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However, the approach to addressing these issues appears inconsistent and a survey reported by CHILD at the HFEA Annual Conference in 2004 (Young 2004) suggests that more than three quarters of patients requesting treatment were not aware that the “welfare of the child” assessment had taken place in the discussions they had with their clinicians. Certainly the assessment is normally undertaken by health professionals in a clinic environment, the evidence base is unclear and the criteria will be applied differently between clinics. Perhaps understandably, patients requesting treatment and clinics providing it would be very reluctant to have similar assessments to those for adopters introduced.

This comparison raise a number of questions. Can the differences in assessment and approach between adoption and treatment be justified either by lack of relevance (i.e. the child is “born” to the donor assisted parents but is not “related” to both of them) or because the respective laws place different weightings on the child’s welfare? Will the lifting of donor anonymity change the context in which such decisions are made? Would there be more donors if the process of assessment was more robust and they could therefore be confident that the safety and welfare of their possible child was assured? Finally, we must remember that a huge number of people have had their lives touched by adoption and their experiences have had a major influence on adoption practice. However, adults born as a result of donor assisted conception are still too small in number to be a significant lobby. It is right and appropriate that we should learn from the experiences of adopted adults and consider the areas where we need to improve our practice to better safeguard the children born of donor assisted conception. If we do not do so, we risk creating new problems for tomorrow’s children.

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## **Infertility and the dark age of enlightenment: making a case for mind/body medicine**

### **Elizabeth O’Donnell**

For centuries many cultures had interpreted the experience of the body in relation to the condition of the mind. During the period of the Enlightenment, which peaked in the middle of the eighteenth century, the powers of science and reason became dominant forces in the way that human beings continued to explain their understanding of the world (Case, 1996). As a result thoughts, feelings and beliefs, factors which influence people deeply but are difficult to measure, were given a back seat to the kinds of physical or mechanistic conditions that can, in contrast, be observed or more accurately evaluated. In other words, what we can count and see began to have greater value than what we could think or feel (Allen, 2003; Hooker, 1996).

Of course this does not mean that emotions have no value, or are not still a powerful driver on the route through life. Ultimately, how we register, interpret, and respond to our emotions runs a parallel course to the action we choose to take to reconcile them. Emotion is the nuance through which we forecast our lives: the sensation that tells us in the immediate that something might be important and, for some people, it is rarely ever clearer than that. Still, we might call this intuition rather than sound empirical evidence, a kind of vagary of the soul. This dilemma by its very nature is what creates anxiety in human beings; having to trust instinct and make judgments that do not guarantee a perfect outcome (Frankl, 1986). However, to what extent emotion drives personal choice, or manifests as a consequence to our spiritual and physical health, is and often has been, a topic of extensive debate. Welcome to the uncertain world of mind/body medicine and the anguish of infertility.

During the 1950s psychodynamic theorists started to ask whether some cases of infertility were a function of an unconscious desire or defence against pregnancy, with particular focus on unexplained infertility. As a result women were often blamed for their inability to conceive and given descriptors such as, conflicted maternal identity, ambivalent or frigid (Wischmann, 2003). Although we now know that psychogenic causes of infertility are rarely the reason behind most cases of involuntary childlessness the legacy of this belief often made the use of the terms 'stress' and 'infertile' together suspiciously self-accusatory. As though if patients would only relax, then everything could be permitted to happen. More recently studies to determine the negative psychological consequence of the diagnosis and treatment of infertility have attempted to put the role of stress into better perspective (Facchinetti, Matteo, Artini, Volpe, and Genazzani, 1997, Domar, Clapp, Slawsby, Dusek, Kessel, and Freizinger, 2000).

The development of more sophisticated scientific techniques has allowed researchers to assess the state of the world, and the health of human beings with better precision. Precision in diagnosis one hopes

leads to efficacious care and is still the current goal of all scientific or medical experimentation

and treatment. The desire for precision in the management of infertility, and indeed most physical ailments, means that thought and emotion are often not given the same regard as the size of follicles, the quality of sperm, or the thickness of the lining of the uterus, all of which can be more accurately evaluated than sadness, joy, or grief.

Body/mind, according to the English philosopher George Henry Lewes (1817-1878) is a way of understanding how what plagues us mentally and emotionally is manifested within us physically. Rather than describing the subjective experience of being as less valid than the objective ability to study behaviour, Lewes believed that the metaphysical process of thought and affect cannot be separated from the body's physiology; each are integral to and interconnected to the other.

Few would argue that it is our ability to feel pleasure which feeds our desire to search for the things that bring us joy, but oh how so much harder it is to say exactly how joy is operating in the body. Consider where you might feel physical discomfort when you hear bad news, the head, the heart, the belly? Do you experience the pain as real? Can we argue that the ache from emotional loss is less profound than the pulsing throb of an infected tooth? The turmoil inside the gut is the physical messenger that informs the sufferer of the condition of their broken heart as much as giddy euphoria might mean that they are indeed in love. How rational beings give credence to sometimes irrational thought is the eternal human struggle (Frijda, 1988). We have searched the words of Plato, Descartes, Freud, and of course God in our quest to understand that which is not clearly known. Does this lack of clear understanding mean that we are to deny the existence of those things we cannot explain? Perhaps, or maybe this is the point at which many people encounter the notion of faith; faith, which in the hands of the fathers of enlightenment, meant abdication from reason and descent into passion (Case, 1996).

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Having faith in something implies that one has confidence things will turn out well despite not having absolute proof. Faith hinges on our acceptance of the mysterious making faith paramount on the march toward fertility via the use of assisted reproductive technology. When Patrick Steptoe and Robert Edwards successfully helped Lesley and John Brown create their first child it was after years of collaborative research, numerous trial patients, and indeed the development of a relationship of intense importance between all of the participants (Marsh, and Ronner, 1996). The faith inherent in these relationships it would seem were every bit as vital to the outcome of a healthy baby as a mature follicle, stable hormones, ambitious sperm, and a receptive uterus.

Research that is destined to herald dramatic change in life as we have known it is both omnipotent and consuming. It requires dedication, resilience, several people on a united mission, and perhaps more than anything, unmitigated passion (a passion synonymous with the love ache of human beings who are longing for a child). The symbiotic struggle of healer and patient, when harmonious, is a glorious lilt; a rhythmic movement guaranteed to lift the heart (Epstein, 2003). It is not biology in its strictest empirical form, for it is only that which we can measure to which we give account. Does this mean that the effect that cannot be explicitly quantified is submitted to the idealism of philosophical thought does not really exist, and therefore cannot represent truth? Human emotion has perhaps been subjected to such a role.

Many researchers have shown that individuals who have some spiritual force present in their lives live longer, recover from illness faster, and get sick less frequently than those who do not (Kabat Zinn, 2003). Developing this personal trust however, particularly in the midst of a health related crisis viewed through the reductionistic lens of medicine, is extremely difficult. For individuals facing infertility the mind frequently directs the body toward fear with statements like, "my uterus has failed me... I feel useless... I cannot even do what any sixteen year old can do." However, to mitigate the impact of such declarations we

must first acknowledge their effect (Beck, and Perkins, 2001). Or, stated more explicitly, "... what we feel is influenced by what we think and, to feel better, we need to avoid "dysfunctional" thoughts (Weinrach, 1988, p.159).

We now know that the kind of verbal self-beating described above takes a physical as well as emotional toll. Recent brain imaging research has demonstrated that different areas of the frontal lobes are activated during negative and positive thought processes resulting in different kinds of brain wave activity. These variable wave patterns are associated with calm or arousal based brain effects which then go on to impact other physiological systems in the body (Davidson and Irwin, 1999). So are we now coming full circle? With the advent of new technology are we now able to acknowledge that perhaps what we think and how we feel emotionally is intimately linked to what we sense physically?

Given the immense stress it is known that patients undergoing infertility treatment experience it is also clear that this stress, in addition to the infertility diagnosis, can have an influence on how well patients are able to cope (Factinetti, Volpe, Matteo, Artini, and Genazzani, 1997; Kee, Jung, and Lee, 2000; Kupka, Dorn, Richter, Schmutzler, van der Ven, and Kulczycki, 2003). When coping skills are limited or not utilized secondary physical/physiological consequences such as headaches, insomnia, cardiovascular vulnerability, decreased immune response, anxiety, depression, irritable bowel syndrome, and irregular menstruation, may develop. These secondary effects have been shown to impact the reproductive hormones response to hyper stimulation, as well as disturbing naturally occurring body rhythms (Csemiczky, Landgren, and Collins, 2000; Berghuis, and Stanton, 2002; Facchinetti, Tarabusi, and Volpe, 2004).

The internal experience of distress surrounding the inability to conceive is also compounded by the social construct toward childlessness that individuals inherit from the culture in which they live (Akker, 2001). Having babies in committed heterosexual relationships is generally seen as a good thing to do. Having babies if you are a

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teenager, single woman, gay, lesbian, or infertile, is seen as something else and, it appears, open to general forum and public debate. With the birth of the world's first baby conceived by in vitro fertilization (IVF) in 1978, the door flew open to the multiple voices ready to deliver a treatise on the topic of assisted reproduction. Now infertile individuals had to make room for not only their physician, but it seemed the entire world, to climb into their bed and offer discourse on the individual's arguable right to create a baby. Mon dieu, I am already depressed.

Although the literature abounds in the past two decades with articles that document the psychosocial negative effects of infertility and various treatment options, lending credence to the emotional angst of being unable to have a child, few meet the stringent criteria of the empirical standard (Boivin, 2003). Those that come close, according to Boivin, are studies which attempt to implement intervention strategies that are educational, reproducible, and have had some relative measure of success. Several of the intervention methods utilized are supported by reported evidence of their efficacy in areas of generalized psychological distress that is not specific to infertility. For example, stress management, cognitive behavioural therapy, mindfulness based stress reduction, progressive muscle relaxation, and meditation (Benson, and Klipper, 1975; Chambless, and Ollendick, 2001; Baer, 2003; Proulx, 2003; Bower, and Segerstrom, 2004).

Perhaps what must be de-emphasized in designing appropriate support programmes for individuals and couples dealing with infertility is the diagnostic framework surrounding current intervention techniques. Already stigmatized by the label of infertility, a pronouncement of anxiety or depression further excoriates an already infinite wound (Sandelowski, 1990).

Rather than looking to the DSM-IV for behavioural interpretation, the unique existential crisis of infertility deserves description in a unique language. It appears that twentieth century technology has not only confounded the question of reproductive right but continues to reduce

the essential nature of human experience to a category to be defined and appropriately medicated. Infertility is less a psychological state and more a profound and transforming narrative of loss (Dyer, Abrahams, Hoffman, and van der Spuy, 2002).

Each of us finds a different way to attribute meaning and purpose in the action of our lives. An unexpected deviation from a path we have placed great comfort in is then experienced as an assault against what we consider to be our reason for being. Creating a child is no longer about simply having a baby. It is about the experience of parenting, and being parented; fulfilling a wish for attachment that is heart deep and without compromise; responding to an emotional longing that transcends verbal description to sit as a physical ache at the seat of the soul (Kossman, 2000).

A mind/body programme is intended as an emotional and physical compass, not a recipe for minimizing the significant turmoil of threatened parenthood. It is not possible to diminish that which causes this kind of spiritual pain, nor does it make sense to. The fear of not being able to have a child is painful. To attempt to find some way to pretend that it isn't disrespects and trivializes the enormity of this want. On the other hand it is important to discover the best way to console, support, and empower individuals throughout treatment and beyond.

Infertility, it appears, does not end with pregnancy. Many men and women describe themselves with this label despite birthing biological children, adopting, creating family through surrogacy, sperm, and egg donation, or deciding to remain childless (Daniluk, 1988). What is it about the experience of being denied the freedom to reproduce in our own time at our own will that has such sustaining power, regardless of the eventual outcome? I believe the answer to this question is partly what is missing from the psychological support frequently offered to individuals and couples undergoing infertility treatment and perhaps explains, in part, the reason why, even when counselling is offered, it is frequently not utilized (Domar, 2004).

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Often, it is not what we cannot have that we mourn but the dream we have built around acquiring it. How best to understand and reconcile a shattered dream is complicated by the intensely personal and culturally assumed nature of the desire to parent. Beyond the biology of procreation sits this mysterious concept, 'instinct': a natural drive attributed to human beings when they act in predictably human ways. Instinct of course implies something more primitive than rational choice. Instinct speaks to something fundamentally coded in our genes that makes the desire to reproduce regress into a drive. So maybe wanting a baby really is about biology after all? Or is it about the mechanicalization of conception in particular as it relates to infertility; the reduction of the birth of a child to the level of ovary, oocyte, sperm, and uterus; the dark age of enlightenment? Questions of the spirit are by their very nature, elusive and in constant flux. As our physical circumstances change, so do our thoughts about those circumstances. Often rather than finding answers to questions we must learn to find peace in not knowing, finding meaning through the personal transformation of infertility - message of creation beyond procreation or perhaps the capacity to live with great ambivalence.

Mind/body medicine has begun to capture the attention of several health related disciplines, including reproductive endocrinology (Facchinetti, Tarabusi and Volpe, 2004). It is a compelling step in assuring that clients maintain belief in the power of their own decision making at a time when the potential to feel completely powerless is at its peak. The message of ART is far greater than its use in assisted reproductive technology. Art it appears is also a vague concept in the hands of great thinkers. Art is creative and created; art is about imagination, fantasy, and appreciation. Art can be and is the experience of simply 'being.' Art is the cognitive, affective, and spiritual foundation of a mind/body programme.

Alice Domar, in 2000, reported her findings on the effect of group based psychosocial support on infertility and pregnancy outcome, results, which according to Boivin, are ripe to be expanded upon and further

clarified (Domar, Clapp, Slawsby, Dusek, Kessel, and Freizinger, 2000).

In 2004 Facchinetti et. al., building upon their earlier research, determined that use of cognitive behavioural strategies in women waiting for infertility treatment was effective in reducing heart rate response, blood pressure, and plasma cortisol levels (Facchinetti, Tarabusi, and Volpe, 2004). Although stress reduction programmes, from the board room to the school room, currently flourish in the United States, what actually constitutes a mind/body based stress reduction programme is widely interpreted. However, according to Ong et. al. "...the majority of the studies endorsed a multi-component cognitive-behavioral approach." (Ong, Linden, and Young, 2004, p.134).

I believe it is important that we research the ability for a mind/body programme to reduce symptomatic stress, and by doing so perhaps support reproductive endocrine function, maybe even improve pregnancy outcome. However, just as important is the need for those patients who do not have a biological child to be able to move forward with their life in a way that is productive despite not being reproductive.

The programme I envision, indeed plan to implement and study, will incorporate the best of what we know about the effect of thought and feeling on the function of the body. However, as a graduate of infertility treatment and the mother of two sons born from IVF, now 15 and 13, I firmly believe that my success had as much to do with my belief in 'the perfect cup of tea' as it did in the individualization of gonadotrophin administration. "... specific conditions or environmental signals elicit a patterned array of hormonal and neural changes that are designed to ready the organism to deal with the specific nature of the threat" (Kemeny, 2003, p.127). Mind/body medicine is about respecting the conviction that has no certainty. What we believe about our circumstances often dictates what we strive to achieve, sometimes meaning that we will strive to achieve little, self sabotage, or simply give up in defeat. Fertile vision requires a commitment to pay attention to the way one functions in the world; a pledge

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to oneself to productive change. This is at the ART and heart of self care, this and the belief that minding indeed matters.

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Tanner Stage 2 who were diagnosed with cancer and offered fertility preservation. Sperm banking for under 18s is regulated in the same way as for adults, i.e. through the

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### **Experiences of the sperm banking process for teenage males with cancer**

#### **Marilyn Crawshaw**

This paper reports in brief on a small scale exploratory research study which looked at the experiences of teenage males under 18 and post

Human Fertilisation & Embryology Act 1990 (HFE Act) under the auspices of the Human Fertilisation & Embryology Authority (HFEA). This has created a unique situation whereby it is only the young men themselves that can consent to semen storage and there are no circumstances at all in which there can be substituted consent (HFE Act, Schedule 3). Where mature gametes are present, the young men therefore must be Gillick competent to use fertility preservation services.

Decisions have to be made between diagnosis and commencement of treatment, when they are in a state of shock. The paucity of research into the experiences of teenagers and their parents or of professionals (this was the first study of its kind in the UK) is a significant drawback to service development.

The study was funded by the NHS (Executive) and undertaken in three parts:

1. Interviews (22) with professionals from paediatric oncology and reproductive medicine, nursing, reproductive science, and social work in two geographical areas in the North of England to establish professionals' understanding of, and concerns about local fertility preservation services (Crawshaw et al, in press)
2. Postal surveys of UK assisted conception units (ACU5) and regional paediatric oncology centres to document common practices, areas of variance and professional issues (Glaser et al, in press).
3. Qualitative interviews with teenagers and their parents to explore issues around talking to them about their experiences of being offered sperm storage and the concerns they raised. Due to high levels of relapse in the potential sample, only nine young men were approached. Of these, seven young men and five sets of parents agreed to participate and it is this part of the study which is reported here.

