Misattributed Paternity in Hematopoietic Stem Cell Transplantation: The Role of the Healthcare Provider

Stephanie Jacobson, FNP-C, Julie Eggert, PhD, GNP-BC, AOCN®, Jane Deluca, PhD, RN, and Dawn Speckhart, PhD

Background: With emerging technologies and genetic advancements in the field of oncology, ethical controversies and questions on how to approach them will continue to grow. Advancements in the field of hematopoietic stem cell transplantation have led to increased testing of transplantation recipients’ children and parents as potential donors related to an increase in the use of haploidentical transplantations. This testing opens the door for an increased incidence of misattributed paternity findings.

Objectives: This article attempts to address the ethical conflicts and provide potential solutions to assist in the transition from individual-focused care to family-focused care.

Methods: The principlist approach was used.

Findings: Healthcare providers should be educated on methods of incidental finding disclosure and how to provide adequate support for those individuals.

With genetics roles in oncology continuing to grow, the platform for ethical controversy is likely to magnify. Ethical dilemmas become further complicated when the focus shifts from involving one individual to issues that may affect an entire family. Hematopoietic stem cell transplantation (HSCT) is a common form of treatment for patients diagnosed with serious blood cancers and disorders, such as acute myeloid leukemia and acute lymphocytic leukemia (National Cancer Institute [NCI], 2013). Frequently, family members are selected to serve as marrow or stem cell donors for HSCT. Human leukocyte antigen (HLA) testing for potential donor compatibility has been used for decades to determine the best match for the best possible survival outcomes (NCI, 2013). Related parents and children share at least one complement of HLA genes along a chromosome; in other words, they have at least a one-haplotype HLA match (Young et al., 2009). Previously, HSCT was primarily performed with a full sibling or full matched unrelated donor because transplantation with less than a full HLA match led to severe complications of graft-versus-host disease (GVHD). However, new medical treatments, such as post-transplantation cyclophosphamide, have allowed for methods of performing a haploidentical transplantation from a one-haplotype match without significant increase in the incidence of GVHD. Any of the potential recipient’s relatives (siblings, children, and parents) are at least a haploidentical match for HSCT (Huang et al., 2012). This advancement has allowed for recipients to undergo transplantation who may not have previously been eligible because of a lack of a suitable donor.

With the improvement of haploidentical HSCT methods to prevent complications, this form of transplantation has been used more frequently in patients who do not have a full matched donor available (Huang et al., 2012). As more children and parents are being HLA typed as potential donors, the incidence...
of misattributed paternity cases are likely to increase as well. Because of the increased number of haploididentical transplantations and a risk for an increase in misattributed paternity findings, healthcare providers (HCPs) may find that their role will become more complicated as they are faced with decisions regarding whether or not to disclose these findings to donors and recipients. HCPs will be challenged to find a balance between honoring truth, individual autonomy, and confidentiality because they are likely to be faced with increasing ethical dilemmas, such as misattributed paternity.

Review of the Literature

According to Ross (2010), an estimated incidence range of 1%–10% of living related donors for transplantations are found to be misattributed paternity cases. This estimate includes both incidence within HSCT as well as solid organ transplantation because, to date, the majority of literature available has focused on solid organ transplantation with haploididentical HSCT from children and parents, until recently, being rarely performed because of the significant risk of complications associated with that form of transplantation. HLA testing for donor-recipient compatibility is essentially the same for HSCT and solid organ transplantation. If cases of misattributed paternity are noted in HLA typing for solid organ transplantation, a logical assumption would be that the rise in haploididentical transplantations also will give rise to more misattributed paternity within HSCT. Within the transplantation community, controversy exists regarding the HCP’s role in reporting these findings in the clinical setting.

Young et al. (2009) conducted a survey of 102 participants regarding disclosure of misattributed paternity within the realm of kidney transplantation. The participant group was made up of potential recipients, potential donors, and transplantation professionals. Among the group of potential recipients surveyed (N = 35), 60% (n = 21) agreed that this information should be disclosed. Among the group of transplantation professionals (N = 32), however, only 43% (n = 14) agreed with disclosure of misattributed paternity. Potential donors (N = 35) were divided evenly in their opinion of disclosure (Young et al., 2009). The findings demonstrated a clear disconnect between the patient desire for autonomy and truth and the HCP’s opinion of disclosure. The data may even indicate the existence of a persistent paternalistic view among HCPs in their desire for nondisclosure, which appears to be inconsistent with patient preferences.

Opinions on disclosure of misattributed paternity within the transplantation field vary widely. Professionals who are against disclosure focus on the potential for errors within the HLA testing itself and the feeling that discussion of misattributed paternity is not the role of the transplantation HCP (Ross, 2010). Ross (2010) presented a case for nondisclosure, stating that the HLA testing used within transplantation programs are sometimes inadequate to determine misattributed paternity. Ross (2010) used one case study as an example in which misattributed paternity was wrongly identified because the mother was found to be a tetragametic chimeric female. In other words, her cells were from two fertilized eggs fused together, and each population of cells kept its character but was expressed in different tissues. In rare cases such as this, HLA incompatibility may be from chimerism within the parent and not related to true paternity (Ross, 2010).

Ross (2010) also provided information on other rare forms of HLA incompatibility caused by genetic abnormalities within the parent and used that information to comment on the role of the HCP, saying that performing forensic evaluations, such as those necessary to determine the accuracy of HLA results suggesting misattributed paternity, are beyond the scope of the screening process. In rare cases of parental genetic abnormality, it may be difficult to determine the accuracy of a misattributed paternity finding, and not all HCPs are prepared to interpret abnormal findings. Ross (2010) suggested that inconsistencies in HLA inheritance be reported to the patient as merely a variation, and that families who wish to have further clarification should be referred to genetic counselors. An HCP who reports these findings as inconsistencies but does not explain the possibility of misattributed paternity may be viewed by the patient as being deceptive if they were to learn the HLA testing revealed potential misattributed paternity.

Principlist Approach

Autonomy

The National Society of Genetic Counselors (NSGC) code of ethics supports the principlist approach to respect autonomy. The code states that patients should be enabled to make informed decisions based on facts provided by the genetic counselor and without any influence of coercion (Lucast, 2007). Lucast (2007) affirmed that autonomy means that the patient has the right to informed consent and confidentiality; they have a right to be told any information that relates to their health care and testing results as well as the right to control that information in the form of maintaining privacy. This principle can be applied to the role of the transplantation HCP as well in that the recipient and donor have a right to be made aware of any HLA testing results that might indicate misattributed paternity. Respect for autonomy also is a key feature of the patient-provider relationship.

Many HCPs support disclosure to patients to respect autonomy and allow each patient to be able to give true informed consent. Soderdahl et al. (2004) described a case study of misattributed paternity in a kidney transplantation scenario in which it was decided to inform the father, son, and mother of the test results. Reportedly, the family was adamant that disclosing the information was the right thing to do, and the son was still able to proceed forward with donating a kidney for his dialysis-dependent father (Soderdahl et al., 2004). The case study provided was used to present the authors’ position that, above all else, truth and autonomy for the patient must be respected.

To set the framework for potential incidental findings of misattributed paternity, Lucast (2007) suggested that the informed consent process prior to transplantation workup include discussion about the possibility of this finding during HLA testing. Lucast (2007) suggested that being up front with this potential finding prior to the process initiation allows for open and honest communication when the results are shared. The difficulty lies in when and how to inform a patient and potential donor of the results (see Figure 1). Including the possibility of discovering misattributed paternity in the informed consent
process is one method of at least preventing any unanticipated results; however, many transplantation HCPs are not properly trained to deal with the potential emotional and psychological fallout of disclosing such a deeply personal finding.

Beneficence and Nonmaleficence

Many HCPs support nondisclosure of incidental findings, such as misattributed paternity, on the basis of beneficence, that an HCP is to do good for the patient. Most HCPs felt that nondisclosure was doing well by the patient in that it honored the principle of nonmaleficence, which is doing no harm (Meachum, Starks, Burke, & Edwards, 2010). Support for this argument is based on the idea that disclosing misattributed paternity could not only be emotionally harmful to the patient, but also could potentially be harmful to the family as a unit. Disclosure could breed feelings of doubt and anger and even split up a family.

Many HCPs use the concepts of beneficence and nonmaleficence in support of nondisclosure as a means to medically protect the patient. With solid organ transplantation, if the child is found to not be a biologic match, they may still be able to donate an organ and the HCP may simply be able to avoid the topic. That is not the case with haploidentical HSCT (Soderdahl et al., 2004). With HSCT, the discovery of misattributed paternity eliminates that parent or child as a potential donor, leaving the HCP with the decision of whether to disclose or to potentially deceive the patient and potential donor by withholding an explanation as to why the child or parent is no longer a potential donor. If the patient discovers the deception, significant harm could be done to the provider-patient relationship.

Justice

The principle of justice is based on the idea that all people should be treated equally and fairly; in other words, similar cases should be treated the same way (Wueste, 2000). For this to be applied to misattributed paternity in the transplantation setting, standards and policies need to be developed that address how disclosure should be handled. To date, no policies or procedures on how to deal with these incidental findings are in place, and individual HCPs and genetic counselors are addressing these concerns based on personal opinions and interpretations. That leads to inconsistencies in how patient information is handled and distributed. Justice can only be maintained when all cases of misattributed paternity are handled in a uniform manner with respect to autonomy, beneficence, and nonmaleficence.

Potential Alternatives

The American College of Medical Genetics and Genomics (ACMG) published a policy statement regarding clinical genetic testing and how results should be reported to the patient. Specifically, ACMG strongly recommended that incidental findings noted on genetic screening tests should be reported to the patient (Green et al., 2013). This policy statement has been highly debated, but if clinicians are moving toward following these guidelines regarding incidental findings of genomic sequencing, the premise is essentially the same when evaluating incidental findings of misattributed paternity during HLA screening for a donor. With a focus on patient autonomy and right-to-know, the disclosure of such findings would be the responsibility of the HCP, and nondisclosure would be seen as a violation of patient rights.

To ensure that controversial issues, such as disclosure of misattributed paternity, are addressed in a manner that is equal and consistent, standards and policies should be developed to address methods for disclosing. Focus groups could be formed to discuss the risks and benefits of information disclosure and the most appropriate avenue to respect patient autonomy and right-to-know without trampling on confidentiality. Another difficult component is the question of whether the donor and mother should be informed in addition to the patient. Some researchers feel that discovery of hereditary risk in an individual should be shared with that individual’s family members who also may be at risk; others fear that this is a violation of patient confidentiality (Patterson, Robinson, Naftalis, Haley, & Tomlinson, 2005). The transplantation physician certainly has a duty to the recipient as his or her patient, but is the HCP also obligated to inform the donor of the results as well? The donor, once enrolled in the haploidentical HSCT process, also becomes a patient of the transplantation provider with the same rights as the recipient.

Lucast (2007) argued for including potential misattributed paternity as a risk factor within informed consent. This could be included in the informed consent for the recipient and donor and may allow the HCP to have a more open conversation if results do confirm this issue and the individuals involved anticipate the possibility. Another important aspect to consider is the right to not know. Although patients certainly have a right to learn about their genetic testing results and HLA testing for transplantation evaluation, they may, with the knowledge that misattributed paternity could be discovered, choose not to be informed of the result. This decision could be assessed up front to eliminate any concern of what the results may show; however, another dilemma is presented if the donor chooses to be informed of misattributed paternity but the recipient chooses not to be informed (Lucast, 2007).

If the HCP is to be responsible for disclosing misattributed paternity in the HSCT evaluation process, extensive education and training should be provided to HCPs regarding how to explain to the patient the implications of such a finding and how to provide emotional and psychological support at the disclosure of this information. Perhaps Ross’s (2010) viewpoint that the HCP should refer the patient to a genetic counselor if that individual wants further clarification on how a child or parent is not a match is an appropriate approach. A trained genetic counselor may certainly be more prepared than the transplantation provider to explain the implications of a misattributed paternity finding and provide adequate support to individuals learning this potentially life-changing information (Ross, 2010). Avoiding the topic and referring the individual to a genetic counselor is not an option. More research is needed in this area so that HCPs can provide the support and guidance needed to help patients make informed decisions.
counselor may, however, make the patient question why they were not informed of this possibility prior to HLA testing, or even make them angry or feel deceived or that their provider was not honest with them about the meaning of the test results.

Conclusion

As demonstrated in a survey conducted by Young et al. (2009), HCP paternalism is still a concern within the realm of genetics, including how it relates to ethical decisions. HCPs are either practicing paternalism in their desire to protect the patient from harmful information by keeping misattributed paternity a secret or, perhaps, nondisclosure is a stronger indication of the HCP level of discomfort in how to approach that information and explain the potential implications to the patient. Perhaps the best approach is to take an informative and interpretive stance between provider and patient. With this approach, the recipient and donor will have all pertinent information regarding HLA testing for transplantation and the potential findings and can make their own informed decision on how to proceed from that point.

Recipients and donors should be provided with a detailed informed consent when moving forward with the transplantation process, including the potential risks of unsought results, such as misattributed paternity. Consent should include the option for a donor or recipient to choose not to be informed of paternity results. HCPs must be better trained to discuss these potential results and their implications to a recipient and his family. HCPs, and nurses in particular, must also be prepared to provide adequate emotional and psychosocial support and be aware of the implications for HCPs. If the HCP is uncomfortable providing this support or is not adequately trained to discuss the findings, then the assistance of a genetic counselor should be obtained. Finally, standards should be developed to address incidental findings related to HSCT and how HCPs should approach disclosure in an effective, efficient, and respectful manner so as to maintain a good patient-provider relationship.

References


