Published in final edited form as:

Am J Bioeth. 2008 October ; 8(10): 77–79. doi:10.1080/15265160802495622.

Directives for retained DNA: preferences of adolescent patients with substance and conduct problems and their siblings

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INTRODUCTION

The findings of Hull and colleagues (2008) describe patients' attitudes and preferences regarding use of anonymous and identifiable clinical samples for genetic research. Adolescents who participate in behavioral genetic research are less studied concerning these questions. We examined adolescent patients in treatment for substance and conduct problems (SCP) and their siblings with regard to directives for their retained DNA and the traits or factors potentially associated with their decisions. Our data support the findings of Hull et al. (2008) with regard to the association of race/ethnicity with preferences and the utility of empirical data as one factor in designing research practices.

BACKGROUND

Ethics research conducted on adolescents' participation in genetic research focuses broadly on issues related to family studies of disease (Borry et al., 2007; Arar et al., 2005), behavioral research (Tercyak et al., 2006), and attitudes of parents and children regarding the informed consent process (Geller et al., 2003). We were unable to locate any information regarding attitudes of adolescent SCP patients and their siblings toward participation in genetic repositories.

Data from adult studies indicate that some traits can impact preferences about storage and use of DNA; we will focus here only on race/ethnicity and age due to space limitations. Hull et al. (2008) demonstrate that adult African Americans are significantly more likely to want permission sought prior to using their anonymous DNA rather than just notification of use. Other studies also report that African American participants are less likely to grant permission for storage or future research use of their DNA samples (Sanner and Frazier, 2007; Aagard-Tillery et al., 2006).

In addition, Hull et al. (2008), report that younger respondents are more likely to require permission be sought for use of their identifiable DNA rather than just notification of use. Another recent adult study on characteristics that influence consent for genetic research (n=1,071) states that age is unrelated to willingness to donate or allow storage of DNA (Mezuk et al., 2008). In contrast, Sanner and Frazier (2007, n= 599) report that older adults are less likely to participate in genetic repositories. A study by Aagard-Tillery et al. (2006) in pregnant women (n=5003) found that age is significantly associated with an increased likelihood to have samples discarded. The discrepancies among such studies indicate the timeliness of this research.

Disclosure

Marilyn Coors is married to the Chairman of MillerCoors; the company has not contributed any funds nor had any influence on the study. The other authors have no financial relationships that relate to the topic of this research.

METHODS

Participants

We evaluated subject directives from 1208 participants: 593 patients with SCP aged 14–18 years and 615 siblings aged 14–33 years. Participants were enrolled through the Center for Antisocial Drug Dependence in a psychiatric genetic research study at two sites: University of Colorado Denver and University of California San Diego. Because control subjects for the CADD genetics study were not given a choice for use of their retained DNA, there were no independent controls for this study and the siblings provide the only comparison group.

Participants over 18 years provided informed consent. Participants younger than 18 years provided assent with parental or guardian informed consent.

Measures

Participants were given three options for use of their retained DNA and other phenotypic information: 1) only for this specific study, 2) only for genetic studies of substance abuse or related medical problems, 3) any genetic study. For analytic purposes, options 1) and 2) were combined into a category of “limited use” and compared with option 3) “any use”.

Participants completed diagnostic interviews and other assessments. The Composite International Diagnostic Interview—Substance Abuse Module provided DSM-IV symptom counts and diagnoses on 11 drug classes (tobacco, alcohol, cannabis, cocaine, amphetamines, sedatives, hallucinogens, inhalants, opioids, PCP, and club drugs); the sum of dependence symptoms across these drug categories (sumdep) provided a severity measure for substance use. Depending on subject age, the Diagnostic Interview Schedule for adults and Diagnostic Interview Schedule—Children for adolescents provided a count of the number of lifetime conduct disorder symptoms (LCD), which provided a severity measure for conduct problems.

Analyses

Patient and sibling groups were compared on continuous and categorical variables with independent t-tests, Wilcoxon Rank Sum tests, and chi-square tests. Subject directives from participants who consented were compared with those who assented using a chi-square test. Within patient and sibling groups, associations between race/ethnicity and subject directive were assessed with chi-square tests. Multiple logistic regressions predicting any genetic use were first conducted within patient and sibling groups separately and then conducted on the combined sample, adjusting for correlation among family members.

RESULTS

Groups were similar in that the majority of patients (57%) and siblings (58%) chose permission for any use of their retained DNA. Whether participants were old enough to provide informed consent as compared to those who could only assent with parental or guardian consent did not impact subject directive. The majority of participants under 18 years who provided assent (58%; n=843) and participants over 18 years who provided informed consent (58%; n=365) chose any use for their retained DNA.

As expected, patients had more severe substance use and conduct problems than their siblings. In terms of severity of substance use, patients averaged 11.9 sumdep symptoms (range = 0–41); siblings averaged 6.3 symptoms (range = 0–46) ($p < 0.0005$). In terms of conduct problems, patients averaged 5.5 LCD symptoms (range = 0–15); siblings averaged 2.8 symptoms (range 0–15) ($p < 0.0005$).

We also examined variables potentially related to subject directive. There were no significant differences between patient and sibling directive by site, gender, years of school completed or tobacco use. In patients, there was a small but significant association between an increasing number of sumdep symptoms and choosing any use for retained DNA (Odds Ratio=1.02, $p < .04$). The odds of choosing any use for retained DNA increased 2.4% with an increase of 1 sumdep symptom and 27% with an increase of 10 sumdep symptoms. In patients, there was no significant association between LCD and subject directive. In siblings, neither sumdep nor LCD was associated with choosing any use for retained DNA. The results reported thus far have evaluated the associations between sumdep and LCD separately in patients and siblings. We also examined these variables across groups. Accounting for the likely correlation between family members in analyses that combined patient and sibling groups did not meaningfully change any results.

Table 1 illustrates the distribution of subject directive across race/ethnic categories. African American and Hispanic participants were significantly less likely to choose any use of retained DNA than non-Hispanic whites in patients ($p < 0.015$) and siblings ($p < 0.002$). The lowest consent rate for any use was among African Americans (45%) compared with non-Hispanic whites (63%) and other participants (60%) who had the highest rates.

DISCUSSION

First, the data from our study concur with findings from Hull et al. (2008) that African American participants are significantly more likely to require permission be sought for use of their anonymous DNA. Our data extend these findings to SCP patients and their siblings. Racial and ethnic participants in our study were willing to donate their samples to a repository but were significantly more likely to restrict future use of their DNA to substance abuse genetic research and related medical problems. Studies examining impediments to participation in research among racial and ethnic minorities indicate that discrepancies in willingness to participate are largely due to a decreased level of trust in researchers (Sengupta et al., 2000).

Second, while Hull et al. (2008) report that age was associated with attitudes and preferences regarding use of anonymous samples, our data did not find that age was associated with directives of adolescent SCP patients and their siblings. The differences in the demographics of the study populations and the questions posed to participants make any direct comparisons between the studies impossible. However, this is an important area for future research, which should examine the impact of age on attitudes of participants to assess whether current practices are consistent with their needs.

Third, our results support the claim of Hull et al. (2008) that empirical data about patients' preferences have utility in deliberations about the design of research practices. Our data have direct relevance for the disclosure of risks in the informed consent process for SCP patients and their siblings. A robust consent and assent process prior to enrollment should include special emphasis on risks of genetic research such as violation of privacy and confidentiality, genetic discrimination, ownership of DNA, and others. The importance of the above risks may seem nominal for SCP patients whose diagnostic criteria can include criminal behaviors such as armed robbery and firesetting, and their siblings whose symptom counts are not inconsequential. This population's tendency to disregard potentially harmful consequences of behavior may be reflected in that the majority of our sample granted unrestricted permission for future research of their retained DNA. These data regarding preferences suggest that the informed consent process should focus on potential harms that are relevant for a risk prone population, including potential criminal justice uses, enforced therapy and an altered notion of responsibility (Coors and Raymond, in press).

Acknowledgements

This research was supported by NIDA Grant DA011015 and DA012845. The authors would also like to acknowledge the thoughtful contributions of Joseph Sakai, M.D.

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Table 1
Percent of each Race/Ethnicity Category Choosing Any Use in Patients and Siblings

RACE/ETHNICITY	Percent Any Use Patients: n=593 $\chi^2(3) = 11.4$, p<.015	Percent Any Use Siblings: n=615 $\chi^2(3) = 17.0$, p<.002
African American	45% (n=60)	44% (n=55)
Hispanic	51% (n=188)	50% (n=191)
Non-Hispanic White	63% (n=262)	65% (n=275)
Other	60% (n=83)	63% (n=94)
Native American	44% (n = 9)	70% (n = 10)
Asian	57% (n = 7)	67% (n = 12)