Third-party reproduction in the Internet Age: the new, patient-centered landscape

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The rise of the Internet Age has brought a host of sweeping changes to the landscape of third-party reproduction. What began as a dyadic relationship between doctor and patient has evolved into a more complex system in which patients are able to access information online from a variety of external sources. Patients often seek to play a more active role in their third-party reproductive care, and the Internet allows them to do so. Further, demand for both medical and psychosocial information about donors and donor-conceived siblings, available online through patient forums and genetic registries, has altered the perception of gamete donation from a one-time event to an ongoing relationship. The advantages and disadvantages for patients and providers of this freer flow of information between third-party participants are examined. Search motivations of recipients and offspring, as well as types of information sought, are detailed. Recommendations are made regarding strategies fertility programs can use to optimally support their patients and navigate this new landscape. (Fertil Steril 2015;104:525–30. ©2015 by American Society for Reproductive Medicine.)

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At the advent of third-party reproduction, physicians held all the data about treatment options and donor candidates. The first documented case of donor sperm insemination occurred in 1884 in Philadelphia and is an excellent example of the physician-led care model. A wealthy merchant and his wife sought treatment for infertility with Dr. William Pancoast. When azoospermia was diagnosed, Dr. Pancoast asked the most attractive medical student in his class to serve as a sperm donor and later inseminated the wife. The donor was selected by the medical team with no input from the couple, and the wife was inseminated with donor sperm without the knowledge or consent of either her or her husband. The husband was later informed of the insemination, but neither the wife nor the resulting child was told of the use of donor gametes.

More than a century later, the third-party reproductive landscape bears almost no similarities to this original case. Physicians are now sought as advisors and partners in the treatment process, but prospective patients have access to a wealth of data outside the clinic. Patients often come to their initial consult having sought input from friends, relatives, and especially, the Internet. Patients find their own gamete donors and gestational carriers online, donors share detailed profile information with recipients, and donor-conceived offspring send their own DNA samples to genetic registries in hopes of learning more about their donors or siblings conceived through the same donor (donor-conceived siblings). These patient-initiated searches challenge traditional assumptions about donor anonymity and optimal future contact between third-party participants. Braverman summarizes that access to “...information via the Internet has thrown open the door of the doctor's office; it is no longer solely the doctor–patient relationship which informs the decision-making process” (p. 481). This freer flow of information online is associated with both potential benefits and clear challenges. In this review I will highlight key issues relevant to practitioners of reproductive medicine and...
make recommendations for providing third-party reproductive services in the Internet Age.

PRETREATMENT USE OF ONLINE INFORMATION ABOUT THIRD-PARTY REPRODUCTION

Eighty percent of adults who have Internet access seek health information online, and infertility is one of the most commonly used search terms (3). Fertility patients are often well-educated consumers of information who seek data to better understand the problems they face. As a result, individuals considering third-party reproduction often visit online resources for advice and information before their initial physician consult. Prospective recipients compare program characteristics, such as number of available donors, approach to anonymity, cost, and screening requirements. They preselect a program on the basis of this research and come to the clinic armed with questions, stories of other patients, and thoughts about their treatment options. The online resources individuals consult can vary significantly in quality, with some providing misleading or inflammatory information and others providing helpful, well-researched reviews. Prospective donors also engage in a significant amount of online research before making contact with a donor program. Donors compare fertility centers, agencies, and egg banks to assess their reputation, proximity, screening requirements, and compensation.

Taken to the greater lengths, patients also can use the Internet to organize many of the necessary participants in a third-party cycle, bringing those participants to a fertility center only once already recruited. For example, in 2008, Amy and Scott Kehoe selected an oocyte donor from an online agency, a sperm donor from California Cryobank, a gestational carrier from surromomsonline.com, and only then contacted a fertility center for implementation of the fertility plan they had developed without prior physician consultation (4). Their carrier ultimately underwent an IVF cycle that resulted in twins. In another example of family-building made possible through the Internet, individuals desiring donor sperm conception now can procure sperm directly through their social networks or online forums to do at-home inseminations. One such online forum, the Known Donor Registry (knowndonorregistry.com), launched in 2010 and now has more than 16,000 members seeking independent alternatives to identifying potential donors (5).

Online access to information about prospective donors or carriers can create a scenario whereby a recipient preselects an individual who has characteristics or preferences with which the fertility program might not be comfortable (e.g., a donor who desires future contact or a gestational carrier who wants to post cycle details on Facebook) (2). Provided the individual continues to meet criteria outlined by the American Society for Reproductive Medicine (ASRM), the medical team may find that the patient’s use of the Internet has expanded their choices in ways not previously possible. The moral of these stories is not that all patient-initiated cycles are ill-advised or untraditional, but rather that patients often seek to play a more active role in their care and that the Internet facilitates this practice.

For patients facing local barriers to third-party reproductive care, the Internet can provide geographically distant alternatives, a phenomenon known as cross-border reproductive care. Patients may seek cross-border reproductive care when needing more specialized medical expertise, facing long treatment waiting times, or seeking less-expensive treatment (3). This approach to seeking fertility treatment unavailable, inaccessible, or even illegal locally has been called “reproductive tourism” (6). The authors argue, however, that given the more complex logistical, emotional, legal, and financial implications of receiving fertility treatment far from home, the term “reproductive exile” might be more fitting. In India, cross-border reproductive care represented a $450 million dollar business in 2006, with estimates that it would grow by 600% in the near future (7, 8). Individuals pursuing cross-border reproductive care use the Internet to research treatment options, costs, and success rates in other countries. Clinics respond to this demand by advertising online, publishing everything from their success rates to their luxury accommodations and post-ET spa services.

POSTTREATMENT INFORMATION SOUGHT ONLINE

Once treatment is over and a child is born, desire for information and initiation of online research often increases. Donor-conceived children and their parents may seek information online when the donor information they have is nonexistent, out of date, abbreviated, or incomplete (9–11). Clinical practice indicates that recipients differ in their desire for information about the donor, with many wanting detailed information at the time of the match but some desiring more limited information. Recipients’ desires for donor information also can change over time. Some recipients want information early, to select a donor, and others seek greater information only once a child is born and curiosity arises. It is also the case that donor offspring themselves, rather than their recipient parents, may later desire greater information about their donor (10, 11).

Recipient parents searching for their child’s gamete donor report a variety of motivations, including curiosity about similarities in appearance or personality, a desire to give the child a more secure sense of identity, and interest for medical reasons (9). With regard to donor-conceived offspring, the most common reason cited for searching for one’s donor was curiosity about the donor’s physical appearance (10, 11). This information was best communicated through an adult photograph of the donor, something the fertility center where they were conceived may not have provided. Interest in the donor’s adult photograph can be summarized by the saying “a picture is worth a thousand words.” Offspring seek to compare their own features to the donors, answering questions like “Did I get my nose from my donor?” or “Do I look like her?” (11). Donor-conceived children also report anxiously that seeing an adult photograph of their donor allows them to stop wondering whether the
man or woman they passed in the grocery store might be the one who contributed half of their DNA.

Donor-conceived offspring often report a desire for information about their donor to learn more about their roots and assist in the process of identity formation (10, 12). Offspring may express frustration that the prevailing anonymous approach to donor conception prevents them from identifying their ancestry or genetic history (13). Donor-conceived children may establish a more cohesive sense of personal identity by being able to trace their genetic roots (10, 11). Significantly, offspring often report how meaningful it is to connect with donor-conceived siblings, particularly if they are only children (9). Offspring connecting with donor-conceived siblings frequently describe a sense of having a larger group who care for them and with whom they share a special connection (9, 10, 13). Family configuration influences both recipient parents’ and offspring’s desire for information and contact with donors, with donor searches being more commonly initiated and discussed in same-sex and single-parent families (9–11). Finally, recipients and offspring may search for information online because they recognize that the donor’s health history form was a snapshot from the time of the donation and is now significantly out of date. They may wonder whether the donor (or his or her close family members) has experienced a change in health status (10, 11); this interest may be sparked by simple curiosity or because the child has developed a medical problem of her or his own.

It is important to distinguish between desire for more information about a donor and a desire to make direct contact with a donor. In a sample of 791 recipient parents recruited through an online patient forum, nearly twice as many parents were searching for donor-conceived siblings (87%) as for the donor him or herself (47%) (9). Seventy-three percent had found donor-conceived siblings, and 18% had found their donor. Current data from recipient parents and offspring reporting their experiences of contact with donors and especially with donor-conceived siblings suggest that this contact is perceived as quite positive overall (9–11).

A variety of patient-centered websites and forums have been established since 2000 to meet this demand for information about donors and donor-conceived siblings. The nonprofit Donor Sibling Registry is the largest such forum in the United States, with 45,000 members and approximately 11,800 matches to date made between donor-conceived siblings or between donors and offspring (14). The Donor Conception Network reports more than 2,000 mainly United Kingdom–based members, consisting of donors, recipients, and offspring seeking information and support (15). Forums have been created to address the needs of unique populations within third-party reproduction, such as Single Mothers by Choice (singlemothersbychoice.org) and Parents via Egg Donation (pved.org). Several of the larger sperm banks also now offer patient forums and registries (e.g., California Cryobank’s Sibling Registry).

The plethora of websites that allow for contact outside the physician’s office and usually without the knowledge of the medical team has a variety of implications. Patients report a number of advantages resulting from the more open exchange of third-party information online (9, 10, 16). Able to review detailed donor profiles, recipients are afforded greater autonomy to decide for themselves what donor characteristics would be the best match for their family. Sibling registries and gamete bank forums make it easier for recipients to identify when they have used the same donor and thus are raising children who are genetic half-siblings. This information allows recipients to be more informed about the number and location of genetic-half siblings and thus better able to consider consanguinity risks. Patient access to these data also likely encourages programs to strictly enforce policies about when a donor has reached his or her offspring limit or cycle limit and should no longer be able to donate. Finally, if able to identify a donor or donor-conceived sibling through an online search, offspring may gain access to information that addresses a medical question or fills an emotional need.

There are undoubtedly some increased risks associated with this freer flow of online information as well. Donors, recipients, and offspring may be surprised or upset by unanticipated or unwanted contact coming from another third-party participant. Individuals and families differ in their communication styles, cultural attitudes, and level of privacy. Nuanced, high stakes conversations may take place outside the clinic without any professional guidance or support. Second, data accessed online may be disappointing or disheartening. As was the case in the major motion picture “The Kids are Alright” (2010), what if the donor ultimately turns out to be less amazing than his or her profile suggested? What if an oocyte donor initially comfortable with future contact gets married to a partner who prefers that she communicate only with their biological children and not also the donor-conceived offspring she helped create? What if a donor found the first several contacts with donor-conceived offspring to be positive but is now overwhelmed with an expanding number of offspring making contact? What if a donor-conceived child and his family were excited about connecting with two or three other families who used the same donor but can now see through an online forum that they are genetically linked to 25 other families? Given that Pandora’s Box is not likely to be resealed, it is vital that we address questions such as these through systematic and longitudinal research.

ANONYMITY

The prevalence of third-party participants seeking and receiving information online challenges long-held ideas about donor anonymity. Can gamete donors be called “anonymous” in an era in which detailed profile information is available online? Sperm bank donor profiles include adult photos, detailed biographical information, personal and family medical histories, writing samples, and sometimes audio recordings. Many fertility centers with oocyte donor programs seek to attract recipients by offering similarly detailed information about donors. Oocyte donor profiles may contain detailed biographical information, personal
statements or responses to open-ended questions, personal and family medical histories, and childhood or adult photographs. Photographs provided to recipients may include the donor’s family members, including the donor’s own children, and friends. Some fertility centers strive to preserve donor anonymity by providing only childhood photographs of donors to recipients. However, age progression software makes it possible to produce an adult likeness that can then be compared with thousands of images online through facial recognition programs. These steps certainly require motivation on the part of the searcher, but as noted, current data indicate that both recipients and donor-conceived offspring can show significant interest in learning more about their gamete donor (9–11).

Recipients and offspring have even developed websites that give specific guidance on the best search tools to use, depending on the type of information about the donor one has (17). Recipients and donor-conceived siblings can use information such as birth date, birth city, university attended, graduation date, extracurricular activities, physical description, and city of donation to generate potential matches to donors and donor-conceived siblings. Although much less commonly reported, online forums and genetic registries also could allow gamete donors to search for their donor-conceived offspring.

Additionally, young adults, who are both the population serving as donors and the offspring interested in data on their donors, overwhelmingly participate in social media networks, including Facebook, Twitter, Instagram, Snapchat, and LinkedIn. As greater amounts of data about donors are shared with recipients and as young adults post greater amounts of personal information online, counseling donors about the limits to their anonymity becomes increasingly critical. Interestingly, many donors report mistakenly assuming that all the data they give to an anonymous donor program are shared with recipients. Having grown up in the Internet Age, in which everything from your first word to your thoughts on breakfast are posted online, young adults serving as donors may have different thresholds for personal privacy.

As recipient demand for information about donors has increased and assurances of donor anonymity become more problematic, the United States has seen a corresponding trend toward greater numbers of open-identity or identity-release sperm donors (18). The larger numbers of single women and women in same-sex relationships seeking donor insemination and assuming disclosure to their children has also increased this demand for open-identity donors. Scheib and Cushing (18) further found that the proportion of open-identity sperm donors offered by a bank increased the longer the bank existed. Currently 40% of California Cryobank’s donors and 80% of Xytext Cryo International’s donors are classified as open-identity (19, 20). Particularly on the West Coast and through private agencies, open-identity donation for oocyte donors also has become more common. We can anticipate that recipient and offspring demand for information also will result in a growing number of open-identity oocyte donors recruited by frozen oocyte banks.

DIRECT-TO-CONSUMER GENETIC TESTING AND ONLINE GENETIC REGISTRIES

The advent of direct-to-consumer genetic testing offers yet another pathway for third-party participants to seek information about each other online. Individuals using these genetic testing kits mail in a biosample (often saliva), from which information about their personal risk profile for a variety of genetic diseases can be generated. These DNA samples also can be compared with the samples submitted by other customers to identify likely familial relationships. Male and female offspring conceived through donor oocytes can look at search results for mitochondrial DNA matches to identify women who might be their egg donor. Male offspring conceived through donor sperm can look at search results for Y chromosome matches to identify men who might be their sperm donor. Women conceived through donor sperm (who do not have a Y chromosome through which to search for their sperm donor) often reach out to male siblings or male donor-conceived siblings to provide this data point and continue their search. One of the most popular genetic testing sites, 23andme.com, notes that they currently have more than 800,000 genotyped customers (21). The website even offers a “Relative Finder” feature that allows customers to view close relatives. Ancestry.com also offers access to online genetic registries. The company reports that its subscribers have made in excess of 8 billion connections between their family trees and other subscribers’ trees since the matching feature was added to the site in 2008 (22). The growth of interest in genetic registries means that even parents who did not disclose their use of donor gametes to their child are not insulated, because adult offspring could learn of their parents’ use of donor gametes even if only doing an online search because of an interest in family genealogy.

RECOMMENDATIONS

Fertility programs can use a variety of strategies to navigate this new third-party landscape and to help their patients do the same. First and foremost, providers increasingly need to spend time educating patients about the complexities of third-party reproduction in the Internet era and the reason for clinical practices that follow ASRM guidelines. Psychological evaluations of oocyte donors by a mental health professional are required by the ASRM (23). These evaluations should not just screen for psychopathology but also should provide education to donors about issues like the limits of anonymity, consanginity between the donor’s children and donor-conceived offspring, the reasons for cycle limits, and potential for future contact. Given these complexities and the freer flow of online information between third-party participants, prospective sperm donors would benefit from the same evaluation and education by a mental health professional.

Consultation with a mental health professional for recipients of donor gametes is strongly recommended by the ASRM (23). The function of these consultations is not to evaluate for fitness-to-parent. Rather, recipients benefit greatly from discussion of issues including [1] common emotional responses to third-party reproduction,
[2] addressing the biological inequality between recipient parents, [3] limits to anonymity, [4] consanguinity, [5] data on family outcomes after disclosure of the use of donor gametes and provision of age-appropriate resources to aid in disclosure conversations, if desired, [6] types of information about donors and donor-conceived siblings commonly desired by offspring, and [7] the clinic’s protocol for future contact in the event of either medical need or psychosocial interest on the part of the recipient parents or the child. Recipients typically come to these consultations nervous about being “evaluated” by a mental health provider and leave feeling relieved to have found an expert with whom to address the many social and emotional aspects of third-party reproduction. Programs must recognize that the needs and preferences of donors, recipients, and offspring are not static and may need to be revisited over time. Changes in the legal landscape also may require such review, as was the case in 2011 when the State of Washington passed Statute 1267, which gave donor-conceived offspring the legal right to request release of their donor's identity at age 18 years, with the donor's permission.

In addition to integrating a mental health professional into the care of all third-party participants, fertility programs should consider a number of data management policies. First, to allow for repeated access by both parents and future offspring, programs should provide recipients with a copy of all non-identifying donor profile information. Given the significant interest among offspring regarding their donor’s physical characteristics, programs should consider providing adult photographs of oocyte donors in the same way that sperm banks provide adult photographs of sperm donors. Second, mirroring the practice of sperm banks, donor oocyte programs should provide each egg donor with a unique identification number. This number would allow donors, offspring, and donor-conceived siblings who desire it the ability to identify each other using online search tools. This number should be shared with the donor at the start of her cycle and should be included in the donor profile information given to recipients.

Third, the ASRM Ethics Committee [24] recommends that programs “should maintain accurate records related to gamete donation and are encouraged to set up systems to maintain the donor’s psychosocial information and enable information sharing in the future with any offspring, if such information sharing is acceptable to both the donor and the offspring” (p. 675). The Committee reframed the relationship between donors, recipients, and offspring as being lifelong and noted that is does not end with the initial procurement of gametes. Programs should develop a policy for handling patient inquiries, often from donor-conceived children, about their donor. Offspring often understand that the donor’s identifying information cannot be shared by the program but seek to learn a donor’s unique identification number to allow an online search or identification of donor-conceived siblings. Without some planning on the part of the program, offspring who return with inquiries years after their birth may find that relevant medical records have been destroyed; or they may find that records were kept regarding the care provided to both donors and recipients, but no provision was made to identify which donor was matched with which recipient. Programs providing third-party reproductive care should keep records indefinitely and should use a database to link donors with specific recipients and offspring. Finally, programs also need to develop an awareness of the recruiting, screening, and compensation practices of the agencies and banks from which they accept gametes. Many are established, reputable, and adherent to ASRM guidelines; others are not.

CONCLUSION

The rise of the Internet Age has brought a host of sweeping changes to the landscape of third-party reproduction. What began as a dyadic relationship between doctor and patient has evolved into a more complex system in which patients are able to access information online from a variety of external sources. Patients often seek to play a more active role in their third-party reproductive care, and the Internet allows them to do so. Further, demand for both medical and psychosocial information about donors and donor-conceived siblings, available online through patient forums and genetic registries, has altered the perception of gamete donation from a one-time event to an ongoing relationship. The freer flow of information between third-party participants made possible by the Internet is associated with both advantages and disadvantages for patients and providers. Additional systematic, longitudinal research into the evolving needs and preferences of all parties is greatly needed. Fertility programs providing third-party care can use a number of strategies, from thorough patient education to conscientious data management, to optimally support their patients and navigate this new landscape.

REFERENCES


