Breaking bad news concerning fertility

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Introduction

The subject for this opinion paper is breaking bad news, a complex and integral part in the area of infertility. From the couple’s point of view, involuntary childlessness is not a question of once receiving bad news but repeatedly receiving bad news during the infertility investigation and treatment. Already before seeking medical attention, the couple will have had monthly bad news in the form of unwanted menstruation. To exaggerate a little, one could say that there is, in this respect, only one form of good news for the couple – that of a successful pregnancy.

From research regarding the impact of infertility it is obvious that both the infertility itself and the medical process evoke many feelings in the couple (Lalos et al., 1985a; Kentenich, 1989; Möller and Fällström, 1991). In most cases, the woman is the first to recognize infertility as a problem and to initiate open discussion on the subject. Usually she also arranges the first medical contact. Both from reports and daily clinical work, it has been established that couples attending infertility clinics generally experience feelings of frustration and inadequacy and show signs of emotional stress (Collins et al., 1992; Reading, 1992; Laffont and Edelman, 1994).

The ability to control fertility is often taken for granted, both in the medical profession and by the public at large. Perhaps the impact of medical interventions has left us more vulnerable to disappointment; there is a prevailing ideology of curability which influences both the medical staff and infertile couples. Most couples assume that they can have children if and when they desire, and there are both internal and external motives for wanting a child (Lalos et al., 1985b; Wikman et al., 1992; van Balen and Trimbos-Kemper, 1994).

Although great progress has been made with medical investigation and treatment of infertility, it is still often a protracted and time consuming process, with many couples never getting their desired child. The somatic aspects are generally considered in great detail, but in too many cases little or no attention is paid to the psychological, social and sexual consequences of infertility.

The crisis of infertility

A large portion of human life is centred around reproduction, parenthood and raising a family, and the ability to conceive is closely related to self-esteem, identity, sexuality and body image (Kraft et al., 1980; Lalos et al., 1985c; Möller and Fällström, 1991). When a couple becomes increasingly aware of delays beyond their control or that reproduction is perhaps unattainable, an emotional crisis may occur. A crisis is characterized by definite psychological stress and behavioural changes; it is a state where earlier experiences and learned patterns of behaviour are not sufficient for understanding and coping with the actual situation (Caplan, 1964). The couple often face emotional turmoil and the crises have to be dealt with individually and within the marital relationship.

Regarding infertility as a crisis is of utmost importance, since medical investigation and treatment of infertility usually appear in conjunction with this existential life crisis. We must be aware of the fact that breaking bad news to infertile couples means that we will interfere in an already vulnerable process. The crisis of infertility is very complex and difficult to work through. The first reaction includes shock, surprise, disbelief and denial, followed by feelings of frustration, anger, loss of control and anxiety. Subsequent reactions often include feelings of guilt, embarrassment, disappointment, isolation, depression, grief and mourning. These symptoms follow a pattern similar to that experienced generally in a crisis situation, in which four main phases have been identified originally by Caplan (1964): shock (e.g. denial), reaction (e.g. anger, depression), adaptation (e.g. acceptance) and resolution (planning of solution).

Nevertheless, the crisis of infertility differs from that of a general traumatic crisis, in which the duration of the reactive phase is usually ~6 weeks. New events, new hopes and new forms of bad news prevent the adaptation to and resolution of the previous trauma, e.g. an ectopic pregnancy, a miscarriage or an acute laparotomy. Many individuals therefore remain in a state of prolonged chronic crisis (Menning, 1980; Lalos et al., 1986).

The fact that crisis reactions specific for infertility are inhibited, prolonged and repeated is, for example, shown in a longitudinal interview study with 30 couples in which the woman was to undergo surgical treatment for tubal infertility (Lalos et al., 1986). It was found that before the tubal operation most women were judged to be in the reactive phase and nearly all who had not achieved a normal pregnancy were in the same reactive phase of their crisis 2 years after completion of testing and treatment. The majority of the men were at the first interview in the initial phase, while 2 years later most had reached the reactive phase. At both interviews one-third
of the men had no apparent symptoms of a crisis reaction and nearly all of them had become fathers previously. Among many different psychological reactions three main groups of symptoms were distinguished. One group was dominated by symptoms of depression, another by guilt and a third by social isolation and loneliness (Lalos et al., 1986). All these are parts of the reactive phase of the common crisis reaction.

Furthermore, it seems as though the psychological trauma of infertility is more apparent in the sterile individual. She/he may experience both a traumatic crisis, caused for example by the knowledge of damaged Fallopian tubes or azoospermia, and a developmental crisis, caused by their inability to have children with their loved one and by being denied one of their main goals in life. If the other partner is fertile, she or he does not experience the same kind of traumatic crisis, but might suffer from a similar developmental crisis.

In addition, the two partners can have varying attitudes towards childlessness and sometimes conflicting opinions on how infertility influences their relationship and sexual life. For instance, in nearly half of the couples in the above mentioned study, the man and the woman did not experience the influence of infertility on their marital relationship in the same way (Lalos et al., 1985c). This must be kept in mind when breaking bad news. It is not a couple as a unit that receives the information; we have to deal with two separate individuals with different reactions and behaviour. Thus, there is a need for individual supportive counselling parallel to the psychological treatment of the couple.

Coping

As mentioned by way of introduction, infertile couples have to face many forms of bad news. To be able to handle bad news adequately, there is often a need for extensive reorganization of personal maps or personal constructions of reality (Caplan, 1964). It is a question of finding new ways of being and to achieve a new understanding. The process of receiving and adapting to this news can be a painful process which is complicated by the fact that on the surface life seems to be the same as before. This has to do with the fact that identification of loss is difficult. In society there are rituals to handle loss through death, and such rituals can be helpful in adapting to the loss. But there are no rituals to deal with lost dreams and future possibilities – such as the dream of a child. Involuntary childlessness can be regarded as an invisible handicap; the social network might not even know of the experienced loss and grief, or have only very superficial knowledge about the couple’s experience (Menning, 1980; Lalos et al., 1985c).

As stressed previously, we should look upon infertile couples during infertility investigation and treatment as people facing a crisis. When new events trigger that crisis of infertility, it is not always easy to remember that two events become intertwined, the first being the actual event or series of events, while the other is the crisis itself (Lalos et al., 1986; Wirtberg, 1992). Crisis has its own structure and course, while the trigger event has yet another significance, often needing its own specific response and handling. Frequently, this new event, for example an unsuccessful in-vitro fertilization (IVF) treatment or the diagnosis of azoospermia, prevent the adaptation and resolution of the previous trauma. Therefore, infertile individuals can remain in a state of prolonged or so-called chronic crisis (Lalos et al., 1986). They live their life balancing between hope and despair, see-sawing around the menstrual period perhaps until menopause. This is naturally very anxiety-provoking.

One way of coping during the crisis of infertility is to try to hang on to the medical system in order to get support and comfort. This is more understandable in the light of what has been mentioned earlier about the tendency of infertile couples to be isolated with their problems and experiences. In this the doctor has a key role, and the couple could define the doctor as ‘the problem solving agent’ who will help them to get their desired baby. The doctor presumably also sees him/herself in this role and when the doctor and the couple meet they will attempt to co-operate. They have a common goal and complementary roles. This should logically be fairly simple; however, it is more difficult than it sounds.

The relational triangle

The doctor and the couple form a relational triangle, and from family therapy, we know that a triad is a complex relational structure and potentially unstable (Figure 1). In a triadic relationship system, organizational aspects assume more importance than in a dyad, and such factors as hierarchy, power, secrecy and the possibility of coalitions assume greater importance. The couple and the doctor form a triad, regardless of the husband’s presence or absence in the doctor’s office. The man, the woman, and the doctor are inevitably involved in everything that is done in order to try to produce a baby (Wirtberg, 1992). The triangle is a sensitive social system, since every individual member’s behaviour will affect one, or both of the other participants to a greater or lesser degree – and in doing so will alter their relationship in some way.

Involvement with the medical system and its examinations, tests and treatment is two-pronged. It holds the possibility of a cure or bad news of incurability. The doctor, in the role of ‘expert’, controls, suggests and recommends various courses of action, but all leaders are dependent on a mandate from the led in order to keep and maintain their appointed role. If the triangle of man–woman–doctor is to function satisfactorily, an awareness of the sensitive nature of the situation, coupled with a willingness from all the participants to discuss, negotiate,
compromise and support each other, is required (Wirtberg, 1992).

The doctor and the couple have to adapt to the changing circumstances that emerge during investigation and treatment, for example when the doctor discovers that the couple has a poor prognosis for becoming biological parents. The way in which each individual defines the meaning of such information will affect their relationship to the other two. Some changes may be defined as pleasant, but others as unpleasant, or causing conflict. In all cases the individual will seek to adapt to the new reality and his/her adaptation will influence the others. Thus, triangles in conflict situations are potentially unstable units, for example when one member of the triad changes her/his behaviour in order to avoid a conflict situation with a second member, her/his changed behaviour may influence the third member (Wirtberg, 1992). Another example is when one member attempts to block communication between the other two members in order to avoid conflicts or to mask differences; his/her behaviour may influence all three relationships in unpredictable ways. As a final example, there is a possibility that two persons may form an alliance against a third; for example the couple may identify the doctor as the cause of their problems.

If we look upon infertility investigation as a game of triangles, it is easy to realize how crucial it is to bring both bad and good news to both members of the couple (Figure 1). In reality, misunderstandings and lack of insight can cause great stress in the couple when, for instance, only the woman is informed about the result of the semen analysis. It was indicated in a study that half of the men were informed by their partners about semen analysis results (Lalos et al., 1985a). We can never know how often wives choose to protect their husbands from bad news. In another investigation, it was shown that one woman had been told that her husband’s sperm count was low and did not dare to tell him (Wirtberg, 1992). Three years later she was still waiting for the right moment to tell him. Thus, both partners should be involved and addressed during investigation and treatment, regardless of who is diagnosed as having the infertility factor. In too many cases we hear about the man feeling excluded from the relationship between the doctor and the female partner.

There are a number of points which add to the importance of the triad which must be taken into consideration. One point is that one of the three actors, the doctor, may be changed one or more times during ongoing treatment. Although it is desirable to have the same doctor throughout investigation and treatment, reality does not always permit this. When the doctor is changed, or when one of the triad starts to have new or different ideas about the significance of treatment, it is important that new exchange of information and new negotiations can take place. In this way, all three members of the triad can pull together, sharing the same definition of the meaning of what they are engaged in.

Medical staff
Concerning the medical staff, identification of the stages of infertility and increased understanding of the psychological experiences that couples undergo during treatment would enable nurses and other health professionals to help patients cope with their situation (Lalos et al., 1985a; Guerra et al., 1998; Kemeter and Fieg, 1998). Specific communication skills on the part of the whole medical staff are desirable in order to develop a professional helping relationship. One communication skill concerns the nature of language itself. Instead of being a means to pass on information, language has an orienting function; words suggest to the individual relevant experiences which can be used to create a context and understanding (Wirtberg, 1992). When language is thought about in this way, we have to pay constant attention to the actual responses that follow the communication. One can describe communication as a non-predictable activity and the meaning of communication is the response received (Grinder and Bandler, 1976). In other words, one can never predict with certainty the outcome or the result of any interaction between individuals. Thus, one can never predict what will happen when breaking bad news.

Although the couple’s relationship with the doctor is of crucial importance, a lot of counselling work during investigation and treatment of infertility is performed by, e.g. nurses and counsellors. In those situations, each professional forms a new and separate relational triangle with the couple, which in turn influences the primary doctor–couple triangle (Figure 1).

In ongoing communication, the doctor and the staff can vary and adapt their behaviour according to the responses that they get. Each patient/couple represents a unique challenge to adapt the language and style of communication. The technical and foreign language of medicine acts not only as a hindrance to intellectual understanding for the couple, but also as a relationship barrier between them and the professionals (Wirtberg, 1992). In such a stressful context the couples’ ability to cope with their situation constructively becomes unnecessarily difficult. If we succeed in reducing the stress experienced by the couple, we are not only increasing their psychological, social and sexual well-being we may also increase their fertility. Since the IVF programme is considered by many as the final step of treatment, couples participating in an IVF programme can be extremely stressed, especially after a failed IVF cycle (Reading, 1989; Collins et al., 1992; Laffont and Edelman, 1994). Some reports claim that high stress reduces the possibility of successful IVF treatment. Thus, there is a high risk of a vicious circle.

A question arises as to what might explain the unprofessional ways of informing and communicating with this vulnerable group of patients/couples? The underlying cause presumably has a more complex origin than a lack of knowledge and insight among physicians and medical staff. Probably, the personality plays a role as well as the working conditions at the department. In an infertility unit, the reproductive medicine could be regarded as an ideal field for medicine without emotions (Kentenich, 1992). Almost everything can be examined or measured; for example, uterus, levels of hormones, semen profile and quality of embryos. On the other hand, as Kentenich has emphasized, all these belong to the patients, and if you deal with patients, there are feelings and emotions involved. The patients provoke both positive and negative
feelings, and it often depends on the emotional structures within the infertility team, whether a couple is met with pleasant or cooler reactions.

Since each team is made up of individuals, there will be differences in thinking and acting and there can be quick changes between feelings of omnipotence and helplessness. Along with uncertainty, work in an infertility unit can be the source of fears as well – fears of miscarriage, tubal pregnancy or multiple pregnancy (Kentonich, 1992). It ought to be obvious, that team members must talk among themselves about their duty as well as emotions, since they exist and need to be accepted. Since responsibility rests with the team as a whole, every team member must be involved. This will improve team work and will lead to a more adequate communication with the infertile couple. In my opinion, success stands not only for a healthy baby; it is also about helping couples to adapt to bad news.

The doctor’s role

From several years of seminars with medical students I find it crucial that the doctor’s education, as well as of social workers and psychologists, should comprise training in recognizing one’s own reactions and behavioural responses. This awareness is of major importance also for doctors working on a daily basis with patients exposing their feelings, as common in infertility treatment. Therefore, the possibility to encounter in a small group one’s own reactions to meeting patients should continue in clinical practice, e.g. as suggested by Balint et al. (1966). These needs have been emphasized by several doctors after graduation. Obviously, in the flow of stressful events doctors in clinical practice need support in order to be empathetic and supportive to patients and couples.

There are some parallels within the field of oncology and reproductive medicine concerning the doctor’s feelings and experiences of communicating bad news. In a study on difficulties and coping strategies of oncologists in cancer care, it was found that the stated difficulties deeply affected the doctors as human beings. Various categories of coping strategies were found (Andrae, 1994). Presumably these different strategies entail different ways of informing a patient on a diagnosis (Lalos, 1997). If, for instance a doctor applies a coping strategy of ‘denying the severity of the situation’ or the strategy of ‘building up a relation to the patient’ this should have indications for the communication with the patient or the couple. There are also different strategies when focusing on gynaecologists in reproductive medicine. Some gynaecologists may feel that the management of emotions is not their responsibility and that their task is to deal mainly with somatic problems. Other gynaecologists, although they would like to consider the whole psycho–social context, claim that there is too little time and/or knowledge for the management of complicated psychological problems.

Furthermore, we can learn from oncology that training courses for doctors can increase their capacity for empathetic understanding, make them feel more secure with patients with emotional problems and more aware of what happens in their interaction with patients, e.g. when conveying bad news (Maguire and Faulkner, 1988; Aspegren et al., 1996). When medical treatment of infertility fails, the couple and the physician both become frustrated. Therefore dubious investigations and treatment, which are usually fruitless and merely protract the suffering, are sometimes repeated. We cannot expect that the couple themselves will suggest termination of the infertility treatment, since acceptance of childlessness is hampered by denial or the persistent hope for a miracle (Reading, 1989; Collins et al., 1992; Laffont and Edelman, 1994). Thus, the role of the doctor also includes termination of treatment.

One of the most important basic rules in communicating bad news is that the doctor should not talk too much. Studies have shown that doctors should practise in listening more attentively and staying quiet and silent after they have given the patient a short and informative summary of the problem (Aspegren et al., 1996). This will give the patient the opportunity to reflect, react and ask questions. It is of no use to give more information than the patient asks for or is able to handle. One of the most professional challenges for the physician is to explore on what specific level a patient is able to communicate. By encouraging the patient to put questions, this level becomes obvious. Furthermore, when breaking bad news the doctor must be aware of the necessity to talk to the patient or the couple more than once (Lalos et al., 1985a). Only when the physician has overcome his/her own frustration is it possible to support the couple in their mourning process.

According to the triad, it is not self-evident that all three involved in the triangle agree about what is bad news. Some individuals/couples claim that the most stressful information, the worst bad news, is that of not having a diagnosis, not knowing the cause of infertility. Not knowing the cause of the problem emerges as a significant source of stress for both men and women, and still a lot of infertile couples never get a definite medical message concerning the state of their infertility, simply because it is often impossible to give such statement. Thus, the loss is uncertain, and to start grieving before one is absolutely sure of having lost something is difficult and unnatural. Sometimes the act of swinging between hope and despair becomes a lifestyle.

Conclusion

In this review on breaking bad news, focus has been on infertility as a life crisis, the key role of the doctor, pattern in the relational triangle, specific communication skills and feelings among team members in an infertility unit. The need for considering the couple as a unit has also been stressed, but at the same time we must be aware that each partner can have completely different experiences and opinions.

In conclusion, it must be emphasized that the problem of infertility demands a holistic approach. Infertile couples deserve to be managed by an astute and empathetic doctor and a skilled team with social and mental health professionals. Since the crisis of infertility is complex and difficult to work through, there is a need for psychological and social counselling in parallel to the medical investigation and treatment.

When breaking bad news, physicians and staff have a
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responsibility to help the couple to put the problem into perspective and discover inner sources of self-esteem. A major goal of the management of infertile couples is to facilitate a positive resolution of the crisis, regardless of whether a pregnancy is achieved or not.

References

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