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information services gwasanaethau gwybodaeth Failure after fertility treatment: Regulation strategies when facing a blocked parenthood goal.

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#### ABSTRACT

Biological parenthood is a central life-goal for many couples that can become blocked when they experience infertility. Many couples who undergo fertility treatment will face failure and consequently have to decide whether to continue with treatment. The present study used the qualitative methodology of Interpretative Phenomenological Analysis to examine self-regulatory approaches that underlie decision-making about continuing treatment. One-time, one-on-one, semi-structured, in-depth interviews were conducted with 16 individuals (8 heterosexual couples) after they had experienced at least one treatment failure and were considering whether to undergo another treatment. After treatment failure, individuals used several approaches to remain engaged with biological parenthood, including reframing treatment failure as a learning tool and emphasizing the importance of persistence in achieving success. The apparent decision to continue with treatment was considered non-negotiable and largely made by women in the partnership. Once the decision was made to pursue treatment, it was not discussed further. Given individuals' willingness to engage in treatment, patients should be offered additional support to consider wide psychosocial implications of continuing treatment.

**Keywords**: assisted conception; counselling, fertility treatment; infertility; IVF treatment

#### Introduction

Achieving a life-goal of parenthood can become blocked when couples are diagnosed with infertility. Infertility is a disease of the reproductive system and is defined as the inability to achieve a clinical pregnancy after 12 months or more of regular, unprotected, heterosexual intercourse with the same partner (Zegers-Hochschild et al., 2017). Over 9% of reproductive-aged women worldwide are in a couple affected by infertility (with lifetime rates between 5-25%) and, of those affected, about 56% will choose to undergo fertility treatment (Boivin, Bunting, Collins, & Nygren, 2007). About 78% of people who are recommended *in vitro* Fertilization (IVF) are willing to undergo at least three cycles (Gameiro, Verhaak, Kremer, & Boivin, 2013). The cumulative live birth rate for one cycle of IVF is between 26.4 to 31.5% but chances increase to 50.7 to 61.5% if individuals undergo three cycles (Luke et al., 2012). After each failed cycle, couples must decide whether to undergo an additional treatment cycle. This decision space can be considered to be an active phase of individual and dyadic regulation as couples must reevaluate their motivation to keep pursing biological parenthood, reflecting on the chances of being successful by doing more treatment.

Patients generally have unrealistic expectations about treatment success at the start of fertility treatment (Hammarberg, Astbury, & Baker, 2001). Some patients have reported doctors omitting relevant information about the chances of treatment success until close to the end of treatment (Peddie, Teijlingen, & Bhattacharya, 2005), however, patients may also undervalue such information in light of their desire for biological parenthood (Gerrits, 2014). Even after having stopped treatment, many find it difficult to accept biological childlessness (da Silva, Boivin, & Gameiro, 2016). Given a strong parenthood goal, it is important to examine how individuals and couples

assess the experience of a failed treatment cycle and how it is assimilated into their decision of continuing treatment or not.

The importance of understanding how individuals and couples conceptualize failed treatments is important because of the implications on well-being. According to developmental regulation theories, when people face a blocked goal they can use three main self-regulatory strategies: (i) goal engagement; (ii) disengagement; and (iii) re-engagement (Heckhausen, Wrosch, & Schulz, 2010). These three self-regulatory strategies are characterized by the existence of cognitive levels of commitment and behavioral levels of effort to achieve the goal. Theories of developmental regulation purport that when a goal becomes unattainable, staying engaged (i.e., in terms of commitment and effort) is expected to lead to poor wellbeing whereas disengaging from the goal or re-engaging in new life goals is expected to contribute to positive wellbeing (Heckhausen et al., 2010).

In the case of infertility, a recent systematic review and meta-analysis concluded that parenthood goal blockage was not associated with goal disengagement or re-engagement in other life goals, which runs counter to prevailing theoretical assumptions (da Silva et al., 2016). In light of these results, there is a need for deeper exploration of individuals' and couples' self-regulation strategies as they face parenthood goal blockage and consider whether to undergo another treatment cycle. The present study focuses on the period after a failed treatment cycle and uses Interpretative Phenomenological Analysis (IPA) - an approach to psychological qualitative research - to lend insight into how individuals and couples, in the context of a failed treatment cycle, make meaning from the experience and intend to move forward with treatment.

#### Materials and methods

#### Research Participants

Participants were Portuguese heterosexual couples. At the time the data collection, the legal context in the Portuguese health system allowed three funded IVF cycles under the national health plan for heterosexual couples living together for at least two years, thus allowing insights into self-regulation strategies and decision-making processes that are not as largely influenced by concerns about cost as other areas of the world. Nevertheless, some participants presumably underwent treatment in private clinics based on having reported exceeding the three funded cycles, however no data was collected directly from participants on cycles conducted in public vs. private clinics thus we do not distinguish the results based on public/private setting. The study inclusion criteria included having experienced a failed IVF or Intracytoplasmic Sperm Injection (ICSI) in the last six weeks to one year. The interval of six weeks to one year was selected because six weeks allowed for couples to recover from a failed cycle (Verhaak et al., 2007) and one year was the upper boundary after which couples not opting to undergo treatment are considered to have discontinued treatment (Gameiro, Boivin, Peronace, & Verhaak, 2012). While couples were excluded if they were explicitly advised by healthcare providers to discontinue treatment, each couple was currently deciding whether or not to undergo another cycle given the recent treatment failure.

The purposive sample was composed of eight couples (16 individuals), which is within the range of standard for IPA (Smith, Flowers, & Larkin, 2009). IPA typically draws on a small sample of people, usually between 3 and 15 participants (Smith et al., 2009). The average age was 36.5 (range = 31 - 45), 35 for women (range = 31 - 39) and 38 for men (range = 35 - 45). On average, the couples had been trying to conceive for approximately 4.1 years (range = 1.8 - 6.3 years). None of the participants had biological, adopted or step children. The mean number of previous treatment attempts of IVF or ICSI with own or donor gametes was three cycles (range = 1 - 5 attempts). Overall, 62.5% of the participants had done three or fewer cycles and 37.5% had completed more than three cycles.

#### Procedure

An invitation to participate in the study was posted on the Facebook social media website and consumer forum of the Portuguese Fertility Association (the largest Portuguese fertility advocacy group). Prospective participants had the opportunity to view the study description and provide electronic consent to be contacted to schedule a day, time, and location for the interview. Each member of the couple participated in a one-hour semi-structured interview. The Research Ethics Committee of the School of Psychology at Cardiff University [Reference number: EC.13.07.02.3485GR] provided ethical review and approval for this study.

#### Interviews

The interviews were performed by the first author in a private and quiet room in a mutually-agreed upon location. The interviews were audio recorded using a digital recorder. The interview guide was developed by the first author to address the main theoretical assumptions of developmental regulation theories in the context of infertility (please see the supplementary file for the full interview guide). The interview guide covered the topics of parenthood goal importance, goal blockage, and individual and dyadic regulation, although the words used to talk about those topics were more colloquial to facilitate understanding (i.e., 'motivation' instead of 'psychological

engagement'). Interviews were transcribed verbatim in Portuguese and pseudonyms replaced names.

#### Data Analysis

Interpretative Phenomenological Analysis was implemented according to the procedures recommended and developed for sample sizes larger than six participants (Smith et al., 2009). The analysis was performed in order to find group level patterns but, as advised by Smith et al. (2009), we preserved the individual-focused nature of IPA by presenting specific examples of each participant. The data analysis steps involved the first and second author reading the transcripts independently and making conceptual notes line-by-line, creating emergent themes, and finally working together to search for higher-order themes; these steps are described in detail in the supplementary file. Discussion between the first and second authors and reflective journaling during the analytic process was done to maintain a double hermeneutic perspective (Smith et al., 2009). Finally, the data was checked for validity using an independent audit with four outside experts in the fields of developmental regulation and infertility, as recommended by the IPA standards of practice, by carefully documenting all the information and steps involved in the different phases of the study (Smith et al., 2009). Data was also checked for credibility by presenting the data to the infertility and developmental regulation researchers who gave their critical appraisal of the plausibility of the conclusions given the information documented in the previous research steps. Although the general interpretation of the data remained the same, feedback was incorporated after discussion with the experts. After some minor changes in the analysis, consensus on the higher order themes was reached.

#### Results

The following higher-order themes were identified and are presented in Tables 1 to 3. In the tables, attention is paid to whether or not the theme was present in each male and female participant's data.

#### Positive Interpretations of Treatment Failure Mitigates Perceived Goal Blockage.

The data in Table 1 shows that majority of both male and female participants (10 out of 16) framed experiences of treatment failure as learning tools that would ultimately help them increase engagement with the parenthood goal. One woman said, "After we realized the cycle failed [...] the feeling was immediately 'Let's learn something from this.' I mean, like, the doctors will know us better, maybe things ... in the next treatment our doctor will know how to better adjust the medication for us." (Adele, two failed treatment cycles). Another woman explained the relationship between past failure and future success, "The probabilities [of success] get a little bit better because of the knowledge we have about what has already happened." (Camilla, three failed treatment cycles). About half of participants (7 out of 16) also mentioned moving treatment to a new facility or a new provider as a way to overcome the obstacles, with more women than men reporting this. One woman said, "We think that if we go to a new place, where we have confidence, something we did not have this last time, I think that it will make everything better. I think, for now, it will help us achieve our goal." (Cathy, four failed treatment cycles).

# Persistence is Seen as Crucial in Achieving Treatment Success and Serves as the Motor for Engagement.

The data in Table 2 shows that after a failed cycle attempt, the majority of male and female participants (10 out of 16) discussed the importance of persistence because

treatment was perceived as a game of probabilities that required consistency to achieve positive results. Cathy (four failed treatment cycles) said, "Because...we want to become parents...so we do not want to give up. Basically...I say let's go for it [the next treatment]!"

Giving up on the parenthood goal was not considered an option for over a third of equally male and female participants (6 out of 16) who experienced several failed treatment cycles in the past and had recently experienced another failed treatment cycle. When asked about the possibility of continuing or stopping treatment after his fifth failed cycle, one man said, "At this point it doesn't make any sense, I mean, to have such a big conversation with her. It doesn't make any sense at all to stop [treatment] right now. If failures continue to accumulate [...], but we won't give up so early. So early... no, only if we're forced to by external factors. Only then." (John, five failed treatment cycles).

The majority of participants (14 out of 16) - notably all women and most men said that maintaining goal engagement was crucial and independent of treatment failure. Rebecca said, "[...] I will exhaust every last possibility that there is [...] The first [treatment] failed, the second failed, we'll try a third time. No...I cannot say, 'Oh, it's over now,' because...I always have this question, 'Will I be able to achieve it or not? Will the last [treatment] work or not?' I prefer to exhaust my chances." (Rebecca, two failed treatment cycles).

Over a third of male and female participants (6 out of 16) stated that they continued to pursue the parenthood goal because they were interested in avoiding future regrets. When asked about the chances of getting pregnant by doing more fertility treatment, Charlotte said "...I do [the treatments] because I don't want to think

later on, 'and what if I had done them, it could have worked,' but frankly, no...no, I'm not very optimistic." (Charlotte, one failed treatment cycle).

# Passive rather than Active Decision-Making Underscores Engagement with Treatment.

Over a third of participants (6 out of 16) reported that they had made a pre-determined decision to continue to do treatment until pregnancy was achieved or until opportunities were exhausted; more women than men reported this (Table 3). One male participant said, "Even before we started undergoing treatment we had already thought, the next one will work, and if the next one does not work, even facing adversities, we will try until there are no opportunities at all." (Albert, one failed treatment cycle). When asked if a decision about doing more treatment was already made, Albert replied, "There wasn't any decision, it was already pre-established even before [we started treatment]... I do not remember if we even talked about that [...]" (Albert, one failed treatment cycle). A majority of male and female participants (11 out of 16) avoided communication about undergoing another treatment cycle due to the partner's negative emotional reaction with respect to the failed cycle or worry about an upcoming cycle. "We never spoke, and, we have not spoken a lot because... some things, it is really hard to talk about it..." (Cathy, four failed treatment cycles).

In addition, about two-thirds of participants (10 out of 16) reported that the nature of fertility treatment meant that men were less actively involved in the treatment process than the women (i.e., injections, blood tests, scans are procedures done on women). Consequently, most male participants mentioned that women were the ones who had to decide about undergoing more treatment or not. One man said, "...but in fact, physically she is the one who is suffering, you know? It's the woman who suffers

in physical terms. So, I don't feel particularly comfortable saying let's do it or not." (Bradley, four failed treatment cycles).

#### Discussion

Participants used several approaches to mitigate the impact of treatment failure. For example, positive interpretations of treatment failure seem to serve the function of making the blocked goal appear less threatening and may contribute to ongoing treatment engagement. Contrary to assumptions in developmental regulation theories, people might not always adjust engagement according to the level of objective goal blockage, but instead they might discount the level of blockage to maintain engagement.

Our results suggested that disengagement is not the obvious alternative when opportunities to achieve parenthood appear unfavorable (i.e. after a failed cycle) or even extremely unfavorable (i.e., more than three failed cycles). Opting for more treatment was sometimes influenced by the desire to avoid future regrets about giving up on the parenthood goal. As a result, goal engagement appeared to continue, regardless of the probability of treatment success. The strategy of choosing the appropriate time to invest in a given goal considering the opportunities available is called *meta-regulation*, or *optimization* (Heckhausen et al., 2010). Our findings suggest individuals not only do optimization by considering the present and future opportunities to achieve the goal, but also by anticipating the negative long-term consequences of failing to achieve it.

Our findings show low exchange between partners about treatment decisionmaking. First, some participants emphasized that the decision to do more treatment and exhaust all the treatment opportunities was made prior to the first treatment. Second, most male participants mentioned that women should make the treatment decisions because of the implications to their body. Past research on infertility has revealed that women used more coping strategies based on accepting responsibility for infertility than men (Peterson, Newton, Rosen, & Skaggs, 2006) and place more emphasis on treatment outcome compared to men (Frank, 1990). Our results suggest that men place the responsibility on women regarding the decision to pursue treatment or not, thus making the men's decision-making more passive.

Our results also suggest that the distress of failed treatments leads participants to avoid communication about doing more treatment. Communication is crucial for efficient goal coordination as it increases the amount of interaction between partners and allows members to share and divide resources during goal pursuit, which leads to a greater likelihood of goal achievement (Fitzsimons, Finkel, & van Dellen, 2015). A lack of communication might decrease the chances to achieve biological parenthood as it can increase the likelihood of treatment termination for men (Vassard, Lund, Pinborg, Boivin, & Schmidt, 2012). Furthermore, lower levels of communication prevent couples from updating perceptions about goal importance and blockage. Evidence suggests that couples would benefit with increased communication (Pasch, Dunkel-Schetter, & Christensen, 2002).

We acknowledge several limitations of this study. First of all, we do not know how many participants actually continued with treatment since the study was performed in the decision-making period and as it is a cross-sectional study, we do not have access to follow-up data. However, all patients indicated they intended to continue with treatment. Also, not all participants were in the same stage during their fertility treatment experience, meaning that couples may have been experiencing different levels of blockage depending on the number of failed cycles completed. This limitation was addressed by presenting the number of failed cycles experienced by each patient when reporting data and thus allowing for greater clarity about the level of parenthood goal blockage. Another limitation is related with a possible representativeness bias of the sample since patients who were highly motivated to achieve parenthood, and who might have paid to undergo treatment in a private clinic, may also have been more motivated to take part in the present study, thus influencing the existence of the high levels of engagement found in the study sample. In addition, only one-on-one interviews were conducted and none with the couple together, thus couple dynamics that would be observed in a joint interview were lost. Finally, we recognize the results are influenced by social context, including feelings about parenthood as a life goal, stigma attached to childlessness, country-specific infertility rates and treatment statistics, and intersections with social class, economic resources, financial stress, and treatment in public or private clinics. Additional research is needed to explore these factors in Portugal.

In conclusion, the findings from this study suggest that some patients who experience infertility may be unwilling to disengage from the biological parenthood goal, despite mounting obstacles, and this is related to how they positively frame the experience of treatment failure. After failed treatment, the patients in this study do not engage in an active decision-making process, and this is related with the value they place on persistence and fear that such decision-making creates stress in the partnership. Fertility patients have a strong need for results and treatment information tailored to their own particular case to assist decision-making (Dancet et al., 2010), particularly after a failed cycle. Fertility clinics should consider developing decision-support technologies that can help couples during the decision-making periods. While we did not consider the communication patients may have received from their

healthcare provider, future research should assess whether healthcare providers ensure that the benefits and the implications of continuing or stopping treatment are openly communicated to patients at different stages of treatment decision-making.

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## **Disclosure of Interest**

The authors report no conflict of interest.

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**Table 1:** The emerging themes that comprise the higher order theme, represented by the number of male (n=8) and female (n=8) participants whose data reflected the emerging theme.

	Moving to a new clinic or provider is a way to overcome obstacles	Past experience of treatment failure is a learning tool
Present in the data		
Male (%)	2 (25)	5 (62.5)
Female (%)	5 (62.5)	5 (62.5)
Total	7	10
Not present in the		
data	6 (75)	3 (37.5)
Male (%)	3 (37.5)	3 (37.5)
Female (%)	9	6
Total		

**Table 2:** The emerging themes that comprise the higher order theme, represented by the number of male (n=8) and female (n=8) participants whose data reflected the emerging theme.

	Persistence	Disengageme	Maintaining	Avoiding
	is key to	nt is not an	goal	future regret
	success	option	engagement is independent of treatment failure	is motivation for engagement
Present in the data				
Male (%)	5 (62.5)	3 (37.5)	6 (75)	3 (37.5)
Female (%)	5 (62.5)	3 (37.5)	8 (100)	3 (37.5)
Total	10	6	14	6
Not present in the				
data	3 (37.5)	5 (62.5)	2 (25)	5 (62.5)
Male (%)	3 (37.5)	5 (62.5)	0 (-)	5 (62.5)
Female (%)	6	10	2	10

**Table 3:** The emerging themes that comprise the higher order theme, represented by the number of male (n=8) and female (n=8) participants whose data reflected the emerging theme.

	Predetermined decision to continue treatment	Avoidant decision- making style of communication	Women's physical burden makes her the decision leader
Present in the data Male (%) Female (%) Total	2 (25) 4 (50) 6	6 (75) 5 (62.5) 11	6 (75) 4 (50) 10
Not present in the data Male (%) Female (%) Total	6 (75) 4 (50) 10	2 (25) 3 (37.5) 5	2 (25) 4 (50) 6