

# SYMPOSIUM: GENERATING FAMILIES THROUGH ART

# **INTRODUCTION**

# Families formed through assisted reproductive technology: Causes, experiences, and consequences in an international context

# Introduction

In helping people to have the children they desire, assisted reproductive technology (ART) challenges conventional definitions and understandings of what constitutes a family. The nuclear family is still often considered as an entity defined only by biological ties, even though living arrangements with children (families) have become increasingly diverse in recent decades, with unmarried families, adoptive and stepfamilies, and families with same-sex parents becoming more and more common. ART adds to this growing complexity by providing treatments, to single people and gay and lesbian couples as well as to heterosexual couples to whom the conventional definition of infertility applies (Zegers-Hochschild et al., 2017). These former groups have also been described as facing 'social infertility' (Daar, 2017).

These developments open up or even deconstruct what we consider to be a family. Biological and social parenthood no longer have to coincide. Children conceived by ART can have more than two parents if donor gametes are involved. In addition, the use of donor gametes and/or surrogacy across borders can make the process of family formation much more complex, raising a number of ethical and legal questions about the nature of parenthood.

Since 1978, when the first baby was born in the United Kingdom through IVF — which is the central medical procedure of ART — we have started to include ART in our thinking about family formation. ART families are present in all societies, and involve actors from all over the world. However, the existing research on the causes, experiences, and consequences of ART has largely been focused on individuals in developed countries, mainly in North America, Oceania, and Europe. This research gap motivated us to initiate a conference that takes a more international perspective. A global comparative view appears necessary, because, in a globalized world, the use of ART is not limited by national boundaries. Much can be learned by examining the usage of and the different experiences with ART in varying national contexts.

Bringing together different perspectives on families formed with medical assistance was the central aim of our international conference titled 'Making families through assisted reproductive technologies: Causes, experiences, and consequences in an international context'. This implies taking into account findings based on different methodological approaches, including qualitative and quantitative analyses. The meeting was funded by the German Research Foundation (Project number 427286529) and took place in September 2019 in Wiesbaden. The participating researchers came from various countries, including Austria, Canada, the Czech Republic, Germany, Hungary, Italy, Nigeria, Portugal, Turkey, the United States, and the United Kingdom. To ensure that the conference attracted a wide range of contributions, we sent out a call for papers in advance through German and international sociology and population science associations. The participating researchers from diverse disciplines illuminated different aspects of the making of families through ART, such as social egg freezing, single motherhood, and transnational reproduction; as well as the demographic aspects of infertility and treatment use. Nicky Hudson contributed as a keynote speaker, framing the conference with a talk about 'assisted world families' based on findings from a research project on globalized gamete donation (Hudson, 2017).

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Finally, the conference motivated us to encourage more scholarship and to take further action. We invited all authors who made oral and poster presentations at the conference to contribute papers on their research to a special collection about making families through ART. As the special collection structure came into focus, we invited more experts to submit papers to strengthen the perspectives of immigrants on ART, as this topic has received little attention in recent debates. The considerable efforts of the authors have resulted in this special collection, for which the conference title was slightly adapted.

# ART use from a global perspective

The use of ART is increasing in an international context. Worldwide, over 9 million infants have been born following ART procedures since 1978 (ESHRE, 2020). For the year 2011, Adamson et al. (2020) have estimated that the number of births after ART treatments globally (including in China) was approximately 0.5 million. It is easier to grasp the meaning of these numbers at the national level in relation to the total number of births. Within Europe, Spain has the most IVF clinics, and is among the four countries with the highest treatment numbers. In 2017, the share of ART-related births was 7.9% in Spain (Wyns et al., 2021), whereas the share of ART-related births was only 1.4% in Poland (Wyns et al., 2021).

Not every treatment cycle, with all its challenges for patients and physicians, produces a baby. Globally, the number of treatment cycles performed in 2016 has been estimated at 2,788,858 (Adamson et al., 2020). However, the numbers of treatments performed differ greatly by region. Of all treatment cycles reported in 2016, 48% were performed in Europe, whereas only 2% took place in Africa (Adamson et al., 2020). Since many countries do not yet have ART registries, the number of treatment cycles performed worldwide is likely to be underestimated. Efforts are underway to initiate or improve reporting, including in Africa (Dver et al., 2020). Still, because information is missing even for regions where many treatments are taking place, such as the Asian Pacific region (Fauser, 2019), there is a long way to go before we have a complete picture of the global use of fertility treatments.

According to market analysts, providers of IVF reported profits of \$12.5 billion in 2018, and are expected to generate profits of up to \$25.6 billion in 2026 (Allied Market Research, 2021). This predicted increase in profits in the coming years clearly shows that there is a large and highly profitable market for fertility treatments. A global reproductive economy already exists (Hudson, 2017). According to Crawford and Ledger (2019), there are no signs that the market for ART is about to become saturated. Instead, new markets are opening up. In the Asia-Pacific context, the demand for IVF treatment is expected to increase due to fertility tourism and a growing awareness of ART through initiatives such as ASPIRE (The Asia Pacific Initiative on Reproduction) (Crawford and Ledger, 2019). Moreover, there are regions such as sub-Saharan Africa where ART is yet inaccessible to most prospective parents because there are no or only a very few fertility clinics per country, despite the pressing need for such treatments (Inhorn and Patrizio, 2015; Ombelet and Onofre, 2019). Providing affordable fertility treatments is a massive challenge in these contexts (Chiware et al., 2021).

In light of the large number of treatments currently being performed and the increasing demand for ART in countries around the world, it is clear that more research is needed to better understand the individual, social, and demographic causes that underlie the making of families through ART, and their implications.

# Research gaps in recent studies on making families through ART

Authors from various disciplines, including sociology, ethnography, social psychology, and demography, have contributed insights into the causes and consequences of, and the different experiences with making families through ART. While this field of research is vibrant and growing, several gaps emerge when we look more closely at recent research on family formation through ART.

#### Causes

Among the leading reasons for the increasing demand for medically assisted reproduction are the demographic changes that have occurred since the second half of the last century. In Europe and other developed countries, there has been a tendency to postpone family formation to advanced reproductive ages (Billari et al., 2006; Frejka et al., 2008). At the individual level, a consequence of the increase in the ages of women and men at first birth is a reduction in the amount of time available for reproduction. Postponing deliveries to later ages means that the desired number of children might not be achieved (Habbema et al., 2015). because there are age-related fertility declines among both women and men (Balasch and Gratacós, 2012; Dunson et al., 2004; Hassan and Killick, 2003). Especially for women aged over 35, fertility intentions become more difficult to realize (Beaujouan et al., 2019; Waldenström, 2016).

Due to the biological limits of fecundity, especially for women, the postponement of the first birth to later ages is a principal cause of increasing demand for ART treatment. With a few exceptions, there has never before been a period when a large proportion of parents had their first child as late in life as they have in recent years. In most OECD countries in 2019, the mean age of women at the birth of their first child was 30 or above (OECD, 2021). It appears unlikely that the age at first birth for women will decline again, as the cultural, structural, and economic causes responsible for the postponement of parenthood are still at work. These complex causes include changing values, women's expanding participation in education and the workforce, shifts in gender relationships, changes in partnership formation and dissolution patterns, economic uncertainty, the rise of precarious employment, increased social expectations surrounding parenthood, and the availability of effective oral contraception in Western societies (Mills et al., 2011; Schmidt et al., 2012; Waldenström, 2016). Among women, the tendency to postpone parenthood can be attributed to

the conflicts they face when seeking to balance the optimal biological timing of motherhood with their education and career goals (Balasch and Gratacós, 2012). Thus, it is widely expected that the need for ART will continue to rise in developed countries.

#### Experiences

Many women experience fertility problems over their reproductive years. For women in the USA, the current prevalence of impaired fecundity, which includes problems getting pregnant and carrying a pregnancy to term, is 12.1% (National Center for Health Statistics, 2021). Reviews on the implications of infertility show that the experience of infertility is associated with negative psychological outcomes in the short term, including higher rates of stress and depression in women and men (Greil, 1997; Ying et al., 2015). Experiencing infertility at the individual or couple level implies that an important personal goal may not be realized, causing strong emotional reactions in some individuals. ART can help people achieve their goal of having children.

ART encompasses a range of medical technologies, such as IVF, intracytoplasmic sperm injection (ICSI), and preimplantation genetic testing (PGT). However, medical treatments for infertility go beyond ART. Other types of fertility treatments, including hormonal treatments and insemination, fall under the broader definition of medically assisted reproduction (MAR) (Zegers-Hochschild et al., 2017). Unfortunately, data on these types of treatment are often not available. For example many fertility treatment registers do not include hormonal treatment and insemination in their regular reporting (Adamson et al., 2018). As social scientists, however, we should not restrict ourselves to the medical perspective on ART. It is essential to understand the different forms of medical assistance that are used in making families, including hormonal treatments and insemination. These treatments are lower cost and have fewer side effects than ART, and they are often effective in enabling people to have the children they want (Passet-Wittig and Bujard, 2021). In the following, we use the term ART for the purposes of consistency.

While it may be assumed that in contexts in which reproductive medicine is broadly available most people experiencing infertility will seek medical help, this is not the case. Studies from the USA that differentiate between the stages of help-seeking - e.g., from talking to a doctor through to receiving IVF - provide a nuanced insights into the help-seeking process, and paint a broader picture of the different types of treatments used, including hormonal treatment and insemination. While many women have spoken to a doctor about fertility problems, invasive treatments such as IVF or ICSI are used relatively rarely (Chandra and Stephen, 2010; Greil et al., 2013). Prevalence rates of medical help-seeking for infertility vary enormously, even in Western developed countries (Boivin et al., 2007; Passet-Wittig and Greil, 2021b; Schmidt and Münster, 1995). Whether these reported differences are real - e.g., they are driven by cross-country differences in the regulation of the reimbursement of treatment costs or are attributable to methodological differences between studies, remains unclear. One methodological issue that arises when comparing these existing studies is that they use widely differing definitions of the central concepts of infertility and medical help-seeking (Passet-Wittig and Greil, 2021b).

The reasons why people decide for or against seeking any help at all, or to stop treatment, are not very clear, even though a large body of research on this topic has accumulated over the last two decades (Passet-Wittig and Greil, 2021a). One reason is that fertility treatments are costly, and public funding for ART differs widely across the world, posing a critical barrier to accessing treatment. Health insurance systems that cover at least part of fertility treatment costs are mainly found in highly developed countries. For example, in sub-Saharan Africa, ART remains inaccessible for most people with fertility problems (Inhorn and Patrizio, 2015). The various 'social inequalities' associated with reproduction via fertility treatments are persistent issues that require further attention. Other reasons for not seeking medical help are related to socio-demographic characteristics, reproductive history, attitudes and psychological factors (Passet-Wittig and Greil, 2021a).

According to psychosocial research, people facing fertility problems report finding stressful not just the experience of infertility, but fertility treatment as well (Rockliff et al., 2014; Verhaak et al., 2007). Although most of the research on the psychological effects of undergoing fertility treatment focuses on women, there is some evidence that both women and men are affected, albeit in somewhat different ways, and that men's and women's approaches to handling this stressor differ (Wischmann and Thorn, 2013; Ying et al., 2016). Undergoing fertility treatment can be stressful in various ways: e.g., it is time-consuming, costly, and associated with physical and psychological burdens. The latter two sources of stress in particular often cause women to stop treatment (Gameiro et al., 2012). However, stopping treatment can also be difficult for women who feel subject to pronatalist cultural and normative expectations regarding motherhood (Carson et al., 2021).

For patients, the medically complex process of undergoing fertility treatment to create a family can involve a wide range of emotions, expectations, uncertainties, concerns, and dilemmas (Finamore et al., 2007; Greil, 1997; Kowalcek et al., 2003; Lacey, 2007; Verhaak et al., 2005). This insight has inspired research on patients' conceptualizations of the fertility treatment process (Palmer-Wackerly and Krieger, 2015), and of the genetic material created during the IVF process, including frozen human embryos (Haimes et al., 2008). There is evidence that the relationships patients have with their frozen gametes or embryos have an impact on how they navigate their way through treatment, including on how they decide what happens to their genetic material that remains after the completion of the medical procedure (e.g., oocytes, frozen embryos), and regardless of whether the IVF treatment was successful (Lacey, 2007; Laruelle and Englert, 1995). However, this field of research remains underdeveloped (Bleakley, 2017).

#### Consequences

Family formation through ART can have broader implications for the children and families involved, as well as for societies. For example, concerns have been expressed about the health and cognitive and psychological development of children born after ART. An important guestion that arises is whether the children conceived with the help of ART may be disadvantaged in terms of health. Recent research has shown that children conceived with the help of ART are more likely to be born pre-term, have a higher risk of perinatal death, have a lower birth weight, and have a higher need for postnatal intensive care (Davies et al., 2017; Declercq et al., 2015; Halliday, 2007; Henningsen et al., 2011; Ludwig et al., 2006; Marino et al., 2014; Wolff and Haaf, 2020). In addition to these short-term effects, studies on the long-term effects of ART on children's health indicate that children born after ART face an increased risk of cardiovascular and metabolic problems in later life (Hart and Norman, 2013a). However, no significant differences in growth have been found between children conceived via ART and naturally conceived children (Basatemur et al., 2010). To date, it is not clear whether the health issues observed in ART children are a consequence of the treatment itself, or are related to factors associated with infertility, the age of the mother, or the adverse birth outcomes mentioned above (Kondapalli and Perales-Puchalt, 2013; Romundstad et al., 2008).

The long-term effects of ART on children extend to life domains other than health. For instance, birth outcomes like low birth weight, which are more frequent among ART children, are linked to children's future cognitive development (Black et al., 2007). Nonetheless, children born through ART do not seem to have any disadvantages compared with naturally conceived children in terms of their cognitive development, school performance, or social skills (Bay et al., 2013; Cozzani et al., 2021; Hart and Norman, 2013b; Wagenaar et al., 2008). Since ART children are, on average, born to socioeconomically advantaged parents (Goisis et al., 2020), this finding is not surprising. Parents from socioeconomically advantaged settings can invest more financial and human capital in their children's educational success, including in their social competence.

Furthermore, the quality of the parent—child relationship is also relevant for child development. Recent findings suggest that the stress parents underwent to conceive with medical help does not translate into more difficult parent child relationships (Colpin and Soenen, 2002; Goisis and Palma, 2021; Golombok and MacCallum, 2003). Indeed, there is even evidence that the couple relationships of families who underwent successful ART treatment are often better than those of families with spontaneously conceived children (Strauß et al., 2004). Recent research has also suggested that when ART-produced children know how they were conceived, this positively influences their relationship with their parents (Applegarth et al., 2016; Zadeh et al., 2018).

The availability and the use of ART may have implications at the macro level, affecting the quantum and the timing of fertility in contemporary societies. It has been observed that the level of public trust in ART is to some extent based on incorrect information or a lack of knowledge about the limits of ART (Daniluk and Koert, 2013; Ezabadi et al., 2017; Sabarre et al., 2013; Stoebel-Richter et al., 2012). The public tends to overestimate the success rates of ART treatments, especially at advanced female ages (Sabarre et al., 2013; Stoebel-Richter et al., 2012; Wyndham et al., 2012). These misconceptions may result in the further postponement of birth in older age-groups, which can, in turn, lead to increased demand for ART. Based on the current success rates of fertility treatments, it seems likely that the share of patients who end treatment without achieving a pregnancy will increase. Thus, societies need to engage in an informed debate about infertility and family formation using ART, based on sound scientific research from various disciplines. For people to make well-informed decisions about family formation and/or extension, it is essential to increase public awareness of the impact of advanced female and male ages on reproductive outcomes (Schmidt et al., 2012), and of the limitations of reproductive medicine.

The increased use of ART also has implications for countries that have to adapt their legislation to the continually developing technologies and the changing needs and expectations of users. Reproductive travel is a challenging issue, as the legal regulation of ART differs substantially across countries. Thus, people's use of ART is not limited by national borders. For example, surrogacy is allowed in the USA, but is not permitted in many European countries (Allan et al., 2019). Some countries have secured the right of the child to know his/her descent, while others have not (Culo Margaletić et al., 2019; Harland, 2021; Igareda González, 2020; Mulligan, 2020). It might not be possible for a child to trace back his/her origin depending on the country where s/he was conceived, and on whether donor gametes or a surrogate was involved. The legal challenges also extend to the emerged family, which may consist of more than two parents if donor gametes or a surrogate mother are involved. The inconsistencies in regulations and rights make family formation challenging for individuals, and for states trying to regulate treatments in ways that are compatible with their norms and values. Societies have to debate these issues against the background of their ethical and moral norms.

# Overview of papers in this special collection

The articles included in this special collection in *Reproductive Biomedicine and Society Online* advance our understanding of some of the research gaps delineated above. This section highlights the authors' contributions to expanding our knowledge of family-making with medical help in contemporary societies.

The first study in this special collection contributes to our understanding of the 'demographic causes' of the increasing demand for reproductive medicine. For Austria, Beaujouan (2022, this issue) observes that births postponed to higher ages are often not recuperated. The study explores the gap between fertility intentions and achieved fertility at higher – and, thus, less fertile – ages. Beaujouan observes that late intentions have been increasing across cohorts, and that the numbers of women and men who are falling short of their intentions have been rising as well. Moreover, even for women with strong intentions, their probability of having a child decreases as they get older. The causes of the failure to realize fertility intentions include, but are not restricted to, biological reasons. How aware are people about age-related fertility decline? Studies on fertility awareness frequently point to the need for increased efforts to educate people about the limits of reproduction, and about how reproductive medicine can assist those with problems procreating. However, social group differences in fertility awareness and attitudes, especially between immigrant or ethnic minorities and the majority group, are rarely the focus of attention in such studies (Haug and Milewski, 2018). Milewski and Haug (2022, this issue) show that immigrant women in Germany have lower fertility awareness, and that this gap cannot be 'explained' by the socioeconomic composition of this group. They convincingly argue that to better address the needs of minority women, more efforts to understand their disadvantages are required.

The risk of experiencing fertility problems increases with age for both women and men. Still, other risk factors related to lifestyle demand our attention, as they increase the risk of infertility independent of age. The contribution by Westerman and Kuhnt (2022, this issue) sheds light on metabolic risk factors - most importantly, obesity - as significant causes of female infertility. Since the prevalence of obesity among women is increasing, and this trend is expected to continue, the relevance of metabolic status is worth exploring. While there is a body of medical literature on the causes of infertility, studies that combine a medical perspective with a social science perspective are scarce. The authors discuss the associations between infertility and various metabolic risk factors, such as obesity, female athlete triad, and oxidative stress. While they confirm that obesity has a direct impact on female infertility, they note that the effects of other risk factors need to be confirmed by future large-scale population studies.

Given that the risk of experiencing fertility problems is rising for a number of reasons, it is crucial to understand how this experience affects the well-being of women and men. Most psychosocial research on this issue is cross-sectional, and has focused on clinical samples. The contribution by McQuillan et al. (2022, this issue) provides strong evidence of a negative association between the perceived inability to procreate and life satisfaction using German panel data by applying fixed-effects modeling techniques, and thus implicitly controlling for all potential time-constant predictors of an individual's well-being.

Under ideal circumstances, people who are making decisions about family planning and the use of ART should be well-informed about the conditions for its use, and be able to weigh the pros and cons of receiving such treatments. The study by Szalma and Bitó (2021, this issue) assesses people's general knowledge and attitudes about ART in Hungary, a country that has not received much attention in social scientific research about ART. They find that in addition to expressing very positive attitudes toward ART, both women and men in Hungary have significant gaps in their knowledge about the success rates, risks, and costs of treatments. Thus, the findings indicate that there is a need to educate the public about age-related fertility declines, and about the availability, costs, and limitations of ART. Moreover, the results shed light on the role of religion in promoting ART. In Hungary, where Christian churches and communities predominate, religious individuals report having less supportive attitudes toward ART.

The contribution by Köppen et al. (2021, this issue) broaches the issue of social selectivity in medical help-seeking for infertility. This topic is important because we know surprisingly little about who seeks help, primarily due to a lack of appropriate data. This problem is especially acute in the German context, where no register data are publicly available, and the information provided in social science data sources is restricted in terms of numbers or content. The study shows that the use of MAR (non-ART treatments are explicitly included in the definition of help-seeking) is highly selective in Germany, as it is based, among other factors, on high income and marital status. In the German context, marriage is still an essential precondition for the reimbursement of treatment costs by statutory health insurance, which highlights the importance of marriage as the cultural ideal for a 'normal family'.

During the treatment process, users of reproductive medicine are confronted with many issues that are new to them, including the in-vitro creation of human embryos and their handling during and after treatment. The paper by Delaunay et al. (2021, this issue) contributes to our understanding of the meaning Portuguese IVF users assign to their embryos using a metaphorical approach. The study extends recent research by including in their analysis metaphors for embryos at all stages of treatment. Delaunay and colleagues show that IVF beneficiaries perceive their embryos in many different ways.

#### Conclusion

Research about the causes and consequences of ART, and about people's experiences with fertility treatments, has challenged our thinking about the family, and will continue do so in the future. From our current perspective, social science research about the making of families with medical help will continue at the frontier of scientific research, because it brings in an interdisciplinary perspective that is currently missing when we look at ART through the lens of single scientific disciplines. In this article, we have highlighted a range of research gaps at the international and interdisciplinary levels, and we hope that the agenda for future research we have laid out, and the contributions to this special collection, will inspire other researchers to contribute new insights on ART and MAR families. These (future) insights are important, because they will help to (i) improve the evidence base on ART and MAR families, (ii) promote the development of better clinical practices for patients, and (iii) influence future policymaking regarding family formation and family extension with medical help. These insights are based on country-specific social science data that take into account socio-demographic variables, in addition to providing detailed information on the use of reproductive medicine. With a few exceptions, such data sets are not yet available for most countries.

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