselling/therapy.
- b. A member in good standing of a provincial or national professional body specific to their discipline which requires adherence to a code of ethics
- c. Membership in the Counselling Special Interest Group of the Canadian Fertility and Andrology Society is highly recommended¹
- d. A comprehensive and current knowledge of the:
 - etiology, diagnosis and treatments of reproductive difficulties
 - knowledge of AHR interventions
 - regulatory legislation governing AHR activities federally^{2,4}, and provincially
 - research and clinical literature on the psychosocial aspects of fertility challenges
 - literature on the psychosocial and developmental issues of children conceived through assisted reproduction
 - ethical issues inherent in reproductive investigations and treatment options
 - theories of grief and loss
 - theories of stress and coping
 - knowledge of literature regarding relationship/marital dynamics and potential conflicts
 - literature regarding sexual identity and functioning
 - literature related to pregnancy loss and parenting after infertility
 - short- and long-term needs and implications for donors, gestational carriers, and their significant others
 - issues of privacy, confidentiality and patient rights
 - psychosocial supports, community resources, and complementary therapies
 - impact of psychotropic medications
- e. Competence in:
 - clinical and mental health assessments
 - individual and couple counselling
 - issues related to self esteem, body image, and identity
 - diversity sensitive and culturally competent counselling
 - supportive counselling
 - crisis intervention

f. Continuous professional development and education in the field of AHR counselling such as attendance at annual meetings and postgraduate courses offered by the Canadian Fertility and Andrology Society and other international societies in reproductive medicine

Note: If individuals present with issues beyond the professional training and scope of practice of the AHR counsellor (e.g. psychological testing; sex therapy), s/he is knowledgeable about and able to provide appropriate and timely referrals.

SECTION B

THE CONTINUUM OF AHR COUNSELLING

AHR counselling may be undertaken with prospective parents, gamete donors, gestational carriers, significant others, and donor offspring. Individuals may benefit from counselling prior to, during, and following treatment.

1. Contemplation

Clients sometimes struggle to make decisions concerning the pursuit of medical treatment or particular treatment options. Feelings of uncertainty or ambivalence may arise. Conflicted or mixed emotions may be present. Disagreement between partners can occur and patients may need assistance with decision-making.

Counselling interventions include:

- Exploration of the impact of involuntary childlessness on the individual and relationships
- Discussion of concerns regarding treatment options
- Examination of personal values and belief systems relevant to AHR
- Provision of information and emotional support
- Review of the barriers to, and benefits and risks of, treatment and other parenting options

2. Treatment Preparation

Patients may be apprehensive about, and lack familiarity with, the demands of the treatment protocol and the short- and long-term implications of their decision.

Counselling interventions include:

- a. Providing an introduction to counselling
 - Explanation of the purposes of counselling
 - Discussion of confidentiality, limits of confidentiality and who will be recipients of information obtained
- b. Obtaining a thorough psychosocial history (refer to Appendix A) including
 - Marital/cohabitation history
 - Number and ages of any children, (custody and access if relevant)
 - Infertility history, diagnosis, and other relevant medical conditions and treatments

- Mental health history previous counselling, therapy or pharmacological treatment for individual or relationship issues
- c. Identifying psychological and emotional vulnerabilities
 - Impact of infertility on emotional and social functioning
 - Impact on self-image and self-esteem
 - Impact on a couple's relationship
 - Impact on a couple's sexual interactions and intimacy
 - Extent of family or social pressure
 - Motivations for treatment
 - Other current sources of stress
- d. Identifying strategies to facilitate coping
 - Providing validation and support
 - Individual coping strategies (e.g. information seeking, distraction, seeking social support, distancing/detachment, problem-solving, identification of positives)
 - Ability of a couple to provide each other with emotional, verbal, social or practical support
 - Availability of family or other support
 - Preferences for external support versus privacy and autonomy
- e. Discussion of the implications of treatment
 - The psychosocial implications of treatment and of treatment success or failure, for patients, their extended family and any child created as a result of treatment
 - The success rates of treatment
 - Ensuring patient awareness of pertinent laws and regulations concerning AHR
 - Provision of any other relevant information to facilitate informed consent
- f. Making recommendations to the treatment team regarding:
 - The patients' chief concerns
 - The patients' preferred coping styles and strategies
 - Ways in which the team can facilitate treatment
 - The need for ongoing psychosocial support or follow-up counselling
- g. Documentation and record keeping in accordance with the counsellor's professional standards of practice and clinic requirements

h. In cases of third-party reproduction, a number of additional issues are important to address. Refer to Section D.

3. Treatment

During the course of treatment, some patients find the demands of the medical protocol challenge their coping capacities. Doubts and anxiety about being able to manage and complete the treatment, side effects related to the medications, disappointment with failed cycles, and relationship friction are not uncommon.

Counselling interventions may include:

- Crisis intervention
- Assisting patients to access support and information
- Stress management and anxiety reduction
- Addressing individual distress and/or couple discord
- Decision making related to embryo transfer and disposition, fetal reduction, ending treatment, alternative parenting options
- Expectation management
- Discussion of complementary therapies

4. Post Treatment

Following completion of a treatment cycle or termination of treatment, patients may need assistance in managing treatment outcomes.

Counselling interventions may include:

- Crisis intervention
- Grief and loss counselling
- Addressing relationship issues
- Decision-making concerning alternate options such as life without children, third-party reproduction, adoption, foster parenting
- Strategies for achieving closure
- Referrals for ongoing counselling and support as indicated
- Coping with pregnancy and adjusting to parenthood

Note: In cases where intimate partner violence (IPV) or other risk factors such as concerns about childrearing competence are identified prior to or during treatment, further evaluation and consultation should be undertaken. Intimate partner violence includes acts of physical aggression, psychological abuse, sexual coercion, and other controlling behaviours such as isolation from family and friends. It is the obligation of the counsellor to report any knowledge of IPV or child welfare concerns to the appropriate authorities.

SECTION C

COUNSELLING PATIENTS IN TREATMENT USING THEIR OWN GAMETES

1. Definitions

Intrauterine Insemination (IUI) – a procedure in which sperm are injected directly into a woman's uterus, usually in combination with the use of drugs to stimulate egg production by the ovaries.

In Vitro Fertilization (IVF) – a procedure which involves extracting eggs from a woman's body, fertilizing them in the lab with sperm, and transferring the resulting embryo(s) to her uterus

Intra Cytoplasmic Sperm Injection (ICSI) – A technique used in conjunction with IVF treatment whereby each egg is injected with a single sperm most often used in cases of male factor infertility.

In Vitro Maturation (IVM) – A technique in which immature oocytes are retrieved from the ovaries and matured in the laboratory and then the mature eggs are fertilized using ICSI and transferred to the uterus as in conventional IVF. No hormone therapy to stimulate follicular growth is required.

2. Common Counselling Issues

The goals of counselling with patients about to undergo treatment with their own gametes should include:

- Obtaining a psychosocial history (refer to Appendix A)
- Exploration of treatment implications
- Identification of psychosocial vulnerabilities which might impact treatment
- Psychosocial preparation and support for treatment participation
 - Coping with treatment procedures such as blood tests, self injection of hormones (needle phobia), oocyte retrieval
 - Attitudes toward and concerns about medications required during treatment
 - Managing workplace issues such as arranging absences, disclosure to an employer, loss of income
 - Concerns about financial costs of treatment
 - Anxiety related to provision of a semen specimen
 - Expectation of partner during treatment

- Relevant factors that might negatively affect treatment participation such as financial, emotional, physical stress, diminished quality of life, employment disruption, and relationship distress
- Expectations concerning treatment and success rates
- Implications of multiple pregnancy
- Information/discussion about alternative options to proposed treatment such as the use of donor gametes, adoption, life without children
- The influence of lifestyle factors such as weight, exercise, smoking, substance use
- Impact of stress on fertility and treatment outcome
- Maintaining appropriate boundaries and information sharing with family and social network
- Recommendations to the treatment team

3. Counselling Considerations Specific to IUI

- Attitudes towards risk of multiple pregnancy and option of fetal reduction
- Attitudes and feelings towards possible IVF conversion where hyperstimulation occurs versus cycle cancellation

4. Counselling Considerations Specific to IVF

- Managing egg retrieval (identification of patients in need of additional assistance in managing anxiety)
- Views and/or concerns about embryo freezing and the potential options for future disposition of unused embryos
- Implications of multiple embryo transfer, attitudes towards multiple pregnancy and fetal reduction

5. Counselling Considerations Specific to ICSI

- Understanding the psychosocial implications of ICSI such as increased risks of possible birth abnormalities
- Male concerns and anxiety about surgical sperm retrieval
- Psychosocial and emotional implications when donor sperm is being considered as a back-up option during the treatment cycle

6. Counselling Considerations Specific to IVM

- All issues relevant to IVF
- Higher rates of treatment failure
- Greater risk of multiple pregnancies and the possibility of fetal reduction

• The higher risk of birth defects and the experimental nature of the procedure

Note: in any situation where the use of donor sperm is a treatment consideration the AHR counsellor shall provide Sperm Donation Counselling (Section D) in advance of treatment.

SECTION D

COUNSELLING PATIENTS IN TREATMENT USING DONOR GAMETES

I. SPERM DONATION

1. Definition

Donor Insemination is the process of inseminating a woman with sperm from a third party (i.e. someone other than the woman's partner) for the purpose of producing a pregnancy. Donor sperm may also be used in IVF.

There are three types of donor sperm recipients: heterosexual couples, lesbian couples, and single women. The sperm donor may either be anonymous or known to the recipient(s).

2. Counselling Sperm Recipient(s)

Recipient(s) and known donors should each be seen independently, ideally followed by a joint session with the donor (and his partner, if any) in cases of known donations, to ensure the decisions being made are mutually acceptable to all parties.

a. Common Counselling Issues

- Obtaining a psychosocial history (refer to Appendix A)
- Motivations, readiness, and acceptance
- Consideration of other options
- Psychosocial preparation and support for treatment participation
- Extent to which the decision is acceptable to the recipient(s) and free of coercion (refer to Appendix B)
- Understanding of the complexities of this form of family building in contrast to shared genetic parenthood
- Boundaries and limitations of information sharing between the donor and recipient(s)
- Choice and availability of a known vs. anonymous sperm donor
- Attitudes and feelings towards existing and/or resulting offspring (genetic inequality)
- Relationship and familial challenges
- Cultural and religious concerns
- Emotional impact and grieving process in the recipient couple
- Implications of the male partner's lack of genetic connection to the offspring

- Stability of the recipient couple's relationship and expectation of each partner's relationship to/with the child
- Disclosure issues (refer to Appendix B)
- Support system throughout and following treatment
- Resources and information related to donor conception, such as reading materials, websites, support groups and community resources⁵

b. Counselling Considerations When Using a Known Sperm Donor

- Advantages and disadvantages of using a known donor⁶
- Psychosocial implications of using a donor known to the recipient, such as privacy, personal and familial boundaries, expectations, obligations
- Reactions of significant others, if applicable
- Implications of the donor being rejected based on psychological assessment and/or health screening
- Impact of a negative outcome on the recipients' relationship with the donor and his family
- Implications of the donor's non-compliance
- Role clarity and expectations among parties
- Legal issues and awareness that Canadian law only allows for altruistic donation^{2,3}

c. Counselling Considerations When Using an Anonymous Sperm Donor

- Advantages and disadvantages of using an anonymous donor
- Availability of donor information such as medical and personal profiles, childhood and adult photos
- Limitations of the information provided by sperm banks
- Uncertainty related to the donor's medical, genetic and social history and the implications of this on the future offspring
- Criteria for donor selection (e.g. physical features, ethnicity, education)
- Identity-release option and implications
- Existence of voluntary and mandatory donor and sibling registries
- Implications on the donor offspring of not knowing the identity of the anonymous donor
- Implications of other individuals and couples using the same donor
- Possible use, and availability of the same donor for subsequent pregnancy attempts

d. Counselling Considerations Specific to Lesbian Couples

Commonly, lesbian couples will not be dealing with a biological fertility problem, but require assistance in creating their families. Empirical research has

consistently shown that lesbian and gay parents do not differ from heterosexuals in their parenting skills, and their children do not have more psychosocial difficulties when compared with children raised by heterosexual parents.

Counselling issues may include:

- Decision making about who will be the genetic and/or gestating parent in each cycle
- Criteria for donor selection (e.g. physical features, ethnicity, education)
- Perceived implications of genetic inequality between partners
- Issues related to the legal rights and responsibilities of both genetic and nongenetic parents
- Psychosocial considerations for same sex families
- Resources such as local LGBTQ support groups, websites and reading materials⁵

e. Counselling Considerations Specific to Single Women

Counselling issues may include:

- Motivations and readiness to be a single parent
- Emotional and practical support during the AHR procedures
- Social and emotional support system after the birth of a child
- Financial resources required for sole support parenthood
- Common stresses of sole support parenting
- Dealing with social inquiries about paternity of offspring
- Psychosocial considerations for single parent families
- Risks and implications of multiple pregnancy or having a child with special needs

3. Counselling Sperm Donors

a. Counselling Considerations for Known Sperm Donors

- Obtaining a psychosocial history (refer to Appendix A)
- Motivations for donation and possible presence of pressure or coercion (refer to Appendix B)
- Implications of sperm donation on the donor's partner, if applicable
- Understanding and awareness of donation process such as time commitment and lifestyle expectations
- Current life stresses
- Boundaries and limitations of information sharing between the donor and recipient(s)

- Personal family building desires and implications for the donor's existing and future children
- Expectations concerning identity disclosure to donor conceived offspring
- Expectations about future relationship with donor conceived offspring
- Implications of disclosing the donation to the donor's existing and future children

b. Psychosocial Criteria for the Potential Exclusion of Known Donors

- Presence of untreated and acute psychopathology
- Current substance abuse
- Evidence of coercion (refer to Appendix B)
- Cognitive impairment resulting in the inability to give informed consent
- Current engagement in high risk sexual practices
- A family history of inheritable psychiatric diagnosis
- Unresolved or current legal issues potentially disrupting or complicating the donation process
- Extreme psychosocial distress such as divorce, death of a family member

c. Counselling Considerations for Anonymous Sperm Donors

• Typically, the screening and preparation of anonymous donors is carried out by sperm banks with their own protocols.

II. EGG DONATION

1. Definition

The procedure whereby a female donor undergoes hormonal stimulation, her oocyte(s) are retrieved and fertilized with the sperm of the recipient male partner (or a sperm donor), and then the resulting embryo(s) are transferred to the uterus of the recipient female. Egg donation may also be performed in the absence of hormonal stimulation.

Recipients may elect to use a *known donor*, someone they know personally (e.g. family member, friend, acquaintance), a donor with whom they do not have a prior relationship (e.g., internet), or a donor who is completely anonymous (via an egg bank or egg exchange program or cross-border treatment).

2. Counselling Egg Recipient(s)

Recipient(s) and known donors should each be seen independently, ideally followed by a joint session with the donor (and her partner, if any) in cases of known donations, to ensure the decisions being made are mutually acceptable to all parties.

a. Common Counselling Issues

- Obtaining a psychosocial history (refer to Appendix A)
- Motivations, readiness, and acceptance
- Consideration of other options
- Psychosocial preparation and support for treatment participation
- Extent to which the decision is acceptable to the recipient(s) and free of coercion (refer to Appendix B)
- Understanding of the complexities of this form of family building in contrast to shared genetic parenthood
- Boundaries and limitations of information sharing between the donor and recipient(s)
- Choice and availability of a known vs. anonymous egg donor
- Access and implications of cross-border egg donation
- Attitudes and feelings towards existing and/or resulting offspring (genetic inequality)
- Implications of altruistic donation
- Implications of the donor's non-compliance
- Relationship and familial challenges
- Cultural and religious concerns
- Donor non-compliance

- Emotional impact and grieving process related to her infertility
- Implications of the female partner's lack of genetic connection to the offspring
- Stability of the recipient couple's relationship and expectation of each partner's relationship to/with the child
- Recipients' capacity to accept a child conceived with donated eggs
- Disclosure issues (refer to Appendix B)
- Expectations about the child and each partner's relationship to/with the child
- Perceptions of success rates and feelings about possible risk factors (e.g. no embryo to transfer, birth defects, multiple births)
- Support system throughout and following treatment
- Legal issues and awareness that Canadian law only allows for altruistic donation^{2,3}
- Resources and information related to donor conception, such as reading materials, websites, support groups and community resources⁵

b. Counselling Considerations When Using a Known Egg Donor

- Advantages and disadvantages of using a known donor⁶
- Psychosocial implications of using a donor known to the recipient, such as privacy, personal and familial boundaries, expectations, obligations
- Boundaries possible emotional attachment to the future child; her relationship to, and role in, the child's life; the child's relationship to and with her own children
- Reactions of significant others, if applicable
- Perceived obligations to, and gratitude towards the donor
- Impact of a negative outcome on the recipients' relationship with the donor and his family
- Role clarity and expectations among all parties involved in donation
- Expectations regarding the number of treatment cycles, use and disposition of surplus embryos
- Awareness that not all prospective donors will be acceptable candidates depending on medical or psychosocial evaluation

c. Counselling Considerations When Using an Anonymous Egg Donor

- Advantages and disadvantages of using an anonymous donor
- Discussion of the potential implications on the donor offspring of not knowing the identity of the anonymous donor
- Concerns about the accuracy and limitations of the information provided by the donor
- Coping with uncertainty related to the donor's medical, genetic and social history and the implications of this on the future offspring

3. Counselling Egg Donors

a. Common Counselling Issues

- Obtaining a psychosocial history (refer to Appendix A)
- Motivations for donating including possible financial or emotional coercion (refer to Appendix B)
- Expectations regarding treatment participation and outcome
- Reactions to failed treatment
- Plans for future children and understanding of possible risks to her fertility
- Attachment and boundary issues related to offspring born through her donation
- Involvement and support of partner in her decision to donate
- Social support feelings and perceptions of significant others
- Understanding of medical procedures and risks
- Consent issues related to the disposition of surplus embryos
- Consequences if she decides not to donate or withdraws prematurely from a treatment cycle
- Legal issues and awareness that Canadian law only allows for altruistic donation^{2,3}

b. Counselling Considerations When Donor is Known to the Recipient

- Donors current and future relationship with the recipients
- Family members knowledge of, and feelings about, her donation
- Possible coercion (refer to Appendix B) to donate
- Boundaries possible emotional attachment to the future child; her relationship to, and role in, the child's life; the child's relationship to and with her own children
- Emotional impact if fertilization fails, there are no embryos to transfer, treatment does not result in a viable pregnancy, multiple births, birth defects.
- Expectations regarding identity disclosure

c. Counselling Considerations When Donor is Anonymous

- Examination of the advantages and disadvantages of her anonymous donation
- Living with uncertainty regarding the outcome of her donation
- The potential implications on the donor offspring of not knowing her identity
- Awareness that donor anonymity might not be fully guaranteed

d. Psychosocial Criteria for the Potential Exclusion of Donors

- Presence of untreated and acute psychopathology
- Current substance abuse
- Evidence of coercion (refer to Appendix B)
- Cognitive impairment resulting in the inability to give informed consent
- Restrictions on donations based on age or number of previous donations
- Current engagement in high risk sexual practices
- A family history of inheritable psychiatric diagnosis
- Unresolved or current legal issues potentially disrupting or complicating the donation process
- Extreme psychosocial distress such as divorce or the death of a family member

III. EMBRYO DONATION

1. Definition

Due to the success of current cryopreservation techniques, patients who have excess embryos following IVF treatment can store these embryos for personal use in later treatment attempts. However, not all patients utilize these stored embryos. If these stored embryos are no longer needed or wanted, one option for disposition is the donation of these surplus frozen embryos to another woman or couple. Those who elect to donate some or all of their surplus embryos may donate them to anonymous or known recipients.

2. Counselling Considerations for Embryo Recipient(s)

Counselling considerations relevant to gamete recipients (see Section DI and DII), are applicable to recipients of embryos. In addition, counselling issues should include:

- Obtaining a psychosocial history (refer to Appendix A)
- Capacity to form an emotional attachment to a genetically unrelated child
- Implications of raising a child who may have full genetic siblings in other families
- Uncertainty related to the medical and genetic background of their offspring
- Advantages and disadvantages of anonymous vs. known donation
- Disclosure to the child, family and social network
- Awareness of differential success rates with surplus cryopreserved embryos

3. Counselling Considerations for Embryo Donors

All counselling considerations relevant to gamete donors (see Section DI and DII), are applicable to donors of embryos. In addition, counselling issues should include:

- Obtaining a psychosocial history (refer to Appendix A)
- Options for the disposition of their frozen embryos
- Implications of knowing they may have genetic offspring whom they are not parenting
- Advantages and disadvantages of anonymous vs. known donation
- Living with the uncertainty they might never know the outcome of the donation
- Potential implications for the donor offspring of not knowing the identity of their genetic parents
- Disclosure to, and implications for their existing child(ren) in having full genetic siblings who are unknown to them

4. Psychosocial Criteria of Donors for the Potential Exclusion of Embryos

- A family history of inheritable psychiatric disorders
- Current substance abuse
- Cognitive impairment resulting in the inability to give informed consent
- Presence of untreated and acute psychopathology
- Evidence of coercion (refer to Appendix B)
- Extreme psychosocial distress divorce, loss of a child
- Incongruence in donor couple's motivations or desire to donate
- Problematic attachment to embryos
- Extreme psychosocial distress such as divorce or the death of a family member

IV. COUNSELLING DONOR CONCEIVED OFFSPRING

The implications of being a donor conceived offspring will vary depending on the timing and manner of disclosure, with late disclosure often requiring psychosocial intervention. It is not uncommon for support to be required at different developmental stages in the life of the child and his or her family.

Common Counselling Issues:

- Emotional impact of the disclosure information
- Psychological and emotional implications for self esteem, identity
- Issues of loss and grief
- Desire for, and availability of information about the donor
- Implications of having unknown genetic siblings
- Attachment issues with the non-genetic parent
- Relationships with birth family members
- Relationship with donor, if applicable
- Awareness of supports and resources for donor offspring

V. GESTATIONAL SURROGACY

1. Definition

There are two categories of surrogacy, gestational and traditional. Gestational surrogacy involves a procedure whereby the intended parents create embryos using their own eggs and sperm, or donated eggs and/or sperm, with the resulting embryo(s) transferred into the uterus of a woman (the gestational surrogates) who has offered to carry a pregnancy with the intention of relinquishing the child at birth to the intended parent(s). The carrier might be previously known to the intended parents (e.g. a relative or friend), or previously unknown (meeting via the internet).

In traditional surrogacy, the surrogate's eggs are fertilized with sperm from the intended parent or a donor, and she then gestates the resulting pregnancy. Although traditional surrogacy involves a relatively simple medical procedure, this arrangement has significantly more emotional and legal complexities.

The following guidelines are specific to gestational surrogacy but also apply to cases of traditional surrogacy.

2. Counselling Intended Parent(s)

a. Common Counselling Issues

- Obtaining a psychosocial history (refer to Appendix A)
- Motivations, readiness, and acceptance
- Consideration of other options
- Psychosocial preparation and support for treatment participation
- Perceptions of success rates, medical expectations, and feelings about possible risk factors (e.g. birth defects, multiple birth, pregnancy loss, fetal reduction, pregnancy termination)
- Emotional impact of non-gestational family-building on both partners (grief and loss)
- Understanding of the complexities of this form of family building
- Stability of the intended parents' relationship and congruence of family building desires
- Choice and availability of a gestational surrogate (known vs. previously unknown; local vs. cross-border)
- Awareness that gestational surrogate may be excluded for medical or psychosocial reasons
- Awareness of federal and provincial laws regarding surrogacy arrangements^{2,3} and benefits of legal consultation
- Boundaries and limitations of information sharing between the gestational surrogate and recipient(s)

- Expectations regarding number of embryos transferred
- Managing the relationship with, and expectations of the gestational surrogate during pregnancy such as lifestyle and nutritional choices, travel, attendance at medical appointments, pregnancy termination
- Extent of interaction with the gestational surrogate and her family during pregnancy and following the birth of the child
- Birth plan such as location of birth, who is present, non-gestational lactation/breastfeeding)
- Female partner's feelings about being unable to carry a child
- Female partner's ability to accept a child carried by another woman
- Concern about attachment difficulties during pregnancy and after the child is born
- Disclosure issues to the child, immediate and extended family members, friends
- Support system throughout and following treatment
- Attitudes of extended family and community toward gestational surrogate pregnancy

b. Counselling Considerations When Using a Known Gestational Surrogate

- Advantages and disadvantages of using a known gestational surrogate⁶
- Boundaries relationships between the intended parent(s), the gestational carrier and her family, and any resulting offspring
- Sense of obligation/gratitude toward the gestational surrogate
- Impact of a negative outcome on their relationship with the gestational surrogate and her family

c. Counselling Considerations When Using a Previously Unknown Gestational Surrogate

- Advantages and disadvantages of using a previously unknown gestational surrogate
- Concerns about the accuracy and limitations of the information provided by the gestational surrogate
- Coping with uncertainty related to the gestational surrogate's motives and lifestyle
- Implications if surrogate elects not to relinquish the child

3. Counselling Gestational Surrogates

a. Common Counselling Issues

Obtaining a psychosocial history (refer to Appendix A)

- History of post-partum depression
- Understanding of medical procedures and risks
- Motivations for being a surrogate
- Involvement and support of partner in her decision to be a surrogate
- Cultural and spiritual beliefs and values that may affect lifestyle choices, behaviours, and health care decisions
- Possible financial or emotional coercion*
- Expectations regarding treatment participation and outcome (multiple gestation, number of embryos transferred, prenatal testing, fetal reduction; pregnancy termination)
- Managing the relationship with intended parents during pregnancy and postpartum
- Disclosure of her role to others (including what she tells her children)
- Reactions to failed treatment cycle, miscarriage, multiple gestation, birth defects
- Impact on gestational surrogate's spousal relationship and children
- Feelings for the unborn child during pregnancy, attachment complexities
- Social implications such as perceptions and reactions of colleagues, friends, family members
- Birth plan such as location of birth, who will be present, choice of obstetrician, non-gestational breastfeeding
- Implications if she decides not to relinquish the child

b. Counselling Considerations for the Gestational Surrogate who is Known to the Intended Parent(s)

- The gestational surrogate's relationship with the intended parent(s) past, current and future
- Family members knowledge of, and feelings about, the pregnancy
- Boundaries possible emotional attachment to the child; her relationship to, and role in, the child's life; the child's genetic connection to, and relationship with her own children
- Expectations and implications regarding disclosure
- Potential implications if the circumstances of the intended parents change during pregnancy, such as divorce, illness or death

c. Counselling Consideration for Gestational Surrogate who was Previously Unknown to the Intended Parent(s)

- Uncertainty about future contact with the child
- Potential implications for the child of not knowing the surrogate's identity
- Possible future regrets

- Concerns about the accuracy and limitations of the information provided by the intended parent(s) and their parental capacity
- d. Psychosocial Criteria for the Potential Exclusion of Gestational Surrogates
 - Not having had a live birth
 - Under 21 years of age
 - History of reproductive loss
 - Presence of acute and untreated psychopathology
 - Current substance abuse
 - Evidence of coercion*
 - Cognitive impairment limiting the ability to give informed consent
 - Current engagement in high risk sexual practices
 - Current engagement in unhealthy lifestyle choices
 - Unresolved or current legal issues potentially disrupting or complicating the donation process
 - Extreme psychosocial distress such as divorce, loss of a child, death of a family member

SECTION E

SPECIAL ISSUES

I. FERTILITY PRESERVATION

1. Definition

Preservation of fertility is possible via a variety of procedures, such as sperm cryopreservation (freezing), egg and embryo cryopreservation, ovarian tissue cryopreservation and ovarian transposition.

Fertility Preservation for Medical Reasons

Many medical conditions and treatments can cause damage to the reproductive system and impair fertility. Therefore, fertility preservation prior to treatment for a number of medical conditions such as cancer, can be a consideration.

Fertility Preservation for Social Reasons

Women who want to preserve their fertility can choose to freeze their eggs using an IVF or IVM procedure and then have them cryopreserved for future use. When they wish to become pregnant, frozen eggs are thawed, fertilized and transferred as in routine IVF.

2. Common Counselling Issues

- Informed decision-making about the risks, limitations and complications of preservation options, ideally with partner present
- Awareness of the treatment process both at the time of preservation and then later at time of usage
- Determination of best treatment option for preservation
- Alternative options for family building such as egg/sperm donation and adoption
- Disposition considerations for frozen embryos/gametes

3. Counselling Considerations for Medical Reasons

- Impact of dealing with two significant life issues simultaneously
- Coping with feelings of isolation, frustration, fear, despair and anger
- Anxieties around physical changes such as menopause, hair loss, mastectomy
- Coping with depression that often accompanies cancer treatment
- Impact of cancer/infertility on identity, sexuality, self-esteem

- Uncertainty about future use and disposition
- Partner's reaction to medical treatment and fertility preservation, if applicable
- Risks of preservation procedure, such as exacerbating the disease or delaying treatment
- Capacity to cope with procedure given current state of health
- Posthumous donation requests (refer to section EIII below)
- In the case of minors, parents should be included in decision-making
- Resources and information related to fertility preservation, such as reading materials, websites, support groups and community resources⁸

4. Counselling Considerations for Social Preservation

- Chances of success based on current research fertility preservation is not a way to "stop the biological clock"
- Alternatives to oocyte freezing, e.g., frozen embryos with donor sperm
- Motivations, readiness and expectations
- Coping with possible failure to collect many or good quality oocytes, necessity of serial trials
- Financial implications of preservation and future use
- Current life stresses and coping skills
- Disclosure to friends and family and future offspring
- Coping with possible feelings of shame and regret for not having a partner or family
- Implications for future relationships
- Managing the stresses of the preservation process
- Possibility of future sole support parenting or parenting at an older age
- Family-building plan for future, e.g., when and how to use frozen gametes/embryos

II. PRE-IMPLANTATION GENETIC DIAGNOSES (PGD)

1. Definition

For couples at risk of having children with an inherited disease, PGD can prevent the birth of affected children. With PGD, IVF is used to create embryos, after which one or two cells are removed from each embryo by micromanipulation. This allows the genetic material in these cells to be analyzed for the genetic defect and then only those unaffected embryos are transferred to the recipient. Preimplantation Genetic Screening (PGS) assesses for aneuploidy and chromosome translocations that could contribute to miscarriage or birth defects.

2. Common Counselling Considerations

- Informed decision-making related to the financial costs and risks of having no embryos to transfer, risk of a false negative, possibility of birth defects, time constraints and chances of success
- Awareness of alternative procedures such as prenatal testing, and the possibility of pregnancy termination if the fetus does carry the disease
- Possible feelings of guilt on the part of the parent who contributes the gene mutation and blame on the part of the unaffected partner
- Possibility of multiple births, associated risks, and the option of fetal reduction
- Disposition plans for affected and surplus unaffected embryos

III. POSTHUMOUS ASSISTED REPRODUCTION (PAR)

1. Definition

Posthumous gamete retrieval or donation involves the retrieval or use of sperm or oocytes after death, with the explicit prior consent of the deceased. Posthumous reproductive use of embryos could arise if the surviving partner chooses to use frozen embryos that were created with a partner who is now deceased, with the explicit prior consent of the deceased partner.

2. Common Counselling Considerations

- Capacity to make a rational and informed decision, given the emotional impact of loss and the emotional reactions of the surviving partner
- Capacity to rear a child as a sole support parent
- Religious, moral and ethical implications
- Stage of the grieving process, and whether it is complicated or unresolved
- Psychosocial impact on, and disclosure to the resulting child
- Awareness of legal complexities related to the future child's status
- Possibility of emotional coercion* from other surviving family members, such as parents of the deceased

IV. HLA TYPING – SAVIOUR SIBLING

1. Definition

A savior sibling is a child selected at the embryonic stage based on genetic screening and matching to help save the life of an existing brother or sister. HLA (human leucocyte antigen) typing in combination with PGD and IVF, allows for the selection of embryos which, if they result in a live birth, can provide life-saving tissue to a sibling. Most commonly it is the stem cells from the umbilical cord of the saviour sibling that are used to cure a life-threatening disease via bone marrow transplant.

2. Common Counselling Considerations

- Facilitation and promotion of informed decision-making regarding the risks, complications and chances of success with this treatment
- Implications of this treatment on all members of the family
- Grieving process regarding existing child's illness and the fears and anxieties regarding the child's ongoing health
- Risk that no matched, unaffected embryos will be found
- Current life stressors including a critically ill child
- Implications of a pregnancy or parenting an infant while caring for a critically ill child
- Disposition of embryos that are not HLA compatible
- Spousal agreement to procedure
- Disclosure of the circumstances of the future offspring's birth to the child and others
- Evaluation of the risk of psychological harm to the future offspring
- Religious and moral implications
- Parent's commitment to the best interests and well-being of the future offspring
- Readiness to adjust their lives and goals to expand their family
- Consultation with an ethicist to address the implications of creating a life to save another

REFERENCES

¹Professional Organization

Canadian Fertility and Andrology Society (www.cfasonline.ca)

²Assisted Human Reproduction Act 2004

http://laws.justice.gc.ca/en/A-13.4/index.html

³Assisted Human Reproduction Canada (AHRC)

www.ahrc-pac.gc.ca

⁴Health Canada Report

Counselling Services Under the Assisted Human Reproduction Act, Public Consultation Document, Spring, 2007 (http://www.hc-sc.gc.ca/hl-vs/reprod/hc-sc/public/_counsel/index-eng.php)

⁵Patient Resources

Infertility Awareness Association of Canada (www.iaac.ca) Infertility Network (www.infertilitynetwork.org) LQBTQ Parenting Connection (http://www.lgbtqparentingconnection.ca/home.cfm)

American Society for Reproductive Medicine (ASRM) Ethical Guidelines

⁶'Family members as gamete donors and surrogates', *Fertility and Sterility*, vol 80(5), 2003

⁷'Informing offspring of their conception by gamete donation', *Fertility and Sterility*, vol 81(3), 2004

⁸Fertility Preservation

Fertile Future (wwwfertilefuture.ca)

Fertile Hope (www.fertilehope.org)

APPENDIX A

PSYCHOSOCIAL HISTORY

Depending upon the form of AHR treatment under consideration, psychosocial information obtained might include:

- marital, sexual, and reproductive history
- current relationship status and stability
- family and educational background
- personal and family history:
 - psychological and major personality disorders
 - substance abuse
 - abuse and neglect
 - criminal record
- current use of psychotropic medications
- stress and coping skills
- current mental health status (may include psychological testing)
- past and current substance use/abuse
- current sexual behaviour
- social support network and resources
- parenting relationship with existing children
- religious or cultural influences

APPENDIX B

GLOSSARY OF TERMS

Coercion is defined as influencing the actions of another, either implicitly or explicitly, by taking advantage of a weakness (exploitation), or unduly exerting power or influence. To identify any evidence of coercion the counsellor should inquire about:

- Motivations to participate
- Financial compensation
- Pressure from others
- Consequences of withdrawing from procedure

Disclosure issues: There is a growing body of evidence to support the benefits of disclosure to children about their donor origins at developmentally appropriate times and in age-appropriate ways. A discussion with recipients about managing information, and about the differences between privacy/secrecy and openness, and what level of disclosure they are comfortable with is recommended.⁷