Posthumous assisted reproduction

Posthumous assisted reproduction (PAR): cancer patients, potential cases, counselling and consent

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Essential sperm banking facility for cancer patients about to receive chemotherapy or radiotherapy has been offered in our unit for 20 years. The recent media attention regarding the use of a deceased husband's spermatozoa by the widow has raised numerous issues (Brahams et al., 1996; Dyer et al., 1996). The main issue had been the apparent lack of consent, which at the time of sperm retrieval was impractical as the patient was in a state of coma after contracting bacterial meningitis. We examined our own patient records to gauge the extent of the potential number of women who could resort to posthumous assisted reproduction (PAR), and their general status. In this debate, the practice of counselling, obtaining consent and our experience with these patients is reported.

We are aware of 71 (4.26%) deceased patients out of a total of 1667 cancer patients. Feedback on such occasions is good. Of those deceased, 23 (32%) were single, 40 (57%) married, and the marital status of 8 (11%) patients was unknown. Only 12 (17%) of these patients had children, of whom two patients were single fathers. Those deceased married men were in greater numbers in view of the fact that >75% of the patients were single, and this reflected more the cancer type. The distribution of widows expressing the following requests and actions was as follows: to dispose of samples immediately (n = 12); to keep samples, but no further use had occurred (n = 11), to keep samples, with serious intent to using the spermatozoa — in over half of these cases preparations for use are in progress (n = 7); withdrawn for in-vitro fertilization/artificial insemination by husband (IVF/AIH) for use at another centre, but the outcome unknown (n = 3); no further guidance after notifying us of death (n = 6); left for research specifically (n = 1). However, six widows from the immediate disposal group did not mind the use of spermatozoa for research either, although most of the deceased had consented to research already.

Most of the widows or partners had wished to keep the spermatozoa initially (21 widows, 52.5%), reflecting the commonly perceived mourning period which is thought to last from 6 months up to 1 year, but subsequently with over half not following up with the PAR treatment. This may in part reflect the counselling that is commonly conducted before any decision is taken. During counselling the issues relating to the off spring born under the circumstance and any peripheral familial support which the child may gain are explored and taken into account. The child born under the circumstance is legally fatherless and the only parallel in English law is when lesbians or single females conceive. Equally, if an embryo is produced using the egg of the woman who has since died, that woman is not the legal mother (Human Fertilisation and Embryology Authority, 1995). Where necessary, the issues relating to possible genetic transmission of cancers are also discussed. Some of these factors may have been decisive where widows no longer wished to follow through the PAR process. In four cases, the strength of the mourning was buffered by knowledge that a part of the 'deceased' was still alive and that the widow still had a chance to have a baby with someone close to her. This view is probably more widespread amongst widows and, although widely accepted as a norm, still remains to be properly explored. It has even been argued that the use of donor gametes constitues a breach of marriage vows (Pennings et al., 1996). Such an idea makes the potential for PAR treatment relatively more acceptable, at least during the mourning period. As part of the process of sperm banking it is important to take account of the widow's views. Destruction of sperm samples should occur only when the widow finally feels the bond to be broken.

At present there is relatively little known of the overall state of sperm cryopreservation for cancer patients. The only formal statement on posthumous insemination appears to be enshrined in a two line statement on consent: 'state what is to be done with the gametes or embryos if they die, or become incapable of varying or revoking their consent' (Human Fertilisation and Embryology Act, 1990). This does not address any complex and diverse issues facing the individual widows. Presently, there are no data on the 'mourning period', which is generally perceived to be of the order of 6 months to 1 year. There ought to be at least a 9 month period of grace to prevent any hasty decision for PAR treatment.

Serious consideration for the use of spermatozoa had occurred with 10 women. Of these, three women withdrew the samples from our bank for IVF at a centre where a better pregnancy outcome could be possible with the quality or quantity of spermatozoa stored. Feedback on any use and pregnancy outcome was unavailable. These widows were single minded and strong willed, supported by family members, of stable characters and unwilling to consider spermatozoa from an unknown donor. Each longed to have had a child earlier, but each delayed in the hope of a recovery in the husband's condition. It is therefore easier to understand the immediate reaction towards using the spermatozoa soon after the husband had died. In these cases, PAR treatment was mentally pre-planned as opposed to a reaction to mourning.

Two widows, who strongly requested continued sperm storage with legitimate consent, were no longer contactable.
However, it was understood that they had remarried and one had moved abroad. In these cases, sperm samples must still be kept for the legitimate consented period, after which we will attempt to contact the women concerned. It may be that the women no longer wish to be reminded of that episode of their life or they may even have kept it a secret from their present partner. We did, however, need to be specially careful with two women who had only cohabited with the now deceased, and we could perceive conflict with his family. In one case, there was obvious mistrust from the man’s family, where the gain of estate was at stake.

Since the Human Fertilisation and Embryology Act (1991), the issues have become clearer. The Human Fertilisation and Embryology Authority (HFEA) form, replaced recently by the HFEA 96(6), should be filled in at the time of storage. The content of the form seeks to delineate the manner in which the spermatozoa or embryos are to be used during life, death or mental incapacitation. The form needs to be completed after informed counselling. This in turn is very dependent on the counsellor being properly informed of all the issues of storage and the use of stored spermatozoa. Additionally, the counsellor should be reasonably versed with all the relevant issues pertaining to each individual cancer patient which is the largest patient category seeking sperm storage. Widespread information and experience with such a group of patients is at present lacking. Consent may be altered and consent itself may be written on a blank sheet of paper, preferably witnessed. Such a consent if written at a later date could technically override the consent written on the official HFEA form. The validity of the latter can only be tested in court. The consent content may also reflect the views of the clinic and thereby introduce bias in the choice of possibilities. Most clinics appear not to treat widows and this, according to the Act, could legitimately be based on conscientious objection. This attitude towards widows may be a symptom of when the Warnock committee, on which the 1990 act was based, ‘actively discouraged’ posthumous treatment (Committee of Inquiry into Human Fertilization and Embryology, 1984). There appears to have been no real reason given as to why PAR treatment was discouraged, especially in view of the fact that such cases were unheard of then. At present there is a reasonable case for clinics to declare their position in order that false hopes are not raised when widows seek PAR treatment. Two widows felt their time had unfairly been wasted at separate clinics near them and this was evident to them from the bias in counselling they had received. Eventually, these two widows did not have PAR treatment.

In view of the fact that very few women are likely to seek PAR treatment there is a case to re-examine individually the use of spermatozoa where complete consent is not available. Based on our experience, this figure is anticipated to be under 50 potential cases for the whole UK. We have to try to understand what had happened before, assess the extent of the sacrifice the woman has made for the ill husband, the strength of the relationship before the partner deceased, and finally, the position and support of family and friends. It is also important to establish that the widow has not been placed in an unfair position by the deceased partner, where she could feel morally and psychologically obliged to accept his ‘gift’. Where the consent is contested, there is a need to look for counselling bias by virtue of the clinic philosophy (Corrigan et al., 1996), and to allow for this bias. There may be incomplete information which could alter the consent outcome. Unfortunately, such a line could be unwelcome as an uneasy relationship between the patient and clinic could develop, leaving much to subjective interpretation. Where treatment can proceed, it may be necessary to restrict the number of embryos transferred in an IVF cycle, to take account of the level of support at home. There is also a case for extending any change of policy to all IVF patients, especially in view of the increased risk of multiple births.

In rare cases, such as where spermatozoa are retrieved in a state of coma, where consent does not exist, we need to assess whether it was ‘consent actively denied’, or whether it was ‘consent impractical’. Parallels exist, since numerous embryos created using donor spermatozoa were destroyed forever, against the wish of the couples, causing much anxiety and distress (Craft et al., 1996; Trounson et al., 1996; Wise et al., 1996). Similarly, in those cases, a sensible outcome should have been possible in these unforeseen circumstances, which would have alleviated distress and allowed the families for which the couple had wished to come to life. In general, consent is a technique for safeguarding the patient’s autonomy. Unfortunately, consent is presently being viewed in a one-dimensional manner, without taking into account the numerous factors and of the overall circumstance (Deech et al., 1996; Quintavalle et al., 1996). Likewise, where no family friction or disagreement amongst family members or loss of interest exists to deflect the custody of the frozen gametes, then it should become possible to request further examination of consent by an independent arbitrator. Similarly, any ‘will’ can be contested, especially since most people do not have a ‘will’ so this does not necessarily place the recipients at a disadvantage.

In the HFEA code of practice, a reasonable time and pace is allowed for each patient with regard to counselling. This pace is necessary to allow for a proper consent to be obtained. The code of practice also requires the consent to be obtained before the sample is produced, causing practical difficulties with some cancer patients. Apart from going against the grain of this HFEA principle, the pace does not take proper account of a terminally-ill cancer patient’s condition, dignity and mood. Discussion of the issues arising from death before sperm production in our experience is in the incorrect order and one which may hinder a successful sperm storage and secondly, preempts discussion with the wife or partner. Wives are only too willing, for the wrong reasons, to accept what has already been signed as being their husband’s true wish. If the correct sequence, as perceived from our experience, is followed, then some patients may wish to defer completing the consent until they have discussed the issues with their partners, whom we routinely encourage to attend our laboratory. Should death have occurred in the interim then we could invoke the concept of ‘consent of intent’, which can eventually be settled in court if necessary. In this case the ‘motivation factor’ of the deceased
in seeking guidance for consent from the partner should then strongly favour the widow.

Understandably, this sequence of obtaining consent may introduce an element of uncertainty for the clinic storing the spermatozoa. However, it is a price worth paying if it can help the patient to arrive at the consent correctly and comfortably. Under these circumstances, the partner must be offered at least telephone counselling if she is unable to attend in person. The practical nature of the problems associated with the cancer disease for the whole family are enormous. Problems such as stress and the time taken off work, are reasons why they may not be able to attend the counselling in person. If, at the time of completing the HFEA 96(6) consent form, certain men were very ill or under the influence of medication, those men were approached 1–6 months later, to ensure that the issues raised were understood and that the consent form was fairly completed. There may be a case for extending this type of periodic review of their consent form, perhaps once every 2 years, to all the patients having spermatozoa cryopreserved.

Posthumous use of spermatozoa is not a modern day issue. It is ironic that the idea and application of sperm banking arose 150 years ago, when it was envisaged that women could still have children from men who did not return from battle (Steele et al., 1995). Any notion that PAR undermines the fabric of traditional family structures is inappropriate and closes our eyes to the world as it exists (Schuster et al., 1991). Canada, France, Germany and Sweden have legislation that forbids PAR. No such bars exist in Belgium, Greece and the USA. In the UK, the Human Fertilisation and Embryology Act of 1990 insists that under the circumstances, the welfare of the child should be taken into account (Aziza-Shuster et al., 1994). ‘Consent’ in the 1990’s has become a fad word for fringe individuals and groups to defend actions, which seemingly catalyse declining moral standards in our society. In reproductive medicine, consent is a vitally important instrument (Deech et al., 1996) and its value must be upheld. Consent to date has been deemed as ‘not negotiable’. In unforeseen circumstances however, there is a need to introduce the additional dimensions to consent, which can take account of the whole situation and enable arbitration to be achieved with sensible and respectable outcomes.

References
