Transforming Hope: The Lived Experience of Infertile Women Who Terminated Treatment After *in Vitro* Fertilization Failure

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ABSTRACT: Assisted reproductive treatments provide the hope of pregnancy for infertile women, but do not always turn this hope into reality. The purpose of this study was to explore the lived experience of infertile women who terminated treatment after *in vitro* fertilization (IVF) failure. Using a qualitative research design, 24 subjects were recruited who had experienced IVF failure and decided to terminate their treatment. Data were collected through interviews, and analyzed using interpretive research strategies of phenomenology. This study protocol was reviewed and approved by the University Review Board for Research. Informed consent was obtained from each subject. The theme of lived experience which emerged from the data was "transforming hope". This theme included three categories: (1) accepting the reality of infertility, (2) acknowledging the limitations of treatment involving high technology, and (3) re-identifying one's future. The results illustrated that counseling for these women should involve the provision of both positive and negative information, evaluation of the response to treatment, and assistance in defining their future.

Key Words: transforming hope, infertility, *in vitro* fertilization, lived experience, hope.

Introduction

Hope is necessary for human life; it is the desire for a possible future. Human beings actualize a possible future through expectation and participation (Clarke, 2003; Farran, Herth, & Popovich, 1995). Hope is also a combination of cognition and belief; it is a subjective feeling of a possibility (a chance, a method, an idea, or a choice) to reach a goal or have a wonderful future (Farran et al., 1995). In the perspective of the hoping person, hope is reality-based. It depends upon the hoping person's perception of the situation, the timing of reality considerations, and the extent to which, as well as the manner in which, persons examine and assess reality in relation to the desired object (Dufault & Martocchio, 1985). While hope is dynamic and uncertain, it is influenced by time, and by different situations or subjective feelings. It can even be lost (Benzein & Berg, 2003; Gibson, 1999; Holt, 2000; Rustoen & Wiklund, 2000). When one gives up hope, therefore, transforming hope is a process necessary to the restoration or preservation of one's well being. Through transforming hope, people can transcend their present feelings and increase their vitality (Li, 2000; Moore, 2005).

For most societies, becoming a parent is one of the social norms; most couples hope to become parents (LaRossa, 1986). Almost 10 to 15% of couples, however, suffer from infertility (McQuillan, Greil, White, & Jacob, 2003; Yang, 1999). For these couples, achieving parenthood can become a major problem. Many infertile women feel compelled to pursue all possible avenues to achieve their goal of parenthood.

In 1978, the firs IVF baby was born in England. The development of reproductive technology has provided infertile women with the wonderful hope of pregnancy

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and, indeed, the last chance to achieve it (Chuang et al., 2003; Schoener & Krysa, 1996). When they receive the first cycle of *in vitro* fertilization (IVF), women always hope they will be successful in becoming pregnant because of the treatment. But, reproductive technology cannot solve all of the reproductive problems of infertility. At present, the pregnancy rate of IVF treatment is between 20 and 50% (Chao et al., 1997; Jee et al., 2004; Olivius, Friden, Lundin, & Bergh, 2002; Yang et al., 1991). This indicates that only a minority of these women will fulfill their hope of pregnancy through IVF, while more than half of them will not. Those women who fail typically describe the experience as an emotional roller coaster. It has a great impact on them and it takes a long time for them to mitigate the distress caused. Indeed, the road towards doing so becomes a very long and bumpy one (Boivin, Takefman, Tulandi, & Brender, 1995; Creac'h-Le Mer et al., 1999; Menning, 1980; Su, Chen, Hung, & Yang, 2001).

In general, the factors that influence the success of IVF are complex. Many studies indicate important predictors influencing the success of IVF, including: women over 40 years of age, basal FSH over 15 IU/L, the etiology of infertility, and a high level of anxiety (Chuang et al., 2003; Csemiczky, Landgren, & Collins, 2000; Facchinetti, Matteo, Artini, Volpe, & Genazzani, 1997; Jee et al., 2004). Klinkert, Broekmans, Looman, and Te Velde (2004) indicated that those women whose response to IVF is expected to be poor (age ≥ 41, FSH level ≥ 15 IU/L) should be advised to withdraw from treatment after failure of the first cycle, because of the poor prognosis . They also indicated that for women who had an unexpected poor response in the first cycle of IVF (age < 41, FSH level < 15 IU/L), but a normal response in the second cycle (Klinkert et al., 2004).

However, in the clinics, the women whose treatment has failed often do not know whether they should terminate the treatment or not. Some women had received four cycles of treatment or even more. Medical staff should help women whose treatment has failed to assess their prognosis realistically (Li, 2000).

The purpose of this study was to explore the lived experiences of infertile women who terminated treatment after IVF failure.

Methods

A qualitative research design was used for this study. The setting was a medical center in northern Taiwan. The study protocol was reviewed and approved by the University Review Board for research involving human subjects. Informed consent was obtained from each subject.

The subjects were infertile women who experienced IVF failure and decided to terminate treatment. Women who experience failure of IVF, may either give up treatment immediately or after a period of time. In this study, we considered that they needed to accommodate their psychophysical impact for one or two cycles of menstruation after treatment failure. In addition, given the steep decline in female fertility after 35 years of age, the women always do their best to receive treatment before the age of 35 years. One of the important selection criteria for the sample used in this study, therefore, was that the infertile women had experienced IVF failure one year ago and given up their treatment. Twenty four subjects were recruited.

The data were collected by telephone interviews. Each interview lasted between 30 and 60 minutes. The subjects were asked to talk about their experiences of discontinuing treatment and encouraged to express their feelings, perceptions and thinking. The interviews covered: (1) their health condition, (2) their discontinuation of treatment: the reasons for it, and their feelings, (3) their life at present and during the previous year.

The data were recorded and analyzed using Benner's (Benner, 1985, 1994; Leonard, 1989) interpretive research strategies of phenomenology. The first step was thematic analysis. The data for each subject were read several times in order to achieve a global analysis. The reasons, feelings, and thoughts of subjects about their failure in IVF and their discontinuation of treatment were identified and listed carefully. The meaning of these categories were analyzed and integrated into a theme. The second step was to analyze exemplars, and perform repeat reading of the data in order to compare and analyze differences, to make corrections, and to add new categories. The purpose of this analysis was to compare different subjects and different situations simultaneously. The third step involved the identification of paradigms, strong instances of particular patterns of meaning. The categories and themes that emerged in relation to every subject were rechecked and corrected in order to establish paradigms that reflected all of the subjects. All three interpretive strategies worked both as discovery and presentation strategies. The goal of identification of the categories was to achieve understanding of the lived experience in the subjects (Benner, 1985, 1994; Leonard, 1989). The themes and categories of the lived experience,

therefore, were specific and meaningful to the individual subjects.

Lincoln and Guba (1985) held that rigor in qualitative research data involves credibility, confirmability, dependability, and transferability. In this study, to increase the probability of producing credible findings, the researcher engagement in the field. As well as, the researcher has been involved in IVF treatment and completed a series of studies in the field. The clinical competence and abilities in qualitative research enhanced the confirmability of this study. To enhance dependability, during interviews data were taken by the researcher and, at the end of the interview, translated immediately into a narrative form in order to avoid loss or confusion of data. The operational definition of each category was defined and the context of data collection was described clearly in order to enhance transferability.

Results

A total of 24 women participated in this study. The mean age of participants was 40 years old. Table 1 illustrates the demography data of the subjests.

Theme of Lived Experience: Transforming Hope

The essence of the experience of infertile women who discontinued treatment after IVF failure is embedded in the main theme: transforming hope. The infertile women received IVF with the hope of becoming pregnant. After IVF failure, however, they terminated treatment and gave up this hope under their perception. They felt the impossibility of accomplishing the goal of pregnancy, and therefore transformed their hope of doing so. At this time, they found realistic ways of perceiving an entirely new set of possibilities. The experience, reflected by the data of changing from hope of pregnancy to acceptance of reality was termed "transforming hope". In transforming hope, the infertile women faced their infertile reality and the prospect of life without children.

The lived experience of "transforming hope" included three categories: (1) accepting the reality of infertility, (2) acknowledging the limitations of treatment involving high technology, and (3) re-identifying one's future (Table 2).

Table 1.
Demography Characteristics of Subjects (N = 24)

Variable	*n*	%	*M* ± *SD*	Range
Years of Age			40 ± 4	32~47
Work Status				
Working women	20	83.3		
House wife	4	16.7		
Educational Level				
≤ 12 years	6	25.0		
14 years	8	33.3		
≥ 16 years	10	41.7		
Etiology of Infertility				
Female	12	50.0		
Male	4	16.7		
Couples	2	8.3		
Unexplained	6	25.0		
Cycle of IVF			3 ± 2	1~10
Months after IVF Failure			16 ± 4	12~23

Table 2.
Lived Experience of Infertile Women Who Discontinued Treatment After in Vitro Fertilization (IVF) Failure

Theme	Category	Sub-category
Transforming hope	Accepting the reality of infertility	1.Being convinced of having done one's best 2.Feeling advanced in age 3.Having a poor reproductive function 4.Reducing the pressure to become a mother
	Acknowledging the limitations of treatment involving high technology	1.IVF treatments could not identify one's etiology of infertility 2.IVF treatments could not solve one's reproductive problems
	Re-identifying one's future	1.Re-identifying the importance of wellbeing 2.Rejecting obsessiveness about infertility 3.Making new plans for the future

Category One: Accepting the Reality of Infertility

The infertile women's abandonment of IVF treatment reflected their recognition of the deficiencies of their reproductive systems, and of the consequent impossibility of pregnancy. It won them the empathy of their families. From this point of view, they transformed hope and accepted the reality of infertility.

Four sub-categories were included in "accepting the reality of infertility": (1) being convinced of having done one's best (2) feeling advanced in age (3) having a poor reproductive function, and (4) reducing the pressure to become a mother (Table 2).

Being convinced of having done one's best

Having received several cycles of IVF by renowned doctors and in many famous hospitals; the participants were convinced that they had done their best.

> For example, Case 1 who experienced several cycles of IVF failure remarked: *"I have done my best! There is no chance of pregnancy for me! Because I have had three cycles of IVF, and each cycle was a failure, I don't want to continue these treatments any longer."* Case 8, who visited many well-known doctors in different hospitals made a similar statement: *"I have had IVF in so many hospitals! I think I have visited almost all the famous doctors in Taiwan! I have really done my best. I think it is not necessary for me to continue any further treatment."*

Feeling advanced in age

The self-recognition of the inescapable facts about aging led the participants to admit the difficulty of becoming pregnant. They adapted themselves and accepted the reality of infertility.

> For example, Case 3, a forty-year-old said: *"I haven't received further IVF treatment since the failure of the treatment last year. The main reason is my advanced age. It would be fine if I were still thirty years old, but I am now forty years old! I simply cannot get pregnant!"*

Having a poor reproduction function

Assessing the poor reproductive function of themselves or their partners, the participants perceived the impossibility of pregnancy and accepted the reality of infertility.

> For example, Case 6 said: *"Because the function of my ovaries is even worse than before, I will give up treatment now!"* Case 21 stated: *"The activity of my husband's sperm is insufficient, so, I can't become pregnant."*

Reducing the pressure to become a mother

For Taiwanese society, the pressure to become a mother always comes from the individual, the couple, and even the family members. The data showed that the participants' families had been closely involved in the previous treatments and sympathized deeply with the psychophysical suffering that the women underwent during the treatment. This being the case, the participants terminated their treatment with the support of their families. Because of this support, pressure from the families decreased and participants were able to give up their treatment and transform the hope of pregnancy.

> For example, Case 10 said: *"During the treatments, my husband gave me the injection every day. He showed empathy for my suffering during medical procedures. He asked me to quit treatment once it had failed."* Case 15 said: *"Because my mother-in-law understood my suffering during the treatment, she agreed that I should give it up. I no longer experience stress from my family."*

These subjective experiences presented the participants' predicament in a new light, enabling them to accept the reality of their infertility and adjust themselves to not having the hope of becoming pregnant.

Category Two: Acknowledging the Limitations of Treatment Involving High Technology

Because of the limitations of treatment involving high technology, the participants transformed high expectations for IVF into stark recognition of the technology's ineffectiveness. They were convinced that current technology could not solve their infertility problems.

Three sub-categories were included in "acknowledging the limitations of treatment involoving high technology": (1) IVF treatments could not identify one's etiology

of infertility (2) IVF treatments could not solve one's reproductive problems (Table 2).

IVF treatments could not identify one's etiology of infertility

Each time a cycle of IVF failed, the participants thought that there must be a reason for the failure, which should be identified clearly and completely rectified in order to prevent the failure of any subsequent cycles. But they were unable to get definitive answers about the treatment failure from their doctors. For these reasons, they concluded that it was pointless for them to keep receiving the treatment.

> For example, Case 11 said: *"I have received many cycles of IVF, but all were in vain. Doctors could not identify the reasons for the failures, and I thought that any further treatment would just repeat the same results for me."*

IVF treatments could not solve one's reproductive problem

Although they had once hoped otherwise, the failure of IVF proved that the participants' reproductive deficiency could not be solved by this technology.

> For example, Case 21 asked: *"Is there a new procedure to treat infertility? Why isn't there a new treatment? If there isn't a newer treatment to solve my implant problem, the result will just be the same with the possibility of zero success. I have decided to give it up."*

Such statements expressed the women's disappointment with the current state of medical technology; they understood the limitations well. This being so, they changed their expectations and this helped them give up the hope of pregnancy.

Category Three: Re-identifying One's Future

For the participants, they did not want to continue to endure their previous lifestyle. They rejected the way that they had lived with their infertility and re-defined a new life for themselves without children.

Three sub-categories were included in "reidentifying one's future": (1) re-identifying the importance of well-being, (2) rejecting the emphasis put on their infertility, and (3) making new plans for the future (Table 2).

Re-identifying the importance of wellbeing

Participants found the procedures of IVF filled with suffering for them. Failure left them feeling frustrated and discouraged. At the same time, they also perceived that their health was threatened in the process of IVF treatment. Because of the impacts on their physical and psychological health, the participants re-identified the importance of wellbeing for them and gave up the IVF treatments.

> For example, Case 2 said: *"I feel so tired! I don't want to receive treatments (IVF) any more!" "Having the IVF treatment once was so terrible! The feeling of failure was so painful! It was not only the pain in my body but also a strong assault on my feelings. It was like a great hurt or a fierce comedown. I always needed a long time to calm myself down. I didn't have courage and I couldn't continue! If I were to have it (IVF) again, I would be very afraid of facing the same frustration!"*

Rejecting obsessiveness about infertility

The participants thought that it was not worth devoting their whole life to receiving ineffective IVF treatments. Thus, they rejected obsessiveness about infertility.

> Case 12, for example, said: *"It is not worth spending all that time on nothing but childbirth! I certainly don't want my whole life spent on nothing but childbirth!"*

Making new plans for the future

The participants said that they now expected to live life as they pleased, to be concerned about themselves and to design their own future.

Some participants expressed the fact that they were really busy at work, and now they could devote themselves to their jobs. It meant that the participants were now more concerned about themselves and had transformd their specific hope of pregnancy into a general hope.

> For example, Case 18: *"There are many things waiting to be done in my life. Getting treatments is really wasting my life. I want to do the things that I want to do!"*

In short, the hope of pregnancy was terminated in the infertile women after the failure of IVF. Between their past

infertile experiences and their future lives, the participants were able to reconsider and take better care of themselves. They endeavored to remove themselves from their infertile situation and to learn to live without having children.

Discussion

Influence of Traditional Culture on Infertile Women

In this study, the experience of transforming hope indicated that the infertile Taiwanese women kept their balance between traditional culture and the modern environment. According to Taiwanese culture, the family is patriarchal, with inheritance depending on the male offspring. In addition, the Taiwanese culture entrusts the women with the mission of perpetuating the generations, with the pressure of being "without children, without filial piety". In the traditional society, infertile Taiwanese women try to cope with their infertility. As in this study, the participants did their best to succeed with IVF before terminating their treatment. Transforming hope, however, for the participants involved accepting the reality of infertility, acknowledging the limitations of treatments involving high technology, and re-identifying the future. The experience of transforming hope in these women illuminated the fact that self-identity, family support and medical effectiveness were the indicators which led the participants to assess the possibility of pregnancy as well as to transform the hope of pregnancy in the present modern environment. When women find out that they can not control their own inner space, they begin to change their mind as far as following the traditional culture goes and they themselves expand further into the modern society. It also means that the infertile women's changing their mind, the family's understanding and informed consent for treatment are the important factors that help them depart from the reproductive stresses of traditional culture in order to succeed in transforming hope. This finding is the same as that of Johansson and Berg (2005), except that it interprets the experience in infertile women who have discontinued treatment. It also indicates that the transformation of hope is essential to the healing and recovery process in these women living in the reality world.

Assurance Consent to High Technology Treatment is Truly an Informed Consent

The participants perceived that their reproductive functions were impaired. Their infertility problems, however, could not be solved through the use of medical high technology. So they stopped treatment and transformed their hope of pregnancy.

IVF treatment increases the chances of pregnancy for infertile women (Miller, 2004). Medical staff and the media emphasize the effectiveness of medical technology. But its negative impacts include the influences it has on the body and mind during treatment, the complication of ovary hyper-stimulation, multi-fetal pregnancy and reduction, its high cost, and ethical concerns (Hjelmstedt, Widstrom, Wramsby, & Collins, 2004; Reame, 1999; Ryan, Zhang, Dokras, Syrop, & Van Voorhis, 2004; Shanner & Nisker, 2001; Su et al., 2001). Recently, the pregnancy rate after IVF treatment has been between 20% and 50% (Chao et al., 1997; Jee et al., 2004; Olivius et al., 2002; Yang et al., 1991); more than half of the women could not realize their hope of pregnancy. In general, women are recommended to undergo three cycles of IVF (Jee et al., 2004; Klinkert et al., 2004; Olivius et al., 2002). Many studies indicate that the most important factors in influencing the success of IVF are the woman's age and the function of her ovaries (Chuang et al., 2003; Jee et al., 2004; Klinkert et al., 2004; Olivius et al., 2002). Beckman and Harvey (2005) also emphasized that we need to know not only about the technology, but also about the individuals who intend to use it.

Informed consent for IVF infertile women should therefore include both the positive and the negative information. That will help these women to see new possibilities for the future. During the process of the transformation of hopelessness into hope, medical staff should not mislead infertile women or give them unrealistic hopes. They should assess the effects of treatments in infertile women continuously. They should also provide opportunities for infertile women to ask questions and discuss matters with them, thus helping them to make proper decisions with the benefit of a clear understanding.

Conclusion

Infertile women who receive IVF treatments have high expectations, but the failure of IVF often results in their losing their specific hope of pregnancy. Some of them therefore give up their treatment. The lived experiences of the women who give up treatment is often a process of transforming hope, which includes their accepting their infertile reality, acknowledging the limitations of treatment involving high technology , and re-identifying the future. They evaluate their long-term expectation of the

hope of pregnancy after IVF failure and they recognize that they have done their best. Often feeling uncomfortable in body and mind, they sooner or later face the limitations of technology, and accept the reality of infertility. At the same time, their stress is decreased as they accept the fact of infertility and receive support from their family. They reidentify themselves and focus on their own life without having to take account of children.

The lived experiences of transforming hope among infertile women were as complex as they were private. Medical consultation for women who receive IVF treatment should include provision of both the positive and the negative information on the treatment, continuing assessment and discussion of the treatment response with the individuals and their families, and help in identifying meaningful ways of life for childless couples.

Because of the qualitative research design and small sample size, the limitation of this study was the generalization. We suggest that a future study be designed with a questionnaire based on these findings as data are collected from more diverse settings. We also suggest that a longitudinal design study compare the differences in experience between these findings and findings in relation to women who continue to receive IVF treatment over several years.

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轉換希望 — 放棄治療之體外受精治療失敗婦女的生活經驗

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摘 要： 生殖科技帶給不孕者高度的懷孕希望。但是，並非每個人都能實現。本研究目的爲探討經歷體外受精治療失敗後並放棄治療的不孕婦女之生活經驗。本研究採質性研究設計，研究情境爲台灣北部一所醫學中心。研究對象爲曾接受體外受精治療失敗後一年，並已放棄治療的不孕婦女，經其同意，逐一收集，共 24 人。研究者依據會談指引，採訪談法收集資料，以文字紀錄，經由 Benner 現象學之解釋性研究的三個策略分析：主題分析、範例分析及典範案例分析。本研究經過該醫學中心倫理委員會審查通過，並獲所有研究對象之同意參與。研究結果：由資料歸類出研究對象之生活經驗的主題爲轉換希望；包括三個類目：對不孕事實的接受、對高科技醫療限制的感慨、與對未來生活的重新定位。結論：放棄治療之不孕婦女的醫療諮詢需包括告知治療的完整訊息、持續評估治療的反應及協助患者重新自我定位。

關鍵詞： 轉換希望、不孕症、體外受精、生活經驗、希望。

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