#### **ORIGINAL PAPER**



# To Tell or not to Tell? Parents' Reluctance to Talking About Conceiving Their Children Using Medically Assisted Reproduction

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#### **Abstract**

While more and more researchers are investigating the effects of disclosing conceptions achieved through heterologous fertilization, even couples who use homologous medically-assisted reproduction (MAR) often do not tell their relatives and children how they conceived, possibly because they find it embarrassing. The present study explores the perception of stigma, and the reticence of Italian couples resorting to homologous MAR when speaking about conception. Interviews were conducted with 30 participants recruited through a fertility clinic at a public hospital in northern Italy, and through social media and snowball sampling. Content analysis was used to identify respondents' various attitudes to talking about their MAR experience. Their reluctance to tell their relatives and children about their conceiving experience may reflect, but also perpetuate the social stigma associated with in vitro fertilization. Further research and scientific dissemination campaigns are needed to emphasize the importance of normalizing and sharing these experiences within the family—addressing not only heterologous, but also homologous MAR—especially in the more traditional cultural and legal settings, such as Italy.

**Keywords** Medically-assisted reproduction · Stigma · Disclosure · Qualitative research · Children

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## Introduction

One of the most important issues for parents who resort to medically-assisted reproduction (MAR) techniques concerns talking about how they conceived to other people in general, family, and especially their children. The decision to do so or not has strong ethical and moral implications, which have changed over the years with advances in MAR techniques and their greater accessibility. More than 20 years ago, in a study concerning several European countries, Golombok (1996) found that most participants who had received a gamete donation (75%) had no intention of telling their children about it. This was true of 100% of the Italian parents involved, 76% of the Dutch, and only 46% of those in Spain. Ten years later, Murray et al. (2006) found that 88% of mothers who went through homologous MAR in London (UK) had told or were willing to tell their children about how they were conceived, while this was true of only 46% of those who benefited from a gamete donation; and this latter percentage was confirmed in a subsequent study (MacCallum and Keely 2008).

The increasing number of families resorting to MAR has aroused interest in the link between children's knowledge of how they were conceived and their psychological well-being. It has been claimed in the literature that secrecy surrounding a child's conception may affect and impair not only the construction of their sense of identity, but also the quality of their relationship with their parents (Landau 1998).

According to family therapists, secrets in families threaten the harmony of family relationships, distancing those family members who know the secret from those who do not. As Papp (1993) argues, before discussing the damage of silence, more should be done to investigate the effects of such secrecy on family functioning and relationships, how the secret is managed, and what happens if children accidently discover their origins. Children may even become aware of the secret surrounding their conception because certain topics have become taboo in family discussions. This can make children confused and anxious, and some may even go on to develop symptoms of a psychological disorder.

On the other hand, several reasons have been advanced to justify keeping the matter "secret", including the idea of protecting the child from potential trauma, or protecting the infertile parent, or fears that people outside the family would find out about the couple's need for MAR (Golombok and Murray 1999). Some of these concerns were not only expressed as regards egg donation, but also reflected a general unease about the impact of infertility on parenting (Murray et al. 2006).

The stigmatization of infertility is strongly associated with the stigmatization of MAR. Unlike the latter, the former has been investigated by several authors because of its psychological costs for the individual in terms of isolation, lack of social support, and tendency to avoid self-disclosure (Greil et al. 2010). As Whiteford and Gonzalez (1995a, b) emphasize, in order to fully grasp the liability of infertility, we cannot ignore the cultural construction of procreation. This means considering the role of reproduction in our society, and the effects of



childlessness, as well as the part played by societal values (Cipolletta and Faccio 2013). Reviewing how MAR has been configured in the various discussions on the topic may help us to gain a clearer idea of the complexity of the phenomenon, and better explain its stigmatization. A study by Slade et al. (2007) showed that, among people undergoing fertility treatments, a stronger perception of stigma correlates with a more limited disclosure, less social support and greater distress. The authors emphasized the importance of considering the influence of stigmatization as part of the counselling offered during the fertility treatment. A recent investigation conducted in the UK (http://fertilitynetworkuk.org/, retrieved April 2017) found that reasons for non-disclosure included fear of stigmatization or related issues. The perceived stigma may stem from various aspects. For one, rapid developments in reproductive technologies have made them increasingly sophisticated and widespread, while changes in people's attitudes to them have lagged behind (Niederberger et al. 2018). Then there is the fact that infertility is sometimes perceived as "deviant" (Whiteford and Gonzalez 1995a, b), so couples may tend to hide it to avoid being judged negatively, although it can also be difficult and stressful to keep such a secret (Smart and Wegner 2000). The idea of infertility as deviant emerges from a deep-seated conviction of a normal/ abnormal dichotomy that disregards the fact that reality (and therefore what is seen as normal) is merely the result of a social construction. According to Whiteford and Gonzalez (1995a, b), people see infertility as an illness, and being cast in the role of someone who is ill can have a pervasive effect on an individual's self-esteem. It is also worth adding that many studies emphasize how women seem more likely to be blamed for infertility, and to carry the greater burden of it (WHO Report 2001; Carmeli and Birenbaum-Carmeli 1994; Van Balen 1993). Similarly, literature about the perceived stigma in patients with cancer in various sites shows that stigmatization is lowest among prostate cancer patients, and so high among women with breast cancer, that they should be focused in individual therapies regarding the negative consequences accompanied by perceived stigmatization (Ernst et al. 2017; Faccio 2011).

The idea of "keeping secrets" nourishes the concept of stigma in the sense used by Goffman (1963), as a mark of discredit, especially if it concerns a limitation (Faccio and Costa 2013). Stigmatization occurs when some members of a community differ in some way from the majority, and their diversity is seen as something undesirable (Faccio et al. 2013; Iudici 2015). This can give rise to a sense of shame at being unable to satisfy social expectations (Goffman 1963). As in other spheres of reproductive health, resorting to MAR can be seen as a sign of weakness, a couple's inadequacy, and can consequently be stigmatized (Cook and Dickens 2014; Faccio et al. 2018). Most of the studies on this topic have focused largely on the stigma of infertility per se, nevertheless, and on the stigmatization of couples benefiting from gamete or embryo donations (Baiocco et al. 2015).

Returning to the secrecy issue, Goffman draws an interesting distinction between what is *discredited* and what is *discreditable* (1963). From this perspective, couples that engage in MAR can be seen as discreditable because what they do is not overtly visible, and by keeping it secret they might be "spared" the associated stigma. This can help to explain why, especially in the case of heterologous MAR, parents may



reject the idea of telling their child how they were conceived, partly for fear of others finding out. Faced with the decision of whether to tell others about their resorting to MAR, parents may well have their doubts. They cannot guess how others may classify their behavior, or even what they really think, and this can lead to embarrassment and to words going unsaid. The couple is fearful of other people's moral judgment (Ellison and Hall 2003), and the situation can be embarrassing for the other party too. In fact, according to Goffman (1963), people who fear the stigma of MAR tend to talk about their situation either with people going through a similar experience (as the various patients' associations demonstrate), or with people they know well and who are likely to be more understanding. Many aspects of the stigma surrounding MAR remain to be addressed (https://www.eshre.eu/, retrieved March 2017), but patients' associations are a step in the right direction. They point to the need for more awareness about MAR, and about infertility in general, in order to reduce the related social exclusion, and prevent stigmatization (https://www.eshre.eu/; WHO Report 2001).

Studies in the literature agree that the difficulty of talking about MAR relates particularly to the possible involvement of a donor (Carone et al. 2018). This would suggest that telling children about homologous MAR is not a problem. Guidelines written to help parents tell their children the story of how they were conceived almost exclusively concern heterologous MAR. For instance, the British association Donor Conception Network developed its "How to tell" project, which included guidelines on how to talk about these topics. Books have been published on the issue, such as Sometimes it takes three to make a baby: explaining egg donor conception to young children (Bourne 2002), and documentaries have been produced, such as Telling and Talking about Donor Conception (Donor Conception Network), raising awareness of the need to provide support for all parents who face such situations.

According to Flamigni and Borini (2012), there are two ways to tell children about their origins: one is what the authors call "speed planting", the other the "right time". The former refers to the case of parents who talk about the MAR procedure right from the very beginning, introducing the topic when the child is 3 or 4 years old. The latter describes the case of parents revealing their child's origins when "the time is right". The researchers describe different ways to tell the "secret", some more direct than others. For example, some parents could tell their child there are various ways to build a family; others could start with the parents' "defect" and explain that they needed a doctor's help; others could simply focus on how much they loved their child even before he or she was born. For older children, the story of their conception can be more "scientific", once the child has some understanding of the basics of reproduction (*ibid.*).

Very few publications or illustrated books have been dedicated to explaining homologous fertilization to children. The present research aims to shed light on the experience of stigmatization by parents who resort to homologous in vitro fertilization (IVF) in a cultural setting that has proved scarcely receptive regarding the legitimate use of such techniques.

In Italy, access to MAR techniques is still regulated by Law 40 of 2004, which has been widely disputed for its restrictive approach. In fact, pre-implantation genetic diagnosis (PGD) and artificial insemination by donor are not permitted.



According to the original text of the law, access to assisted reproduction is reserved only for sterile adult couples of different sex, who are married or cohabiting, of potentially fertile age, and both alive. Over the years, the Law has undergone several radical changes following intervention by the Italian Constitutional Court, the European Court of Human Rights, and single Italian Courts of Law. These changes have enabled many more people to access MAR techniques, but there is still a large gap between the biotechnologies available and their acceptance by the general population, and use by those in need.

# **Study Aim**

The research goal was to explore parents' experience of MAR, addressing two main points: the associated sense of stigma (self-inflicted or attributed by others); and the story "test tube" children are told about how they were conceived. These themes were investigated from the personal perspectives of parents, others (family, friends, or other people in a respondent's life), and from that of society at large. All three levels are considered to respond to the need to investigate not only the experiences of the parents involved, but also their perception of any stigmatization by others (be they friends and family or generalized "others"), in a country with a cultural and historical reticence to the introduction and legalization of MAR techniques.

## Method

## **Participants**

Thirty Italian adults, 24 women and 6 men (who were partners of 6 of the women involved), took part in the study. The original plan was to interview 15 couples, but many male partners refused to be interviewed; their motives, according to their partners, related to "work issues", and a feeling of "shame regarding the topic".

All participants went through homologous MAR procedures. Four stopped at Level I techniques (homologous intrauterine insemination [HIUI] and various hormone treatments); the remaining underwent Level II procedures involving either IVF (61%) or intracytoplasmic sperm injection (39%). Some already had one child but encountered difficulties in conceiving a second, and some had a natural pregnancy after using assisted reproduction technologies (ART). In total, there were 6 participants with a child conceived naturally (before or after beginning MAR). One couple adopted a child after the successful outcome of their MAR procedure, and 7 participants had a second child with the aid of ART.

The female participants were a mean 43.4 years old (range: 30–58 years), and the males were 45.3 (range: 40–53 years). Almost all participants were married, while 3 were living with their partners, and 1 was divorced. Most participants were in employment and said their partners worked well; only 3 women were housewives. It is worth noting this occupational factor, since some participants made the point that MAR involves investing a lot of time and money.



#### Recruitment

Participants were recruited through a fertility clinic at a public hospital in northern Italy (Arco di Trento), through social media, and through snowball sampling. The interviews were held face-to-face and audio-recorded. All participants were recruited and interviewed between April and July 2017.

#### Measures

An ad hoc semi-structured interview was prepared to investigate the two themes of interest in this research. Each question was drafted by identifying certain facets relating to the views of respondents, others, and society. The interviews were conducted in the form of guided conversations, as this approach ensures flexibility, and enables participants to elaborate on their perspectives.

As an example, in investigating the sense of stigma, the following areas were explored.

Personal point of view Have you ever talked about your MAR experience with other parents? If you have, how did you feel in this situation? If you haven't, how do you think you might feel?

Others' point of view What do you think other parents might think if they knew about your choice? Have you talked to your family about your choice? If you have, what do you believe they think about it? If you haven't, what do you believe they might think about it?

Society's point of view Have you ever thought about public opinion regarding MAR?

The same structure was used to investigate the participants' views on telling their children about how they were conceived.

The interviews lasted 30 min on average, and the audio recordings were transcribed in full by one of the authors (EF).

## **Data Analysis**

Two authors (AI and EF) conducted a thematic analysis of the interviews; the third author (SC) supervised the process and contributed to writing the present article. Thematic analysis is a procedure recognized for its 'theoretical freedom' and its potential to yield a detailed and complex account of a set of data (Braun and Clarke 2006). The analysis began with reading a first transcript and coding the data in categories that summarized and systemized the content. The categories drawn from the data were grouped into broad themes, and further reading identified subthemes. This first analytic step provided us with a thematic framework (Ritchie and Spencer 1994) against which the first author analyzed the remaining transcripts. The thematic framework was refined throughout the analytical procedure by adding new themes and expanding the original ones. Each theme was printed, further examined and, if necessary, recoded as new or existing themes. The data were continually open



to reinterpretation and, while we recorded the contradictions and similarities within the themes, we also endeavored to remain faithful to the participants' accounts. The final framework contained two main categories, and 10 subcategories. The text excerpts were assigned to the various thematic categories and subcategories taking into account the opinions expressed by two independent judges (AI and EF), whose level of inter-rater agreement coincided with a Cohen's Kappa coefficient of 0.92.

## **Ethics**

Ethical approval for the study was obtained from the Ethics Committee at the University of Padua, thus ensuring that conditions of confidentiality, anonymity and non-deception were met (Protocol approval number 2254, dated 10/04/2017).

### Results

The results are outlined following the thematic framework. It should be noted that, because the categories were developed by means of an inductive process, starting from the text, they are not entirely separate. Some of them overlap because participants' conceptualizations sometimes provided information about more than one of the topics addressed. The most meaningful excerpts are reported and briefly discussed. Respondents are identified using fictitious names.

## Stigma

# Diffusion and Consequent "Normalization"

Many participants (9/30) report having noticed that more and more couples are resorting to MAR, with a consequent increase in the debate around it. The other 21 participants do not mention this thematic. This gives us the impression that participants felt stigmatized when they first embarked on their MAR procedure, but now feel less so as a result of its "normalization". Similar feelings are reported by participants who have children of different ages. Lucia's metaphor expresses this well:

Perhaps it's such a common thing now. It's as if, before going through all this, we thought it was a really rare thing. It felt like we stood out like a sore thumb. The truth is that, since everyone hides it, it's only afterwards, maybe from little things, that you understand it, even if they don't tell you. Nowadays I think there are lots of us. I see the number of twins in the classes has increased enormously so, even if the parents don't say anything, I think we're absolutely not alone nowadays, and therefore there won't be the big reaction (*if someone else hears about our using MAR*) that we might have expected back then.

One of the fathers interviewed describes the same feeling:



So, maybe at the beginning we had some, let's say, doubts about telling or not telling about it. Then I saw that lots of my friends had the same problem and I even gave them some advice about where to go, what to do, how to behave. So I think that nowadays there are so many who have the same problem that no-one pays attention to it.

His wife (Sonia) confirms his initial doubts and fears, but also that this idea of the "diffusion" of MAR makes it easier to talk about:

Probably, after discovering that the problem (and I say 'problem' even though I don't like this word) was on his side, I think he felt at fault, and so he was saying, "No, let's not tell...". Then we realized that there are really a lot of couples, so we "took it well", you might say. We could "laugh" about it, and now he's more relaxed. I never had any problem, I kept quiet because he was telling me, "Don't tell anyone, it's something private.

#### Who was Told About the Use of MAR

Nearly two in three of our participants say they spoke openly about their choice (18/30), and had told family and/or friends, and even strangers about it. The others (12/30) preferred to keep the information to themselves and their partners, or to share it only with very close friends or family. The participants' attitudes vary not only from one person to another, but also in the same individual over time:

Well, since I've lived through it very serenely, I've always said everything. I've always talked very openly, even if I had the feeling that something was wrong, to serve as a sort of "witness", because I realized that it's sometimes a hard topic to discuss. For example, my poor neighbor has probably tried six times, but she hadn't said anything about it. We were in the same situation and we'd never talked about it. So, after that experience, I've never hidden it from anyone. Everyone knows about it (Jessica).

Marta, who has had two children with IVF, detects a small transformation in her experience too:

No, we hadn't said anything, except to close family members. For example, not all my husband's family knew about it, just a small circle of friends. Then, with time, we talked about it more, depending on the friends we met and the situation. But not to everyone... not everyone knows, and for the moment that's ok.

# **Hiding information**

Many participants (14/30) speak about other people (rather than about themselves) hiding this aspect of their life. Some (8/30) mention that they used to conceal their use of MAR for various reasons, mostly due to a sense of shame. People do not always decide to talk about their experience straight away, as Giulio explained:



At the time, we thought about it, and then we decided that hiding this kind of situation would have been more emotionally damaging then the actual damage of saying 'I have a problem'.

Others voice different points of view:

Well, I'm fine with it. Maybe because, after I had two children naturally, we were hiding this thing a bit at the beginning because the problem was on my husband's side and, you know, men feel embarrassed and so on. I can see that this MAR is considered like a ... I mean, it isn't explained clearly. I mean, like, people who have children at the age of 42, I mean, you can guess, can't you? But, instead, these people tend to hide this thing. (Alessandra)

Alessia also described this "denial of the obvious":

I don't think it's something to hide. I don't feel ashamed about doing this thing. But there are some people, I tell you, people I know, that I saw at the hospital, that I saw the day they had medical treatments, who pretended not to know me. And I absolutely ... it's not as if we've killed someone. Actually, it's something that I've done, the fertilization, naturally. They [the babies] didn't come and we asked for help. I don't feel less good or inferior to other people who had one naturally.

Elisabetta, on the other hand, explains why she and her husband kept their MAR secret, shedding some light on how couples may feel about this experience, and what makes them decide to hide their recourse to MAR:

Well, when we started, we hid it from everyone. You feel inadequate. Why is it that you're unable to have children? Everyone has children and you don't. So you feel a bit awkward towards others. Maybe this thing that we carry with us, the idea that if you don't have a child you're not a man, or a woman, don't you think? So, you hesitate a bit.

The social construction of infertility, and consequently of MAR too, emerges clearly from Elisabetta's words.

Valentina points out a noteworthy difference: she said that she felt a little bit ashamed, but this feeling disappeared when talking in online communities. There are a few online forums for parents resorting to MAR, developed and managed by the parents themselves (e.g. cercounbimbo.net), where contributors can remain anonymous, and that probably explains why people feel free to talk, share their experiences, and express their doubts.

Andrea also speaks about the reasoning behind the decision not to talk about going through MAR:

Well, it's a sign of something lacking, an impotence in someone, so I think that it's hidden partly because of that, maybe only for that.

Lucia, his wife, is of the same mind:



It's probably because we want to give a better image of ourselves, which is related to functioning. Childlessness is like a malfunction, a deficiency, and so you hide your deficiencies. I mean, there's always this idea of being perfect, and all that. I mean, this shouldn't be considered as an imperfection, but in actual fact, in an omnipotent society, it is.

Mirta confirms that some people are determined to conceal the fact that they used MAR, and her explanation for this concerns:

Fear for the kid's future, in my opinion, not for the parent, fear of the kid being labeled in the future. In my opinion, the fear is that [people will say] 'that kid is the one born with unconventional methods'.

The labeling of a child that Mirta describes is the consequence of a transition from being discreditable to being discredited. She judges that the label of "deviant" from the norm concerns the child, not the parents. Who would label the child?

Schoolmates, other parents, the community in general. There's a lot of ignorance. There are people who think the child isn't yours, that maybe the eggs came from Spain, and the sperm from South Africa. I mean, people who don't go through MAR don't know that my kids were born through a process of HIUI, with my eggs and my husband's sperm, so they are MY children.

Although the argument is not linear, it contains many elements that could help to shed light on some of the stigmatizing discourses surrounding MAR. The concept of judgment emerges, and the picture is multifaceted and complex: the stigma focuses on the child, who can be classified as "different", but also on the parents because of their infertility. At the same time, the prejudice seems to be due mainly to the fact that, when people think about MAR, they think about the heterologous procedure, which appears to be judged more harshly.

To sum up, our participants' narrations indicate that, even if most of them do not hide their use of MAR, the fear of stigmatization is strong-strong enough to induce many couples to keep it to themselves, especially to reduce the risk of people thinking their children were the outcome of heterologous fertilization.

Another good reason for not talking about using a MAR procedure relates to the moral implications. Some participants had access to MAR before the radical improvements made to Italian law 40/2004. The original text of the law prohibited PGD, so couples did not have to deal with the moral quandary relating to the possibility of implanting a diseased embryo. Paradoxically, this seemed to make the parent's role easier, as Andrea explains:

We had many doubts. To what extent is it morally correct? Out of 13 fertilized eggs only one was healthy [...], so we had the fortune/misfortune that we couldn't choose. We couldn't say, 'We'll keep the one on the right or the one on the left'. But when this can be 'managed', as it were, the idea that you can choose to give life to a male rather than a female, to one that might be blond rather than dark-haired, that would worry me as well.



It is as if the opportunity to select one embryo over another were seen as immoral. Since this is possible nowadays, with it comes another potential accusation: that of passing for someone who has chosen their child's features.

Here again, the willingness to talk about having MAR is negatively affected by advances in the techniques that give people more room for maneuver in terms of influencing or manipulating the conception event.

## How People Feel When Talking About Their MAR Experience

Quite a few participants report feeling generally "comfortable" with the topic (12/30), others do not talk about their feelings (11/30), and some explain that their feelings vary, depending on factors such as who they are talking to, or the situation they are in (7/30): one was "uncomfortable with people I've never spoken to about it before..."; and one (Olga) says she wouldn't be comfortable talking with a person she describes as a strongly Catholic woman.

Let's say it's a lack of understanding. I mean, it's always seen as ... problematic. I only felt fine talking to people who had been down the same path (Sabrina).

I was talking to friends who didn't have this kind of problem. They already had children or they didn't want any, so they had never faced this. So, I felt uneasy (Lucia).

# How Participants Judge Their Partner's Feelings

Though the question was not asked specifically during the interviews, quite a few participants describe how they think their partner feels about MAR (8/30). They mainly describe feelings of shame and guilt. Five women report the infertility problem being related to the male reproductive system, and that was why their husbands felt guilty.

Interestingly, Michela says she thinks her husband still feels responsible for the experience they went through:

I don't like to talk about it because I know that he would feel bad. I mean, we did the MAR because of his problem so maybe, he felt it was his fault. And then to say, 'we went for assisted reproduction because of my problem', basically I think he didn't want to say it was his problem. I mean, he felt very badly about this thing, and when we told our daughter about it, we said that it was just because of some problem that we had. We didn't tell her the true reason. In my opinion, he didn't want to because it still makes him feel like a failure, physically.

#### What Families Think About the Decision to Resort to MAR

The scenario emerging from the interviews is quite diversified. Only two participants (2/30) say they chose not to tell their families, citing various reasons, such as their parents' age and mentality, or because they wanted to keep it between the couple. The other 28 participants decided to share their decision, albeit to a variable



extent, sometimes telling only some members of the family, or only the wife's family (Elisabetta).

For those who did inform their families (28/30), the timing of the disclosure and the reactions reported varied. Some couples spoke to members of their families as soon as they embarked on the MAR procedure, others only once a pregnancy was underway. As for the families' reactions, some approved, others did not. When families were in favor of MAR, some participants report receiving economic help, encouragement, and moral support. Cristina adds an interesting comment about her in-laws, who were not against their decision, but preferred not to talk about it:

For example, my in-laws are rather narrow-minded. It's hard to talk about it. For heaven's sake! Once the grandson arrived, they were really happy. They adore him. But, in my opinion, they tend to hide the thing. Whereas we speak openly, they avoid talking about it in public because they don't feel comfortable.

Some of the negative reactions were quite strong. Andrea explains that his infertility is a genetic problem, so the geneticist advised him to suggest to his male relatives (especially his nephews) that they take a test. He tried, but:

Every time I tell them, they look the other way. This goes to show that it's very worrying to discuss some issues, even if you have a brother who had the problem. I mean, it [the answer] is to deny it completely.

As for the reaction that Irene had to deal with: "Well, at the time my sister kept saying, 'Oh my God! What are you doing?! What aren't you doing?!'. They were scared, that's it."

## The Opinions of Others and Society at Large

More than half of the participants (16/30) tend to classify others' opinions in two hypothetical categories: people who know, and those who know nothing:

In my opinion, there are two sides, ranging from those who are more "radical", mainly meaning the Catholics, who see it as an abomination, as going against nature, to those who are indifferent maybe, to those who may have experienced it themselves, or who know people who've been through it, and they're in favor of it.

I think that, in certain situations, there is still a degree of, what's the word? Judgement? Because people can think there are weird mechanisms involved, people who know nothing about it, and don't know how the procedure is actually carried out. They reason in religious terms, or think there's some kind of genetic selection behind it. Because people hear these things, and if they don't know about the topic, who knows what they might think.

Our participants' narratives also reveal the difference between what people say and what they really think:



These are topics that, when people don't accept them, they may be ashamed to say they don't accept them, or that they are even against them. So you have to avoid the matter to avoid feeling obliged to lie or to say something, ehm,... inappropriate.

Andrea even compares infertility (and MAR) with homosexuality, possibly because both are publicly debated and could be perceived as a taboo. The idea of MAR as a taboo emerges in other narratives too (8/30).

In short, these excerpts reveal various facets of the stigma associated with MAR, which is not always socially constructed as being within the realms of normality. This generates mixed feelings, which are sometimes distinctly negative ("I was treated like an alien"). People who resort to MAR can feel judged, and they may either fight against this taint, or keep it secret.

## The Story of a Child's Conception

# How Participants Did or Would Tell Their Child About Their Conception

Most participants are inclined to tell their children about the steps they took to conceive them (26/30), but their ideas about when or how to do so, and their reasons differ. Several participants distinguish between when they will explain how babies are conceived and born, and when they will talk about the path they took to have their child.

From the way in which participants describe telling this story, it is also clear that they have different ideas about the significance and burden of talking about MAR.

Elisabetta claims that: "You don't have to worry, to say, 'Oh God, how can I tell them?' It's only a matter of finding the right moment, the right intimacy. Maybe knowing how much they were wanted could be a source of greater happiness, of greater ... not self-esteem, but 'If mum and dad wanted me enough to go through all that, this means they must have really wanted me'." Elisabetta's embarrassment would concern not MAR, but the topic of conceiving in general.

Some participants expressed doubts about telling their child about MAR: "I don't know whether to do it or not, or if it's something that has to be done. I wonder if it's really something that has to be done."

# When to Tell Children About Conception and Birth, and When to talk About MAR

Participants largely seem to think that MAR should presumably be addressed later than talk about conception and birth in general. In fact, 16 participants say the right age for talking about how babies are made is at the end of primary school (around 11 years old, when children reach puberty), whereas 11 parents say they will talk about MAR when their child is around 14 years old. Several participants did not specify an appropriate age for discussing these matters (this applied to 10 respondents as concerned speaking about conception in general, and 8 on the matter of speaking about MAR). Two participants were sure they would never speak to their children about MAR.



## The Importance of Telling Children About MAR

Participants' views differ on this point, but their comments can be roughly divided into six main categories (with some respondents' comments fitting into more than one category), as outlined below.

- 1. Some participants (6/30) say that not telling a child how they were conceived means that the parents experienced it as some sort of burden.
- 2. Some (5/30) claim that it is fundamentally important to tell the truth.
- 3. Worry that children might learn about their conception using MAR from a source other than their parents is good reason for speaking about it before that can happen (6/30).
- 4. Some participants (6/30) emphasize the positive aspects, comparing MAR with other situations that it might be better for children not to know about: "A baby conceived 'by accident' ... I'm not sure a child would be happy to know about that. For sure, less than one whose parents had been longing for a child for years. So, it's what it can mean to the child that makes it right or wrong to tell him. I can tell him because I did MAR. If it were another story, less positive, I certainly wouldn't tell him. If I were an abandoned single mother I wouldn't tell him." Another participant says she has no problem with talking about MAR because she went through homologous IVF; the difficulty would be in cases of heterologous MAR.
- 5. Another point raised by several parents (7/30) on the importance of telling their children about MAR is the fact that the child might have similar problems in the future: "If one day, let's knock on wood, he has these kinds of problems too, he will cope more calmly if someone has explained it to him. I mean, I hope he never has it, but if one day, I mean, maybe he will feel more encouraged."
- 6. A few participants (4/30) feel that telling their children how they were conceived is unimportant, or potentially disturbing: "If it's not necessary for me, or for medical reasons, it would feel to me like stealing something from him ... some kind of illusion, an innocence ... It would feel to me more like an excess of truth than something useful" (Lucia).

#### Discussion

The stigmatization of MAR emerged from the analysis as a crucial issue. The narrations revealing the perception of this stigma can be examined in the light of Goffman's theorization (1963). Before exploring our findings, nevertheless, it is important to underscore that the perception of stigma was not voiced by all our participants as something they had to bear themselves. In several cases, even when they did not feel it personally, it was projected onto other people undergoing MAR, or on society at large.

Excerpts relating to the increasing diffusion and consequent normalization of MAR practices shed light on the social construction of such a stigma. It was perceived differently over time, as the procedure became more common, and this makes



the socio-cultural origins of the stigma clear. Whereas many participants initially felt odd about their "diversity", like "sore thumbs", this oppressive feeling has since diminished. It could be claimed that the stigma surrounding MAR is slowly fading. This is what seems to be happening in Italy, as well as elsewhere in Europe. The ethical debate is still heated, nevertheless, and there are signs of adjustments to the lens through which MAR is seen on a legal level and in the number of people resorting to such techniques (Riezzo et al. 2016).

Many of our respondents had talked about their MAR procedure with family members or close friends. These people are described as being "sensible", having a "normal" attitude, and seeing no reason for any stigma. They are supportive for the couple feeling stigmatized. They understand and accept the situation. Some participants mentioned having also spoken to other people who were resorting to MAR: sharing the stigma meant really understanding the situation, and the difficulties these people were experiencing.

The dynamics for managing the stigma associated with MAR are complex due to its invisible nature. It is important for couples to gauge who might or might not know enough about it, and to bear this in mind, to predict situations in which the risk of not being accepted is greater, and to cope with the embarrassment when the stigma comes to the surface. But the burden of secrecy has been widely discussed in the literature (Smart and Wegner 2000): hiding such information has a personal cost both during and long after the treatments.

Concerning situations where it is best to tread carefully with information about MAR, some participants identify mentioned churches, and said they would not share their experience with strongly Catholic people. The stigma was reportedly sometimes more apparent in particular settings: at the hospital or at public events, when participants met someone who knew about their MAR and spoke about it. The stigma was also felt more clearly when people saw clues in the age difference between the parents and their child, or a woman experiencing multiple pregnancies, or couples who had been married for quite a while and still had no children. Such elements confirm that the stigma relates to a couple failing to comply with society's expectations. Another important sign of our respondents' perception of stigma emerges from their own feelings about resorting to MAR, or when they explain their reasons for keeping it a secret. Many use negative expressions, speaking of feeling inadequate, being defective, having a malfunction or deficiency.

The stigmatization perceived by our participants is described using some rather remarkable metaphors. Some, for example, speak of MAR as a taboo, "something prohibited", or they compare it with other situations considered unusual or not wholly acceptable, such as homosexuality, abortion or adoption (Iudici and Verdecchia 2015). In such cases, the situation may be embarrassing not only for the bearers of the stigma but also for the people interacting with them. For many of our interviewees, this uneasiness is probably due to MAR being seen as a taboo due to a lack of knowledge about what it really entails. This would confirm the ESHRE policy audit on fertility (https://www.eshre.eu/), which found literacy on the topic of MAR limited, emphasizing that this issue has been underestimated and remains to thoroughly addressed. Some patients' associations and governments in several European countries have been taking steps to improve this situation by means of information



campaigns. More research is needed in this field, nevertheless, not only to study the reality surrounding MAR and its stigmatization, but also to identify action to reduce the stigma by reconstructing the phenomenon from other perspectives.

The perception of stigma is clear from what our participants said about the opinions of others and society too. As Goffman explained, stigmatized people are aware of society's theories and beliefs about their stigma. Some studies (Ellison and Hall 2003; Cook and Dickens 2014) have shown, in fact, that couples who resort to MAR often fear others' moral judgment. Disseminating more information should help people to adjust their point of view on MAR and be guided by their common sense. Our participants reported encountering more than one stance on MAR. Some people see it as something aberrant, going against nature, or against God's will. This attitude has been applied to homologous MAR as well, but more especially to heterologous fertilization. Many of our participants (some clearly more than others) exploit this distinction, relegating the stigma to couples who undergo heterologous MAR, sparing themselves from society's disapproval. It would seem that the stigma is more severe for certain types of ART. Society adopts a system of values, judging "in a sense, who does and who doesn't deserve to access MAR". The latter may include not only heterosexual couples, but also-and possibly more especially-homosexuals and singles. The paradoxical effect of these distinctions, as our research highlights, lies in that participants fear being mistaken for those who have used heterologous IVF, or pre-implantation genetic control, and this makes them want to keep their MAR a secret.

When it comes to telling their offspring about how they were conceived, our sample of parents generally seemed willing to talk about their MAR procedure, confirming other reports (Murray et al. 2006). Their ideas varied somewhat as regards when this should be done, and the meaning they attributed to this disclosure.

On the timing, our parents' narrations confirm the literature (Flamigni and Borini 2012): some talk to their child about the MAR from the start ("speed planting"); others wait for the "right moment". Many of our participants separate talk about conception and birth (coinciding with puberty) from the topic of MAR, which can be addressed when they are a few years older. In short, talking about how babies are made does not necessarily entail explaining the parents' own experience at the same time, although most participants plan to share this with their child at some point too. Our results suggested six main thematic areas regarding the disclosure: (1) concern that the child might have similar problems in future; (2) the idea that not telling the child about the MAR procedure would mean the parents are ashamed they needed it; (3) the importance of being truthful; (4) fear the child might find out from someone else; (5) the potentially positive effect on the child of knowing how much the parents wanted him/her; and finally, (6) a conviction that the revelation is either not particularly important, or nothing to worry about.

In general, studies on this issue have consistently indicated that: a disinclination to disclose any recourse to MAR is due to the fear of a stigma associated with such technologies (Golombok and Murray 1999); and disclosure is seen as more difficult for heterologous than for homologous fertilization procedures (MacCallum and Keely 2008; Golombok 1996; Golombok et al. 2002).



# **Conclusions, Limitations and Future Prospects**

First of all, the different ages of our participants' children could be seen as a limitation of the present study, alongside the gender imbalance of our sample, which included only six men. In several cases, a male's viewpoint was addressed by his female partner, giving the impression that the former felt ashamed and guilty about being infertile. This rather contrasts with some reports of women carrying the greater burden of infertility and MAR (Carmeli and Birenbaum-Carmeli 1994; Van Balen 1993; WHO Report 2001). More research should be conducted on this aspect to better elucidate the meanings men attribute to the use of MAR.

Another limitation of our research lies in that the people who agreed to be interviewed are probably individuals who feel the stigma associated with MAR less severely, since they are willing to talk about their experience.

It has to be said that virtually no research has focused on the social configuration of homologous MAR. The impression is that MAR generally has yet to be fully accepted by society (especially in Italy, and countries where MAR has been introduced only recently), and couples opting for such a procedure worry about society's opinion (Ellison and Hall 2003; Cook and Dickens 2014). Despite the evidence of stigma surrounding MAR in Italy (https://www.eshre.eu/), this problem has not been addressed as in other countries. Germany, for instance, has developed the Wunschkind campaign, and the UK has created a fertility network that provides not only information, but also support for any individual or couple having difficulty conceiving a child (https://www.eshre.eu/). The fertility network in the UK is a great example of how a country can deal with taboos and ignorance concerning this topic. It has developed a large network where people can share their stories and difficulties. It also organizes charity events to get the whole community involved in providing economic support for people who cannot afford MAR. It arranges informative meetings, where various specialists describe their work and the procedures involved in IVF (http://fertilitynetworkuk.org/). More such campaigns and official networks could be developed to engage with society on the topic of MAR, thereby addressing the issue of literacy and taboos, and dealing with the pervasiveness of any stigma associated with ART in general (whether it involves heterologous or homologous procedures).

Our participants more or less inadvertently suggested a great way to help parents faced with the "problem" of disclosing their recourse to MAR, and also to improve societal awareness of what these procedures entail. They see themselves as a potential source of appropriate information, as experts on a topic that is often misunderstood. They can help combat prejudice and provide support for people considering MAR. This kind of support could be extended to members of the families of couples resorting MAR, such as the future grandparents, who often have little knowledge of reproductive technologies, and may not fully understand what the couple is going through.

Promoting networks or services whereby people who have used MAR can communicate with those who are planning to do so could be a great opportunity for all parties concerned: the former can benefit from sharing their experience



and supporting others facing issues they understand; and the latter will feel less isolated and "odd", and more comfortable with situation and decision to try MAR. Such people probably need to hear other voices, and not just the words of medical experts, in order to avoid interpreting their experience as a disease that technology can fix.

# **Compliance with Ethical Standards**

Conflict of interest All authors declare that they have no conflict of interest.

**Ethical Approval** All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent Informed consent was obtained from all individual participants included in the study.

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