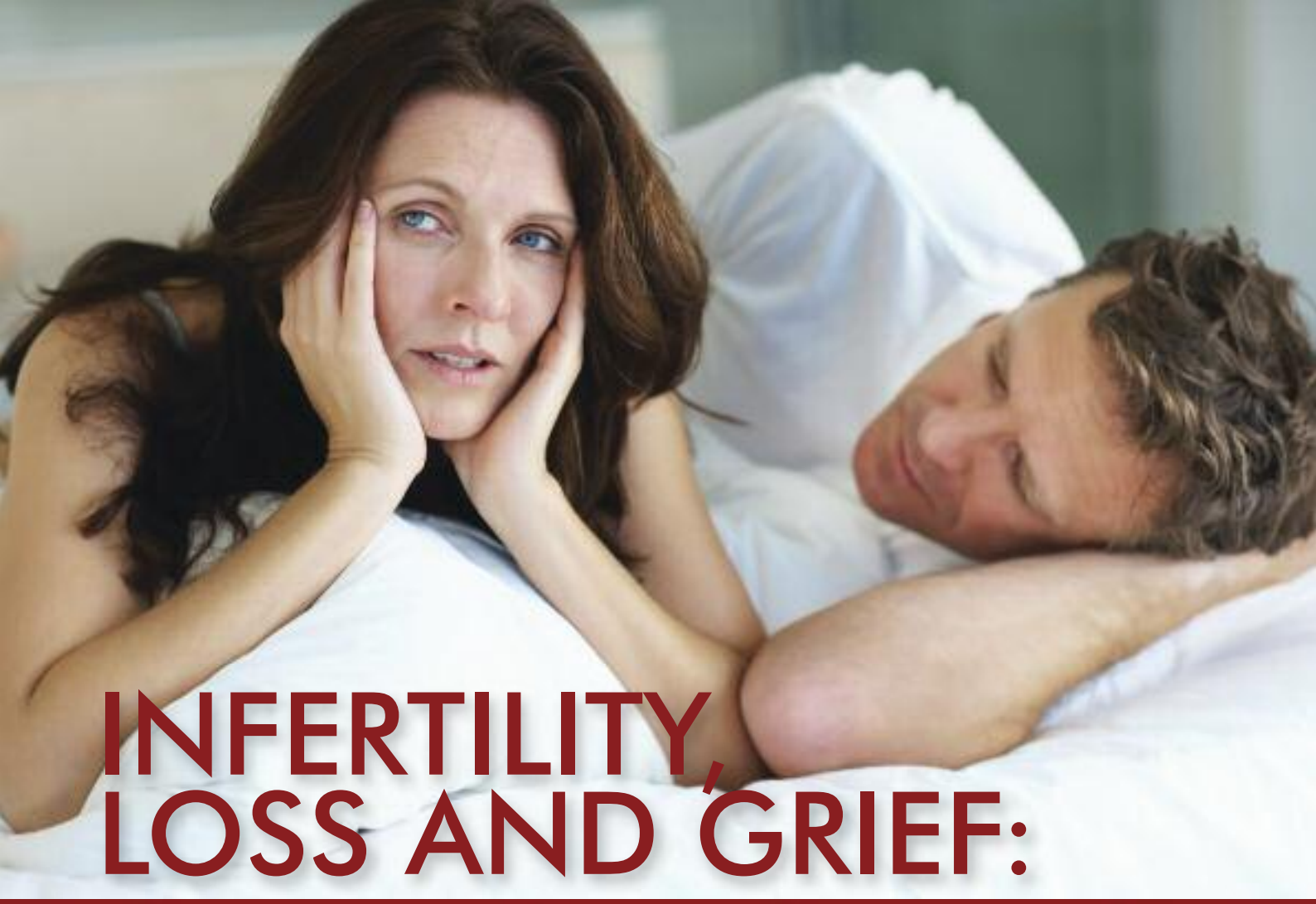


INFERTILITY, LOSS AND GRIEF: do we truly understand?

by **Caroline Rock**

Infertility is a problem of global proportions. The World Health Organisation estimates that 10-18% of couples around the world experience difficulty conceiving a child, or 1 in 6 couples worldwide. The prevalence of fertility-related problems is not likely to decrease in the near future. This implies that professional counsellors are more likely to have clients who have feelings of grief and loss, often intense, if their treatment efforts fail (Daniluk, 1997). A couple's need for counselling and support has long been emphasised in the literature. As Judith Daniluk (1991) states; "It is important counsellors familiarise themselves with the experiences and difficulties of infertile clients and with intervention strategies that may serve to reinforce experiences as an opportunity for psychological and marital growth".

Despite its prevalence infertility still remains a taboo subject. Couples encountering fertility problems can be reluctant to share their experiences. Very often those who have no experience of infertility may be ignorant to the facts and feelings associated with it and may unintentionally come across as insensitive. In order to have empathy towards clients, counsellors must try and touch on the pain felt by couples and individuals going through this life crisis. Looking at infertility through the lens of grief and loss can help us to do so.

Background:

Johansson and Berg said of Infertility:

> "It is not only a medical phenomenon, but also a life crisis as the possibility to have biological children may give a feeling of eternal life. Everything that has to do with involuntary childlessness, where the original and in a wide sense, biological function is threatened, is culturally, socially, psychologically and existentially charged"
>
> (Johansson and Berg, 2005, p.58).

One of the predominate aspects and one which is least understood among society is the feeling of loss and/or the disenfranchised grief experienced by couples going through infertility.

If current predictions are correct the rates of infertility are set to increase. Many couples struggle to come to terms with a diagnosis on their own. Reconstructing new meanings and identities can be difficult to do without guidance and can result in relationship breakdown, depression, anxiety and overall decrease in life satisfaction. However, with the help of a therapist, couples and individuals can negotiate the grieving process associated with infertility, heal their relationships and reassess their motivations and life plan.

It helps to look at both the female's and male's perspective, because as counsellors it is likely that we may be working with both in the therapy room.

The Female Perspective:

> "That's the one experience that women who have children easily miss out on in life.....The intensely female grief which accompanies the fear that those children might never exist"
> (Elton, B., 2000, p.316,).

In a study carried out by Abbey, Andrews & Halman (1992), it was reported that, on the whole, women experience higher levels of fertility-reported stress than men. This is supported by other literature. Miall (1985, p.391) describes how childlessness disqualifies infertile women from being part of the "in-group of mothers". In brief, compared to men, women are more likely to have lower self esteem, blame themselves, avoid children and pregnant women and initiate treatment (Abbey, Andrews & Halman, 1991). Matsubayashi et al (2001) reported that depression is more common among infertile women as compared to fertile or pregnant women.

In a study carried out by Sandelowski, Holditch-Davis & Harris (1990), women intimated that their inability to have a child may have constituted a punishment for past transgressions, including failed marriages, elective abortions and feeling relief after the loss of an unwanted pregnancy. This underlines the feeling of guilt which the woman may also have to bear.

"When I discovered I was infertile, I felt damaged. Why couldn't I accomplish something as 'natural' as conceiving a baby? Suddenly, my sense of self-worth was shaken" (Mahlstedt 1985, p.339).

Women more often than men will internalise images of the self as abnormal, defective or failing. They will not see infertility as just an element of the body but the entire self as damaged. Women tend to incorporate infertility into the self, interpreting it as a state of being. It is seen as an 'I am illness' as opposed to men who see it as an 'I have' or 'I had' condition which they share with their wives (Estroff, 1989, p. 189).

Women who are trying to conceive, and in particular women undergoing fertility treatment, have a heightened awareness of their bodies. They experience an increased sense of their physical body, sensitising them in particular to their menstrual cycles. According to a study by Allan, (2005), menstrual cycles were "subjectively experienced as painful or disappointing and objectively as recorded fact".

When a woman realises she cannot beget a biological child her womanliness can be questioned. "Infertility appears to most profoundly affect an individual's sense of femininity or masculinity and confidence in themselves as sexual beings" (Abbey, Andrews, & Halman, 1992, p.410).

With the perception of the sense of self distorted, the associated feelings of lower self esteem, anxiety, guilt and frustration will follow. Studies show that compared to their fertile counterparts, women with fertility problems are far more likely to feel depressed. Hormonal changes in relation to drug therapy regimes for women undergoing IVF can also contribute to these reactions (Robinson & Stewart, 1995).

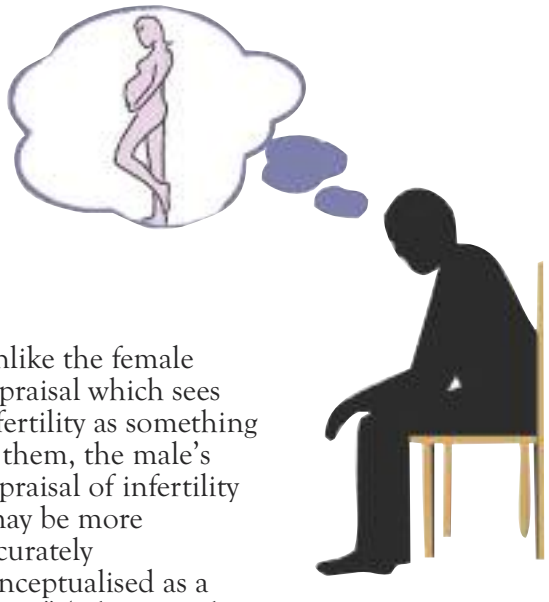
This emotional turmoil is usually not afforded an outlet, leaving the woman to silently carry her pain as she participates in a life which continues on oblivious to this sorrow. On a daily basis she will often have to carry the burden of infertility alone, hide it from friends and family and maintain a certain facade in particular around family gatherings involving children and the announcements of pregnancies amongst friends.

The Male Perspective:

> "The thread connecting sexual potency, fertility, strength and manhood is deeply woven into every culture, marking a corresponding fault-line of insecurity"
> (Winston, 2006, p.xvi)

The male perspective can be overshadowed by the female experience of infertility. Although results of the studies performed by Newton (1990) and Wischman (2005) showed that depression is higher among infertile women than infertile men, infertile men still experience levels of depression higher than fertile men. It seems men are presumed to be less sensitive to the subject of infertility and people may be less compassionate towards the male. Compared to females the issue can be a source of humour with such everyday phrases as 'shooting blanks' in our colloquial. This could be because the fertility problem may be presumed to say more about his female partner and therefore it may not affect him as much. But either way, whether the male is solely responsible for the issue or it is a female factor or it is combined, there is still a level of emotional anguish to be dealt with. Statistically males are not as willing to speak about their fertility issues with any other person other than their wives or partners.

Although male partners may cope differently they still experience painful emotions. In a study by Smith et al (2009), of 256 couples treated unsuccessfully with IVF, male partners were found to have increased marital and social stress, decreased overall mental health, increased physical stress, more feelings of sexual failure and increased coping effort. According to Shindel et al's study (2008) the male partners reported depression, erectile dysfunction and sexual relationship problems; in addition they reported significantly lower standardised scores on mental health.



Unlike the female appraisal which sees infertility as something in them, the male's appraisal of infertility "may be more accurately conceptualised as a threat" (Glover et al, 1996). According to Sandelowski et al (1990, p.204) "men tended to encapsulate infertility, to halt its spread, to keep it from becoming a master status or from spoiling their identities as intact males". This may be the reason why they are less likely to talk about it than their female counterparts.

According to Feuer (1983 cited in Daniluk, 1991, p.317) the female often presents with the most overt emotional distress, whereas reactions of the male partner are often less overt and may be more difficult to assess. It is therefore important from the outset for couples to acknowledge infertility as a couple's problem and not an individual one. This will eliminate blame and guilt.

Grief and loss:

> "Viewing a diagnosis of infertility through the lens of grief and loss allows for a more in-depth exploration into the personal and relational meanings of an often devastating disruption in life course"
> (Bridges, 2005, p.12).

One of the predominant aspects of infertility common to both the male and the female is the feeling of loss and the silent mourning that accompanies it. It is not a typical loss and often cannot even be identified cognitively.

Researchers and therapists alike agree that a diagnosis of infertility is a disruption in a person's life course which is similar to the disruption caused by death, with grief and mourning a natural outcome. The loss associated with infertility is different, though, as the grieving is for a hope or desire, for an assumed life course event rather than an actuality (Bridges, 2005). According to Doka

(2002 cited in Bridges 2005, p.10) "because loss of an aspiration does not involve death, a profound traumatic event or a removal of a tangible beloved object, this kind of loss is often socially disenfranchised as loss". There are no social rituals, for instance funerals or graves, when mourning the loss of fertility. When there are no clear social and relational pathways to begin to understand this process of loss, couples and individuals turn to traditional models of loss and coping that present a stage model as a way of 'moving on' (Bridges, 2005).

There are a number of losses experienced throughout the ordeal of infertility. There is the loss of control over one's body: this can be at the outset when a couple first realise they are having difficulties conceiving and it can also refer to the lack of control during the fertility treatment processes. There is the loss of the ability to conceive a baby naturally. For those who do not choose IVF or those with unsuccessful treatments there is the loss of the potential to have a child. There is also the loss of identity within society where the couple no longer fits into the 'parent group' but the minority 'childless' group. There is loss of immortality as children may be seen as the way to live on. There is also loss of the experience of pregnancy, loss of sexual identity or loss of confidence. The Kubler-Ross (1970) model of grief delineates five stages; shock, denial, anger, bargaining and acceptance. The losses are multiple and may mean moving in and out of this grief model a number of times and visiting and revisiting the different stages. This is why the process of trying to conceive is described as a rollercoaster. The couple has very little time to grieve the previous failed attempt at pregnancy before their hopes are raised at the next chance. This oscillation between hope and despair eventually takes its toll and there arrives a point where the couple has to move into the next phase which might be accepting the idea that they may never conceive naturally or at all.

Gibson, (2007, p.281) compares the experience of infertility with death attitudes and notes that the most striking similarity is how individuals seek to make meaning. She says that "for infertile individuals existential meaning-making is closely linked to the social constructions of parenthood in our society. This is also true about individuals' beliefs and assumptions about death". Part of helping the couple with fertility problems is to deconstruct these beliefs and assumptions in the quest to form new identities. Like death and dying it is a process of meaning making.

Providing Support:

Counselling and psychotherapy can help a couple through their grief and help them to take their finger off the pause button and try and live life. It can help couples achieve a level of acceptance. Sometimes it may even be enough for couples to know there are others out there going through the same experience.
In Ireland the state agency The Women's Health Council has published two reports in relation to infertility. The reports deal with the effectiveness of current infertility treatments and the psychological and social difficulties which couples affected by fertility problems will encounter. They have recently called out for increased information on treatments, success rates and risks. The council has predicted that the demand for advice and treatment for fertility problems will increase in Ireland over the coming years because of the trend here to delay parenthood to pursue career and financial security. This emphasizes the need for available information on all issues of infertility including possible preventative measures and management measures (www.rte.ie/news/2009/0923/fertility.html.). Importantly it also highlights the need for awareness around the subject among counsellors and society as a whole.

Conclusion:

For a lot of people the desire to have children comes from deep within, it is instinctual, emotional, cognitive and it is also conditioned. When this longing is not satisfied it can wreak havoc with a person's sense of self. Cognitive distortions can take over, adverse emotions and feelings can erupt and the overall psychological well being of the person is compromised. Infertility can be a long and arduous journey. Because no two persons' experience is exactly the same it can be very lonely at times. Family, friends and society are usually not equipped to respond to the pain felt by a couple faced with infertility. Professional help, in particular fertility counselling, is therefore highly important.

The vehicles for acceptance, hope and recovery are therapeutic counselling and a proactive role taken by society. Counsellors can guide couples to reconstruct and reevaluate their lives while they are going through these challenging times. In doing so couples may eventually find personal growth and learning through the experience. Society can be proactive in encouraging awareness of infertility among

couples, providing facts and choices, providing financial assistance, letting people know there is counselling help out there and sharing the experiences of real people. Most importantly society could take responsibility for creating a feeling of empathy towards those struggling with this issue.

Society evolves through learning. People grow through learning, whether from other people's experiences or their own. Infertility is deeply personal and painful. Being aware of this can open people's minds to questioning their own position on the subject and to relate it to their own lives. As with any taboo subject the way to remove the stigma is to include it in everyday language and discussion. This can promote empathy as well as choice. It can spread learning as well as healing. The sharing can encourage caring, beginning in the therapy room, then amongst family and friends and then society too.

The following is a quote from a woman undergoing infertility therapy. It eloquently expresses the anguish of an infertility patient. From it we can learn about the grief and the level of pain associated with infertility, and harness a sense of empathy and understanding toward the struggle that is infertility.

> "My infertility is a blow to my self-esteem, a violation of my privacy, an assault on my sexuality, a final exam on my ability to cope, an affront to my sense of justice, a painful reminder that nothing can be taken for granted. My infertility is a break in the continuity of life. It is above all a wound... to my body, my psyche, to my soul."
>
> Jorgensen
> (1981 in Scharnowski 2011).

Caroline Rock graduated from PCI with a BSc in Counselling and Psychotherapy. She currently works from her private practice in Ashbourne, Co. Meath and is specialising in the area of Fertility Counselling. Caroline also works as part of the counselling team in SIMS IVF Clinic in Clonskeagh, Dublin. The article is an excerpt from her thesis titled "Awareness, Appropriate counselling intervention, and a more evolved societal response can greatly ease the burden of those affected by the global phenomenon of Infertility."

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