Clinical Vignette: A 28-year-old male with a new diagnosis of cancer elected to store his sperm for fertility preservation prior to the onset of cancer therapy. The consent form the patient signed during the cryopreservation process allowed him to transfer custody of the sperm to his wife in the event of his death. One year later, despite aggressive treatment, the patient passed away. After discussing her decision with her former in-laws, the deceased patient’s parents requested custody of the sperm. The wife agreed to the transfer of custody. The would-be grandparents planned to have a grandchild conceived using their son’s sperm: they procured an unrelated egg donor, and the patient’s sister agreed to be the gestational surrogate. Given the inadequacies of the current consent process, we argue that a new, comprehensive consent procedure for sperm and oocyte cryopreservation present challenging ethical issues with regard to informed consent, given that the context for this procedure is often a disease that carries a significant risk of mortality. As the case above illustrates, the current consent process for sperm cryopreservation does not provide adequate information about a patient’s wishes in the case of premature death, and these shortcomings will only be exacerbated with the widespread introduction of oocyte cryopreservation.

Given the inadequacies of the current consent process, we argue that a new, comprehensive consent procedure for sperm and oocyte cryopreservation present challenging ethical issues with regard to informed consent, given that the context for this procedure is often a disease that carries a significant risk of mortality. As the case above illustrates, the current consent process for sperm cryopreservation does not provide adequate information about a patient’s wishes in the case of premature death, and these shortcomings will only be exacerbated with the widespread introduction of oocyte cryopreservation.

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ESHRE, we argue that these objections can easily be met, and we argue that there are sound ethical arguments that speak decidedly in favor of permitting such transfer.

**Clinical use of sperm and oocyte cryopreservation**

While the above case involved the use of cryopreserved sperm, cryopreservation of oocytes presents the same ethical challenges. In fact, the discussion in this paper is perhaps more pressing for cryopreserved oocytes due to the comparative ease of utilizing the gametes posthumously. If a family member other than a spouse is attempting to utilize cryopreserved sperm, they must secure both an egg donor and a gestational carrier. If a family member is attempting to use cryopreserved oocytes, they will still need a gestational carrier, but donor sperm is much easier and less expensive to procure.

In addition, oocyte cryopreservation is becoming an increasingly common clinical option. Over the past several years, advancements in oocyte preservation methods have led to success rates approaching those of fresh egg transfers (Griço and Noyes, 2010; Rienzi et al., 2010). As a result, the practice has become more widespread; recent data have shown that over 50% of clinics in the USA are using oocyte cryopreservation, and in Europe its use is extremely popular in countries averse to freezing embryos, like Italy (Rudick et al., 2010; Scaravelli et al., 2010).

Currently, oocyte cryopreservation use is still deemed ‘experimental’ in the USA by the ASRM. However, many have called for a removal of this label as there is good evidence for its safety and efficacy (Borini et al., 2004; Levi Setti et al., 2006; Noyes et al., 2010). One result of the elimination of the label will be the lifting of IRB-regulated consent forms. At present, patients freezing oocytes through an IRB study consent form do not have the option to designate a custodian for their oocytes—the only options are donation to research or destruction. The elimination of the experimental label by the ASRM would change this, and allow the cryopreservation consent forms to more closely resemble those of sperm cryopreservation. Many programs currently provide an option for designation of a custodian in the event of death of the sperm donor. However, we are not aware of any practices that allow a ‘roll-down’ option that provides the designation of an alternate recipient if the original recipient is no longer interested in using the gametes to create a child. In fact some institutions specifically prohibit the transfer of custody of the gametes.

Ethical guidelines for the posthumous use of cryopreserved gametes are critical, as patients often choose the option to preserve their gametes when faced with a life-threatening illness. The risk of mortality in cancer patients is a well-known possibility, and thus it is imperative that the patient’s wishes are known.

The regulating bodies in both the USA and Europe have already provided some guidance for the use of cryopreserved gametes after a patient’s death. The ASRM’s statement on posthumous reproduction urges programs to insist that donors make their wishes known, but does not comment on who may be eligible to receive the gametes and under what circumstances (Ethics Committee of the American Society for Reproductive Medicine, 2004, 2005). The ESHRE Task Force on posthumous reproduction also advocates that the option of posthumous reproduction be offered in the consent form for cryopreservation. However, they specifically note that the surviving partner is the acceptable recipient, and they explicitly state that ‘to avoid the danger of a ‘commemorative child’, it is recommended that the gametes or embryos cannot be directed at or requested by specifically others like parents or other family members of the deceased person(s)” (ESHRE Task Force on Ethics and Law et al., 2006). We posit that a more comprehensive consent form that allows for a ‘roll-down’ option and allows non-spousal custody of gametes will best protect the patient’s autonomy, and that the concerns of ESHRE can be adequately addressed.

**A recommendation for new ethical guidelines: justifying a universal ‘roll-down’ option**

In the case above, the patient’s family of origin was denied the request for sperm custody transfer on the grounds that the patient’s wishes were not known; the rationale was that permission would have been granted had the patient consented. In contrast, the ESHRE takes the stance that such transfer would be ethically problematic, even if the transfer were what the patient requested. We argue that the important concerns raised by the ESHRE can be effectively addressed and that a ‘roll-down’ option allowing the provision of gamete transfer from one designee to another (or explicitly prohibiting such transfer) will best meet the needs and life goals of the patient, while safeguarding the interests of both the patient’s family and any future child(ren) conceived through such transfer.

The first argument in favor of a ‘roll-down’ option is that it safeguards patient autonomy. It enables a patient to clearly state his or her wishes with regard to the future conception of his or her children, placing the decision squarely in the patient’s hands rather than in those of third parties: the spouse or life partner, the family of origin, the hospital, the hospital ethics committee or even the courts. In the case we are considering, the central argument used by the hospital ethics committee in denying the transfer request was that they did not know the patient’s wishes because there was no consent given by patient to grant the transfer. Their concern was that if he would not have wanted his child conceived and reared in this way, the transfer could not be performed. We argue that per such transfer, though others surely would. The only remedy to this conundrum, and thus the only way to preserve patient autonomy posthumously, is to have a provision for asking about the patient’s wishes at the time of the cryopreservation. Having the provision of a ‘roll-down’ option not only enables the patient to make important decisions while competent to do so, but also allows for more nuanced end-of-life discussions to occur than what we are currently providing for patients. For instance, the provision on a consent form of a roll-down option may prompt the patient to have a conversation actively involving both his spouse and his parents and siblings, thus ensuring that his end-of-life wishes are discussed and clearly known.

Just as allowing the conception of a patient’s child without the patient’s permission could constitute a type of posthumous harm, prohibiting that conception when it is what a patient would want can also constitute a parallel harm. There are four important benefits that patients might see in having the ability to transfer the custody of
their gametes from the current spouse or life partner to a family member who would use them to create the patient’s child. First, the transfer option might allow for the fulfillment of an important life goal for the patient. Having children is understood by many as one of the central goods in human life and it is treated as an important life goal by those individuals. Being denied the opportunity to have children because of an untimely death compounds the tragedy of a shortened life. It is our recognition of this need that allows the provision for a spouse to gain custody of gametes in the case of a patient’s death. But not uncommonly, the current partner or spouse may decide to ‘move on’ rather than start a family in the absence of that partner. Or, the patient may have no partner or spouse at the time of cancer treatment, yet welcome the possibility of his or her parents or siblings aiding in the fulfillment of this important life goal. It is an important benefit to patients to have the possibility of more than one avenue to fulfill this life goal.

Second, having the possibility of custody transfer when the spouse or partner may not wish to use the gametes provides solace to both the dying patient and grieving family that the family’s genetic line will continue. Human beings often find an important kind of ‘immortality’ in the continuation of their genetic line, an insight that traces all the way back to ancient texts and world religions. Even Plato talks about this access to immortality in his famous play, the Symposium. It can provide profound comfort to the dying patient and to his or her parents that this genetic line can continue, despite the patient’s not having had the chance to conceive, or having a willing partner to conceive the child with.

A third benefit to the patient of having a roll-down option relates to the second benefit. In addition to the perceived benefit of having one’s genetic line continue, having a child enables the patient to have his or her memory kept alive in the next generation. It is children who are the keepers of the stories of their parents’ lives. They inherit our photos, tales of childhood experiences, personal history and life lessons. Grandparents or siblings are in at least as good a position to convey this history to the next generation as a spouse or life partner would be: they have a longer frame of reference, knowledge of the patient’s (i.e. the parent’s) earliest experiences, history, etc. Patients may value knowing that their life experiences will be shared and cherished by having a child raised by a sibling or grandparent.

And, a fourth benefit to the roll-down option is that it enables the patient to provide a ‘gift of life’ to his or her grieving parents who may have very much wanted a grandchild and won’t be able to have one should the spouse or partner be uninterested in having the patient’s child. A patient may find it redemptive to be able to provide a grandchild for his or her parents in the absence of the ability to personally conceive one him- or herself. Many people are motivated to have children because of the strong desire of their parents to have a grandchild, and this option allows a patient to offer this consolation to parents who will face a terrible loss if the patient dies. It can be empowering to be able to give someone you love something they really want: for the patient, it is a way to preserve one’s moral agency, even though one’s life may be ending.

Returning to our case, then, there are actually compelling reasons for believing that the patient would have wanted the hospital to grant his parents’ request for the gamete transfer. The transfer might have been consistent with his deeply held values and life-priorities. Because there was no opportunity for the patient to express his wishes on the matter, the hospital did not have access to all of the possibly relevant concerns, values and benefits of transferring the gametes from the patient’s perspective because they only had testimony of his preferences in the voice of his wife, parents and sister. It is ethically imperative to give patients the opportunity to directly articulate their values on these weighty questions by providing a roll-down option on the cryopreservation consent form and facilitating the important conversation about the patient’s posthumous wishes that should take place as it is signed.

The concern about the ‘commemorative child’

The foregoing discussion highlights the significant potential benefits to the patient and his or her designees in the case of custody transfer of the patient’s gametes. We have argued that allowing the patient to designate a second, alternative recipient of the gametes, such as the patient’s parents or siblings, would protect the patient’s autonomy and possibly provide access to an important life good that the patient’s untimely death has undermined. But some ethicists have raised concerns about the potential harm that might befall the children who would be conceived if such a transfer took place. The ESHRE, for example, argues in favor of prohibiting gamete transfer to grandparents or patient siblings because of the risk of creating merely a ‘commemorative child,’ or symbolic replacement of the child’s biological father or mother, that would have a detrimental effect on the actual child (ESHRE Task Force on Ethics and Law et al., 2006). They caution clinicians about this possibility even in the case of spousal or partner use of a decreased patient’s gametes, but they believe that the risks to the future child are greater in the case of grandparent- or sibling use. Therefore, although they are wary of spousal use of the gametes, they only recommend advising against its use by the patient’s parents and/or siblings.

Although the current ESHRE guidelines flag an important concern regarding custody transfer, they do not provide a developed argument for the recommendation against one use of the gametes and a mere caution about the other. We believe that their argument for restricting custody transfer can be faithfully fleshed out in the following way: because the child will be viewed and treated as a mere substitute or replacement of their lost child, he or she will not be valued as a unique human person in his or her own right. In other words, the child will not be loved for him- or herself, but only as a kind of ‘clone’ or replacement of the son or daughter who has been lost. In such a case, the child will not be permitted to develop his or her own distinct personality traits, preferences, likes/dislikes, talents, interests, etc., but will be pressured into being a mere replica of his or her father or mother. Unrealistic expectations will be set for this child. And because no unique person could ever really be a true replica of someone else, the child will necessarily be a disappointment to his or her grandparents (or aunt or uncle), and the child will be treated as such, especially when she or he does, in fact, demonstrate unique traits and talents.

If that is a faithful rendition of the argument supporting the prohibition of custody transfer, we believe it can easily be refuted on three separate grounds. First, a grandchild would only be vulnerable in the absence of the ‘clone’ or replacement of his or her decreased parent if
the grandparents were susceptible to making a ‘category’ error with regard to who the child really was: they would have to view the child as their own offspring, rather than the offspring of their son or daughter. For any of these concerns to be plausible, the parents of the patient would have to conceptualize the child as their own child, rather than their grandchild. This would be a very odd mistake to make, given that (i) there is already in human life an established—and much cherished—category of ‘grandchild’, and (ii) grandparents not infrequently raise grandchildren after the death, abandonment or incapacity of the child’s biological father or mother. There is no evidence that these (conventionally conceived) children are pressured into being copies of their deceased or absentee parents, so we would need compelling evidence that the risk would be higher in children conceived in this manner. Bioethicists make this type of argument against human cloning in the case of the death of a child because the cloned child would be an identical genetic replica of the deceased child. But there are no parallel grounds to make this argument about a new, unique genetic life, especially one that would be the deceased child’s child, not his or her sibling.

Second, even in the case of the death of a child whose parents are still in their childbearing years, parents often have another child, and there is no evidence that the later-born children are not treated properly or loved as the unique beings they are (Grout and Romanoff, 2000). Of course, there is always the risk of psychological pathology that comes from unresolved grief, but that small risk in the minority of bereaved parents is not used as a justification for counseling parents to avoid future conception. At most, grief-stricken parents might be counseled to wait for a period of time before conceiving, and that same advice is often similarly warranted in the case of cryopreservation. But if the risk is small to children conceived by the same biological parents who lost a child, it can only be smaller for grandparents who will not be using their own gametes for the conception of a child, but the gametes of their biological child (and some other sperm or egg donor).

Third, in some ways, the new child will be ‘commemorative’—in the best and most life-affirming sense of the word. A would-be grandparent might say, for example, ‘I celebrate my child’s brief life and will commemorate it in the creation of his or her child; I will commemorate all that my child was in the memories and stories I will pass on to that new grandchild about his father or mother’. In this sense, there is pride, not harm, in being the beloved grandchild of a beloved, deceased parent. Of course, if being a ‘commemorative’ child in this sense raises unrealistic expectations for a child to live up to, then a child could certainly be harmed; but that risk is not specific to children conceived of in these unconventional circumstances.

But the most powerful rejoinder to a concern about creating a ‘commemorative child’ is that the patient him- or herself provides a safeguard against this danger in having the ability to consent (or deny consent) to the transfer of custody to his or her parents or siblings. If the patient foresees or worries about any potential harm to his or her future child, then the patient can deny the parents or siblings access to the gametes. If the patient consents to an alternative recipient, the patient demonstrates his or her confidence in the child-rearing abilities of that recipient. In many ways, the patient is in the best position to have confidence or concerns about his or her parents’ capabilities in the arena of child rearing. Having a ‘roll-down’ option allows for the broadening of end-of-life discussions in a way that will allow the patient to ensure that this option is permitted only if the patient deems it important and appropriate.

The future: pre-pubescent children and testicular/ovarian tissue harvesting/preservation

It is important to note that the arguments we make here apply only to adults, and do not extend to the pediatric population. Pediatric oncology patients are often offered fertility preservation prior to the onset of cancer treatment—in these cases the guardians provide consent while the child, if able, is asked for assent. With the developments in ovarian tissue cryopreservation, it is possible that pre-pubertal patients may someday be able to conceive children using gametes matured in vitro. And in kind, it is theoretically possible that gametes matured in vitro from a pre-pubescent child may be available for use by his or her parents after the death of the child. Given the complications arising from the age of the child and his or her lack of ability to conceive of a future parental project for him or herself, this population must be treated separately from the adult population.

Conclusion

We argue that a ‘roll-down’ option allowing the provision of gamete transfer from one designee to another will best meet the needs of the patient, while safeguarding the interests of both the patient’s family and any future offspring conceived. The ‘roll-down’ option gives the patient the opportunity to articulate posthumous wishes, and thus has the benefit of protecting patient autonomy, while also preventing the potential harm caused from the loss of the opportunity to fulfill important life goals, continue the genetic line, preserve memories and create grandchildren for parents. While the concern about the creation of a commemorative child is an important one, it can be effectively refuted and we have demonstrated that the risk here is no greater than in other permissible situations.

This discussion is increasingly pertinent as oocyte cryopreservation nears mainstream use and the removal of its experimental label. Fertility centers and governing bodies are urged to discuss these issues proactively so that comprehensive consent recommendations can be in place when this change occurs.

Authors’ roles

K.E.D. and A.M.F.: Conception, writing, revision, and final approval of the manuscript.

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