

To Disclose and Have Someone to Count on: Infertility and Social Support

Rafaela Teló Klaus¹, Marina Helena Dias Costa¹, Clara Foletto Pimenta¹,
Alessandra Vasconcellos Mendes¹, Daniela Centenaroe Levandowski¹

¹ Federal University of Health Sciences of Porto Alegre (*Universidade Federal de Ciências e Saúde de Porto Alegre [UFCSPA]*)

Received: March 27, 2021.

Accepted: March 13, 2023.

Section editor: Julia Garcia Durand.

Author Note

Rafaela Teló Klaus  <https://orcid.org/0000-0001-8459-3189>

Marina Helena Diasb Costa  <https://orcid.org/0000-0002-7626-4315>

Clara Foletto Pimenta  <https://orcid.org/0000-0002-3334-8834>

Alessandra Vasconcellos Mendes  <https://orcid.org/0000-0002-9869-4770>

Daniela Centenaroe Levandowski  <https://orcid.org/0000-0002-6338-7287>

Correspondence concerning this article should be addressed to Rafaela Teló Klaus, Avenida Augusto Meyer, 40, Sala 704, Bairro Higienópolis, Porto Alegre/RS, Brazil. CEP 90550-110. Email: ola@rafaelaklaus.com.br

Abstract

Infertile couples seeking treatment experience a social stigma that can lead to the need for privacy and, in turn, compromise their access to social support. This multiple case study, which involved the collection of sociodemographic and health data and interviews with four heterosexual couples accessed by convenience, aimed to examine the perception of the couples about the social support received after the disclosure of the condition of infertility and/or of the assisted reproductive technology treatment. The cases were analyzed individually and comparatively. From the couples' statements, it is highlighted that all of them revealed something about infertility and/or treatment at some point in the process, although some considered not revealing it. Both support and lack of support were perceived from the revelations. The non-disclosure was motivated by self-preservation and by avoidance of social pressure. The findings indicate the importance of psychological intervention to expand the couples' social support.

Keywords: disclosure, social support, infertility, couple, assisted reproduction techniques

REVELAR E TER COM QUEM CONTAR: INFERTILIDADE E APOIO SOCIAL

Resumo

Casais inférteis que buscam tratamento experimentam um estigma social que pode acarretar a necessidade de privacidade e, por sua vez, comprometer o acesso ao apoio social. Este estudo de casos múltiplos, que envolveu a coleta de dados sociodemográficos, de saúde e entrevistas com quatro casais heterossexuais acessados por conveniência, objetivou examinar a sua percepção sobre o apoio social recebido após a revelação da condição de infertilidade e/ou de tratamento com técnicas de reprodução assistida. Os casos foram analisados individualmente e comparativamente. A partir das falas, destaca-se que todos revelaram algo sobre a infertilidade e/ou o tratamento em algum momento do processo, ainda que alguns tenham considerado não revelar. Percebeu-se tanto apoio como falta de apoio diante das revelações. A não revelação foi motivada pela autopreservação e pela evitação de pressão social. Os achados indicam a importância da intervenção psicológica para ampliar o apoio social dos casais.

Palavras-chave: revelação, apoio social, infertilidade, casal, técnicas de reprodução assistida

REVELAR Y TENER CON QUIEN CONTAR: INFERTILIDAD Y APOYO SOCIAL

Resumen

Parejas infértiles que buscan tratamiento experimentan un estigma social que puede acarrear la necesidad de privacidad y, a su vez, comprometer el acceso al apoyo social. Ese estudio de múltiples casos, que involucró la recogida de datos sociodemográficos, de salud y entrevistas con cuatro parejas heterossexuales accedidas por conveniencia, buscó examinar la percepción de las parejas sobre el apoyo social después de la revelación de la condición de infertilidad y/o del tratamiento con técnicas de reproducción asistida. Los casos fueron analizados individual y comparativamente. De las declaraciones de las parejas, se destaca que todas revelaron algo sobre la infertilidad y/o el tratamiento en algún momento del proceso, aunque algunos consideraron no revelarlo. Se percibió tanto el apoyo como la falta de apoyo a partir de las revelaciones. La no revelación fue motivada por la autopreservación y por la evitación de presión social. Los hallazgos indican la importancia de la intervención psicológica para ampliar el apoyo social de las parejas.

Palabras clave: revelación, apoyo social, infertilidad, pareja, técnicas de reproducción asistida

It is socially expected that couples will have children throughout the family life cycle (Straube, 2019). However, many couples face difficulties and challenges to achieve this. According to the World Health Organization (WHO, 2020), around 48 million couples and 186 million individuals face infertility worldwide. This condition is characterized by a failure to become pregnant after 12 months of unprotected sex. Because of this, assisted reproductive technology (ART), involving procedures for the manipulation of eggs, sperm, and/or embryos, has become an alternative to achieve the marital and/or personal project of pregnancy (Souza & Alves, 2016).

Barriers and difficulties to getting pregnant impose on couples the breakdown of individual, family, and social expectations, and the challenge of dealing with stigma and social pressure for pregnancy (Simionescu, et al., 2021). Social stigma is identified as the reductionist devaluation of an individual or group based on a certain characteristic or condition, which can harm the health and self-esteem of those stigmatized (Major & O'Brien, 2005). The focus of our study will be the social stigma associated with infertility, which can generate negative feelings in infertile couples, especially in women (Ergin et al., 2018), because of the social pressure to have children and feelings of being regarded as somehow inferior to couples with children. This feeling of being different and outside of social norms (Taebi, Kariman, Montazeri, & Alavi Majd, 2021) can impact self-esteem, leading to self-stigma and self-depreciation (Taebi et al., 2021), and, at more extreme levels, mood disorders (Zurlo, Cattaneo Della Volta, & Vallone, 2020).

A survey of 598 individuals from infertile couples reported that 38% of the participants felt a sense of social exclusion, and 15% a feeling of being socially isolated and having less value; however, 60% felt that having a baby would help them acquire a notable position in the community (Ergin et al., 2018). According to a study by Vatanparast, Ardekani, Anvari, Kalantari, Yaghmai and Royani (2022), infertile couples represent one of the most neglected and silent minorities. In this respect, a survey study conducted in the USA with 327 women found that both fertile and infertile women perceived a stigma towards female infertility. Furthermore, infertile women who felt stigmatized reported the presence of negative emotions (Worthington, Burke, & Leahy, 2019). This is supported by the literature, with studies indicating that feelings of isolation, frustration, guilt, and shame are common in infertile couples (Spotorno, Silva, & Lopes, 2008; Batista, Bretones, & Almeida, 2016; Marque & Morais, 2018; Hayashi & Mariyama, 2019), resulting in significant emotional distress. Thus, infertile couples attempt to fit into the "social norm" of pregnancy by using ART to gestate and thereby conceal and manage infertility (Straube, 2019). However, undergoing ART treatment, which is usually stressful due to the uncertainty of its success, can exacerbate the feelings of inferiority arising from the infertility status, especially in long-term treatments (Zurlo et al., 2020).

In this respect, this condition has been associated with the existence of secrets (Taebi et al., 2021). This stigmatizing character, of abnormality and disability of infertility, as well as of the artificiality about the use of ART, brings questions about what and to whom to disclose this condition, especially in respect of people with whom the couple maintains close relationships, such as family, friends and/or co-workers, putting marital privacy in evidence (Straube, 2019).

When disclosing their reproductive status, these couples may be discriminated against and questioned about taboos concerning their age, the use of donated gametes, and gender and sexual orientation issues (Johnson, 2020). From this, it is questioned how much the couple's decision to disclose or not this condition impacts on the social support received by the people close to them. The stigma associated with infertility can even lead to a delay or even avoidance of seeking treatment, which can lead to a worse prognosis for these patients (Worthington, Burke, & Leahy, 2019). Social support, as an interpersonal resource aimed at preserving and increasing the well-being of those who receive it, has been studied in the field of infertility (Cunha, Carvalho, Albuquerque, Ludermir, & Novaes, 2008; High & Steuber, 2014; Martins, Peterson, Costa, Costa, Lund, & Schmidt, 2012), both with women and infertile couples (Besharat, Lashkari, & Rezazadeh, 2015; Iordachescu et al., 2021; Khalid & Dawood, 2020; Kiesswetter, Marsoner, Luehwink, Fistarol, Mahlknecht, & Duschek, 2019; Kroemeke, & Kubicka, 2018; Saleem, Qureshi, & Mahmood, 2019; Shafierizi, Faramarzi, Esmaelzadeh, Khafri, & Ghofrani, 2022). Although there are several different definitions of social support, in this study we adopt that of Rodriguez and Cohen (1998), which encompasses the resources available through social relationships and networks that help to cope with adversities, social recognition, and personal growth, and is, therefore, considered to be of great importance to mental and physical health. In addition to the composition of the support network, supportive behaviors and the subjective assessment of support are important elements to be considered, as they are associated with positive physical and mental health outcomes (Gonçalves et al., 2011). For example, a systematic review based on 34 articles indicated that people with depression who perceived that they had little social support were those who had the worst outcomes in terms of recovery, social functioning, and symptom type and intensity. The authors also found preliminary evidence of an association between perceived social support and schizophrenia, anxiety disorders, and bipolar disorder (Wang, Mann, Lloyd-Evans, Ruimin, & Johnson, 2018). One theoretical study suggested that there might be an association between perceived social support and longer life expectancy, as well as lower rates of cardiovascular disease (Uchino, Bowen, de Grey, Mikel, & Fischer, 2018). Another study conducted with pregnant women reinforced the existence of a negative association between the level of social support during pregnancy and psychosocial health, although this relationship also depends on the number of children and the partner's occupational status (Değirmenci & Yılmaz, 2020).

In the field of infertility, social support is a protective resource for coping with the challenges imposed by this condition and the treatment (Iordachescu et al., 2021), which can be long-lasting. Several quantitative studies have found an association between social support and mental health in infertile women and couples, especially in respect of lower scores for depression, anxiety, and stress in the presence of a perception of higher levels of support, that is, a perception of satisfaction with the received support (Besharat et al., 2015; Iordachescu et al., 2021; Khalid & Dawood, 2020; Kiesswetter et al., 2019; Kroemeke, & Kubicka, 2018; Saleem et al., 2019; Shafierizi et al., 2022).

Access to social networks for seeking and receiving support is an essential factor for reducing stress both for women and men (Gradwohl, Osis, & Makuch, 2013). This access may be related to the choices made about disclosure, with couples who choose not to disclose their reproductive status having less access to their support network, and thus being in a position of greater vulnerability (Rooney & Domar, 2018). On the other hand, disclosure may be related to a more active search for sources of support, which increases the chances of the couple receiving more support, although there is also the risk of making themselves subject to inappropriate questioning and discrimination due to the aforementioned stigma.

Despite the importance of social support about the health and experiences of infertile couples, few studies have explored the possible relationships between disclosure and social support in the Brazilian context. Recent international studies have investigated social support, predominantly in women, with a focus on mental health. These studies are usually based on the application of standardized instruments, and there is a notable absence of qualitative studies on the theme. Thus, in the present study, we aimed to examine the perception of couples about the social support they received after the disclosure of their infertility condition and/or use of ART, as well as to investigate how they decided to disclose or not disclose this information. Researching this relationship can expand the possibilities of intervention with this public.

Method

This is a qualitative cross-sectional multiple case study. In-depth data from more than one case with the same focus of the study was obtained to compare them with each other and identify similarities and discrepancies to broaden the relevance of the results (Yin, 2005).

Participants

Four heterosexual couples living in the state of Rio Grande do Sul, Brazil, diagnosed with infertility and undergoing treatment with ART (investigation of the causes of infertility and/or follow-up with a specialist physician and/or assisted reproduction clinic) participated in the study. Couples who had already had children (in the current or previous marital relationships) or who had speech and/or cognitive difficulties which could hinder and/or prevent the data collection were excluded.

Table 1*Socio-demographic characteristics of participating couples (n=4)*

Characteristics	Couple 1		Couple 2		Couple 3		Couple 4	
	M	F	M	F	M	F	M	F
Length of Relationship (years)	11		7		13		8	
Family Income (no. of minimum wages)	2-3		Not informed		8-9		10-15	
Age (years)	42	40	43	40	32	34	50	43
Education Level (concluded level)	HS	GR	GR	PG	HS	PG	PG	GR

Legend: M = Male; F = Female; HS = High School; GR = Graduation; PG = Post-Graduation.

The dissemination of the invitation to participate in the study occurred through the social networks (Facebook, Instagram, and WhatsApp) of the authors and other members of the Center for Studies in Development and Health (NEEDS) of the Federal University of Health Sciences of Porto Alegre (UFCSPA). From this dissemination, nine women showed interest in participating (two via email, four via Instagram, one via WhatsApp, and two were indicated through recommendations from individuals within the research team network by indication). In the initial contact with those interested, it was found that six couples met the inclusion criteria. Among them, four agreed to take part in the study and to schedule a meeting for data collection. Thus, the search for participants was closed, because, according to Creswell (2014), this number of cases (four) is sufficient for this type of study design, as it allows the deepening of the analysis, which is sought in collective cases studies (as is the case of the present study), while expanding the robustness and validity of the analyses by allowing the development of a more varied portrait of the processes under investigation (Maffezzolli & Boehs, 2008). The couples' socio-demographic data are detailed in Table 1.

The couples were heterogeneous for various characteristics such as duration of relationship (7 to 13 years), age (32 to 50 years), and education level (from high school to postgraduate). Table 2 presents the health data of the participating couples, which varied for the length of time they had been trying to conceive (from 3 years and 6 months to 10 years) and the period of treatment with ART (9 months to 4 years). Both male and female factors were observed in the couples' infertility. The ART used was programmed coitus with ovarian stimulation and in vitro fertilization (IVF).

Table 2*Clinical data of participating couples*

Clinical Data	Couple 1		Couple 2		Couple 3		Couple 4	
	M	F	M	F	M	F	M	F
Time Trying Pregnancy (years)	10		7		13		8	
Treatment Time with ART (months)	42		12		9		48	
ART Used (number of times)	IVF (3)		PI (1) IVF (1)		PI (1) IVF (1)		PI (3)	
Miscarriage* (number of occurrences)	N		Y (2)		Y (1)		N	
Physical/Hormonal problems	LSM	TROMB	N	TROMB Changes in TSH	N	END	LSM Testicular CA (right orchectomy)	US, Polyp, OC

Legend: M= Male; F= Female; IVF = In Vitro Fertilization; PI = Programmed Intercourse with Ovarian Stimulation; N = No; S = Yes; LSM = Low Sperm Motility; TROMB = Trombophilia; TSH = Thyroid Stimulating Hormone; END = Endometriosis; CA = Cancer; US = Uterine Synechia; OC = Ovarian Cyst.

Instruments and Procedures of Data Collection and Data Analysis

Before the main study, a pilot study was carried out with a couple with a similar profile to that used in the study to check the suitability of the instruments and whether there was a need to make any adjustments. After the pilot study, the dissemination of information about the study for the recruitment of participants was initiated on social media networks.

As previously mentioned, during the first contact, the couples were evaluated to determine whether they met the inclusion and exclusion criteria of the study. Subsequently, a meeting was scheduled for data collection with those couples who confirmed their interest in participating. This took place at a convenient time for the couple in a location of their choosing (office of the first author: n = three couples; residence of the couple: n = one couple). The meeting started with the reading and signing of the Free and Informed Consent Form (FICF) by each spouse. After that, the following instruments were applied, in this order: a Socio-Demographic Data Sheet (adapted from Lopes, Piccinini, Dornelles, Silva, & Passos, 2007), to collect the individual spouses' data (such as age, gender, education, etc.); and a Health Data Sheet (adapted from Lopes et al., 2007), to gather health information on the couples, including that related to infertility and treatment.

After the individual and simultaneous application of the two instruments, a semi-structured interview was carried out with the couple (Interview with the Couple; adapted from Lopes et al., 2007), to explore the decision to have a child and to undertake treatment with ART, to investigate the decision to disclose (or not) information related to infertility and its treatment,

as well as the social support received. All the interviews were audio recorded and later transcribed for analysis. The average duration of the data collection was 2h45min; for one of the couples, it occurred over two meetings, as it was not possible to conclude the interview in only one. Data were collected in person between September and October 2019 in the city of Porto Alegre, Brazil.

After transcribing the interviews, the second and third authors read the material successively and independently, seeking to identify the participants' excerpts according to the study's thematic axes, listed a priori based on the study aims, these being: 1 - The disclosure of the diagnosis and/or treatment for infertility to those close to the participants; and 2 - The participants' perception of support. After this individual and independent selection of the interview excerpts, the two authors then compared the results of their analyses to identify any divergence in the selection and allocation of the participants' excerpts. In general, the same excerpts from each interview had been allocated by both authors to the same axes. In the few examples in which the authors' allocations diverged, a consensus was reached through discussion. The authors then prepared a single file containing the thematic axes and the respective participants' excerpts. This material was then reviewed by the last author, who acted as a "blind judge", reviewing all the excerpts allocated to each thematic axis to verify the appropriateness of the allocation. As all the allocations were pertinent, no adjustments were necessary. Based on this material, a report on each case was organized. It is important to emphasize that these procedures do not represent a standard thematic analysis, although they were carried out carefully to avoid biases. What was sought was a thematic organization to guide the preparation of each case report, to standardize to some extent, the presentation of information from each case and facilitate subsequent understanding and comparison among them. Socio-demographic and health information were organized descriptively in tables to characterize the cases.

The individual analysis of the cases was then carried out through the strategy of theoretical propositions (Yin, 2005), seeking to understand them according to the existing literature on the subject. Then, through the strategy of cross-case synthesis (Yin, 2005), a comparison among the cases was sought to identify the similarities and differences between them regarding the disclosure and perception of support, in order to broaden the understanding of the phenomenon.

Ethical Considerations

The research project was approved by the Research Ethics Committee of the UFCSPA (Opinion 3.420.420) and met the current guidelines in Resolutions 466/12 and 510/16 of the National Health Council (Brasil, 2012, 2016) for research with human beings. The FICF informed the participants about the aims, procedures, and ethical guarantees of the study. The couples' participation was voluntary. Despite the theme of the study, the instruments applied were considered of minimal risk, and no harm was identified due to their application or the need for referral of the participants. The material of the study was duly filed at UFCSPA, for the maintenance of confidentiality.

Results

The presentation and discussion of the cases follow. The themes highlighted in the construction of each case report and in the analysis were: disclosure and non-disclosure (considering the excerpts that referred to telling or not telling people close to them about the infertility diagnosis and/or treatment with ART) and their perceptions of support (presence or lack of) in this process.

Couple 1: Irene (40 years old) and João (42 years old).

The couple had been trying to get pregnant for ten years (the last three years via ART). They said that they had not told their families about their infertility or treatment, because Irene's mother was already deceased anyway and João 'lives the grief of living parents', according to Irene. Although a few people knew about the treatment, the couple thought that many people suspected they had a fertility problem: "I think people began to realize that it has been so many years and it never comes ... 'Is there a problem?' We keep the fact that we are undergoing assisted reproduction very secret, we don't tell. Our family does not know. Very few friends know (...) Other couples know about our infertility, but they do not know about IVF (...) knowing about our infertility is one thing, knowing about the treatment is another" (Irene).

As reasons for not disclosing the treatment, the couple reported social pressure and the lack of understanding of people: "I think there is even a greater demand, too, you know? (...) 'Have you ever thought of doing IVF? Because a friend of mine did it and it worked'. And then I think: 'OK, Will I tell her that I've already done it three times and it didn't work out? What a failure! No, it won't make any difference if I tell her, you know? She won't understand, because for her it always works out (...)" (Irene). Another reason for the couple avoiding disclosure was the belief about people's envy: "People are green with envy" (João); both spouses did not like to talk about the subject with other people: "So I avoid it, unless I feel very safe" (Irene). There was a difference in the spouses' perceptions regarding having a specific space to talk about infertility, as John did not mention the need for this, unlike Irene: "I think that, in a certain way, I miss having a space to talk about it, you know? I think it is important, right? Seeing all the women that I saw in that group (of WhatsApp) and by my experience... And then I realize this lack of... even of preparation, you know, to cope with this issue of infertility, this diagnosis, telling and not telling something about it to others, for example (...) I already felt this difficulty, at the time I chose to tell some people but not others. But then I began to think: 'Why don't I tell? Why did I tell? What difference did this make to me?'" (Irene).

The couple told a few people close to them about undergoing treatment, as they understood that they could offer support and be welcoming: "You tell people who you think will give you support, discuss it with you, understand, and offer comfort, something" (João). Irene told a close person because she is a person with positive energy: "She is a very positive person, you know? She is an understanding person, it's as if you find comfort telling her things". (Irene). The spouses also shared their experiences with people in similar situations: "We have some

friends who are also infertile. So we manage to talk a little more openly, more frankly (...) When we talk, she understands me. When the treatment failed, they came to visit us. Like 'you are in a bad way and we are here, we know how difficult this is'. So it is different" (Irene).

Both spouses perceived changes in the relationship with people close to them after the disclosure (greater closeness) and reported having received encouragement and support from them to continue: "This couple of friends knew we were doing the treatment and when it did not work out we could tell them and they made a point of coming to visit us (...) It is a hug that we ask for, do you understand? With her I can cry, I can say everything, my positive and negative thoughts, right? (...) in the face of an inconstancy like that, I can talk with her" (Irene); "Yes, moral help, incentive. (...) And these friends there... if they hadn't told us to do it again, I don't know if we would have done it, right? I do not know if I would not have stopped at the last (IVF)... They said: 'No, do it! You want to, you can do it!'. And then we stopped to think, we talked... 'Yes, let's do one more!" (João).

However, the couple also reported an experience of lack of support after the disclosure to a childhood friend. Irene talked about how she fell out with this friend, who was pregnant and did not understand her situation: "I lost a friendship (...) She came and said to me: 'Irene, you must be doing something wrong, because if I got pregnant, you can get pregnant!'. And she didn't understand the complexity of my situation. She didn't understand anything and we ended this friendship because of that, it was regrettable" (Irene).

Couple 2: Tânia (40 years old) and Eduardo (43 years old)

The couple had been trying to get pregnant for three years and six months, the last year through treatment with ART. In the first year of trying, a pregnancy was spontaneously terminated in the first few weeks. Approximately one year later they started the investigation of possible difficulties and soon became pregnant again. This pregnancy did not progress either. Soon after this, treatment with ART was initiated. The couple highlighted the importance of their emotional condition and that of the people close to them to receive and deal with the information as the reason for disclosure or not, particularly anxiety: "Our emotional state is the main thing that influences us in respect of telling or not telling. At this moment, our emotional state does not allow us to talk to others. So it is likely that she (Tânia) will talk much less, interact much less" (Eduardo).

Although they had told some people, over time the spouses started to avoid talking about it, even to people close to them, to avoid "pressure", comments, and tips not relevant to their process: "I have avoided talking. After IVF in fact (...) I did not talk about it with my friends and they do not know that I did it and it did not work out (...) I am glad I did not tell them so that they didn't ask me about it (...) Regardless of who it is, whether it is in my family or Eduardo's, there will always be pressure, right, and the pressure is not for badness, but it is for as much anxiety as we go through, right? My mother wants a grandchild, Eduardo's mother wants a grandchild, you know? It is all for the same goal, but it is difficult" (Tânia).

After understanding the need for treatment with ART, the couple, despite some ambivalence and uncertainty, decided to disclose the situation to several people. This decision to share brought, in general, a feeling of support: "From my point of view, the people who I remember talking to, who were the closest, were super positive. (...) They were much more concerned about our happiness than any other medical issue. (...) I think that the more we talked, and the more opinions we listened to, the easier it was for us to assimilate the whole process, and it became more natural for us and everyone" (Eduardo). This support was perceived more clearly in people who live or have lived through similar situations: "It is another type of connection, another type of interaction, with more room for openness and exploration in the conversation" (Eduardo). The couple also mentioned the support of friends and family at specific times (for example, during the embryo transfer and the second pregnancy loss): "When I did the IVF, my mother came to the house, she stayed the whole weekend cooking. When there was a loss, I went to my friend's house (...) And they took care of me all day from the time I entered their house, her husband came and took off my shoes and put slippers on my feet. So we had help, more often support than no support" (Tânia).

For both spouses, some relationships became more intimate after the disclosure, which generated feelings of gratitude in the face of genuine exchanges: "It brought me closer in a way to my family and her family, maybe more than if I had not lived this situation, I would never have approached (...). I would never have talked or created an intimacy maybe with some people, if not because of this (...) I would say that I felt welcomed and supported, you know?" (Eduardo). However, situations of lack of support after the disclosure also emerged: "I also felt that there were some people who lost patience in the middle of the process, much faster than us. There was a friend who thought that I was suffering too much, and that I should have stopped suffering and have taken a holiday and, the moment I took this holiday, I would get pregnant (...) People end up minimizing it by saying: 'Don't worry, it's because it wasn't meant to be... There must have been some problem, that's why it didn't work out. You will get pregnant soon!" (Tânia).

Tânia said she felt that, when faced with the miscarriage, because it was a very delicate situation, people did not know what to do and did not know how to support her in the way she would have liked. But she also recognizes that, despite having felt lost, she did not ask for help.

Couple 3: Sheila (34 years old) and Oscar (32 years old)

The couple had been trying to get pregnant for seven years, having started the use of ART nine months ago. At the beginning of her attempts to get pregnant, Sheila had many consultations and the family followed this process closely.

The couple had different motivations for sharing their situation with people close to them. Sheila had more difficulty than Oscar talking about the subject: "The IVF we shared with everyone, that it happened and then it failed. (...) It is strange, there are times when I think no one should know, but other times when I think that they should know" (Oscar); "When we decided to do the IVF, I am not the sort of person who used to tell others about my problems.

(...) It was very difficult to talk. (...) I had never spoken so openly. But Oscar found it easier to talk than I did, I think” (Sheila).

The couple found it more difficult to deal with comments or advice received from people after some disclosure than to disclose their condition per se: “I think our issue of not talking... it is more related to avoiding to listen to some things that people say” (Sheila). Therefore, the couple oscillated between disclosing and not disclosing their condition to people close to them. Initially, the diagnosis and treatment were disclosed; over time, especially after the pregnancy loss, they decided not to disclose anything, due to the need to protect themselves from comments and advice: “They say a lot of unnecessary things, or they say things out of spite, or they say things without knowing what they are talking about and end up hurting us” (Oscar).

At the same time, they felt relief when they chose to reveal and share their experiences: “I feel that we needed to talk. When we started IVF, we agreed that we would not talk anything about it to people. But whenever we met our friends, we said things such as: ‘Sheila took an injection’, ‘We went to Porto Alegre’, ‘We are coming back from Porto Alegre’ (...) It seems that it was a way of keeping them inside the situation, but also to feel relieved” (Sheila).

Until the first IVF, the couple received help from close people in different ways: their presence, availability, an offer of financial resources and food, and help with the use of medications: “They (friends) know that they simply have to be on our side. (...) When we did the IVF, we were together, they were supporting us. At no time, asking anything. (...) I think that during treatment, we received a lot of help” (Sheila); “When I looked, he (his brother) had already sent me ‘Oh, the money is in your account’ (...) Even in family situations, when I was waiting for a positive result, they did not leave the house. It was everyone there always together with me, and friends going there” (Oscar).

The couple celebrated the pregnancy confirmation with close people. However, after the pregnancy loss, they noticed a distancing from them: “When it was negative, when we lost it, on the day, the house emptied. Only our friends came. No one from the family came” (Oscar). Both spouses consider that this distancing resulted from people’s lack of knowledge about how to support them: “From the moment we lost the pregnancy, perhaps because we had also isolated ourselves, people didn’t know how to talk... They tried to cheer us up, but they wouldn’t talk about it. Oscar’s brother and my sister-in-law took us to stay for four days at the beach. They wouldn’t talk about it, but we wanted to, because they knew our story, you know?” (Sheila). Sheila reported that they decided to isolate themselves more and not tell anyone about it when they talked to the priest (whom they considered a close friend), 15 days after the loss, when he said: “Look, Sheila, you have to get it into your head that if you were born infertile, you will be infertile. You have to think that you are healthy” (Sheila).

The couple also referred to other experiences of lack of support after the disclosure, due to people’s lack of sensitivity. At lunch, the only friend who knew what they were going through said: “Now I want to take a picture of only those who have children” (Sheila). The spouses reported that, due to attitudes like these, they do not reveal much anymore to avoid further hurt

feelings. They also mentioned social events at which they were asked why they had not yet become pregnant or why they had not adopted. Although they understand people's reactions, they consider that only those who live the same experiences can really understand what they felt: "Now we listen to people and realize that they cannot understand what we are going through, right? I think that only those who go through this will be able to understand" (Oscar).

Couple 4 – Fernanda (43 years old) and Roberto (50 years old)

Fernanda and Roberto had been trying to get pregnant for five years, the last four with ART. The couple decided not to disclose the diagnosis and treatment to people close to them, as they thought it was a matter for them and to avoid external comments and interventions: "Fernanda is a person who values her individuality, her space. And at a certain moment, we decided not to tell anyone (...). Not least because it was a demand that came from her. I did not feel so needed about it, and in practice, I have not talked to people about this issue. (...) I think I feel a little embarrassed to have a conversation with someone. (...) Especially because many things concern Fernanda, and I do not know how much she would feel comfortable for me to expose..." (Roberto); "Our decision was partly because of the fear we had, especially in respect of the families intervening negatively, even if they wanted to help, because of taboo issues, you know? Of beliefs that concern them that don't necessarily concern us, you know?" (Fernanda).

Also, there was a desire for non-disclosure to avoid pressure and judgments from close people. According to Roberto, in his family there is not much space to talk about feelings: "So if you say something that you are feeling, the usual reaction is: 'What? What nonsense, it has nothing to do with us' (...) And then there is the question of judgment, right. Soon there will be a cousin who drinks a little more on the weekend saying: 'Yeah, Fernanda is too fat, and because you are still smoking, Roberto, how are you going to get pregnant? So you have to...'" (Roberto). However, as Fernanda begins to feel the need to receive support, the couple decided to disclose their experiences: "I felt a need to feel supported. I realized that this process is delicate, and that I am going through a process of transformation, in which I have to face my vulnerability, in which I need care, in which I may not be so available for some things, and that I may have to say no, or that I cannot say yes" (Fernanda).

When revealing their situation, the couple tried to find a balance between what the others could absorb, without too much emphasis on emotions, so that there was less possibility of creating difficult questions, denoting care for others and for themselves: "It had to do with what people could offer (...) In the measure of not getting worried and not getting other people worried. (...) We know the people around us and, more or less, what each person has to offer" (Fernanda).

Following disclosure, the couple noticed some changes in their relationships; while some people showed more affection, others showed more concern: "There has been a process of very big change in the way Fernanda's parents have been relating to us. So, I think that they are much more affectionate, particularly Fernanda's father" (Roberto); "He [father] is always saying: 'Look,

I am rooting for you. I wanted to say that, if it depends on my positive thinking, it will happen'. And I think this is super cool, you know?' (Fernanda).

The couple, in general, felt supported when they revealed their condition, whether in the form of financial help or offer of services (acupuncture) or in the form of encouragement and emotional support: "In general, yes, in general, there is a supportive environment" (Roberto); "The sharing of joy, support... Positive manifestations and some curiosity too, right? (...) And some people are very concerned with the aspect of money, how much it will cost (...) And also the emotional support" (Fernanda).

There were also differences between the spouses regarding disclosure: while Fernanda revealed information and situations and felt supported, Roberto did not: "I feel, by sharing with people, I am breaking the taboo, and talking about it is very important, because I feel different" (Fernanda); "And I'm very closed, so I, in fact, never approached a person who was exclusively on my side of the relationship, and sat down to say 'we are trying to have a child'. Never. (...) I realize how much I am inside a bubble" (Roberto).

The couple noticed a light social pressure, coming from some family members, due to the disclosure of the infertility and the treatment: "One of my brothers who is more opinionated, who does not have a child, also worries, asking: 'What are you going to do? What are you doing? Don't you think about adopting?'" (Fernanda). There was a much different experience with a couple of friends who had also undergone ART, with the exchange of experiences and the possibility of expressing feelings related to the process: "I was touched by this, because she is at the end of her process, at the end of the pregnancy. She said: 'Ah, thank you very much'. Then I thought: 'It was good for her to talk about it too, so that's why she thanked me'. And I thanked her. (...) This was one of the things that were nice when people express their feelings and intimate things... It is really good to share, right? (...) because we are more or less in the same process. (...) we do not feel like we are E.T. ". (Fernanda).

Discussion

The analysis of the cases showed that there were some similarities and differences among them. Regarding disclosure, the experiences were diverse, but all the couples considered not disclosing their infertility, their attempts to get pregnant, and/or undergoing treatment to people close to them but, at some point, disclosed these experiences.

Although people close to the couples may have concluded that they may have a fertility problem, disclosing the treatment was still difficult because it represents something private and acknowledges the failure of natural conception attempts. Some couples chose to be more reserved after the treatment (Couples 2 and 3) others disclosed this information to a few people (Couples 1 and 4). Although the treatment is a way to solve infertility and conform to social norms to pregnancy (Straube, 2019), at the same time, it is a choice fraught with anxieties and expectations concerning pregnancy, as well as sadness and stress in the face of unsuccessful results and the need to deal with the emotional pain, not only of the partner, but also of everyone

aware of the treatment (Cunha et al., 2008; Spotorno et al., 2008; Nascimento & Tézis, 2010). Thus, not disclosing may be a way to “spare” the support network from experiencing the tensions inherent to the treatment.

A common aspect shared by the cases was the change observed in what and to whom to disclose over time. This may have happened due to the couples becoming more adapted to the treatment situation or even a greater acceptance of the infertility condition, since treatment can provide a sense of control over it (Moutzouri, Sarantaki, & Gourounti, 2021). The need to obtain support to deal with the stress caused by the procedures and their failures (Kroemeke & Kubicka, 2018) may also have motivated this change. Future studies could investigate these issues in more detail.

In the present study, men were more likely not to disclose information about the infertility or treatment than women. This may be due to the quality of their relationships with family members and other close people. However, our findings go against those in the literature, which indicate that women feel more stigmatized by their infertility condition (Ergin et al., 2018; Worthington, Burke, & Leahy, 2019) and are therefore more likely not to disclose their situation. Our results may be explained by the Brazilian socio-cultural context, with being part of an infertile couple representing a failure of masculinity and virility for these men (Valadares, Alves, & Bezerra, 2021), arousing feelings of frustration, inferiority, guilt, and shame, which have been reported in the literature (Spotorno, Silva, & Lopes, 2008; Batista, Bretones, & Almeida, 2016; Marque & Morais, 2018; Hayashi & Mariyama, 2019).

The fact that the couples in this study initially opted for privacy regarding infertility and/or treatment may be a form of emotional preservation (Johnson, 2020) when faced with social pressure or pressure in family and friendship relationships (Couples 1 and 4). In this respect, in a study by Berger et al. (2013), infertile women reported feelings of stigmatization, misunderstanding, discomfort and expectation of a quick solution to the problem coming from others. Stress is commonly experienced by infertile couples due to the difficulties in coping with situations involving family and friends, especially in the absence of social support (Gradwohl et al, 2013). Indeed, the absence of social support (or the perception of less support) is to be associated with worse mental health status of infertile women/couples (Khalid & Dawood, 2020; Kiesswetter et al, 2019; Saleem et al, 2019; Shafierizi et al, 2022).

However, individual aspects, such as attachment patterns may also contribute to this perceived absence/lack of support, as demonstrated by Saleem et al. (2019) in a study with infertile women. Those with an ambivalent attachment pattern perceived less social support and experienced more mental health problems. This may explain the difficulties reported by Couples 1 and 4 regarding the family of origin of one of the spouses. The attitude of each spouse towards the couple's privacy, as well as a lack of emotional support and disagreements with family members are important reasons for family and social conflicts, according to a Brazilian study on couples undergoing ART (Nascimento & Tézis, 2010).

Thus, the restricted communication about infertility in the social context may indicate feelings of shame, frustration, and inferiority of the couples, as mentioned earlier, especially considering that this topic involves the couple's sexual behavior (Spotorno et al., 2008). Together with the social stigma associated with infertility, it constitutes and portrays a painful experience (Straube, 2019) which can cause a sense of failure in the people involved (Batista, Bretones & Almeida, 2016; Marques & Moraes, 2018).

In the present study, the social pressure for pregnancy was perceived in the form of demands, unexpected and 'unnecessary' comments and/or unsolicited 'tips'. Similar findings were reported by High and Steuber (2014) among infertile North American women when investigating discrepancies between the expectations and the actual emotional support received from friends and family. These women felt that they had received an excess of information from their social support network. This panorama expresses the fear of couples of not being sufficiently supported emotionally and, at the same time, being 'bombed' with suggestions and recommendations. In the present study, the couples reported finding this more difficult than the actual disclosure of infertility and/or treatment itself, evidence of the difficulties in communicating with interlocutors who to know on the subject, as is indicated in the literature (Johnson, 2020).

Thus, participants were reticent to disclose information on their infertility and/or treatment for fear of family interference and comments that could bring sorrow, and because of feelings of incomprehension and the desire to avoid worries and the stress caused by having to provide explanations throughout the process. In fact, in this study we observed a change over time in the listening and welcoming of close people, in the sense of decreased patience and understanding of the emotional state of the members of the couple and their perseverance in relation to the treatment (even though their desire to become pregnant remained the same). The couples felt that the anxiety of the people close to them often translated into pressure to rapidly resolve their infertility with the achievement of parenthood (Berger et al., 2013). This may simply have been through a desire to see an end to the couple's suffering, but it may have also been due to a lack of interpersonal skills or emotional unwillingness to support them in the long term.

Thus, the social pressure for pregnancy and the stigma regarding infertility contributed to the couples' difficulties in disclosing the treatment, even to people they considered close to them (Simionescu, et al., 2021; Taebi et al., 2021). In this respect, the findings demonstrate how infertility can be marked by secrets due to the unwillingness of couples to disclose information (Taebi et al., 2021) or even raise doubts about marital privacy (Straube, 2019), which agree with the literature. Thus, when selecting to whom they want to communicate their infertility and/or treatment, couples indicate who their main sources of support are (family and friends), evidencing the strength of kinship and friendship bonds (Batista, Bretones, & Almeida, 2016). In these relationships, couples seem to find characteristics such as availability, confidentiality, and care, which are essential for the perception of social support (Iordachescu et al., 2021).

While, while two couples (Couple 2 and 3) had disclosed the diagnosis and treatment to friends and family, the two others (Couple 1 and 4) disclosed mainly to friends, omitting some

aspects from family members (Couple 4, for example, did not disclose to the spouse's family). These findings are like those of Martins et al. (2012) in a longitudinal study with Danish women and men (at the beginning of treatment and after twelve months of follow-up), in which the vast majority of participants reported having disclosed infertility to close people (91.7% to family and 94.3% to friends). In the same study, the relationship between social support and infertility-related stress was mediated by the decision to disclose this condition to the support network. Even when disclosure to only one close person occurred, the benefits of social support for stress reduction could already be perceived. On the contrary, when this disclosure did not happen, this beneficial effect of social support on infertility-related stress was no longer observed. Similarly, Johnson (2020), in a qualitative study with women in treatment in Cordoba (Argentina), also reported that sharing the treatment experience with extended family and friends can be an effective and valuable resource for obtaining support.

It was clear in the present study that couples disclosed their infertility condition and/or treatment because of their need and expectation of receiving support. The disclosure was made to people who had something to offer (such as being willing to listening and offer support, affection, or practical help) and when couples felt safe or were worried or excited about the treatment, being the emotional state and the inconstancy of the experiences a determinant aspect for the decision to share. These findings agree with those of Straube (2019), who suggested that disclosing information about infertility arises from a need for support, especially when facing successive treatment failures. Therefore, expressing oneself in a safe environment serves to foster the network support, which shows to be, according to Gonçalves et al. (2011), a protective factor for couples in the face of stigmatization, reducing the risk of developing common mental disorders (Cunha et al., 2008). Disclosure allows for openness, the demonstration of vulnerability and the promotion of empathy in relationships, leading to the destigmatization of the use of ART to achieve parenthood (Johnson, 2020).

Some couples (Couples 1, 2 and 4) reported having the experience of disclosing the treatment to people who had gone through a similar process. These reports showed mutual identification with the process of and by others (with greater empathy and a sense of normality) and understanding (sensitivity), which allowed the sharing of these experiences with fewer "filters" and concerns. Although Couple 3 did not have this experience, they did say that they thought that only those who had gone through the process could properly understand it. In this respect, a study by Johnson (2020) found that the social spaces formed by women with experiences of treatment with ART stimulated the communication and sharing of these experiences, allowing the validation of the language and the emotional and physical processes, as well as the verification of the similarity of goals.

The exchange of experiences among people living with infertility can serve as a model for coping with this condition (Hayashi & Mariyama, 2019). Searching the internet for groups or people in a similar condition favors and enables the exchange of experiences, mutual support and identification, and the acquisition of information. Such resources have been increasingly

accessed, especially by women, who tend to feel isolated and misunderstood by those who have not faced this same challenging condition. In particular, the online universe promotes discussion of stigma because of a feeling of safety provided by anonymity (Straube, 2019). However, this can also occur in the face-to-face context, as shown in a study conducted in Curitiba, Brazil. The authors noted behavioural changes in participants taking part in face-to-face group sessions and concluded that the psychological intervention facilitated the learning of new repertoires for coping with the difficulties related to infertility, strengthened positive aspects of marital and social relationships, and promoted emotional regulation (Hayashi & Moriyama, 2019).

Comparing these data with the findings of the present study, it can be observed that, in general, the couples who disclosed their infertility condition and/or treatment to people close to them felt supported and more resilient in the face of adversities, with greater acceptance of their condition. This demonstrates the benefits of disclosure in respect of receiving social support, since the presence/satisfaction with it acts as a protective resource and a promoter of resilience when facing this condition and the treatment (Iordachescu et al, 2021). Moreover, it is associated with better mental health status in infertile women and couples (Khalid & Dawood, 2020; Kiesswetter et al., 2019; Kroemeke, & Kubicka, 2018; Saleem et al., 2019; Shafierizi et al., 2022) and with their better adjustment to infertility (Besharat et al., 2015).

Although they were able to obtain support, at times the couples felt misunderstood by people close to them after the disclosure. In line with this, a study in which American infertile women participated reported that family, friends, and other close people were both sources of support and stress (Berger, Paul & Henshaw, 2013). Disclosure can have positive effects when it results in greater closeness between people through greater presence and emotional availability, demonstrations of interest and affection, genuine exchanges, and intimacy, but can also promote distancing when the couple feels judged, and in some cases can even lead to the breakdown of some relationships (Couple 1). Thus, it was possible to note the positive effects of social support and the negative effects when it lacks. Gonçalves et al. (2011) highlighted different studies that show the importance of social support networks for physical and mental health, considering it to be a protective and health-promoting factor, as it contributes to coping with developmental crises, stress and social or physical vulnerability. This aspect is particularly relevant in the field of infertility, due to the prolonged exposure to stressful situations resulting from the diagnosis and ongoing treatment (Iordachescu et al., 2021).

In summary, the present study showed that all the couples considered not disclosing information about their infertility and/or treatment to people close to them but did disclose such information and experiences at some point. The couples reported both positive and negative aspects of disclosure, which were associated with how they experienced the social support (although the couples did not report the positive effects of non-disclosure). Therefore, both disclosure and non-disclosure can impact the lives of these couples and the perception of support in different ways.

In view of these findings, the work of psychology professionals with this population is very important. They can help to provide a space for listening and dealing with emotional issues, directing their work towards developing strategies for understanding both physical and emotional processes and ways of coping for those who experience infertility and resort to ART. Particularly group intervention could be provided for people experiencing similar processes. It can promote mutual recognition, exchanges, and empowerment to them, building a support network formed by people who understand each other because they face the same situation.

Regarding the theme of disclosure versus privacy about infertility and the use of ART, it is also the role of the psychology professional to encourage reflection on this issue, both at the group and individual level, so that couples can understand the function of disclosure, who it is important to disclose to and how to do it, as well as identify beliefs that may be preventing or hindering the receiving and seeking of support. In this way, the professional will help the couple to become aware of their needs and choices, to establish marital boundaries and strengthen their social support network.

Although this study has contributed to the understanding of the theme, some limitations should be pointed out. Future studies may explore other issues involving disclosure in the context of infertility, such as the characteristics of the personality of both members of the couple and how it happens depending on the specificities of the treatment (for example, gamete donation) or in specific situations and to some people, aspects not covered by this study. Second, as the participants were patients from private clinics, our findings may not reflect the reality of couples from other socio-economic levels. Finally, it is also necessary to explore the perceptions of family and friends about the disclosure of this condition and the use of ART, the support provided to couples and the support requested by them, as only the perspective of couples was investigated in this study.

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