

Attitudes towards Disclosure of Children's Genetic Origins among Japanese Patients Using Assisted Reproductive Technology

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Abstract

Assisted Reproductive Technology (ART), such as Donor-assisted Insemination (DI) relying on anonymous sperm donors, has been used in Japan since the 1940s. Moreover, recent demographic changes such as delayed marriage and childbearing are contributing to increased demand for donor eggs from abroad. However, no official system for the collection and recording of gamete donors has existed in Japan until now. The objective of the present study was to examine the attitudes of infertile female patients toward two issues: 1) the disclosure of genetic information to their children born through donor-assisted insemination and 2) the right of those children to know about their genetic origin. Data were collected from 740 infertile female Japanese patients via questionnaires distributed through 70 accredited ART clinics in Japan (response rate: 29.1%). In summary, infertile female patients in the present study preferred maintaining donor anonymity. On the other hand, they also believed that children have a right to know about their genetic origin if they so desire. The following regulations regarding donor-assisted conception were suggested. First, the relationship between donor and recipient should be defined by law. Second, the social stigma attached to use of a donor should be eliminated to make it easier for parents to disclose this information. Third, a donor registry system should be established to enable children to know whether they were born as a result of gamete donation or not, and if so, to obtain donor's information in the absence of disclosure by their parents.

Keyword: Donor conception; Right to know; Infertile patients; Japan

Introduction

Assisted reproductive technology (ART), such as donor-assisted insemination (DI) relying on anonymous sperm donors, has been available since the 1940s, and it is assumed that tens of thousands of children throughout the world have been born through these procedures. Although anonymous DI has been occurring in Japan since the late 1940s, the use of egg donation has been a more recent development, beginning in 1983. Recent demographic changes such as later marriage and delayed childbearing are contributing to increased demand for donor eggs from abroad. However, no overall regulations regarding reproductive donation, such as sperm and ovum donation have existed in Japan until now.

Guidelines from the American Society for Reproductive Medicine (ASRM) regarding gamete donation state, "a mechanism must exist to maintain these records as a future medical resource for any offspring produced" [1]. In Japan, a 2003 government report recognized the right of children born via donor-assisted conception to know about their genetic origin, including identifying information about the donor [2]. However, this right has not been enacted into law.

Anonymous donor systems constitute a majority of such services throughout the world, including in Japan. However, several Western countries, such as Norway, Germany, Switzerland, Sweden Australia (Victoria), and the Netherlands, have granted children born through donor-assisted conception the legal right to know their genetic origin.

According to previous studies, the majority of DI parents do not disclose this information to their children [3-5]. In England, only 5% of parents told about their children the truth about this issue [6]. Although fewer studies have been conducted about egg donation than about DI, similar results have been reported for this method. In Finland, a study of 40 egg-donation families found that none had told the child about the egg donation procedure [7]. New Zealand, where 30% of the parents had informed their children when they were still young, is an exception to this trend [8]. It is possible that parents hesitate to disclose this information because they fear that the child will be stigmatized, they

do not know when and how to convey this information, and/or they are anxious that disclosure will damage the parent-child relationship.

On the other hand, it is possible that non-disclosure about donor-assisted conception may have a negative impact on the parent-child relationships [9-11]. More recently, some have argued that children's right to know their genetic origin is a basic human right. Moreover, if the child has inherited a genetic anomaly, confidentiality may prevent him/her from accessing crucial medical information. The increasing use of DNA testing may enhance the risk that children born of donor-assisted conception will learn the truth from people other than their parents and that they may consequently experience hostility toward their parents. Some people argue that parents should disclose this information to children during the early stages of their development so that they can come to accept the circumstance of their conception [12].

Public support for the recognition of children's right to know their genetic origin and for the notion of parents' obligation to disclose this information as early as possible, regardless of parents' own hesitations in this regard, is gradually increasing. This change will improve the welfare of children born under such circumstances. The present study examined the attitudes of infertile Japanese female patients toward 1) the disclosure of genetic information to their children born through donor-assisted insemination and 2) the right of these children to know about their genetic origin. Our results provide the basis for recommendation of relevant policies and regulations in Japan.

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Method

Data collection

We collected quantitative data using a self-administered anonymous questionnaire. After obtaining approval from the Ethics Committee of the Kanazawa Graduate School of Medical Sciences, we asked 578 accredited ART clinics to participate in our research; 70 accepted and received 2,568 questionnaires to distribute to their patients.

From February 2012 to April 2013, a total of 2,540 questionnaires were given to infertile patients, and 740 were returned (response rate: 29.1%). We asked each clinic to ask its receptionist to distribute the questionnaire to all patients for a certain period of time to avoid selection bias. As respondents did not specify the clinic that they were attending, the response rate for each clinic is not known. Completed questionnaires were sealed in a white envelope and mailed directly to the researchers by each respondent.

Assessment

Data on participants' demographic characteristics (age, age group, age at first marriage, duration of marriage, major cause of infertility, duration of infertility treatment, experience of *in vitro fertilization*, and number of embryo transfers) were obtained.

Participants were asked about their intention to use conception with donated ovum in the future; response options included "yes," "depends on the situation," and "no."

Participants were also asked the following five questions with regard to disclosure and children's right to know using the response options "agree," "somewhat agree," "undecided," "somewhat disagree," and "disagree."

- Parents don't need to tell their children they were born with the assistance of donation (= Parents do not need to disclose).
- It is desirable for parents to tell their children about gamete donation before they become adults (= It is desirable for parents to disclose).
- Children have the right to know about gamete donation if they want to know (=Children have the right to know).
- Information about donors such as age, address and genetic background should not be disclosed to the children to protect privacy (=Donor's information should not be disclosed).
- Information about donors such as age, address and genetic background should be made available at the child's request (=Donor's information should be disclosed).

Calculations were performed using IBM SPSS Statistics (ver. 19.0 for Mac), a major software package developed by IBM Corporation (Armonk, New York). *Chi*-square tests were used to evaluate differences between categories; *p*-values < 0.05 were considered to indicate statistical significance.

Results

Participant characteristics and potential reasons for the use of egg donors

Data regarding demographic characteristics, treatment factors, and the intention to use donor eggs (*n*=740) are presented in Table 1. The mean age (\pm SD) of participants was 36.5 \pm 4.5 years (range: 25–49), the mean age (\pm SD) at first marriage was 30.1 (\pm 4.8) years, and the mean duration (\pm SD) of the current marriage was 5.6 (\pm 3.7) years.

	N	%	Mean(\pm SD)	Range
Age	735	100.0	36.5 (4.5)	25-49
Age group	735	100.0		
<30	50	6.8		
30-34	199	27.1		
35-39	275	37.4		
40-44	193	26.3		
45-49	18	2.4		
Age of first marriage	735	100.0	30.1 (4.8)	16-49
Duration of the marriage (year)	735	100.0	5.6 (3.7)	0.3-20
Major cause of infertility	616	100.0		
Aging	208	33.8		
Uterine/cervical abnormalities	94	12.7		
Ovum/ovary-related factors	82	11.1		
Fallopian tube factors	65	8.8		
Sperm Issues	54	7.3		
Repeated miscarriages	16	2.2		
Intercourse problem	13	1.8		
Precocious menopause	9	1.2		
Not otherwise specified	75	10.1		
Duration of infertility treatment (year)	718	100.0	2.3 (2.4)	0-20
Experience of <i>in vitro fertilization</i> (yes)	417	56.4		
Number of transfer	404	100.0	1.9 (2.9)	0-20
Intention to use egg donation	743	100.0		
Yes	42	5.7		
Depend on situation	264	35.8		
No	437	58.5		

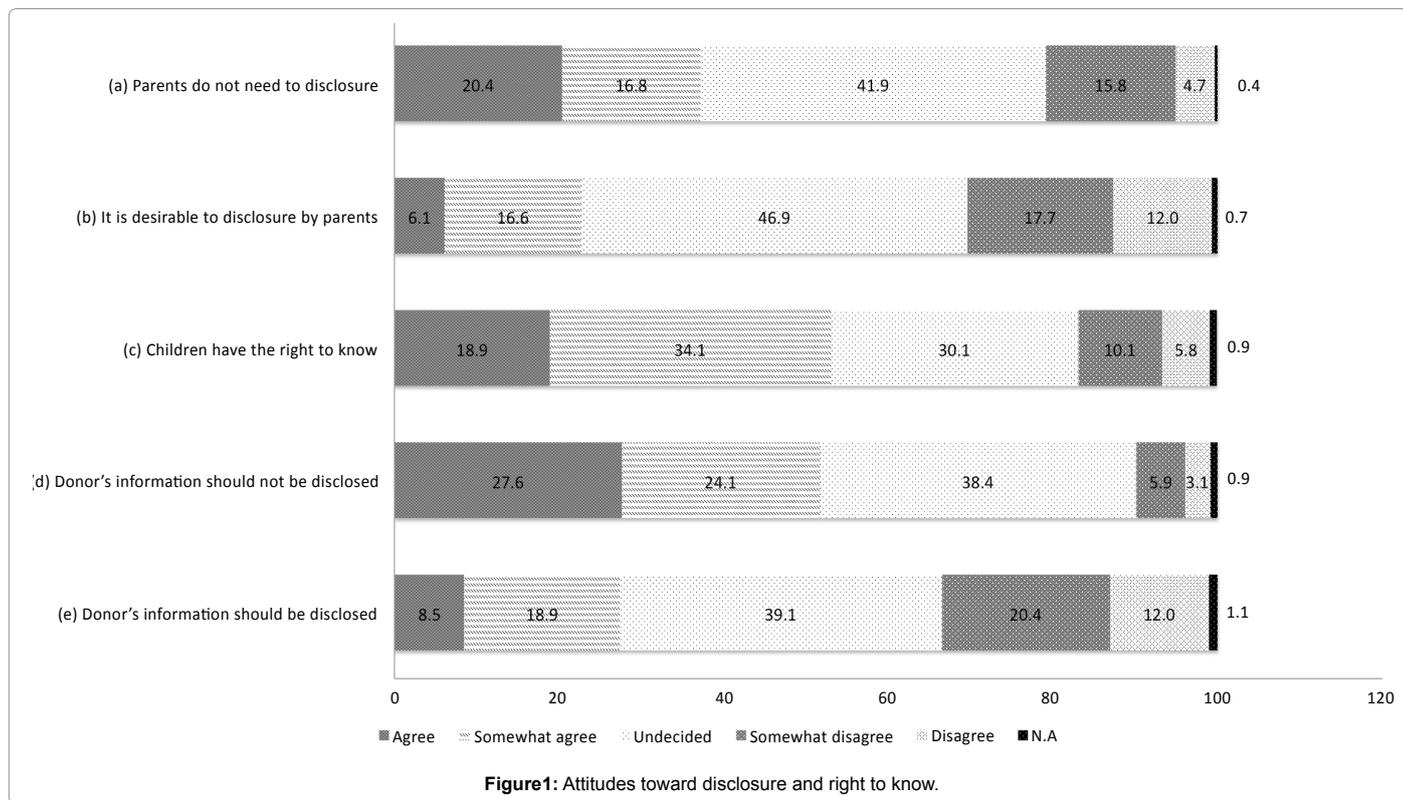
Table 1: Socio-Economic Background and Treatment History of the Participants. (N=740).

The mean treatment history of participants was 2.3 \pm 2.4 years. More than half the respondents (56.4%) reported experience with *in vitro fertilization* (IVF), and most of this group had one such experience (*n*=109; range, 1–20). In terms of the major causes of infertility, "aging" was selected by 33.8% of the respondents, "uterine/cervical abnormalities" by 12.7%, "ovum/ovary-related factors" by 11.1%, "fallopian tube factors" by 8.8%, "sperm issues" by 7.3%, "repeated miscarriages" by 2.2%, "intercourse problem" by 1.8%, "precocious menopause" by 1.2%, and "not otherwise specified" by 10.1% of the respondents.

Relatively few participants (5.7%) reported an intention to use egg donation in the future. The majority (58.5%) of participants had no intention of doing so, and 35.8% participants answered that it depends on the situation.

Attitudes toward disclosure and right to know

Data regarding attitudes toward disclosure and the right of children to know about genetic information are presented in Figure 1. First, 27.4% of respondents agreed or somewhat agreed that information about donors should be disclosed. On the other hand, 51.7% agreed or somewhat agreed that information about donors should not be disclosed. Thus, more infertile patients in the present study would prefer not to disclose than would prefer to disclose the donor's information.



Second, 22.7% of respondents agreed or somewhat agree that it is desirable for parents to disclose genetic information to their children born through donor-assisted conception. On the other hand, 27.2% respondents agreed or somewhat agreed that parents do not need to disclose. More than 54.8% of respondents who reported an intention to use egg donation agreed or somewhat agreed that parents do not need to disclose. There was significant difference between patients who reported an intention to use egg donation and patients do not have such intention ($p < 0.05$). Patients who reported an intention to use egg donation tended to have thought that parents do not need to disclose. Other factors such as age groups, major causes of infertility, experience of IVF were not associated with their attitudes. Thus, the infertile female patients, especially those who reported an intention to use egg donation in the present study do not believe disclosure should be mandatory.

Third, more than half (53%) of the respondents in the present study agreed or somewhat agreed that children have the right to know about the circumstances of their conception.

In summary, infertile female patients in the present study preferred maintaining the anonymity of donors. On the other hand, they also believed that children have a right to know about their genetic origin if they so desire.

Discussion

During the decades in which donor insemination (DI) using anonymous sperm donors has been practiced in Japan, thousands of children have been born through this procedure. However, little is known about the parents and children involved in DI. A follow-up study about attitudes toward the disclosure of their genetic origins to children conceived via DI in Japan [13] found that 62% of male parents with children conceived through this method responded that they “never want to disclose,” 18% responded that they “do not want to disclose, if possible,” 1% answered that they “want to disclose, if possible,” and

0% answered that they “certainly would disclose.” Thus, most fathers of children conceived via DI did not intend to disclose this information to their children, and this result is consistent with those of the present study and of other studies conducted throughout the world.

Results of studies regarding the issue of the confidentiality of donors have found that the great majority of parents did not intend to tell their children about their genetic origins. In this exploratory study, female infertility patients, especially those considering the use of egg donation, exhibited a similar tendency. According to United Nations Convention on the Rights of the Child established in 1989, the child shall have as far as possible the right to know his or her parents. This is also valid for children born through ART and therefore the welfare of the child should be of paramount concern in the practice of ART. To consider this issue, we explored potential parents' attitudes and thoughts regarding their child's right to know, and these data form the basis of several policy recommendations.

First, female infertile patients in the present study preferred anonymous to non-anonymous donation. One reason for this finding may be the lack of regulations defining the relationships among donors, recipients, and children. In this context, recipients may fear that donors will intrude into the lives of their families. In order to preserve familial boundary between recipient and donor, it may be desirable to revise family law to clearly define what constitutes a parent-child relationship when donor-assisted conception is involved.

Second, female infertile patients preferred not to disclose information about their child's genetic origins to their child. This tendency was especially pronounced among participants who would consider the use of egg donation in the future. One possible reason for this finding may involve the social stigma related to donor-assisted conception, which may render parents reluctant to disclose this information. Indeed, they may want to keep this information not only from children but also adults around them such as relatives, friends

and neighbors. Another reason may be the current lack of donor's information such as name, address and genetic background in Japan. According to this reasoning, disclosure may cause distress for children, as pertinent information is unavailable. In this context, one approach to de-stigmatizing donor conception may involve granting official legal recognition to this practice.

Third, although participants believed children should know the facts about their genetic origin, they would prefer not to disclose this information themselves. No official support or counselling is available for people who have become parents through donor-assisted conception, and no manual or guidance about how to disclose this information to one's children is available to these parents. In this context, parents are reluctant to make this disclosure on their own, and it would be difficult to mandate that they do so. Policy makers should consider including a long-term support system for parents and children in regulations governing donor-assisted conception. Moreover, an official registry system should be established so that children who want to know about their genetic origin can obtain this information irrespective of whether their parents choose to disclose it. To enable this, every child can access if he/she has doubt on their genetic origin, they can confirm whether he/she was born from a donor conception or not, and if he/she has born through donor conception, he/she can access the record kept in official registry system and obtain donor's information.

There is increasingly widespread recognition that the right to know about one's genetic origin is in the best interest of children. However, studies of families created by gamete donation have found that the large majority of parents do not intend to disclose the method of conception to their children [14]. However, as DNA testing becomes more widely available, parents will probably be more likely to disclose the truth about their children's genetic origins.

A registry system for gamete donation should be established in Japan to guarantee children's right to know, and this system should be balanced with that used for adoptions. Two kinds of adoption systems exist in Japan. The first, regular adoption, involves an official adoption that proceeds with the consent of both parents in the absence of dissolution of the relationship between the child and the biological parents. The second, a special adoption for children under the age of 6 years, occurs when a family court judge decides that it is the best interest of the child to dissolve his/her legal relationship with his/her biological parents. In cases of special adoption, children can learn about their adoption procedure through a family register system. Therefore, in Japan, adopted children can trace their birth mother if desired, which preserves the right of adoptive children to know their genetic origin. Thus, there is inconsistency and inequality between the rights accorded to adoptive children and those accorded to children born through donor-assisted conception. However, on the other side, adoptive children are forced to know the fact of their adoption procedure through a family register system and therefore they have no choice not to be known. Even the rights of adopted children are not secure in this regard. Policy makers should consider the establishment of an official registry system that would allow children, either adopted or born via ART, to access information about their genetic origin if they so desire.

The limitations of the present study include its very small sample, which was restricted to infertile female patients seeking certain kinds of treatment; thus, participants had not become parents through donor-assisted conception at the time of the study. Thus, the results of the present study are of limited generalizability. Second, the results may have been affected by a social desirability bias. Nevertheless, this study may contribute to our understanding of the experiences of

infertile patients and of the circumstances surrounding donor-assisted conception in Japan in the service of improving policies in this domain.

Finally, ART, including donor-assisted conception, enables people to realize their dream of having children. We must establish the appropriate regulations to ensure the welfare of all parties involved in this process, especially the children.

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