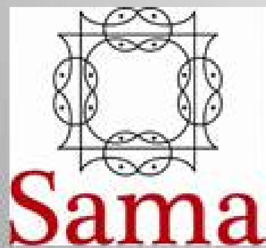
WOREC
Nepal



WORKSHOP ON "REPRODUCTIVE TOURISM; ISSUES AND CHALLENGES"

7th - 8th October, 2012
Kathmandu

Workshop on Reproductive Tourism: Issues and Challenges

On October 7th and 8th in Kathmandu Nepal, Women's Rehabilitation Centre (WOREC) held a workshop on the emergence of reproductive tourism in Nepal. The workshop was held in collaboration with the co-founder and current Executive Director of Our Bodies Ourselves (OBOS) operating out of the United States (US), and Sama Resource Group on Women and Health – an NGO working on women's health issues in India.

Currently, the prevalence of reproductive tourism in Nepal is unknown. The workshop was organized to bring together participants from various backgrounds to discuss their knowledge of, and experiences with, fertility related medical procedures in Nepal. Those working in the maternal health and fertility sectors, counsellors, social workers, public education specialists, nurses, and journalists attended the workshop. Overall, thirty female attendees representing both eastern and western districts of Nepal participated in the workshop. Approaches from the US and India were shared throughout the workshop, in order to allow Nepali participants to become familiar with the issues and strategies used in other contexts, and to determine how they may be relevant to Nepal.

Sunday, October 7th – First day of the Workshop on Reproductive Tourism

The first day of the workshop consisted of five sessions – three were facilitated by SAMA, and two were facilitated by OBOS.

The first session included a presentation conducted by SAMA. This presentation focused on outlining the context of infertility and assisted reproductive technologies (ARTs), with a general introduction to surrogacy. The session also explored definitions of reproductive tourism and established clarity on the technical and medical components of ARTs. Terminology commonly used to discuss the topics was also highlighted.

The presentation answered questions such as "What is surrogacy?" "What ought to be the rights of a surrogate?" "How does surrogacy differ in developing and developed countries?" These questions were answered using a women's rights and feminist framework; highlighting a variety of different issues from varying sides of the argument for and against the use of ARTs, and surrogacy more specifically.

The second session was facilitated by the founder of (OBOS), and focused on the disparity of access to health care between those with the resources to pay for treatments and those who do not. It included discussion of how reproductive technologies are sometimes used not just to treat infertility problems but also to promote the idea of having children with specific desirable traits, thus reinforcing a kind of eugenics. Ironically, while some dream of "designing" their children, others have no access at all to basic infertility treatments. In particular, it highlighted the growing realization that those who have

access to reproductive technologies are able to pursue dreams of a child with specific traits, whereas those without access may not have any options for infertility treatments at all. This is one example where the inappropriate use of medical care continues to be a problem. “Some women get unnecessary health care while other women don’t get necessary health care.” (Judy Norsigian). OBOS noted that the profit motive, and the use of perverse payment incentives for physicians and medical institutions often results in practices that do not serve women well. In some cases, the influence of private corporations seeking to maximize profits has undermined a public health approach that would best serve our communities. Fertility medicine is just one example of how this may be occurring. This session concluded the morning portion of the workshop.

In the afternoon, SAMA gave a presentation on social and cultural perceptions of motherhood, and reproduction. The presenters expressed that “Universally women carry the burden of childlessness... Motherhood emerges as a rite to passage into complete personhood.” Based on this perspective, a discussion was held on whether reproductive technologies should be understood as allowing a woman to express her reproductive role, or if it should be conceptualized as a patriarchal ploy to reinforce gender norms of women as mothers. Similarly, whether reproductive technologies are being used to diminish the significance of alternative parenting (i.e. adoption), by framing it as being less desirable than biological parenting, was discussed. SAMA emphasized the importance of answering these questions within a socio-cultural normative framework relevant to the culture in which the phenomenon is occurring.

Further, SAMA identified the growing concern that there is an absence of basic preventative fertility care within the public health sector resulting in infertility rates bring higher than they may be otherwise. SAMA advocated that primacy should be given to understanding the underlying causes of infertility, and stressed that this is particularly pertinent as the World Health Organization (WHO) states that 8-12% of couples have difficulty conceiving a child. SAMA’s work on fertility has led the organization to believe that growing infertility rates could be caused by poor obstetrics and gynaecology (OBGYN) practice, sexually transmitted infections (STIs), genital tuberculosis (TB), pelvic inflammatory disease, exposure to toxic substances, environmental and work related conditions, along with an array of other economic and social determinants of health.

This presentation also explored issues related to the expansion of fertility treatment in India. Specifically, the session discussed the promotion of the use of tubal sterilization and tubal recanalisation as a method of family planning in India. This method is promoted by the Indian government with the promise that in vitro fertilisation (IVF/ET) will be successful after tubal sterilization is no longer desirable. IVF/ET is considered to be less invasive than tubal recanalisation. However, technologies have rapidly shifted from the public sector to the private sector, which operates at a larger scale in the country.

To follow was a plenary given by OBOS. A discussion was held about sensitive and inclusive terminology for discussing reproductive tourism. This discussion emphasised that the term “surrogacy” often undermines the role of the woman giving birth to the child, and that alternatively the term “gestational mother” could be used to emphasize the role of the woman as the physical mother of the child. It was

also stressed that "reproductive tourism" can dismiss the seriousness of seeking cross-border reproductive services, and that other terms such as "cross-border reproductive health care" are found to be more sensitive to the situation of infertile individuals, who are likely having a stressful experience rather than an enjoyable "tourist" trip while seeking fertility care.

Subsequently, the discussion moved to the risks associated with participating in fertility treatments. Specifically, the lack of adequate safety data for many fertility drugs used prior to egg extraction procedures was emphasized. OBOS discussed the proliferation of misleading advertisements and marketing to increase both demand and supply all over the world.

Recommendations for improving the safety of so-called egg "donation" included: conducting research on young egg donors rather than already infertile women; convincing more U.S.-based fertility centers to participate in the NIH-funded voluntary registry that is tracking the health of individuals involved with any ART (assisted reproductive technology) procedure (currently only approximately 100 centers participate); and encouraging potential egg donors to insist that a fertility clinic participate in this registry before they will considering providing their own eggs to this clinic. Participation involves simply posting a placard and making brochures available to individuals seeking clinics services (for more about this registry, see www.ifrr-registry.org).

Lastly, SAMA held a discussion about the context of medical tourism in India. SAMA provided data about India's medical sector including the statistic that India is the fifth most privatized health care sector in the world, with the sector contributing 6.2% to the country's GDP. The privatized medical industry is the largest service sector in the country, and it is expected to continue to grow. In India, there is a large number of ART clinics. However, with no national registry it is difficult to estimate the number of clinics operating in the country. The reasons for the growth of the industry include:

- A large pool of surrogates and gamete donors;
- The exotic appeal of tourism in India;
- English speaking service providers;
- Absence of any binding regulations;
- Surrogacy specific legal services;
- Surrogacy hostels for health and care monitoring;
- Existing collaborations between foreign hospitals, companies, and Indian ART clinics;
- Ambiguous legal structure;
- Higher likelihood that an Indian surrogate will not seek custody of the child when compared with North American or European surrogates.

Despite the growth of the industry in India, promotional materials for such services do not mention that there is no standardisation of care for donors or surrogates, resulting in a lack of understanding about payment, informed consent, counseling etc. This is particularly problematic as ART clinics spread to rural areas where potential participants may have even less access to information about the rights of donors and surrogates in reproductive tourism. Further, the rapid growth and popularity of fertility treatment in

India has been accompanied by risky practices such as the implantation of multiple embryos, resulting in the birth of more twins and triplets, which are associated with more complications for both the mother and the babies. This is done in order to increase the likelihood of a liveborn baby with each IVF attempt.

To conclude the afternoon session, a documentary on a foreign couple seeking a surrogate in India was screened. The movie, titled 'Made in India,' explored the perspectives of both the foreign couple experiencing persistent infertility, and the motivations of the Indian woman participating as a gestational mother.

Monday, October 8th – 2nd Day of the Workshop on Reproductive Tourism

The second day of the workshop began with an unstructured discussion followed by moderated group discussions on the topics and issues raised during the presentations the day before. Representatives from WOREC, OBOS, and SAMA were all present. The unstructured discussion at the beginning of the day included topics such as:

- Emotional burden of surrogates participating in the pregnancy and birth process on behalf of another couple:
    - Access to counseling for the surrogate,
    - Public policies that either allow or deny the option of a surrogate keeping the baby after the birth should she change her mind;
- Inequitable access to fertility treatments (some can pay some cannot, and relatively few countries make these treatments accessible to poorer women);
- Protecting the rights and interests of a child born through a donor gamete and/or surrogacy (thousands of adult children born from such arrangements are now advocating for public policies that preserve information about their genetic parents so that they can access it once they become adults, if they so choose);
- Definition of marriage, and the impact of this definition on access to services and the recognition of the child in the host or home country – including the impact on citizenship and inheritance rights;
- Payment schedules and fees for surrogates and donors – what is an ethical payment structure and what type of payment schedule best protects the interests of the surrogate?

After the open discussion on issues of pertinent interest from the previous day, the workshop participants were broken up into small groups to brainstorm emerging issues on reproductive tourism and to collaborate on strategies to address them. These were then shared and discussed again as a large group with all workshop participants present. The emergent issues and strategies are summarized in bullet form below:

Issues:

- What rights should be established for the children born through ARTs:

    - What are the rights of a child to access information about the gestational mother and any gamete donors who may are their genetic parents,
    - How are inheritance practices in Nepal impacted by the birth of a child through a gestational mother with the intention of surrogacy;
- Impacts of the stigmatization of a child born through surrogacy are unknown;
- There is very little reliable data and research on the prevalence and context of reproductive tourism in Nepal, and abroad where surrogacy may be more common;
- The sector lacks agreed upon terminology;
- Potential surrogates lack information on their rights, and risks associated with ARTs;
- The impacts on social structure and family are unknown; as well as the acceptability of the practice;
- There are currently no national policies that address reproductive technology;
- Lack of understanding about what happens in the occurrence of a death of a surrogate, donor, client or other participating individuals;
- Trafficking risk associated with surrogacy is unknown;
- What is the technical capacity for ARTS in Nepal if there is a growing demand for fertility services;
- What are the rights of a LBGT (lesbian, bi-sexual, gay, transgender) individual or couple seeking ARTs services in Nepal;
- Uncertainty whether the use of middlemen is necessary or solely negative.

Strategies:

- Terminology in the reproductive health and fertility treatment sector must be established and agreed upon by all stakeholders
- National policy on ARTs must be created and integrated into economic and health policy
- Training for health professionals in technical capacity for ARTs, along with social-cultural and economic sensitization should be employed
- Awareness campaigns at the local, regional, and national levels on emerging issues and experiences from India and other countries must be used to engage the public on the opportunities and risks of ARTs
- Baseline data about ARTs in Nepal must be collected
- Community surveys on the interests and experiences of potential donors and surrogates must be conducted
- The strategic use of media must be encouraged by stakeholders in different sectors to deliver a cohesive, and inclusive message about ART development in Nepal

After the completion of the discussion about issues and strategies for ARTs in Nepal, the participants and facilitating organizations developed a plan for moving forward after the end of the workshop. It was agreed that research on baseline data would need to be collected prior to the implementation of other strategies. It is projected that this research will be conducted between January and July of 2013. In the

interim, films relevant to reproductive tourism in India and Nepal will be screened during the 16 days of Activism occurring in November. It is proposed that questionnaires be distributed prior to the film screenings and after the films in order to determine how these films are influencing individuals' perspectives on reproductive tourism.

The workshop was concluded with the viewing of a rough cut of a film commissioned and produced by SAMA, India (it does not have a title yet). In contrast to "Made in India," which focuses more on the couple seeking the services of a surrogate, this film explores the perspectives and experiences of surrogates in India.

Feedback from the workshop was positive, with participants feeling that they had learned a great deal about an issue that they had not been previously familiar with. Many of the professionals discussed the ways in which they would bring new information back to their workplaces and communities. It is anticipated that, moving forward, the attendees will continue to collaborate on the strategies listed above. However a few specific actions plans emerged from the Nepal context, these included:

- A situational analysis on the accessibility and use of IVF clinics in Nepal will be tentatively conducted between January and July, 2013;
- The development of Nepali public engagement and extension materials on ARTs and surrogacy in Nepal.

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