'Are You Asking Me If We Had Sex To Conceive?' To Whom Do Parents Of Twins Disclose Mode Of Conception and What Do They Feel About Being Asked?

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here are no data on whether parents of twins will disclose mode of conception to researchers or to their children, who will be informants in adulthood. We sent 1600 questionnaires about this via the Victorian branch of the Australian Multiple Birth Association, to be returned anonymously. Parents were asked how their twins were conceived and whether those who used assisted conception would disclose this to researchers studying assisted conception, twin pregnancy or twin children, or to their children. Comments were invited. Altogether 975 (61%) guestionnaires were returned and 389 (40%) indicated use of some form of assisted conception: 75 (19%) ovarian stimulation alone, 165 (42%) In Vitro Fertilisation, 132 (34%) Intracytoplasmic Sperm Injection, and 17 (4%) Gamete Intrafallopian Transfer, with 20 reporting use of donor eggs and thirteen donor sperm. Of those using assisted conception, the proportion reporting that they would not, or may not, tell researchers was 5% for assisted conception studies, 6% for twin pregnancy studies, and 7% for studies of twin children, while 7% reported that they would not, or may not, tell their children. From the comments (from 374/975; 38%) it was clear that questions about mode of conception can be offensive to some parents of twins, unless there is a need to know. Further, the question 'are your twins natural?' should be avoided. We believe the question 'Did you need medical help to conceive your twins', followed up with specific questions, is more acceptable.

Twins are not infrequently conceived with medical help (Blondel et al., 2002), often using assisted reproduction technologies (ART) such as stimulation of ovulation, Gamete Intrafallopian Transfer (GIFT), In Vitro Fertilisation (IVF), Intracytoplasmic Sperm Injection (ICSI), and Intrauterine Insemination (IUI) with partner's or donor sperm or use of donor eggs or embryos.

There is increasing interest in the possibility that some of these technologies may affect outcomes of pregnancy or later child health, (Reddy et al. 2007; Schieve et al., 2004) and mothers of twins are often asked for information about mode of conception. As adults the twins themselves may be asked for this information. Further, genetic parentage is an important issue for some family studies, so knowledge about use of donated gametes or embryos can be important.

When planning to recruit a twin cohort in pregnancy (known as match, [mothers and twin children]; Hopper et al., 2006) we considered the possibility that parents of twins may not be prepared to divulge details of their twins' mode of conception to researchers or their children, but were unable to find any published data on this. We therefore conducted an anonymous survey of members of the local (Victorian) branch of the Australian Multiple Birth Association (AMBA), asking how their twins were conceived. For those who needed medical help, we asked whether they would tell researchers, other health professionals, their children or other family members, or friends.

Materials and Methods

This project was approved by the Human Research Ethics Committee of the Department of Human Services, Victoria. To ensure anonymity, 1600 questionnaires with reply paid envelopes were sealed in stamped envelopes that were delivered to the president of AMBA Victoria, who forwarded an appropriately sized batch to the chair of each local AMBA group. Envelopes were addressed to group members and mailed.

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Table 1

Percentage Willing to Divulge Mode of Conception (N = 389)

	Willing to tell	Not willing to tell	Uncertain whether they would tell, or indicating that they would be selective	
Their twin children	364 (93%)	20 (5%)	6 (2%)	
Close family members	364 (94%)	22 (6%)	3 (< 1%)	
Friends	331 (85%)	49 (13%)	9 (2%)	
GP (family doctor)	375 (96%)	14 (4%)		
Obstetrician	382 (98%)	7 (2%)		
Paediatrician	375 (96%)	13 (3%)	1 (< 1%)	
Counsellor	355 (91%)	33 (9%)	1 (< 1%)	
Researchers studying				
Assisted conception	368 (95%)	19 (5%)	2 (< 1%)	
Twin pregnancies	363 (93%)	24 (6%)	2 (< 1%)	
Twin children	358 (92%)	28 (7%)	3 (< 1%)	

Note: Selective about (a) which individuals they would tell; or (b) the circumstances, for example, the reason the question was asked and the perceived need to divulge the information.

Questionnaires asked members how their twins were conceived. Multiple options were: (1) without medical help, (2) after using medications or hormones to stimulate egg production (ovulation), (3) by IVF, (4) by ICSI (sometimes called microinjection), (5) by GIFT, (6) using donor eggs, (7) using donor sperm, and (8) using donor embryos.

The questionnaire then asked: 'If you needed medical help to conceive your twins, please tell us whether you have or would be prepared to tell these people how you conceived.' Respondents were asked to circle yes or no for the following people: (a) your twin children, (b) close family members, (c) friends, (d) your GP (family doctor), (e) your obstetrician, (f) your pediatrician (children's doctor), (g) a counselor, (h) researchers studying assisted conception, (i) researchers studying twin pregnancies, or (j) researchers studying twin children.

The final question was 'Do you have any comments on this?'

Statistical Analyses

Information from the forms regarding willingness to divulge mode of conception was tabulated, and chisquared tests were used to examine differences in willingness with respect to the various categories of people, according to mode of conception.

Qualitative Data Analysis

Comments made by the respondents were varied in nature, and ranged from general information about their family, to their IVF journey, to their feelings about and experiences of multiple pregnancy. Most made one or two short comments. We found no evidence that people who wrote long comments differed from other respondents. Comments were analyzed manually, line by line, using inductive coding technique (Miles & Huberman, 1994) to assign codes. These were then analyzed to generate patterns which led to development of broad themes.

Results

Altogether, 975/1600 (61%) questionnaires were returned. Of these, 389 (40%) respondents indicated that some form of medical help had been needed to conceive their twins: 75 (19%) had ovarian stimulation alone, 165 (42%) had IVF, 132 (34%) had ICSI, and 17 (4%) had GIFT.

Twenty respondents reported using donor eggs, 8 with IVF, 11 with ICSI, and 1 with GIFT. Of the thirteen respondents who used donor sperm, 2 used it with ovarian stimulation, 6 with IVF, 4 with ICSI, and 1 with GIFT. No respondent reported using donated embryos.

Willingness to Divulge Mode of Conception

In Table 1 we show the proportion of women who were prepared to tell each category of person.

Only a small proportion of respondents indicated that they would not be prepared to tell researchers, 5% for studies of assisted conception, 6% for studies of twin pregnancy and 7% for studies of twin children. A few others indicated that they were uncertain, and some of the comments written on the forms indicated that disclosure would depend on how relevant the information was to the research question. Likewise a small proportion (7%) reported that they would not, or may not, tell their children.

Friends were less likely to be told than the other categories of people (p < .001 by two-sample test of proportions, comparing 53 who said they would not, or might not, tell friends, with the average 16.3 for all other categories of people). Medical professionals (family doctor, obstetrician, or paediatrician) were the most likely to be told.

Table 2

Percentage of Respondents Who Reported They Would Not or May Not Be Happy to Divulge Information About Conception, According to Mode of Conception and the Category of Person to Whom Information Would Be Divulged

0		0,	5				
N	Ovarian stimulation ± donor gametes 75		ICSI ± donor gametes 132	GIFT ± donor gametes 17	<i>P</i> by chi-squared	Donor eggs 20	Donor sperm 13
Their twin children	11%	5%	5%	18%	0.09	0%	0%
Close family members	7%	5%	6%	24%	0.03	0%	0%
Friends	16%	13%	15%	24%	0.7	25%	0%
GP (family doctor)	7%	3%	2%	12%	0.07	5%	0%
Obstetrician	4%	0%	1%	18%	< 0.001	0%	8%
Paediatrician	8%	1%	2%	18%	0.001	0%	8%
Counsellor	12%	8%	7%	18%	0.3	10%	0%
Researchers studying							
Assisted conceptior	n 5%	4%	7%	6%	0.8	10%	0%
Twin pregnancy	7%	5%	8%	12%	0.7	10%	0%
Twin children	9%	7%	8%	18%	0.4	15%	0%

Note: Respondents using donor eggs and sperm are shown separately in the last two columns.

Respondents were less likely to tell close family members and their obstetrician or paediatrician how their twins were conceived if it was by GIFT rather than by some other method (Table 2).

Those who used donor eggs or sperm to conceive were included among the four categories (ovarian stimulation, IVF, ICSI, GIFT). In the last two columns of the table we show data on respondents using donor gametes. There was little evidence that those who used donor gametes to conceive differed in their willingness to divulge mode of conception from those who did not, $(p \times \chi^2 \ge .3$ for each category of person).

Comments

Altogether 374 (38%) of respondents wrote a comment on the questionnaire; these comprised 190 of the 389 (49%) who had needed help to conceive versus 184 out of 586 (31%) who did not need such help (p < .001 by chi-squared). The most prominent theme that arose from the comments made by parents of twins regarded their personal feelings about assisted conception.

Respondents reported finding it offensive when asked if their twins were 'natural' or if they have twins in their family (which they evidently interpreted as a related question).

And they most certainly are 'natural' — not sure what he/she thinks IVF twins should look like! (conceived by ICSI)

Questions such as these were perceived by some as an enquiry into private sexual matters. This was especially true for those respondents who conceived spontaneously.

I often want to say 'We conceived them on the kitchen benches or something to that effect to see their reaction'.

When pregnant I was amazed at people in the street asking me if they were IVF - I responded with 'Are you asking me if we had sex to conceive?'

Essentially they are asking me about my sex life. It is invasive, rude and irrelevant .

They felt that there is a common assumption in the general community that all twins are a 'side effect' of fertility treatment.

Sometimes I get a bit offended that people assume if you have twins that you went through the process of IVF. (no medical help)

I have found the thought that people may think they have been assisted quite offensive. (no medical help)

There is a strong sense that the use of ART is a very private issue and that it needs to be treated with the respect and sensitivity it deserves. Some people commented that they feel judged when asked about their use of assisted conception while some feel inadequate because of their inability to spontaneously conceive a child.

Occasionally you sense some philosophical aversion to IVF in some people, along the lines of it not being 'natural', for example. This makes me a little uncomfortable but also angry, as it's too easy for others to judge who had no problem conceiving children. (ICSI)

I have mixed feelings when telling people as I sometimes feel inadequate having to use fertility drugs. (ovarian stimulation)

I still grieve over my infertility diagnosis. Am unable to discuss further. (ICSI)

People commented that use of ART was a very stressful and emotional journey and they were more open to talking about it once they conceived.

Working through infertility was a horrendous and very personal experience. Once we had succeeded we shouted it from the rooftops and have spoken to many people of our experience, hoping that it can help others going through infertility or working with people dealing with infertility. (GIFT)

Preconception we didn't discuss our IVF tribulations with many friends or family — just to reduce the stress of constant questioning. Once we conceived we were happy to discuss with everyone. (ICSI)

Friends and work colleagues were the group to whom most people had difficulty disclosing information.

The only people I wouldn't confide in is work — it is hard enough just being pregnant at work, let alone all of the prepregnancy IVF activity. (ICSI)

As twins are a 'side effect' of fertility treatment, I felt unable to tell friends that this is how they were conceived. (ovarian stimulation)

On the other hand, some are more accepting of people's curiosity and do not mind answering questions honestly. They feel that IVF is a very common medical procedure and there is no shame in admitting they conceived that way.

We are not ashamed of how our babies were conceived — it takes just as much love as normal conception, there are just more people. (IVF)

If parents aren't willing to openly discuss these issues then it can seem to be something to be ashamed about, rather than a medical problem that is becoming more common. (ICSI)

Most people were happy to talk about their use of assisted conception if it meant helping other couples trying to conceive, or raising awareness about it in the general community.

It is really important to be open about IVF to break down the secrecy and rejoice in its success. (ICSI)

I am a firm believer in discussing the IVF process openly — to dismiss all misconceptions (pardon the pun) and make the public (including family and friends) informed so that they understand. (ICSI)

There was also a general feeling that there needs to be more information and education regarding ART procedures so people are able to talk about it with their children.

We believe that if there were more child-centred information on how families are created (by IVF, using donor eggs etc.) then maybe many parents would feel more comfortable to explain the process to their children. (IVF, donor sperm)

Parents of twins considered it a blessing to have conceived twins, but a few seemed to make a philosophical distinction between spontaneous and assisted conception, seeing the former as slightly superior.

I do feel some sense of superiority that I had a spontaneous pregnancy and so take pride to tell people how they were conceived (if I am asked). (no medical help) Interestingly it seems that many people think twins conceived naturally are much more special than those not. (ICSI)

Most people ask 'is it natural', as if it is not special if it is IVF conceived. I believe it is more special as we fought so long to become pregnant. (ICSI)

Another important issue seemed to be the effect IVF has on twins themselves, with some parents feeling that there is a strong stigma associated with IVF and that their children are often labelled as 'fertility babies'. For some this was a sufficiently strong feeling to justify withholding information until the children are much older, and in some cases the children may never be told.

I believe there is still a stigma attached to IVF children and children do not want to be seen as 'different'. Therefore, we have kept this as private as possible for the children's sake. We may tell them when they reach adulthood if necessary. (ICSI)

IVF children are not freaks of nature and I wish that view to change. (ICSI)

We will probably leave it to the children to decide who they want to tell, rather than divulging information before they can make decisions for themselves. (ICSI)

I did not want my twins being seen as 'fertility babies'. (ovarian stimulation)

Parents feel that the general public needs to be made aware of the offensiveness of questions pertaining to the twins' conception, and are annoyed that people feel they can ask such questions of a complete stranger.

Conception is an extremely private event that no-one has the right to invade. If people are rude enough to ask, then I'll be rude enough to lie about it. (ICSI)

I find it extraordinary that people can ask personal questions to strangers in the shops, that are quite literally to offend and bring up old wounds. (ovarian stimulation)

While I don't really mind people knowing that they were IVF babies, I don't really want to explain our medical history to the local shopkeeper. (ICSI)

Generally I find having twins, people feel that they can ask you whether you conceived naturally or through assisted conception. Certainly not a question that a single pregnancy would provoke. (no medical help)

It was clear that there is some sensitivity about being asked questions regarding conception by medical researchers or health professionals, and that these were not always asked appropriately.

I was asked once, by a research doctor, whether my babies were 'natural'. I found this surprising and a bit offensive. (no medical help)

I was taken aback by the number of people who asked me if they were 'natural'. I found the nurses in the hospital asked me all the time — it was none of their business. (no medical help) Nurses in the delivery room commented 'It's nicer delivering natural twins'. (no medical help)

People who have had assisted conception commented that they would reveal information regarding their children's conception to medical professionals or researchers, if they felt it was relevant to the person asking, or if it involved the health of their children.

If relevant to medical practitioner, then the fact that the children were donor eggs would be revealed, and only if affecting the children's health. (ICSI, donor eggs)

My sonographer, midwife, and maternal child health nurse and paediatrician all asked me this question, and I do not have a problem sharing information where it is required. (IVF)

Do not have an issue discussing it in a confidential forum, or where relevant with medical professionals. (ovarian stimulation)

There would have to be good reasons to discuss what we went through, as it was a deeply challenging and at times painful, depressing journey. (IVF)

Information supplied to researchers would need to be anonymous, as with this questionnaire. (ICSI)

Discussion

To our knowledge this is the first study to investigate the attitudes of parents of twins regarding disclosure of mode of conception. Altogether, 40% of respondents reported needing medical help of some kind to conceive their twins or higher order multiples. We considered the possibility that parents who had fertility treatment may have been more likely to return the questionnaire, but the proportion here corresponds to the proportion we reported in a hospital-based research study of twin pregnancies in Melbourne and Adelaide from July 1999 to January 2003, namely 39% (Morley et al., 2005). The contribution of assisted conception to twin pregnancies, in countries providing wide access to infertility treatments, has been estimated as 30 to 50% (Blondel et al., 2002).

Among those needing medical help to conceive, we found that a small proportion would not, or may not, be prepared to tell researchers, their twin children, or even clinicians how their twins were conceived. However, we do not know whether respondents whose stated intention is to disclose mode of conception to their children will all actually do so. Some of the group who do not plan to disclose may well decline participation in studies that ask for information about mode of conception, and where mode of conception is not relevant to a twin research study, researchers should consider omitting such questions, rather than discourage participation by this minority.

In our study all respondents who used donor gametes reported that they would tell their children

and close family members. This differs from findings in other studies from Australia and elsewhere, suggesting that the majority of donor-conceived children do not learn of the facts surrounding their conception. (Bebe et al., 1997; Leeb-Lundberg et al., 2006; Lycett al., 2005). This difference may reflect some degree of selection bias and the small number using donor gametes (n = 33), but could also relate to legislation in the state of Victoria that protects the child's right to information about their donor.

GIFT is not widely used, and in Victoria couples having GIFT are most likely to be from one particular religious group with strong views about conception. We found evidence that respondents having GIFT differed from other groups in their willingness to divulge mode of conception. This may relate to their religious beliefs (Schenker, 2005).

Many respondents commented on negative views about fertility treatment and some felt there was social stigma relating to their use of ART, with the implication that 'fertility babies' were seen as a bad thing or 'freaks of nature'. This feeling of social stigma was also documented in a study involving focus groups in the United States, where use of fertility treatment was seen as 'moral violations of God or nature' (Ellison and Hall, 2003).

We acknowledge that our study has a number of weaknesses. First, respondents may not be representative of all AMBA members in Victoria, and AMBA members may not be representative of all families with twins. We cannot therefore be certain that these data are generalizable to all parents of twins, even in the state of Victoria. Further, those who replied to us may have felt more strongly about the issue of divulging mode of conception than those who did not, or been more likely to use fertility treatments. Nevertheless, our data do suggest that a small proportion of parents are unhappy about divulging information about mode of conception.

Second, we asked specifically about twin pregnancies, but sent the questionnaire to all members of AMBA. We did not ask whether parents had twins or higher order multiples, but 11 respondents reported that they had triplets and two had quads. We included their data, and do not know whether some other respondents had higher order multiples. Inclusion of these respondents is unlikely to have more than a very minor effect on our findings because higher order multiples will be a small minority. Further, we believe that responses of parents of twins and higher order multiples are likely to be broadly similar in this respect (Ellison & Hall, 2003, who included both).

We did not ask respondents in this study to tell us in which year their twins were born, but the majority of active AMBA members reportedly have young children.

There is some evidence that mothers and fathers of children conceived by IVF/ICSI differ in their attitude to disclosure to their children (Peters et al., 2005). We did not ask which parent had filled in the questionnaire, so we do not know whether it was filled in by the mother, father, or both together. We are aware from our twin research studies that a small proportion of twin children are born to same-sex partners after assisted conception, so we chose not to ask for this information.

We were surprised at the proportion of respondents who wrote comments on the questionnaire, and at the strength of feeling on two particular issues. First, many respondents indicated that they felt affronted when people, and especially people to whom they were not close, asked about their twins' conception. Many commented that this sort of questioning was unlikely to be directed at women with singleton pregnancies and that twins are generally seen as a 'side effect' of fertility treatment. We suggest that it needs to be generally known that questions about how twins or higher order multiples were conceived can be offensive and should not be asked unless there is a need to know.

Further, the question 'are your twins natural?' should be avoided by all, including members of nursing and medical professions. It would be better for medical professionals and researchers to ask 'did you need medical help to conceive your twins?', and go on to further questions only as relevant, and if parents indicate a willingness to answer them.

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