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FACTORS AFFECTING THE REPORTED IMPORTANCE OF HEALTH-RELATED ISSUES IN TRANSGENDER PERSONS

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Ву

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An abstract of

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ABSTRACT

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By Kevin Roy Pharris

Background: The term "transgender" refers to a group of persons who express a need to move across the culturally defined binary categories of gender. The dissatisfaction with one's sexual identity at birth often implores individuals to seek physical changes, including medical gender reassignment. Hormonal and surgical reassignment therapies are common in the transgender community; however long-term health-related outcomes of this type of treatment are unknown. Research that is available to-date has not been conducted with sufficient involvement of the transgender community. The purpose of the current study is to understand the patients' concerns with respect to benefits and risks associated with gender reassignment therapies.

Methods: Data were obtained from the "Transgender Health Priorities Survey." The main outcome variables were questions related to the specific benefits and risks thought to be associated with gender identity disorder and gender reassignment therapy. The participants were asked to prioritize these questions to allow gauging their relative importance. Multivariable analyses were performed to assess the demographic and clinical predictors of the relative priority assigned to each question.

Results: A total of 173 participants were included in the final analysis. Age and transgender direction were the only covariates that were statistically significantly associated with any of the health priorities questions. Both younger participants and male-to-female (MTF) participants were more interested than their respective counterparts in the ability of hormonal and surgical therapies to diminish stress and anguish. Conversely, older participants and female-to-male (FTM) participants were more interested in whether hormonal treatment could decrease the need for antidepressants or anti-anxiety medications.

Conclusion: These findings indicate subtle differences in the health-related priorities of transgender persons, mostly based on their age and transgender direction. Further studies with higher statistical power are needed to better understand the health concerns and research priorities in the transgender community.

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TABLE OF CONTENTS

1	List of Tables	i
2	Background	1
3	Methods	3
4	Results	7
5	Discussion	9
6	Strengths and Weaknesses	10
7	Conclusion	11
8	References	12
9	Tables	15
10	Appendix A: Transgender Health Priorities Survey (THPS)	25
11	Appendix B: SF-36 Questionnaire	31
12	Appendix C: The Gender Identity / Gender Dysphoria	
	Questionnaire for Adolescents and Adults	37

LIST OF TABLES

- Table 1: Demographic, personal, and treatment-related characteristics of respondents to the
 "Transgender Health Priorities Survey"
- Table 2: Summary of research priorities using questions about benefits and risks associated with gender reassignment therapy
- Table 3: Multivariable logistic regression analysis of the impact of age, race, education, treatment history, and transgender direction on reported importance of "Does hormonal gender reassignment decrease stress and anguish associated with gender dysphoria?"
- Table 4: Multivariable logistic regression analysis of the impact of age, race, education, treatment history, and transgender direction on reported importance of "Does surgical reassignment in addition to hormonal treatment decrease stress and anguish associated with gender dysphoria?"
- Table 5: Multivariable logistic regression analysis of the impact of age, race, education, treatment history, and transgender direction on reported importance of "Does hormonal gender reassignment decrease the need for antidepressants or anti-anxiety medications?"
- Table 6: Multivariable logistic regression analysis of the impact of age, race, education, treatment history, and transgender direction on reported importance of "Does surgical gender reassignment in addition to hormonal treatment decrease the need for antidepressants or anti-anxiety medications?"
- Table 7: Multivariable logistic regression analysis of the impact of age, race, education, treatment history, and transgender direction on reported importance of "Does gender reassignment increase risk of HIV infection or other STI?"

- Table 8: Multivariable logistic regression analysis of the impact of age, race, education, treatment history, and transgender direction on reported importance of "Do persons who completed surgical gender reassignment have higher risk of HIV and other STI compared to those who received hormonal treatment only or no gender reassignment at all?"
- Table 9: Multivariable logistic regression analysis of the impact of age, race, education, treatment history, and transgender direction on reported importance of "Does gender reassignment increase the risk of certain cancers (the specific cancers of concern may differ in persons who seek male-to-female versus female-to-male reassignment)?"
- Table 10: Multivariable logistic regression analysis of the impact of age, race, education, treatment history, and transgender direction on reported importance of "Does gender reassignment increase risk of diabetes or heart disease?"

BACKGROUND

As with many marginalized elements of society, the transgender population is largely underserved, understudied, and misunderstood. ^{14, 15, 17, 26} This population makes up the group of persons who express an emotional, psychological, or physical need to stray from the normal culturally-defined sorting of gender, and is alternately called "gender non-conforming." ^{8, 39} Transgender is a subset of the larger classification of "gender dysphoria," which describes those with dissatisfaction and discomfort with one's biologically assigned gender. Some individuals cope with the dissatisfaction mostly internally and psychologically, ¹² but many pursue physical changes as well. The typical person who entertains physical changes to realign himself/herself to another gender has exhausted all internal and psychological changes; the concept of changing the physical self then often dominates his/her life.

Options available for physical gender reassignment are hormonal and surgical. Hormonal therapy is typically the first physical step towards gender reassignment and involves the administration of contra-sex hormones. Secondary sexual changes ensue that affect aspects of life and physical appearance that are not directly related to reproductive organs. These may include changes in one's voice, hair patterns, muscularity, aggression, body fat percentage, and breast development. Since these secondary changes can potentially heavily influence the way a person self-identifies sexually, they are often sufficient to ameliorate the dissatisfaction with biological sexual assignment. The outward physical effects can be quite variable, with some achieving moderate degree of transformation and others experiencing little change. Overall however, hormonal therapy does not offer enough physical realignment to please some persons. These persons are candidates for surgical transformation. Surgical transformation typically progresses from more noticeable areas to less visible parts of the body. Plastic surgery on the face and breasts

(augmentation or reduction) is usually the first step to surgical correction.^{13, 22} Later steps include removal / replacement of external genitalia. It has yet to be studied in depth how much each specific therapy provides relief from gender dysphoria.³

As with any medical treatment, there are associated risks and benefits. In the typical medical setting, the risks and benefits are fairly tangible and easily weighed against each other. In the transgender population, however, the risks are often less well known. While gender reassignment surgeries carry relatively predictable risks, have been inconclusive. Furthermore, the benefits of these treatments are often uncertain. In the typical medical medical setting, the risks and benefits. In the typical medical setting, the risks are often. In the transgender population, however, the risks are often less well known. The risks with hormonal therapy are more difficult to pinpoint, and most of the results have been inconclusive. Furthermore, the benefits of these treatments are often uncertain. In particular, little is known about the long-term effects of hormonal and surgical interventions used for gender reassignment.

As society becomes increasingly familiar with the transgender issues, our lack of knowledge about health-related outcomes in this population becomes more obvious. The need for novel longitudinal health studies related to diseases of ageing in this population is evident. ^{16, 34, 36} For instance, few studies have focused on the progression of chronic conditions such as cardiovascular disease, diabetes, and hormone-related cancers. ^{27-29, 31, 33} With these data gaps in mind the present study aims to investigate issues that are perceived to be problematic by transgender persons. By eliciting the gender reassignment-related concerns of transgender persons, the medical community can better formulate research priorities and more efficiently allocate resources to meet the challenge of providing tailored healthcare. Furthermore, this patient-centric approach allows for a deeper understanding of the psychological aspects that affect gender dysphoria.

HYPOTHESES

- H₀: The importance of specific health-related questions as self-reported by transgender persons is not affected by age, race, education level, treatment status, or transgender direction.
- H_A: The importance of specific health-related questions as self-reported by transgender persons varies based on age, race, education level, treatment status, and/or transgender direction, or some combination thereof.

METHODS

The research data were derived from the "Transgender Health Priorities Survey." This survey is part of a larger study on the health of individuals and populations with gender dysphoria. The survey was designed by Emory University researchers, approved by the Emory Institutional Review Board, and was distributed by the Southern Comfort Conference.

Research participants were recruited based on the following initial eligibility requirements: 1) enrollment in the national Veterans Affairs (VA) health system or Kaiser Permanente (KP) managed care consortium health plans, 2) at least 18 years of age, and 3) one of the following diagnoses (ICD-9 codes) "trans-sexualism with unspecified sexual history" (302.50), "trans-sexualism with asexual history" (302.51), "trans-sexualism with heterosexual history" (302.53), and "gender identity disorder/gender dysphoria of adolescent or adult life" (302.85), or evidence of treatment with

estrogen in a person of male gender without an alternative indication (*e.g.* prostate cancer) <u>or</u> evidence of treatment with testosterone in a person of female gender under 40 years of age with no other identifiable reason (*e.g.* surgical menopause).

A letter invitation to participate in this study was sent by mail to patients in the VA and KP systems that meet the eligibility requirements mentioned previously. The invitation included a description of the study purpose and procedures, as well as a URL (worldwide web)address that would take interested parties to the study website. Also included in the mailed package was a return postcard for those who prefer to fill out the survey on paper, which would then be sent to them by standard mail.

Once participants access the study website, their eligibility is verified again by asking how old they are, and if they consider themselves transgender. Those who are under 18 years old or do not consider themselves transgender were excluded from finishing the survey and are not represented in the final dataset or analyses. Those participants who met the eligibility requirements were taken through an Informed Consent (IC) process to ensure their understanding of the study's purpose, procedures, risks and discomforts, benefits, compensation, and confidentiality. Also included in the Informed Consent process was a statement notifying participants that the study is voluntary and that they may withdraw from the study at any time, if they so desire. Contact information for study researchers was also provided. Participants had to agree to the aforementioned terms in order to participate in the study. The data were obtained from November 28, 2012 through February 13, 2013. A total of 173 participants were included in the final dataset and analyses.

The main outcome variables were the following eight questions that sought to understand the health-related priorities of transgender persons.

Benefits:

- 1. Does hormonal gender reassignment decrease stress and anguish associated with gender dysphoria?
- 2. Does surgical reassignment in addition to hormonal treatment decrease stress and anguish associated with gender dysphoria?
- 3. Does hormonal gender reassignment decrease the need for antidepressants or antianxiety medications?
- 4. Does surgical gender reassignment in addition to hormonal treatment decrease the need for antidepressants or anti-anxiety medications?

Risks:

- 5. Does gender reassignment increase risk of HIV infection or other STI?
- 6. Do persons who completed surgical gender reassignment have higher risk of HIV and other STI compared to those who received hormonal treatment only or no gender reassignment at all?
- 7. Does gender reassignment increase the risk of certain cancers (the specific cancers of concern may differ in persons who seek male-to-female versus female-to-male reassignment)?
- 8. Does gender reassignment increase risk of diabetes or heart disease?

The first four questions dealt with the benefits associated with hormonal and surgical gender reassignment therapy, and the remaining four questions inquired about therapy-related risks that are of particular concern for transgender persons. Within each group of four questions, respondents were asked to rank each question based on its importance. Thus, each question received a priority score ranging from 1 to 4, in the order of descending importance. The ranking was then dichotomized as either "important" (ranked as a 1 or 2), or "not important" (ranked as a 3 or 4) for each respondent. Analyses assessed the difference in question priority across general demographic and specific transgender-related characteristics of study participants.

All participants were characterized as those seeking male-to-female (MTF) or female-to-male (FTM) reassignment. Those participants whose sexual identity at birth matched their current sexual identity were excluded from the study, and only those whose gender identity changed were included in the analyses. The final analyses were stratified by transgender direction.

Age was dichotomized as either less than 45 years, or at least 45 years old at the time the survey was taken. With respect to race and ethnicity, participants were categorized as "Non-Hispanic Whites" vs. "Other." The "Other" group included persons who self-identified as Hispanic or Latino, American Indian or Alaska Native, Asian, Black, or Native Hawaiian or Other Pacific Islander, or multiracial.

Education level was also a binary variable, which contrasted those with at least a four-year college degree versus those who completed an Associate's degree or less.

Respondents were further characterized according to their receipt of hormonal therapy and gender reassignment surgery. The binary "Any Treatment" variable was then used to combine both hormonal and surgical gender reassignment.

The reported importance of each of the questions on risks and benefits of gender reassignment therapy was evaluated using multivariable logistic regression models. The covariates in all models included age, race, education level, treatment status, and transgender direction. Each model was evaluated using all cases combined, and stratified on transgender direction. Results were expressed as adjusted odds ratios, accompanied by the corresponding confidence intervals and *p*-values.

All analyses were performed using JMP Pro 10.0.0, 64-bit Edition (SAS Institute Inc.) statistical software package.

RESULTS

A total of 173 eligible transgender persons participated in the "Transgender Health Priorities Study" from November 28, 2012 through February 13, 2013. Among all study participants 66% (n = 114) identified themselves as MTF, while 34% (n = 59) identified themselves as FTM. As shown in Table 1, 61% (n = 105) of the subjects were 45 years of age or older at the time of survey completion. Among all responders, 80% (n = 130) were non-Hispanic Whites. At least a bachelor's degree was completed by 60% (n = 98) of the total participants. Only 11% (n = 10) completed surgical gender reassignment therapy. When hormonal and surgical gender reassignment therapies were combined, 54% (n = 49) of all participants had undergone treatment, and 81% (n = 76) of all participants reported they planned to undergo treatment in the future.

As shown in Table 2, 75% of the total participants deemed the reduction of stress and anguish with hormonal gender reassignment therapy important or very important, while 57% were equally concerned with the reduction of stress and anguish following hormonal plus surgical therapy. A possible reduction in the need to use antidepressants or anti-anxiety medications due to hormonal gender reassignment was important or very important for 45% of respondents. When asked if gender reassignment therapy affects the risk of sexually transmitted infections (STIs), 53% of participants deemed the question important or very important.

Multivariable analyses stratified by transgender direction were performed. However, the small sample size yielded multiple cells with less than 5 participants. These analyses yielded wide confidence intervals, all including 1.0, and for this reason the stratified results are not reported..

As shown in Table 4, participants over the age of 45 were statistically significantly less likely to be concerned whether or not surgical and hormonal reassignment therapy can reduce stress and

anguish associated with gender dysphoria than those under the age of 45 (OR 0.30, CI 0.10 - 0.91, p 0.033). Likewise, FTM participants were less likely to have this same concern than MTF participants (OR 0.22, CI 0.06 - 0.76, p 0.017).

The associations of age and MTF/FTM status with questions evluating the need for antidepressants or anti-anxiety medications were in the opposite direction (Table 5). Participants at least 45 years old rated the possible decreased need for these medications in relation to hormonal gender reassignment as being more important than those under 45 years of age (OR 3.05, CI 1.00 - 9.29, *p* 0.050). FTM transgender participants rated the possibility that hormonal gender reassignment could decrease the need for antidepressants or anti-anxiety medications as more important than did MTF participants (OR 5.35, CI 1.51 - 18.92, *p* 0.009). No statistically significant results were found for any other health priorities questions.

DISCUSSION

Two questions from the THPS yielded statistically significant results. Younger participants cared more about whether gender reassignment can reduce the stress and anguish associated with gender dysphoria. Their older counterparts, however, were more interested in knowing whether hormonal gender reassignment can decrease the need for antidepressants and anti-anxiety medications.

The second significant factor was transgender direction. MTF participants were more likely than FTM persons to feel that reduction of stress and anguish was a high priority question. Conversely, FTM transgender persons were more likely than MTF persons to place particular value on possible reduction in the need to take antidepressants and anti-anxiety medications. The reasons behind these observations are unclear but the associations were strong and therefore require further evaluation.

This project is based on a relatively new concept of patient-centered outcome research.³⁸ This new type of research aims to place more emphasis on ascertaining health priorities and other health-related issues directly from patients. Reports show that patient-centered approach can help identify research priorities and often leads to better study outcomes than would otherwise be expected.^{2,9,11,35} Since the fundamentals of patient-centered approach are patient involvement and individualization of care, any increase in participant involvement will help produce more tailored findings.³² Previous research with transsexual populations is sparse; thus this present study begins to fill an important knowledge gap.^{1,6,25}

STRENGTHS and WEAKNESSES

Transgender persons are likely to have a deeper understanding of what it is like to be an MTF or FTM person than any researcher would be able to realize. Using their expertise on the subject, transgender persons can help direct research in ways that both benefit them as consumers of scientific information and advance medical knowledge. Studies of this type are rare, and they are particularly rare in the transgender community

The main weakness of the present study is its small sample size which limited the statistical power of many, particularly stratified analyses. The study population was also relatively homogeneous with respect to race/ethnicity and education, with 80% non-Hispanic Whites and 60% college graduates included in the final dataset. For this reason the observed results may not be generalizable to other populations groups. Furthermore, only ten (11%) of the participants had undergone surgical gender reassignment, which did not allow using surgery as a stand-alone covariate. The passive recruitment methods through on-line advertisement raises concerns about selection bias.

CONCLUSION

In summary our findings demonstrate the feasibility of patient-centered research in the transgender community. Our results indicate few differences in the health-related priorities of transgender persons, mostly based on their age and MTF/FTM status. Further studies with higher statistical power are needed to better understand the health concerns and research priorities in the transgender community. Our quantitative results lead to additional research questions that can be addressed through qualitative studies .

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TABLES

Table 1. Demographic, personal, and treatment-related characteristics of respondents to the "Transgender Health Priorities Survey"

Variables		All re	All respondents			FTM	
		(1	n = 173)	(n = 114)		(n = 59)	
		N	%	N	%	N	%
Age							
	< 45 years	68	39.31	34	29.83	34	57.63
	45+ years	105	60.69	80	70.18	25	42.37
Race							
	Non-Hispanic Whites	130	79.76	91	85.85	39	68.42
	Other	33	20.25	15	14.15	18	31.58
At least	college education						
	Yes	98	60.49	63	60.00	35	61.40
	No	64	39.51	42	40.00	22	38.60
Relation	ship status						
	Single	55	33.95	39	37.14	16	28.07
	Married or Civil Partnership	62	38.27	51	48.57	11	19.30
	In a partnership	45	27.78	15	14.29	30	52.63
Sexual o	rientation						
	Heterosexual	61	35.47	38	33.63	23	38.98
	Homosexual	22	12.79	16	14.16	6	10.17
	Bisexual	45	26.16	37	32.74	8	13.56
	Other	44	25.58	22	19.47	22	37.29
Hormon	al treatment						
	Ever Use	51	54.26	36	50.70	15	65.22
	Current use	42	82.35	29	80.56	13	86.67
	Planning to use	74	78.72	54	76.06	20	86.96
Any surg	gery						
	Underwent	10	10.64	3	4.23	7	30.44
	Planning to undergo	58	61.70	42	59.16	16	69.57
Any trea	tment						
	Underwent	49	53.85	36	50.70	13	65.00
	Planning to undergo	76	80.85	55	77.47	21	91.30

Table 2. Summary of research priorities using questions about benefits and risks associated with gender reassignment therapy

Research Questions	Percent responses deeming these questions important or very important			
	Overall	MTF	FTM	
Questions pertaining to benefits of gender reassignment				
Does hormonal gender reassignment decrease stress and anguish associated with gender dysphoria?	75.33	76.36	72.73	
Does surgical reassignment in addition to hormonal treatment decrease stress and anguish associated with gender dysphoria?	56.76	65.39	36.36	
Does hormonal gender reassignment decrease the need for antidepressants or anti-anxiety medications?	45.33	35.85	68.18	
Does surgical gender reassignment in addition to hormonal treatment decrease the need for antidepressants or anti-anxiety medications?	28.67	28.30	22.73	
Questions pertaining to risks of gender reassignment				
Does gender reassignment increase risk of HIV infection or other STI?	52.70	50.94	57.14	
Do persons who completed surgical gender reassignment have higher risk of HIV and other STI compared to those who received hormonal treatment only or no gender reassignment at all?	44.44	37.26	61.91	
Does gender reassignment increase the risk of certain cancers (the specific cancers of concern may differ in persons who seek male-to-female versus female-to-male reassignment)?	53.25	58.93	38.10	
Does gender reassignment increase risk of diabetes or heart disease?	55.26	60.00	42.86	

Table 3. Multivariable logistic regression analysis of the impact of age, race, education, treatment history, and transgender direction on reported importance of "Does hormonal gender reassignment decrease stress and anguish associated with gender dysphoria?"

Participant	Reported i	mportance			
Characteristics	High	Low	OR	95% CI	р
Age					
< 45 years	26	8	1.00		
45 + years	32	11	0.96	0.30 - 3.09	0.946
Race					
Non-Hispanic Whites	46	16	1.00		
Other	12	3	2.75	0.48 - 15.73	0.255
At least college education					
Yes	33	14	1.00		
No	25	5	2.47	0.69 - 8.82	0.165
Any treatment					
Yes	32	13	1.00		
No	24	5	2.22	0.64 - 7.68	0.209
Transgender direction					
MTF	42	13	1.00		
FTM	16	6	0.90	0.25 - 3.27	0.873

Table 4. Multivariable logistic regression analysis of the impact of age, race, education, treatment history, and transgender direction on reported importance of "Does surgical reassignment in addition to hormonal treatment decrease stress and anguish associated with gender dysphoria?"

Participant	Reported i	importance			
Characteristics	High	Low	OR	95% CI	р
Age					
< 45 years	23	11	1.00		
45 + years	19	21	0.30	0.10 - 0.91	0.033
Race					
Non-Hispanic Whites	35	25	1.00		
Other	7	7	0.82	0.19 - 3.53	0.795
At least college education					
Yes	26	18	1.00		
No	16	14	0.67	0.23 - 1.95	0.466
Any treatment					
Yes	23	19	1.00		
No	18	11	1.07	0.36 - 3.21	0.905
Transgender direction					
MTF	34	18	1.00		
FTM	8	14	0.22	0.06 - 0.76	0.017

Table 5. Multivariable logistic regression analysis of the impact of age, race, education, treatment history, and transgender direction on reported importance of "Does hormonal gender reassignment decrease the need for antidepressants or anti-anxiety medications?"

Participant	Reported i	mportance			
Characteristics	High	Low	OR	95% CI	р
Age					
< 45 years	12	22	1.00		
45 + years	22	19	3.05	1.00 - 9.29	0.050
Race					
Non-Hispanic Whites	26	34	1.00		
Other	8	7	1.09	0.27 - 4.44	0.901
At least college education					
Yes	20	26	1.00		
No	14	15	1.45	0.51 - 4.16	0.491
Any treatment					
Yes	22	22	1.00		
No	10	18	0.68	0.23 - 2.05	0.496
Transgender direction					
MTF	19	34	1.00		
FTM	15	7	5.35	1.51 - 18.92	0.009

Table 6. Multivariable logistic regression analysis of the impact of age, race, education, treatment history, and transgender direction on reported importance of "Does surgical gender reassignment in addition to hormonal treatment decrease the need for antidepressants or anti-anxiety medications?"

Participant	Reported i	importance			
Characteristics	High	Low	OR	95% CI	p
Age					
< 45 years	7	27	1.00		
45 + years	13	28	1.66	0.52 - 5.29	0.392
Race					
Non-Hispanic Whites	17	44	1.00		
Other	3	11	0.50	0.09 - 2.81	0.428
At least college education					
Yes	14	33	1.00		
No	6	22	0.58	0.17 - 1.92	0.370
Any treatment					
Yes	13	31	1.00		
No	6	22	0.62	0.19 - 2.04	0.430
Transgender direction					
MTF	15	38	1.00		
FTM	5	17	0.72	0.19 - 2.75	0.628

Table 7. Multivariable logistic regression analysis of the impact of age, race, education, treatment history, and transgender direction on reported importance of "Does gender reassignment increase risk of HIV infection or other STI?"

Participant	Reported	importance			
Characteristics	High	Low	OR	95% CI	p
Age					
< 45 years	19	13	1.00		
45 + years	20	22	0.69	0.25 - 1.87	0.462
Race					
Non-Hispanic Whites	30	29	1.00		
Other	9	6	1.28	0.34 - 4.83	0.714
out.e.	J	Ü	1.20	0.51 1.05	0.711
At least college education					
Yes	24	22	1.00		
No	15	13	1.18	0.43 - 3.23	0.749
Any treatment					
Yes	24	18	1.00		
No	13	16	0.55	0.19 - 1.53	0.251
Transgender direction					
MTF	27	26	1.00		
FTM	12	9	1.12	0.35 - 3.60	0.846

Table 8. Multivariable logistic regression analysis of the impact of age, race, education, treatment history, and transgender direction on reported importance of "Do persons who completed surgical gender reassignment have higher risk of HIV and other STI compared to those who received hormonal treatment only or no gender reassignment at all?"

Participant	Reported	importance			
Characteristics	High	Low	OR	95% CI	р
Age					
< 45 years	16	16	1.00		
45 + years	16	24	0.81	0.28 - 2.30	0.687
Race					
Non-Hispanic Whites	22	36	1.00		
Other	10	4	2.40	0.58 - 9.92	0.225
Cane.	_0	•		0.00 3.52	0.225
At least college education					
Yes	20	26	1.00		
No	12	14	1.08	0.37 - 3.13	0.891
Any treatment					
Yes	20	21	1.00		
No	9	19	0.60	0.20 - 1.78	0.360
Transgender direction					
MTF	19	32	1.00		
FTM	13	8	1.66	0.51 - 5.41	0.404

Table 9. Multivariable logistic regression analysis of the impact of age, race, education, treatment history, and transgender direction on reported importance of "Does gender reassignment increase the risk of certain cancers (the specific cancers of concern may differ in persons who seek male-to-female versus female-to-male reassignment)?"

Participant	Reported i	mportance			
Characteristics	High	Low	OR	95% CI	р
Age					
< 45 years	14	19	1.00		
45 + years	27	17	2.06	0.77 - 5.67	0.151
Race					
Non-Hispanic Whites	35	27	1.00		
Other	6	9	0.95	0.25 - 3.66	0.941
Other	U	9	0.93	0.23 - 3.00	0.541
At least college education					
Yes	26	23	1.00		
No	15	13	1.11	0.40 - 3.11	0.843
Any treatment					
Yes	22	22	1.00		
No	19	11	1.80	0.65 - 5.18	0.263
Transgender direction					
MTF	33	23	1.00		
FTM	8	13	0.71	0.22 - 2.28	0.563

Table 10. Multivariable logistic regression analysis of the impact of age, race, education, treatment history, and transgender direction on reported importance of "Does gender reassignment increase risk of diabetes or heart disease?"

Participant	Reported i	importance			
Characteristics	High	Low	OR	95% CI	р
Age					
< 45 years	17	16	1.00		
45 + years	25	18	1.04	0.38 - 2.84	0.940
Race					
Non-Hispanic Whites	37	24	1.00		
Other	5	10	0.60	0.16 - 2.29	0.455
At least college advection					
At least college education	20	20	1.00		
Yes	28	20	1.00		
No	14	14	0.58	0.21 - 1.62	0.299
Any treatment					
Yes	22	22	1.00		
No	19	10	1.73	0.61 - 4.95	0.307
Transgender direction					
MTF	33	22	1.00		
FTM	9	12	0.55	0.17 - 1.76	0.310

APPENDIX A

Transgender Health Priorities Survey (THPS)

Eligibility Questions

E.1. What is your age in years?

The term "transgender" describes a person who feels a strong need to move across the traditional categories of gender from male to female or from female to male. For the purposes of this survey the term "transgender" also includes persons whose current gender is different from the one assigned at birth, as well as persons who are "gender nonconforming" and do not follow other people's stereotypes about how they should look or act based on the female or male sex.

E.2. With this definition in mind, do you consider yourse	elf transgender?
No 0	
Yes1	

If response to E.1. <18, or if answer to E.2 is NO, end the survey Otherwise continue to the Informed Consent Section

Informed Consent

<u>Title</u>: Transgender Health Priorities Survey

Principal Investigator: Michael Goodman, MD MPH

Sponsor: Emory University

Introduction

You are being asked to be in a study that will be conducted by Emory University's Rollins School of Public Health. The study consists of an online survey. Emory researchers have an opportunity to study health benefits and health problems linked to hormonal shots and other treatments used for gender reassignment. Before we proceed with the study we want to ask members of the transgender community what types of research questions should be of the highest priority. This survey will attempt to learn more about the health issues that are the most important to persons who are planning to undergo, are undergoing or have already undergone gender reassignment treatment. The

survey is designed for all persons who consider themselves transgender. Up to 10,000 participants are expected to take the survey.

Purpose

The study aims to find out about your interest in and understanding of different health issues (both risks and benefits) linked to gender reassignment treatment.

Procedures

If you decide to participate in the study, you will be asked to fill in a survey on your computer. The survey will take about 10 minutes to complete. It will ask you questions about the gender reassignment treatment you received so far and also treatment that you plan or wish to receive.

Risks and Discomforts

There are no major risks with being in this study. You may feel uncertain when answering some sensitive questions, but you always have the right to skip a question that you do not want to answer.

Benefits

This study is not designed to benefit you directly. This study is designed to learn more about health risks and benefits or gender reassignment. Taking part in this research study may not benefit you. But, we may learn new things from this research that will help us improve the health of transgender persons.

Compensation

You will not be paid for being in this study.

Confidentiality

We will keep your information private. The online survey host- Survey Gizmosets the survey so that people cannot click the link at the same computer and see the survey that was completed at that computer. We will not collect any personally identifying information. Certain offices and people other than this research team may look at your study records. Government agencies and Emory employees that oversee the study may view your study records. These offices include the Emory Institutional Review Board and the Emory Office of Research Compliance. The law requires researchers to keep all research records private.

Voluntary Participation and Withdrawal from the Study

Your decision to be in this study is up to you. You have the right to refuse to be in this study. You also have the right to stop the survey at any time. Your decision to be in or leave the study will not affect your e-mail, Facebook, MySpace or any other accounts in any way.

Contact Persons

If you have any questions about the study, please contact the investigator in charge, Dr. Michael Goodman, at (404) 727-2734; mgoodm2@emory.edu.

If you have questions about your rights or you feel you have been harmed by
being in this study, you may contact the Emory Institutional Review Board at
(404) 712-0720 or (877) 503-9797 or irb@emory.edu.

Consent	l
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Being in this study is entirely your choice. You have the right to refuse to participate or to stop taking the survey at any time. Please print a copy of this form for your records. If you agree to the above information and would like to be in the study, please click on the "I Agree" box below.

I agree ☐ I have read the information above. I agree to participate in this study. To print a copy of this consent form for your records, please click here
If informed consent is given move to the Survey Questions
Survey Questions
Demographic characteristics
D.1. What was your physical sex assigned at birth?
Male 1 Female 2 Intersex 3 Refuse to answer R Don't know D
D.2. Do you currently consider yourself to be male, female, or other?
Male 1 Female 2 Other 4 (Specify other gender:) Refused to answer R Don't know D
D.3. Which racial group or groups do you consider yourself to be in? You may choose more than one option.
American Indian or Alaska Native

White5 Refused to answerR Don't knowD
D.4. Do you consider yourself to be Hispanic or Latino?
No
Treatment questions
T.1. Have you ever used hormones to change your body? This would include hormones that are applied topically, taken orally, or injected. "Applied topically" means hormones are applied to the skin.
No
If response to T.1. is Yes (1), go to T.2. Otherwise skip to T.3
T.2. Are you currently using hormones to change your body?
No
T.3. Are you planning to use hormones to change your body in the future?
No
T4. Have you had any surgical procedures to change appearance of your chest?
No

5. Are you planning to have any surgical procedures to change appearance of your chest?
No0
Yes1
Refused to answerR
Don't knowD
6. Have you had any surgical procedures to change your genitalia?
No 0
Yes 1
Refused to answerR
Don't knowD
.7. Are you planning to have any surgical procedures to change your genitalia?
No0
Yes1
Refused to answerR
Don't knowD
riorities questions

Persons seeking gender reassignment often do so because they feel a strong need to cross the "traditional" gender boundaries and because they experience a powerful desire to live and be accepted as a member of another sex. "Gender dysphoria" is defined as dissatisfaction and discomfort with one's assigned gender.

- P.1. From the list below rank the research questions about benefits of gender reassignment in order of importance.
 - Does hormonal gender reassignment decrease stress and anguish associated with gender dysphoria?
 - Does surgical gender reassignment in addition to hormonal treatment decrease stress and anguish associated with gender dysphoria?
 - Does hormonal gender reassignment decrease the need for antidepressants or anti-anxiety medications?
 - Does surgical gender reassignment in addition to hormonal treatment decrease the need for antidepressants or anti-anxiety medications?
- P.2. Feel free use space below to ask additional questions about the benefits of gender reassignment that are of importance to you.

Gender reassignment may have short and long-term side effects. Most of those side effects are related to hormonal treatment. In addition gender reassignment may be associated with increased chances of sexually transmitted infections (STI) including HIV because gender reassignment may lead to changes in behavior.

- P.3. From the list below rank the research questions about risks of gender reassignment in order of descending importance.
 - Does gender reassignment increase risk of HIV infection or other STI?
 - Do persons who completed surgical gender reassignment, have higher risk of HIV and other STI compared to those who received hormonal treatment only or no gender reassignment at all?
 - Does gender reassignment increase risk of certain cancers (the specific cancers of concern may differ in persons who seek male-to-female versus female-to-male reassignment)?
 - Does gender reassignment increase risk of diabetes or heart disease?

P.4. Feel free use space below to ask additional questions about the risks of gender reassignment that are of importance to you.
P.6 We would also want to know what factors serve as barriers to receiving gender reassignment care. From the list below, rank, in order of descending importance,

Lack of insurance coverage

factors that may act as such barriers.

- Difficulty of finding qualified health care providers
- Societal, family or work-related pressures
- Other. Specify using space below

APPENDIX B

SF-36 questionnaire

SHORT FORM-36 (SF36) SURVEY

Please answer the following questions about your health. Select **ONLY ONE ANSWER** for each question

- 1. In general, would you say your health is:
 - 1. Excellent
 - 2. Very Good
 - 3. Good
 - 4. Fair
 - 5. Poor
- 2. Compared to one year ago, how would you rate your health in general now?
 - 1. Much better now than one year ago
 - 2. Somewhat better now than one year ago
 - 3. About the same as one year ago
 - 4. Somewhat worse now than one year ago
 - 5. Much worse than one year ago
- 3. Does your health now limit you in this activity? If so, how much? Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports.
 - 1. Yes, limited a lot
 - 2. Yes, limited a little
 - 3. No, not limited at all

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? 4. Does your health now limit you in this activity? If so, how much? Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf.

- 1. Yes, limited a lot
- 2. Yes, limited a little
- 3. No, not limited at all
- 5. Does your health now limit you in this activity? If so, how much? Lifting or carrying groceries.
 - 1. Yes, limited a lot
 - 2. Yes, limited a little
 - 3. No. not limited at all
- 6. Does your health now limit you in this activity? If so, how much? Climbing several flights of stairs.
 - 1. Yes, limited a lot
 - 2. Yes, limited a little
 - 3. No, not limited at all

- 7. Does your health now limit you in this activity? If so, how much? Climbing one flight of stairs.
 - 1. Yes, limited a lot
 - 2. Yes, limited a little
 - 3. No, not limited at all
- 8. Does your health now limit you in this activity? If so, how much? Bending, kneeling, or stooping.
 - 1. Yes, limited a lot
 - 2. Yes, limited a little
 - 3. No, not limited at all
- 9. Does your health now limit you in this activity? If so, how much? Walking more than a mile.
 - 1. Yes, limited a lot
 - 2. Yes, limited a little
 - 3. No, not limited at all
- 10. Does your health now limit you in this activity? If so, how much? Walking several blocks.
 - 1. Yes, limited a lot
 - 2. Yes, limited a little
 - 3. No, not limited at all
- 11. Does your health now limit you in this activity? If so, how much? Walking one block.
 - 1. Yes, limited a lot
 - 2. Yes, limited a little
 - 3. No, not limited at all
- 12. Does your health now limit you in this activity? If so, how much? Bathing or dressing yourself.
 - 1. Yes, limited a lot
 - 2. Yes, limited a little
 - 3. No, not limited at all

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your PHYSICAL HEALTH?

- 13. During the past 4 weeks, have you had the following problem with your work or other regular daily activities as a result of your physical health? Cut down the amount of time you spent on work or other activities.
 - 1. Yes
 - 2. No
- 14. During the past 4 weeks, have you had the following problem with your work or other regular daily activities as a result of your physical health? Accomplished less than you would like.
 - 1. Yes
 - 2. No

- 15. During the past 4 weeks, have you had the following problem with your work or other regular daily activities as a result of your physical health? Were limited in the kind of work or other activities.
 - 1. Yes
 - 2. No.
- 16. During the past 4 weeks, have you had the following problem with your work or other regular daily activities as a result of your physical health? Had difficulty performing the work or other activities (for example, it took extra effort).
 - 1. Yes
 - 2. No

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any EMOTIONAL PROBLEMS (such as feeling depressed or anxious)?

- 17. During the past 4 weeks, have you had the following problem with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)? Cut down the amount of time you spent on work or other activities.
 - 1. Yes
 - 2. No
- 18. During the past 4 weeks, have you had the following problem with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)? Accomplished less than you would like.
 - 1. Yes
 - 2. No
- 19. During the past 4 weeks, have you had the following problem with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)? Didn't do work or other activities as carefully as usual.
 - 1. Yes
 - 2. No
- 20. During the past 4 weeks, to what extent has your physical health OR emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?
 - 1. Not at all
 - 2. Slightly
 - 3. Moderately
 - 4. Quite a bit
 - 5. Extremely
- 21. How much bodily pain have you had during the past 4 weeks?
 - 1. None
 - 2. Very mild
 - 3. Mild
 - 4. Moderate
 - 5. Severe
 - 6. Very severe

- 22. During the past 4 weeks how much did pain interfere with your normal work (including both work outside the home and housework)?
 - 1. Not at all
 - 2. A little bit
 - 3. Moderately
 - 4. Quite a bit
 - 5. Extremely

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

- 23. How much of the time during the past 4 weeks: Did you feel full of pep?
 - 1. All of the time
 - 2. Most of the time
 - 3. A good bit of the time
 - 4. Some of the time
 - 5. A little of the time
 - 6. None of the time
- 24. How much of the time during the past 4 weeks: Have you been a very nervous person?
 - 1. All of the time
 - 2. Most of the time
 - 3. A good bit of the time
 - 4. Some of the time
 - 5. A little of the time
 - 6. None of the time
- 25. How much of the time during the past 4 weeks: Have you felt so down in the dumps that nothing could cheer you up?
 - 1. All of the time
 - 2. Most of the time
 - 3. A good bit of the time
 - 4. Some of the time
 - 5. A little of the time
 - 6. None of the time
- 26. How much of the time during the past 4 weeks: Have you felt calm and peaceful?
 - 1. All of the time
 - 2. Most of the time
 - 3. A good bit of the time
 - 4. Some of the time
 - 5. A little of the time
 - 6. None of the time

- 27. How much of the time during the past 4 weeks: Did you have a lot of energy?
 - 1. All of the time
 - 2. Most of the time
 - 3. A good bit of the time
 - 4. Some of the time
 - 5. A little of the time
 - 6. None of the time
- 28. How much of the time during the past 4 weeks: Have you felt downhearted and blue?
 - 1. All of the time
 - 2. Most of the time
 - 3. A good bit of the time
 - 4. Some of the time
 - 5. A little of the time
 - 6. None of the time
- 29. How much of the time during the past 4 weeks: Did you feel worn out?
 - 1. All of the time
 - 2. Most of the time
 - 3. A good bit of the time
 - 4. Some of the time
 - 5. A little of the time
 - 6. None of the time
- 30. How much of the time during the past 4 weeks: Have you been a happy person?
 - 1. All of the time
 - 2. Most of the time
 - 3. A good bit of the time
 - 4. Some of the time
 - 5. A little of the time
 - 6. None of the time
- 31. How much of the time during the past 4 weeks: Did you feel tired?
 - 1. All of the time
 - 2. Most of the time
 - 3. A good bit of the time
 - 4. Some of the time
 - 5. A little of the time
 - 6. None of the time
- 32. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?
 - 1. All of the time
 - 2. Most of the time
 - 3. Some of the time
 - 4. A little of the time
 - 5. None of the time

- 33. How true or false is the following statement? I seem to get sick a little easier than other people.
 - 1. Definitely true
 - 2. Mostly true
 - 3. Don't know
 - 4. Mostly false
 - 5. Definitely false
- 34. How true or false is the following statement? I am as healthy as anybody I know.
 - 1. Definitely true
 - 2. Mostly true
 - 3. Don't know
 - 4. Mostly false
 - 5. Definitely false
- 35. How true or false is the following statement? I expect my health to get worse.
 - 1. Definitely true
 - 2. Mostly true
 - 3. Don't know
 - 4. Mostly false
 - 5. Definitely false
- 36. How true or false is the following statement? My health is excellent.
 - 1. Definitely true
 - 2. Mostly true
 - 3. Don't know
 - 4. Mostly false
 - 5. Definitely false
- 37. Are you ...?
 - 1. Male
 - 2. Female
- 38. How old were you on your last birthday?
 - 1. Less than 24
 - 2. 25 34
 - 3.35 44
 - 4. 45 54
 - 5. 55 64
 - 6. 65 & Over

APPENDIX C

The Gender Identity/Gender Dysphoria Questionnaire for Adolescents and Adults (GIDYQAA)

FTM Version [Response options are Always, Often, Sometimes, Rarely, or Never].

- 01. In the past 12 months, have you felt satisfied being a woman?
- 02. In the past 12 months, have you felt uncertain about your gender, that is, feeling somewhere in between a woman and a man?
- 03. In the past 12 months, have you felt pressured by others to be a woman, although you don't really feel like one?
- 04. In the past 12 months, have you felt, unlike most women, that you have to work at being a woman?
- 05. In the past 12 months, have you felt that you were not a real woman?
- 06. In the past 12 months, have you felt, given who you really are (e.g., what you like to do, how you act with other people), that it would be better for you to live as a man rather than as a woman?
- 07. In the past 12 months, have you had dreams?

If NO, skip to Question 8.

If YES, Have you been in your dreams?

If NO, skip to Question 8.

If YES, In the past 12 months, have you had dreams in which you were a man?

- 08. In the past 12 months, have you felt unhappy about being a woman?
- 09. In the past 12 months, have you felt uncertain about yourself, at times feeling more like a man and at times feeling more like a woman?
- 10. In the past 12 months, have you felt more like a man than like a woman?
- 11. In the past 12 months, have you felt that you did not have anything in common with either men or women?
- 12. In the past 12 months, have you been bothered by seeing yourself identified as female or having to check the box "F" for female on official forms (e.g., employment applications, driver's license, passport)?

- 13. In the past 12 months, have you felt comfortable when using women's restrooms in public places?
- 14. In the past 12 months, have strangers treated you as a man?
- 15. In the past 12 months, at home, have people you know, such as friends or relatives, treated you as a man?
- 16. In the past 12 months, have you had the wish or desire to be a man?
- 17. In the past 12 months, at home, have you dressed and acted as a man?
- 18. In the past 12 months, at parties or at other social gatherings, have you presented yourself as a man?
- 19. In the past 12 months, at work or at school, have you presented yourself as a man?
- 20. In the past 12 months, have you disliked your body because it is female (e.g., having breasts or having a vagina)?
- 21. In the past 12 months, have you wished to have hormone treatment to change your body into a man's?
- 22. In the past 12 months, have you wished to have an operation to change your body into a man's (e.g., to have your breasts removed or to have a penis made)?
- 23. In the past 12 months, have you made an effort to change your legal sex (e.g., on a driver's license or credit card)?
- 24. In the past 12 months, have you thought of yourself as a "hermaphrodite" or an "intersex" rather than as a man or woman?
- 25. In the past 12 months, have you thought of yourself as a "transgendered person"?
- 26. In the past 12 months, have you thought of yourself as a man?
- 27. In the past 12 months, have you thought of yourself as a woman?

Notes:

Items 1, 13, and 27 were reversed scored.

Items 1–2, 5–10, 16, and 24–27 are considered to be subjective indicators of gender identity=gender dysphoria;

Items 3–4, 11, 13–15, and 17–19 are considered social indicators;

Items 20-22 are considered somatic indicators:

Items 12 and 23 are considered socio-legal indicators.

MTF Version [Response options are Always, Often, Sometimes, Rarely, or Never].

- 01. In the past 12 months, have you felt satisfied being a man?
- 02. In the past 12 months, have you felt uncertain about your gender, that is, feeling somewhere in between a man and a woman?
- 03. In the past 12 months, have you felt pressured by others to be a man, although you don't really feel like one?
- 04. In the past 12 months, have you felt, unlike most men, that you have to work at being a man?
- 05. In the past 12 months, have you felt that you were not a real man?
- 06. In the past 12 months, have you felt, given who you really are (e.g., what you like to do, how you act with other people), that it would be better for you to live as a woman rather than as a man?
- 07. In the past 12 months, have you had dreams?
 - If NO, skip to Question 8.
 - If YES, Have you been in your dreams?
 - If NO, skip to Question 8.
 - If YES, In the past 12 months, have you had dreams in which you were a woman?
- 08. In the past 12 months, have you felt unhappy about being a man?
- 09. In the past 12 months, have you felt uncertain about yourself, at times feeling more like a woman and at times feeling more like a man?
- 10. In the past 12 months, have you felt more like a woman than like a man?
- 11. In the past 12 months, have you felt that you did not have anything in common with either women or men?
- 12. In the past 12 months, have you been bothered by seeing yourself identified as male or having to check the box "M" for male on official forms (e.g., employment applications, driver's license, passport)?
- 13. In the past 12 months, have you felt comfortable when using men's restrooms in public places?
- 14. In the past 12 months, have strangers treated you as a woman?
- 15. In the past 12 months, at home, have people you know, such as friends or relatives, treated you as a woman?

- 16. In the past 12 months, have you had the wish or desire to be a woman?
- 17. In the past 12 months, at home, have you dressed and acted as a woman?
- 18. In the past 12 months, at parties or at other social gatherings, have you presented yourself as a woman?
- 19. In the past 12 months, at work or at school, have you presented yourself as a woman?
- 20. In the past 12 months, have you disliked your body because it is male (e.g., having a penis or having hair on your chest, arms, and legs)?
- 21. In the past 12 months, have you wished to have hormone treatment to change your body into a woman's?
- 22. In the past 12 months, have you wished to have an operation to change your body into a woman's (e.g., to have your penis removed or to have a vagina made)?
- 23. In the past 12 months, have you made an effort to change your legal sex (e.g., on a driver's license or credit card)?
- 24. In the past 12 months, have you thought of yourself as a "hermaphrodite" or an "intersex" rather than as a man or woman?
- 25. In the past 12 months, have you thought of yourself as a "transgendered person"?
- 26. In the past 12 months, have you thought of yourself as a woman?
- 27. In the past 12 months, have you thought of yourself as a man?

Notes:

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