Infertility treatment and the risk of drop-out of couples in a focus group research.

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Abstract

Conceiving a child and start a family, constitute the deepest desire of each person and it is also an important stage of development by completing the psychosocial individual and marital identity. Numerous studies say that one of the main consequences of infertile couple, are individual and psychological problems. This can lead to the onset of possible states of depression, anxiety, social isolation, sense of incompetence, and also may result psychosomatic disorders. This negative state can involve different areas of life, also at work and interpersonal relationships, furthermore of couple's life, and such as the sexual area (Cousineau, Domar, 2007; Costa, Nazzaro, 2008; Righetti, Galluzzi, Maggino, Baffoni, Azzena , 2009).

Modern techniques in assisted reproduction treatment (ART) can be a good solution to the problem of infertility. To note is that these procedures can create a very high emotional charge with the feeling of lose of control regard intimate sphere and the sense of intrusiveness in different areas of the person both physical and psychological. Stress and too high tension, often can induce couples to abandon treatment prematurely, the so-called drop-out phenomenon. The rate of drop-out in pairs can be up about 60% (Schroder, Katalinic, Diedrich, Ludwig, 2004). It's necessary to understand more about this high rate of drop-out and to try to prevent or at least restrict this phenomenon as well as possible. The support of couples during this process should also be considered.

Unfortunately, since today this topic is still unusual and even in science it is still unclear. This research presents a focus group of eleven students of psychology. Their job is to investigate the representations of the ART and the risk of drop-out in couples and to explore the knowledge related to the ART in a general sample.

Keywords: representations, assisted reproduction treatment, focus group

Introduction

The World Health Organization (WHO) estimates that approximately 8-10% of couples have infertility problems. In a worldwide scale it means that 50 to 80 million people suffer for this problem (World Health Organization, 2011). Specifically, in Italy 15% of couples is infertile (Ministry of Health, 2011).

According to the World Health Organization the impossibility of pregnancy, also called infertility, can be defined in this way: "*Infertility is the inability to conceive a child. Considered a couple may be infertile if, after two years of regular sexual intercourse, without contraception, the woman has not become pregnant [...]. Primary infertility is infertility in a couple who have never had a child. Secondary infertility is a failure to conceive following a previous pregnancy. Infertility could be*

caused by infection in the man or in the woman, but often there is no obvious underlying cause." In other words the WHO distinguishes three different types of infertility:

- The first one is *primary infertility:* when couples after two years of regular unprotected sexual intercourse do not conceive a child;
- The second one is *secondary infertility*: when couples just have a child and after two years of regular unprotected sexual intercourse do not conceive a child;
- The last one is *infertility*: couples have got a reproductive potential but a pregnancy is never brought to term.

The diagnosis of sterility does not necessarily correspond an inability to conceive a child for the entire life, but rather than, the difficulty in conceiving a child over a period of time. Therefore the rate of infertility, will worldwide includes both people with an absolute infertility and persons with a certain rate of probability of conceiving a child.

Psychological aspects of infertility

The conditions of infertility are accompanied by a great physical effort and also a huge psychological stress and this situation is considered as a life crisis or as a trauma in which the couple is not prepared.

Infertile couples can decide among many alternatives techniques of assisted reproduction treatment. They are motivated by a strong desire of conceiving a child and in this decision it's evident that this is the deepest desire of both. . These techniques demand a big involvement of their resources and a great difficulty in carrying out various treatment procedures.

Having a child is a fundamental and crucial role in human life. Parenthood isn't just a biological fact but also involves an unconscious and intrinsic investment connected with the subjective value of becoming a father and a mother. Parenthood is a passage that reveals maturity of the couple, where both accepted their diversity and search each other as a source of support and help (Costa, Nazzaro, 2008; Volpini, 2011).

Couples motivated by a strong desire for a child, creates a physical and psychological space for a third person, conceiving an imaginary baby that is created by unconscious phantasies. Psychological and physical space is constituted by certain nutrient availability, also called *nurturance*. Conceiving a child shouldn't only reduce in a simple physiological act but it's also a complex event which changes the lives of couples and the life of new being, not only created through the psychological existence in the minds of the parents (Ammaniti, Cimino, Trentini, 2007).

Today, through a self-determination, pregnancy is not longer considered as a destiny but as a personal decision, when the internal and external conditions are ideal to take care for a child. Women work for a personal and professional fulfilment, putting off marriage and motherhood in old age. When the couple feels ready for conceiving a child, it triggers an immediate need, but it doesn't happen instantly and so these persons may have experience difficulties in fertilization (Righetti et al., 2009).

When this difficulty persists, the couple is put into a state of deep emotional pain that may affect various areas, such as like the alteration of everyday life, disruption of social life for example in work and in family, the confusion of perception of themselves and doubting their overall functioning. The couple feels precluded by the possibility of entering in the roles of parents and perceives a certain interruption in the continuity of the processes of evolution of personality (Flamigni and Mutinelli, 2001). The two partners can develop feelings of shame because the lack of envy and simultaneously arise negative emotions towards others, who dosen't have this problem. They may feel jealousy when they are surrounded by families or when they go know about a new pregnancy. They are often frightened by these feelings and so they try to hide them with the consequence of not recognizing other, like themselves.
It emerges feelings of lose, that are very similar to those experienced in a situation of death of someone. There are two types of experience that can verify in situation of death: the stable one and the applicant. The first refers to a death in which you can not cry on a person's body just lost but you cry about the absence of a child who never existed. At the same time the child is at all times like in dreams and projects present and often the parents had already given a name to the imaginary child. This mourning is particularly difficult because it doesn't allow the comforting rituals, such as funerals and vigils, which normally accompany these moments. This type of experience of death involves recurrent exacerbation each month when they meet again the menstrual cycle. These couples still want a child and they may have already experienced some failures in a clinic of ART and often they are looking for another clinic to create new hopes. They do never stop to think about this problem and they are always looking for new therapies and solutions (Froggio, 2000).
Numerous studies, including one conducted by Costa and Nazzaro (2008) analysed the possible developments of psychopathological disorder following the diagnosis of infertility such like a depression (20%), anxiety (16%), social isolation with difficulty to relate with other people (10%) and psychosomatic disorders (18%). This reflects the strong link between corporeal and mental states (Costa, Nazzaro, 2008; Righetti et al., 2009). In some cases it can be found a certain alteration of the perception of time where time is measured only through the menstrual cycles (ISS, 2011).

The psychological experiences of patients ART

The complex experience of infertile couples depends on the chosen techniques. The whole experience during the ART is influenced by the high frequency of monitoring, resulting feelings of loss of control of their intimacy in relationship with their partner and as well as of their own body. There is also an exasperated waiting for a positive outcome. The obsessive attention to his bodily processes and changes caused by medicine may cause an alteration of the function of the body. Men can have difficulties in giving seminal fluid and women can present an anovulation. The more stressful procedures are the heterologous artificial insemination and in vitro

fertilization and the less problematic is the GIFT one (Scatoletti, 1996; Righetti et al., 2009).
In general, there are numerous studies that have investigated the emotional state of couples before and after treatment. Pre-treatment of IVF, especially women are ambitious and creative but this is accompanied by a high level of anxiety both state and trait. After a failure of treatment they having a lot of high scores of depression, low level of self-esteem, hopelessness, anger and lower level of adaptation.
In cases of repeated failures couples begin to reflect with the following reorganization until they come to an acceptance of reality (Scatoletti, 1996). To note is that not all couples resist different failures, some not even maintain perseverance until the end of a single cycle. Unfortunately, these couples do not surpass the emotional stress with the consequence of abandonment of the treatment, the so called drop-out phenomenon.

The phenomenon of drop-out
Patients who abandon through medical causes are called *active censoring* and couples who decide to stop the treatment for personal reasons are defined *passive censoring* (Verhagen, Dumoulin, Evers, Land, 2008). There are different types of abandonment for example: abandonment of trying to conceive a child, abandonment of the clinic (in another Italian clinic or in a foreign one) (Levi Setti, 2007).
Most of the studies show that the *passive censoring* is the most present and the most influential in couples (Smeenk, Verhaak, Stolwijk, Kremer, Braat, 2004; Verhagen et al., 2008, Van Dongen, Verhagen, Dumoulin, Land, Evers, 2009). This is also through the elimination of the economic factor because in almost cases at least the first few cycles are funded or reimbursed (Goldfarb, Austin, Lisbon, Loret de Mola, Peskin, Stewart, 1997; Olivius, Friden, Lundin, Bergh, 2002). In fact, all of the researches are oriented in one direction, namely that psychological factors can influence in such as a way that leave the path to the couples who had initially decided to take (Land, Courtar, Evers, 1997; Olivius, Friden, Lundin, Bergh, 2004; Smeenk et al., 2004; Levi Setti, 2007; Verhagen et al., 2008; Verberg et al., 2008; Brandes, Van der Steen, Bokdam, Hamilton, De Bruin, Nelen, Kremer, 2009 , Van Dongen et al., 2009; Domar, Smith, Conboy, Iannone, Alper, 2010). It was found that the psychological stress may adversely affect the success of the treatment. One study compared two groups, one received psychological support and the other one had only conventional medical support. The results show that the first group reported lower levels of anxiety and depression and in addition a higher pregnancy rate (De Vries, De Sutter, Dhont, 1999; Domar, 2004).
The specialists should promote hopes and positive thinking because it has been shown that couples who receive a positive prognosis are more likely to start a new treatment. In other words, patients who receive a positive support have fewer dropouts. The optimism of the doctors can influence the decision of couples and prevent abandonment (Malcolm, Cumming, 2004; Domar, 2004). Levi Setti (2007) explains a part of the drop-out considering possible problems in communication

between specialist and patient. To work more efficient they should pay more attention to these factors, strengthen the work of team with other professionals and interchange more information.
An early and pointed psychological counselling might influence the thoughts towards the abandonment and provide relief to the emotional burden. It is also possible to resolve the conflicts with a relationship and a further support of the couple in overcoming that crisis (Hammarberg, Astbury, Baker, 2001; Domar, 2004 Smeenk et al., 2004 Paul, Berger, Berlow, Rovner- Ferguson, Figlerski, Gardner, Malave, 2010; Domar, Prince, 2011).

Method

The main point of the problem is that the subject of ART is very peculiar and little attention has been paid yet. Even in science it's still poorly known and there are large gaps. This argument tends to remain in background in the way that there is a little interest deducting that people who are involved are still rather marginalized and isolated from society. For this reason couples start have feelings like as shame and as being the only ones with such a problem.

The focus group

The focus group is a useful method that allows to explore in details opinions, attitudes and it permits to understand better the underlying motivations to the thoughts (Zammuner, 2003). There are areas that are characterized by a lack of information such as couples who attempt for the fertility treatment. In this case it's necessary to change the perspective of an absolute rationality, where it's thought that all factors are keeping under control, and take an alternative path that's based on the judgment of experienced observers. Bertin affirms (1994, p. 64) "*if several observers who analyse a phenomenon describe it in the same way, it's very likely that this observation can be reliably*". In other words, the criteria of judgment is the consensus of diverse observation of different observers (Stagi, 2000). According to other authors, the focus group method is more indicative to treat complex and unfamiliar issues and to collect more information as possible (Strauss, 2000). However, the focus group is the best method to investigate knowledge and common perspectives on fertility treatment in a general sample, in this case students of psychology.
The focus group has the ability to collect relevant information through the interaction between the participants, and it represents realistically the process of forming an opinions. This tool is especially used with a homogeneous group of people with the intention to investigate a particular issue. With this group, the moderator follows a semi-structured interview and stimulates the participants with direct questions, definitions and associations. These stimulations should activate a productive discussion and thanks to the interaction between the participants create ideas and opinions related to the issue. In an individual situation this wouldn't possible, to get the same level of quality and depth as in focus group (Losito, 1996; Amaturo, 2003).

It’s also important that the participants have a certain level of homogeneity concerning their social and cultural factors and similarity of opinion and involvement of that specific issue (Stagi, 2000). A homogeneous group will form a mental field that indicates the emotional atmosphere. This mental field is a common element among the members that isn’t attributable to sum individual emotional states but it becomes a "third thing". The sensation of community stimulates to create something new and it makes possible to get conscious and shareable thoughts (Amaturo, 2003; Corbella, Girelli, Marinelli, 2004). However, the level of homogeneity shouldn’t be too high, because otherwise it wouldn’t allow the exchange of different points of view.
Let as summarize a group can be important for an analyse of an issue which the single responses of each individual are the expression of a wider social context (Zammuner, 2003; Peddie, Teijlingen, Bhattacharya, 2005; Massey, 2010).

The focus groups with students of psychology
The general aim of this research is to investigate the representations of the ART and the drop-out of infertile couples in a general sample of students of psychology. The specific goals are: to investigate the level of familiarity with the subject of ART; to explore knowledge of ART; to understand the level of details; to identify the ability to take the point of view of infertile couples; to detect useful information on a general sample and to give the opportunity to explore better this complex issue.
There are 11 participants (N = 11), and all students of psychology with the average age of 24.8 years (age range 20-30 years). The proportion of women is about 64% or seven (N = 7) members. The inclusion criteria for a homogeneous group are the age and the type of study, in this case were selected only students of psychology. These criteria were established preliminary because similar characteristics between the participants can stimulate more a discussion and create a comfortable setting decreasing the time of socialization.
The focus group was conducted in a friendly and comfortable setting, where participants took place in a semi-circle, so that all members could see and communicate without difficulty.
The duration of the focus group is an hour and a half.
During the focus group the moderator has followed a semi-structured interview that is divided into two phases, which has been prepared in advance: (1) a brief introduction of the issue, clarifying the aim of the focus groups and a presentation of the first stimulus that was a general question on the ART. The choice is based on the belief that a general question through the mode of sheets could create order in thoughts and ideas of each member. (2) Questions about the specific areas: questions on general knowledge, on infertile couples, on the support of these couples and then on other aspects of ART, like LGBT parenting. For a completely understanding the questions were formulated in a clear and brief way.

Results

The participants of the focus group have collaborated with a great interest and participation.
In the second phase, at the time of the use of sheets, the concept of the *drop-out* was not associated with any positive term. *Infertility treatment* is often seen as a positive thing, or rather neutral. The concept of *infertility* presents another framework, which is considered like the most negative thing. The only positive intervention that was made is *"[...] I compared the lack of opportunity for new possibilities because the first thing, that came to my mind, is the lack of ability to reach one of the most important goals in my life, but there are all these new methods and strategies.*"
At the question of the Act 40 of 2004 only two people (N = 2) of eleven knew this one, furthermore only one of these two people knew her only superficially. One of them was in favor of the law (N = 1) and a member disagreed (N = 1) because "*[...] the fact that it's not expected the heterologous*" (see Figure 1).

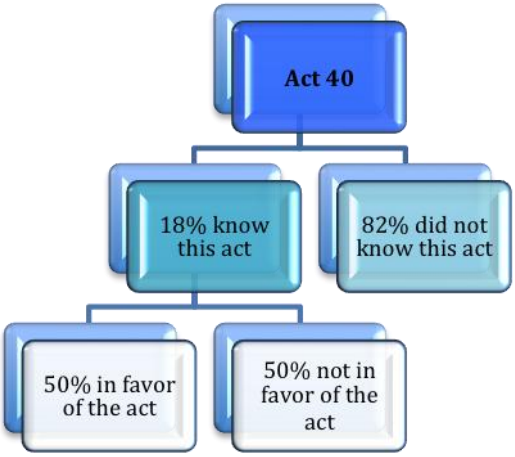

Figure 1: Knowledge of the Act of 19 February 2004, no. 40.

The answers to the question on knowledge about the ART were subdivided up into three different categories: 1) depth knowledge, 2) superficial knowledge, and 3) no knowledge. An example for the first category is *"[...] people who benefits from these new techniques must have a big social background around them because it's hard to accept but I know also the development of new techniques that are important for the prevention of genetic diseases [...]* " an intervention that falls into the second category is *"[...] I know that - it's also very expensive and so not everyone can afford it [...].*" The greatest number of people know about this issue partially (45%) or no notion (45%) and only one person of eleven knew some details (10%).
Only two types of techniques were mentioned: the artificial insemination and in vitro fertilization. When asked to explain, these procedures are recognized only by a little knowledge.
After this, it was been asked if a childless couple could be considered as a family. The whole group was completely unanimous, saying that a couple without children can be considered as a family. Here there are some explanations: "*[...] now talking about family in the classic and traditional sense it has changed [...]", "[...] a sense of*

family can be present even among two people only [...] " or "*[...] because the family is rather the presence of love that the presence of a child.*"
The answers to the likely difficulties that couples can meet are:
a) **accurate analysis of the motivations**. Some participants reflected on the analysis of the reasons that led to the ART and have contrasted alternative ways such as adoption *"[...] I would first analyse my reasons that lead me to IVF rather than adoption, because they are both two different processes, which both have got the same goal, which is to have a child [...]*" that can be highlighted also in the later intervention *"[...] be clear about what you want [...] If the treatment does not go ahead [...] consider another way maybe"*;
b) **problems in the relationship doctor-patient** such as the depersonalization during the treatment. Some participants have mentioned that couples can meet some difficulties at the physical area, which includes the depersonalization and problems in sexual life *"[...] perhaps a woman feels depersonalized of his body and so she can start to think to become almost an object and this can cause problems in the relational and sexual area [...]*";
c) **psychological problems**: sense of incompetence, sense of guilty and difficulties of trusting doctors, fear of being disappointed for the high expectations, "*it could trigger a sense of incompetence in the woman and then she can feel guilty when it turns out not to have children [...]. The sense of incompetence could be extended to other areas of the couple and woman's life, such as a relationship with her husband and at work.*"
Other participants mention fear of being disappointed for the too high expectations and that these must be taken under control *"[...] fear that everything does not happen and then a great difficulty to trust, fear of being disappointed [...]*" and "*[...] to keep expectations under control because you have to be aware, that it can't go immediately to the completion and then also be prepared to fail [...]."*
d) **marital problems**. Participants connect this problem to a possible influence in the relationship causing marital difficulties and they pose the problem of the quality of the relationship before these treatments*"[...] the couple must be one hundred percent solid [...]" and "[...] marital solidarity [...]*";
f) **stress caused by the ART**. Finally, it's mentioned the development and perception of a high stress caused by the many meetings and many psychological steps on the long path of the ART.
The next question was how they could support these couples and how they could prevent the phenomenon of drop-out. All participants (N = 11) have proposed several ideas, recombining different strategies and therapies. The various interventions has been subdivided into five categories and there are more people in favor of therapy of couples, group therapy and then work on the family context, individual therapy and only one person has even mentioned the intervention on the clinic (see Figure 2), including personal training *"[...] try to train the staff of the clinic, doctors, nurses [...]*." The combinations presented by the participants from among these five categories are all very interesting. Two members propose the integration of the intervention between the social background and therapy of couples. The reason why

taking into account of the social context is explained with the fact that the couple is surrounded by it's social network and that this could serve as a support. Others reveal the importance of group therapy that could have effects on change "*the problem of stigmatization [...] and the great prejudice*". It's argued that this therapy could trigger less defence mechanisms and therefore allows a deeper sharing of experiences and thoughts. There are also other combinations of therapies such as the individual with the group therapy or therapy of couples, and group therapy with the work on the social network, and the last one is a combination between the individual and a therapy of couples.

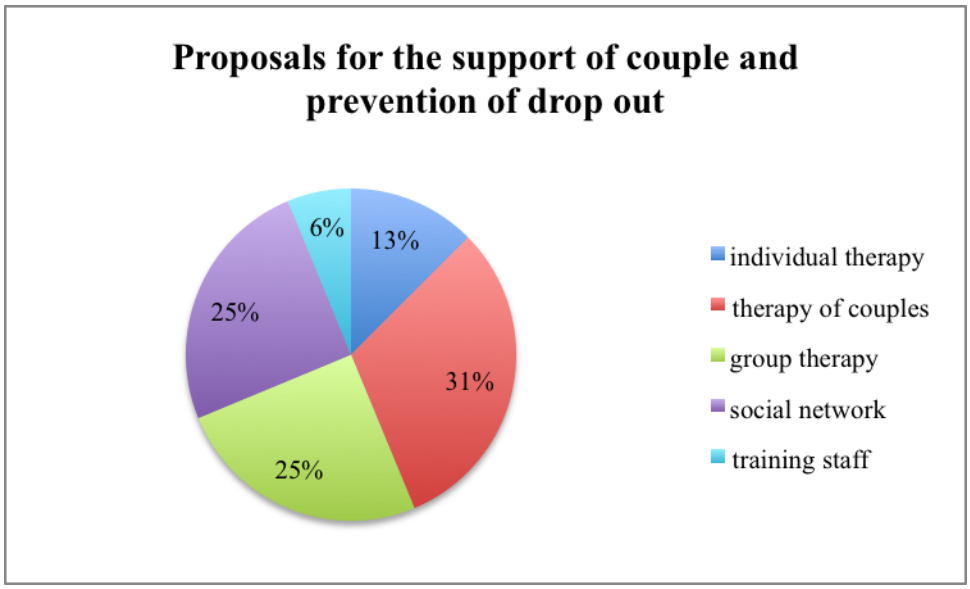

Fig. 2: Proposals for the support of couples and prevention of drop out.

The last question was about the LGBT parenting. They had been asked if they think if a gay couple could have a family and if they agree to the Act 40. More than half didn't participate in this discussion (N = 6) and those who have commented the majority disagreed (60%) to introduce a child in a same-sex couple. Only two persons agreed on the concept of LGBT parenting (40%) (Vayena, Rowe, Griffin, 2002; Golombok and Badger, 2010). To mention is that many of the members had never thought on this issue and they were not informed about the longitudinal studies about children raised in a homosexual couple.

Discussion

The most of the focus group members have little knowledge of ART.
Legal concepts and knowledge of the Act of 19 February 2004 n. 40 are really less present. But it's also important to note the limited number of members of this focus group.
General knowledge on the ART is very limited, almost 85% of participants in the focus haven't any information on this issue.

The discussion of the focus group has stimulated interest of the participants and the construction of new knowledge.
To note is that all participants are university students of psychology, then one might expect greater awareness to this issue, as well as a higher familiarity but this was not able to establish.
The participants showed an empathetic attitude on thinking about the possible difficulties encountered by couples. They were able to imagine such a situation by connecting it to the experiences and feelings of an infertile couple. They tried to take the point of view of couples and reflected on the emotions that can be triggered in such a situation.
Even the question of the possible psychological support for infertile couples and the prevention of drop-outs, could find a large number of positive comments and interventions.
The members of the group have well noted that the problem of infertility lies not only in the individual area but it concerns mainly the couple.
One of the most proposed type of support to couples during the course of ART was the therapy of couples and the group therapy. Some people have also proposed a work to the family of the couples. However, the scientific literature does not provide for interventions in the family, but considers the family just as an important resource for the couple where it can find considerable support in difficult times (Mahajan, Turnbull, Davies, Jindal, Briggs, Taplin, 2009; Paul Berger , Berlow, Rovner-Ferguson, Figlerski, Gardner, Malave, 2010; Van den Broeck, D'Hooghe, Enzlin, Demyttenaere, 2010).
Participants said that the group could be a good resource for reducing the problem of a "self stigma" of the individual and the couple who perceives themselves as different as the others. A work with a group can produce in these couples more the "effect of normalizing" where they aren't the only one that have got this problem.

Conclusions

Let as summarize, this paper evidences that it's necessary to research more about this problem and create more knowledge about the social problems related to infertility and the Act 40 of 2004.
To date, there are no campaigns to raise awareness on this important issue and that collect more information in relation to the prevention of infertility and early intervention on couples.
The important function of good practices of humanization should be implemented and be pointed on needs of the patient, and support them in critical moments.
In future, it would be desirable, define some effective communication strategies between infertile couples and clinics of ART. Such strategies should be defined through the Guidelines from the Ministry of Health and the Guidelines Eshree with the focus on the role of the psychologist in clinical practice with infertile couples.

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