Considerations for Returning Research Results to Culturally Diverse Participants and Families of Decedents

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As genomic medicine advances and immense amounts of data are generated that may potentially affect human health, there is increasing concern around which of these results matter to participants. There has been considerable debate on *which* research results to return to participants[1] and *when* those results should be returned.[2] To date, however, the debates around the return of genomic results have not focused on *how* those results should be returned, especially when the results come from minority and/or culturally diverse participants. This commentary explores cultural and ethical considerations, and shares insight from my own Navajo background, around returning genomic research results to participants and potentially to families of culturally diverse backgrounds, with a special focus on considerations when the research participant is deceased, and raises points for further discussion.

Deliberations about the return of genomic research results raise several key questions for participants from culturally diverse backgrounds, particularly for families of deceased participants. Should researchers and health care providers initiate discussions about returning results to families where taboos exist for discussing the dead? What cultural norms should providers and researchers be aware of when addressing death or the dead? Should discussions involving health-related data that are derived from research studies involving recently deceased individuals fall into the same category as discussions in the medical context? This paper will focus on three elements to consider for returning research results to culturally diverse participants and families: (1) family structures and dynamics in various cultures, (2) cultural views regarding death and the recently deceased, and (3) cultural considerations for initiating conversations on potentially sensitive topics. These topics are important to consider due to different views of family structures influencing autonomous decision making and appointing decision makers, and cultural taboos concerning discussions about death and those who have died.

Family Structures and Dynamics in Various Cultures

Family Influences on Research Participation

Autonomy, a concept rooted in the Belmont Report, focuses on the capability of an individual to deliberate

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about his or her personal goals and choices in research involving human subjects free from undue influence by others.[3] However, members of large extended families within particular cultures, such as in Kenya[4] or in some American Indian communities,[5] may require approval from elders or family members extending beyond first- and second-degree relatives before making health-related decisions. For example, the decision to participate in research studies may require approval because it may have an impact upon their extended family or community. Asian immigrants in the U.S. were influenced by their families and were more likely than non-Asians to agree to participate in research if their son or daughter asked them, even if they initially did not want to participate.[6] Similarly, there is a strong preference for involving family members in group-based discussions on end-of-life decision making for Chinese adults,[7] Japanese Americans,[8] Korean Americans,[9] and Mexican Americans[10] compared to other racial or ethnic groups.[11] These cultural preferences raise questions about how decisions are made within families and who is part of the family unit that influences these decisions. In some cultures, such as the Navajo, matrilineal first cousins are referred to as brothers and sisters;[12] these potentially influential relationships must be considered as well. As with any family, some links are strong with certain family members and weaker with others, so inter-family dynamics will likely vary. These families may work as a collective unit rather than individual autonomous agents, further challenging the paradigm of obtaining consent from individuals for research and essentially engaging in a group decision-making effort.

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In the research setting, researchers typically interact only with the research participant to obtain informed consent, rather than working with multiple family members in order to obtain group consensus and, ultimately, individual consent to enroll a research participant into a study. The notion of group consent, initially discussed in the context of large population-based genetic research studies,[13] introduced an element of working with larger groups, such as families or communities, to obtain consent; however, group consent was met with criticisms, including difficulty determining whose voice emerges as the leader for the group. Engaging families in group discussions to ultimately obtain consent has been a valuable component to build trust and may be a means in community-based participatory research practices to promote discussion within communities about participating in research.[14] Whether intentional or overtly, family members may shape, challenge, and reinforce group decisions both in the research and clinical setting as well as at family gatherings. These discussions may be valuable for families to deliberate about research participation. Consideration for involving family perspectives, especially for enrolling minority participants in genomic research with the possibility of returning results, will be important and may require additional time.

Navigating Family Structures and Dynamics

For researchers and clinicians who have not interfaced much with culturally diverse families in the research or clinical setting, it may be confusing to navigate the hierarchy of family decision makers. In the clinical setting, if their patient lacks the capacity to make decisions, health care providers typically interact with one point person, usually a close family member, who serves as a surrogate decision-maker.[15] Generally, decision makers are spouses, adult children, parents of minors, or siblings who know the patient's preferences and are able and willing to act in accordance with their wishes.[16] In some large extended families, it might be challenging to identify the most appropriate person to make decisions. When major decisions require input from elders in the family, such as the patriarchs or matriarchs of the family, it will be important to allow families time for deliberation to take place. In other families, the decision-making power and guidance may be deferred to those with the most medical knowledge when relevant.

Decision-making power might rest with men in some cultures, or with women in others. For some families, the ultimate decision maker(s) to weigh in or influence decisions are the patriarchs or male elders of the family or community. For example, Hmong traditions involve relevant male stakeholders in medical decision making, especially for unfamiliar procedures:

> When [nurses and doctors] walked into a hospital room, they often had to run a gantlet [*sic*] of a dozen or more relatives. Decisions — especially about procedures, such as surgery, that violated Hmong taboos — often took hours. Wives had to ask their husbands, husbands had to ask their elder brothers, elder brothers had to ask their clan leaders, and sometimes the clan leaders had to telephone even more important leaders in other states.[17]

In other family structures, such as in some traditional Native American[18] or Ecuadorean[19] societies, women and men equally weighed in to dictate major medical or economic decisions for their families and were equally instrumental in deciding when a family member should seek medical care and from whom, such as from a traditional healer or from Western medicine.

Increasingly, medical knowledge holders within families are engaging in these conversations on behalf of their families, particularly if they are trained as physicians, nurses, and health care workers, to guide discussions for their families and make recommendations or guide decisions in consultation with their families. These worldviews have changed and shifted with the influence of Westernization, as minorities are assimilated into the larger American culture that is influenced by laws and regulations regarding informed consent, autonomy, property, and ownership.

Who Is Family?

For returning genomic information to patients with large extended families, providers and researchers should consider the family structure, as these types of results will have impact throughout the family, potentially further than just immediate first-degree relatives. Even if the immediate impact is not extended to relatives, how should knowledge of genomic results be handled and protected?

It is important to consider who the family members are, taking into account cultural identity, current geographic location and level of community integration, and length of time that the participant and family have been in the country. Families are dynamic, constantly changing as members age and gain experience, and are influenced by their surroundings. Traditional and immigrant populations are likely to have different viewpoints than families who have been in the U.S. for a longer period of time, especially if intergenerational views and influences vary within the family or community. In some traditional Alaska Native[20] and African immigrant[21] communities in the U.S., much of the deliberation around tissue or blood donation are likely to be linked to concerns about how samples will be used in research and whether aggregate results will be shared with the community. Who are the holders of familial medical knowledge? How does that knowledge get passed down and who, within the family or community, is entitled to that information and holds decision-making power over how that information is used? The holders of familial medical knowledge may vary by gender, family, or culture and they may choose to divulge that information with certain providers or family members and not others.

Consideration for the timing of returning results is important. There may be an expectation by the participants and their communities to receive results in a timely manner, including shortly after death, that may be important to build trust, enhance transparency, and to receive tangible benefits.[22] Or, it might not be acceptable to discuss results pertaining to a decedent for some specified period of time. Others might believe that talking about their deceased loved one and receiving results is an acceptable and therapeutic part of the healing process that enables them to remember and honor their memory and also learn something with potential health implications.

An important issue to consider is the therapeutic misconception, where genomic research results may get conflated with clinical or medical results.[23] At enrollment into the study, the informed consent process will need to be clear about what genetic results may be returned after death and whether those results are anticipated to be related to the patient's medical condition. Consistent with other recommendations, genetic results that are returned should be analytically and clinically valid.[24] If results are returned to the family in the research context, the research team will need to take care to avoid conflating results from a research protocol with clinical findings and to not create confusion for family members of participants who may be seeking medical answers about their loved one's health. If such results are not available until after a death occurs, family members might wonder why the results are not included in medical record or autopsy reports. Furthermore, family members who were not previously told of their relative's participation in a research study might wonder why they are being notified of new results from a study, especially if it was not explicitly explained beforehand.

Care should also be taken to acknowledge the nature of the relationship between the researcher and participant or between the clinician and patient.[25] Ideally, conversations regarding which results to return, when they should be returned, and culturally appropriate ways to return them should happen at the time of recruitment and consent.

Cultural Differences in Addressing Death

End-of-Life and After-Life Conversations

In many cultures, it is a taboo to talk about or plan for death. The severity of the taboo varies across cultures. For some Chinese communities, discussions about making wills or planning for funerals are forbidden as they invite bad luck to a family.[26] The taboo about talking about one's death may be rooted in taboos against planning too far into the future or to plan for events to occur after one's death.

In the clinical setting, discussions must be sensitive when initiating conversations around advance care planning. If certain topics are not allowable for discussion, how should providers and researchers talk about planning for return of results, including after death, if death itself cannot be discussed?

In the same vein of avoiding topics about death, some people also avoid topics about the beginning of life. For instance, traditionally, people from Navajo[27] or Jewish[28] cultures insist on waiting to have baby showers after the birth of a new baby, as too much preparation and celebration before the event could complicate the birth. While there might be historical reasons to wait for a celebration until a healthy baby arrives, these taboos are rooted in a belief that one should not put too much confidence in the future as plans could change unexpectedly. These cultural considerations, if still held, may influence how participants think about future planning and receiving health-related results when imminent risk of death or disease seems minimal.

In the clinical setting, discussions must be sensitive when initiating conversations around advance care planning. If certain topics are not allowable for discussion, how should providers and researchers talk about planning for return of results, including after death, if death itself cannot be discussed? A family member scheduled for a relatively low-risk, routine surgical procedure was presented with the standard Advance Directive forms. She declined to fill it out, fearing that signing such a form about directives would bring bad luck during or after the surgery. Similarly, a Navajo surgeon working within her community has described these views in her book, *The Scalpel and the Silver Bear*:

> Because Navajos are so uncomfortable with death and dying, speaking to them about making a decision to end life, to stop a life-support system, was nearly impossible and had to be handled very carefully. The discomfort arises partly because of the Navajo belief in the power of language, the belief that you can 'speak' something into existence….Such verbalizing [of hypothetical scenarios] would be seen as asking for it to happen.[29]

Recognizing the challenge of discussing sensitive topics, some practitioners of geriatrics and palliative care on the Navajo Nation took a culturally-appropriate approach to initiating conversations about decision-making at the end of life through poems, written in both Navajo and English, that frames the discussion as, "when that time comes, when my last breath leaves me" rather than focusing on death itself.[30] Although the poem was created for the specific context, similar approaches should be considered to address potentially sensitive topics regarding return of results. Rather than focusing on a decision to be made in the event of death, the conversation can focus on assignment of decision makers or appropriate recipients of results in the event that a participant is not able to receive and comprehend them.

Dealing with Death and Belongings of the Decedent

The obligation to honor and respect the decedent's spirit and kin extends beyond death. In some Native American cultures in the Southwest, it is important to destroy all belongings of the dead, usually by burning or burying, to allow their spirit to break free of ties to this world.[31] Whether this concept of destroying all belongings extends to medical records, clinical or research results, and electronic data has not been fully explored. It is possible that some families may require a ceremony to lift the taboo of receiving such information about a deceased family member before proceeding. Some cultures traditionally forbid the widower to engage in dealings related to their departed one, usually for a specified amount of time that can vary by culture, but whether this extends to receiving health related results remains unclear.[32] In today's American context, where people are asked to name beneficiaries, it can be challenging to engage the widow on these topics too soon, and the time frame will vary by person and their religious or cultural background.

Approaching Conversations with Cultural Sensitivity

Discussions regarding returning results to participants and families of diverse backgrounds pose numerous questions to be explored. How should researchers obtain consent about sharing results after death if the topic of death itself is forbidden? If genomic results become available after a participant's death, how should researchers reach out to family members about results concerning their deceased family member, if, for some groups, naming them may not be not allowed? For some groups, naming is thought to confuse the deceased person's spirit.[33] How can providers and researchers recognize the boundary between what is acceptable or not? This section begins to explore some of the considerations for these issues.

Handling Sensitive Taboo Topics

Although taboos may exist across cultural backgrounds, it is just and more responsible to engage the family than to ignore these issues of how to return results out of fear of violating taboos. Not all families with shared backgrounds are the same; some have been shaped by assimilation, religion, or profession and may approach taboo topics differently than other families. These differences in perspectives regarding taboo topics could vary within ethnic groups, religious groups, and even within families. Ideas and taboos around death are constantly changing, being reinforced, and re-evaluated. People from younger generations might not adhere to some taboos as strictly as their elders, so care should be taken to acknowledge and be responsive to intergenerational differences.

Consent Conversations

Ideally, the participant will consent for return of results at the time of study enrollment. During this conversation, it would be important to have the participant identify a point person who can receive those results in the event that the primary participant cannot receive those results. If the participant states that they do not want to receive certain results, such as results derived from known pathogenic or expected pathogenic variants in 56 genes recommended by the American College of Medical Genetics and Genomics,[34] or allow another person to receive them on the participant's behalf, those preferences should be honored in accordance with the revised policy to allow participants to opt out of knowing that information.[35] Upon identification of a point person, the participant should tell the appointed person of his or her involvement in the study, and provide contact information to the study coordinators at the time of consent. Providing the participant with a document or brochure with information about the study, such as the contact information for the protocol directors, will be helpful for participants to share with family members.

Depending on the study, validated and actionable results may not be immediately available for return to participants. Some studies might take years for the research team to learn something that is actionable and appropriate to return. During study enrollment, researchers should be clear about potential timelines for returning results and the participant should clarify under what circumstances results may be returned to the family, with options ranging from never to only if incapacitated, to after death, or other circumstances. Researchers should also consider how the data derived from these participants will be handled after the participant is deceased, as they are no longer considered as human subjects, and whether or how to disclose that to participants. Regardless, it will be important to continue to honor the participants' wishes after death.

Some communities may have concerns around specimen handling, and even requests for specimen return or destruction, that may be important to address during specimen collection. After the settlement of a lawsuit over misuse of DNA samples, the Havasupai tribe retrieved the remaining samples, some of which came from Havasupai members who have since died, and the tribe arranged to dispose of them with a ceremony.[36] The Nuu-Chah-Nulth also fought to have their DNA samples returned after the lead investigator who collected the samples died.[37] Some Native American individuals[38] and community members[39] have described blood and DNA as an extension of their selves and spiritual being and have special concerns about secondary uses of their samples.

How to Return

Genetic counselors should be involved in the discussions about returning results to participants. Ideally, genetic counselors will have training in cultural competencies and should be culturally aware and sensitive to different perspectives, opinions, and interpretations about the results. In that same vein, study directors

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should ask the participant whether any potential concerns regarding the return of results might arise when family members are contacted. If a participant joins a study involving whole genome or exome sequencing to learn something about their health, they may want to share that with family members. Study directors should also decide in advance and disclose to participants whether their genomic research results will enter their medical records, or remain separate and treated as results from a research protocol. If the results are entered into the medical record, care must be taken to avoid conflation with clinical diagnostic results. If the results are held separately from the medical record, study directors should have clear mechanisms in place for returning these to the family.

Conclusions and Discussion

Researchers and clinicians who are considering returning research results to participants of diverse backgrounds may be unaware of cultural differences and potential cultural issues outlined in this paper. Including diverse participants in conversations on cultural considerations regarding specimen handling and taboo topics of death is important for building ethical and respectful research partnerships. This is so, even if it runs the initial risk of having difficult conversations that may potentially be uncomfortable for patients. More effort will be required to include diverse input from patients, communities, and diverse health care providers. Engaging families of different cultures in discussions on returning research results, particularly after death of a participant, is a just and respectful way to acknowledge diversity in perspectives. These discussions ensure dynamic conversations, and provide insight into how to initiate these difficult issues.

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