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Performance of the University of California, San Diego Brief Assessment of Capacity to Consent (UBACC) questionnaire in mental health genetic research in Africa

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ABSTRACT

Importance Over the last decade, there has been an increase in genetic research on mental health conditions the world over including in Africa. It remains unknown whether individuals who consent to participate in genetics research understand the context, the risks and benefits of their involvement in the research and most importantly the concept of voluntary participation.

Objective The University of California, San Diego Brief Assessment of Capacity to Consent questionnaire (UBACC) can assess decisional capacity during the consent process. We set out to assess how well the UBACC could improve the consent process in the largest genetics study in Africa.

Methods This cross-sectional study was conducted from 2018 to 2022 across multiple sites in Ethiopia, Kenya, South Africa and Uganda. Participants were recruited from mental health facilities and general outpatient clinics. Participants were adults aged at least 18 years, half of whom had a diagnosis of psychosis (cases) and the other half did not (controls).

Intervention For each potential participant, research assistants read participant information sheets and informed consent materials out loud and then asked them questions about the study. This was repeated up to three times for participants who scored less than the maximum score of 20. We calculated the mean scores at attempts 1–4 and conducted regression post hoc analyses to determine the socio-demographic factors associated with a maximal score of 20.

Results Of the 42 953 participants, 57.35% were male. The mean age of participants was 36.69 (SD=11.7). The mean UBACC score improved significantly across attempts, rising from 13.27 (SD±3.5) at attempt 1 to 16.83 (SD±3.0) at attempt 2, 18.10 (SD±2.2) at attempt 3 and 18.37 (SD±1.6) at attempt 4, with each score significantly higher than the previous one. Male sex was associated with increased odds of achieving a UBACC score of 20 (OR=1.35, 95% CI 1.28 to 1.40), whereas being a case was associated with lower odds of reaching this score (OR=0.59, 95% CI 0.56 to 0.61). Lower age was associated with modestly lower odds of scoring 20 (OR=0.99, 95% CI 0.98 to 0.99), while higher education was associated with substantially higher odds of reaching this score (OR=2.69, 95% CI 2.24 to 3.22).

Conclusion and relevance The association of specific socio-demographic variables with maximal UBACC scores is consistent with expectations. An iterative process using the UBACC facilitates informed consent in mental health genetics studies in the African context.

Patient involvement The cross-sectional study was part of a large genetics study where cases and controls were compared across a number of study variables. However, patients and members of the public were not involved in the design of the study.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ The study used a large sample size to answer an important question.
⇒ The study employed nine local languages of consent across four countries in Africa.
⇒ The lack of qualitative assessment to assess how well participants understood the questions.
⇒ The lack of a cognitive interview during translation of the questionnaire into local languages.

INTRODUCTION

Over the last decade, there has been an increase in genetic research on mental health conditions in sub-Saharan Africa (SSA).[1–3] The immediate benefits of this work may include an understanding of the genetics of mental health conditions in a population with the largest genetic diversity globally,[4–6] while the long-term benefits may include the potential for drug discovery.[7–9] The ethical requirements for such genetic research are stringent; obtaining informed consent is particularly important in people with mental health conditions—such persons are, for

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example, considered 'vulnerable' by the Belmont report, which sets ethical principles and guidelines for the protection of human subjects in research.[10]

A number of objective measures that assess whether individuals who provide informed consent have understood the research, are willing to voluntarily participate and understand the risk as well as the benefits of involvement, are available, including the University of California, San Diego Brief Assessment of Capacity to Consent Questionnaire (UBACC).[11] The UBACC, a 10-item questionnaire assesses three domains including (i) understanding the contents of the consent form, (ii) appreciation of the knowledge in the consent form and (iii) engagement in the comparative reasoning about the contents of the consent form and consenting process.

The UBACC is administered in an iterative process. A participant who does not provide a correct response to a question is given an opportunity to discuss their response with a research assistant and has up to three additional opportunities to answer the question. Participants who score below a threshold 14.5[11] after the fourth attempt are considered to have an insufficient understanding of the consent process—the iterative process is intended to improve the consent process, with UBACC scores expected to increase after each attempt to the maximum score of 20. The lower (14.5) and upper (20) cut-off scores are recommended by the scale developers.[11]

Most work with the UBACC[11] has been done in high-income countries (HIC). A number of socio-demographic factors (age, sex and education level) as well as the presence or absence of disease states (cognitive difficulties or psychosis) have been shown to predict the scores of the UBACC during the iterative process.[12–14] In SSA, little has been done to examine how well the UBACC can improve the consenting process and the socio-demographic variables that predict this process.

An earlier report from our group undertook an analysis of the psychometric properties of the UBACC, focusing on the scores at first attempt.[15] The UBACC had a two-factor model for the overall sample, with differences in the model fit by country and language of administration.[15] In this study, there was no determination of how the scores of the UBACC changed with each attempt, as well as the factors that determine those changes.

Objectives

Our objective here was to determine by how much UBACC scores would improve through an iterative process and the socio-demographic factors (age, sex and education level) that were associated with a maximal final mean score of 20 in cases and controls. Individuals with psychosis were classified as cases and those without psychosis as controls. This is the largest mental health genetics study in Africa, undertaken in Uganda, Kenya, Ethiopia and South Africa (n=42 593).[16]

METHODS

Study design

The cross-sectional study was part of a large genetics study where cases and controls were compared across a number of study variables. However, patients and members of the public were not involved in the design of the study.

Study setting

The study was conducted in mental health units and general outpatient departments across two sites in Ethiopia, 2 in Kenya, 5 in Uganda and 2 South Africa.

Eligibility criteria

All participants were at least 18 years old and able to speak either English or one of the local languages spoken at the study site. Participants were ineligible if they were acutely ill, intoxicated or suffering from an emergency for which treatment was required.

Matching criteria

Participants were matched by case and control and age group.

Study variables

The study variables included participants demographic characteristics (age, sex, education status), whether they were cases or controls.

Sample size

The sample size of 42 953 participants was calculated to answer the meta-analysis component of the genetics study. This sample size is adequately powered to answer the study objectives.

Procedures

The UBACC was translated and back-translated from English into nine languages across four SSA countries and administered to 42 953 participants (March 2018 to December 2022). In Uganda, it was translated into Acholi, Luganda, Lugbara and Runyankole. In Ethiopia, it was translated into Amharic and Afaan Oromo, in Kenya it was translated into Kiswahili and in South Africa it was translated into Afrikaans and isiXhosa. The translation process did not involve extensive cognitive interviews, given that this was beyond the scope of the study.

Trained research assistants administered standardised consent forms in either English or one of the other languages predominantly spoken at the study sites over ~45–60 min. The research assistants informed the potential participants that another instrument would be administered to ascertain whether they had fully understood what participation in the study entailed. Participants who scored 20 on the first attempt were considered to have understood the consent process and would not go through the iterative process; they would be recruited into the study immediately. Participants were informed that in the event that they did not get a score of >14.5 by the fourth attempt, then they would be invited to participate after some days and try

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again. Research assistants were trained to ensure that the iterative process did not seem like an assessment of the participant's intellect.

Potential participants were provided with the consent forms, and would refer to them during the interview process. Research assistants would point out the questions where potential participants had not scored well, and give them an opportunity to answer again. This iterative process was repeated a total of up to three more times. If a participant scored <14.5 at the fourth attempt, then their understanding of the consent process was deemed to be insufficient. The table below shows the UBACC questions and the domain they assess.

UBACC questions and the domains they assess

Question	Domain
1. What is the purpose of the study that was just described to you?	Understanding
2. What makes you want to consider participating in this study?	Reasoning
3. Do you believe this is primarily research or primarily treatment?	Understanding
4. Do you have to be in this study?	Appreciation
5. If you withdraw from the study, will you still receive regular treatment?	Appreciation
6. If you participate in this study, what will you be asked to do?	Appreciation
7. Please describe some of the risks or discomforts that you may experience.	Understanding
8. Please describe some of the possible benefits of this study.	Understanding
9. Is it possible that being in this study will not have any benefit to you?	Appreciation
10. If you agree to be in this study, is it possible that your DNA and health information will be used for other research studies?	Appreciation

Statistical analysis

We conducted a post hoc analysis of the collected data. Socio-demographic variables, including age, sex, marital status and education level, were compared between cases and controls, using t-test for numerical variables and χ^2 for categorical variables. Analysis of variance (ANOVA) was used to compare mean UBACC scores at baseline, attempts 2, 3 and 4. We used repeated-measures ANOVA because the four UBACC assessments were sequential attempts within a single consent process, not independent longitudinal visits. Our goal was to test whether mean scores differed across attempts, not to model individual change. Multivariable linear regression analysis was conducted to determine the predictors of a UBACC score of 20. We used STATA 15.1 for data analysis.

RESULTS

In this section, we report (i) the participant demographic variables comparing them by cases and controls (ii) mean scores of the UBACC at each attempt and (iii) factors that are associated with high scores at attempt 4.

Demographic variables

The majority of participants n=13 000/42,953 (30.27%) were recruited from Ethiopia. The mean age of participants was 36.69 (SD=11.7); there were more males n=24 633/42,953 (57.35%) than females. The number of cases and controls was split almost evenly (21 618 vs 21 335 respectively). Approximately one third of the participants n=12 770/42953 (29.73%) had no formal education, attended some primary school or completed primary school. Amharic was the language used to recruit the majority of participants n=12 499 (29.10%). Almost half of the sample was never married n=19 754 (45.97%). At bivariate analysis, there were statistically significant differences between cases and controls across all the variables apart. Table 1.

UBACC item scores

Item (question) overall scores

At baseline (the first attempt), <50% of the participants provided the correct responses to questions 1, 2, 4, 6, 7, 8. With each attempt, there was an increase in the number of correct responses apart from question 4 which had a negative trend. Question 4 assesses voluntariness/appreciation. After four attempts, up to 20% of participants were still unable to provide correct responses to questions 1, 2, 7 and 8. The domain for these questions included understanding (questions 2, 7 and 8) and reasoning (question 2). The highest increase in correct responses was recorded on question 6 (assesses appreciation of study activities). Figure 1 illustrates the overall scores 1–10 versus attempts 1–4.

Item (question) scores for cases versus controls

At baseline and after the fourth attempt, the cases had lower scores compared with controls (apart from question 4). The highest difference between cases and controls was observed in question 5, which was about whether treatment would be altered. At baseline, there was almost no difference in response to questions 2 and 7 among cases. Figure 2 illustrates the scores 1–10 by (case vs control) at baseline and attempt 4.

UBACC scores

Our results show an increase in UBACC scores from baseline to attempt 4, and statistically significant difference from the prior score to the current score with each attempt in the pooled dataset.

The mean score of the UBACC for the overall sample at baseline was 13.27 (SD=3.5). The mean scores were 16.83 (SD=3.0) at attempt 2, 18.10 (SD=2.2) at attempt 3 and 18.37 (SD=1.6) at attempt 4 (table 2). The mean scores were significantly higher among controls in comparison to cases (table 3).

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Table 1 Demographic variables of the participants and a bivariate analysis

Variables	Cases	Controls	Difference	95% CI	P value
Age, mean (SD)	36.90 (SD=11.6)	36.47 (SD=11.8)	0.43	0.21 to 0.65	<0.001
Sex, n (%)					
Male	12 522 (57.92%)	12 111 (56.77%)	1.16	0.22 to 2.09	0.015
Female	9096 (42.08%)	9224 (43.23%)	−1.16	−0.2 to −0.22	0.015
Education level, n (%)					
None/primary	7438 (34.41%)	5332 (24.99%)	9.41	8.56 to 10.27	<0.001
Secondary or higher	14 180 (65.59%)	16 003 (75.01%)	−9.41	−10.27 to −8.56	<0.001
Marital status, n (%)					
Married	5454 (25.23%)	9143 (42.85%)	−17.63	−18.51 to −16.74	<0.001
Cohabiting	663 (3.07%)	1148 (5.38%)	−2.31	−2.69 to −1.93	<0.001
Widowed	742 (3.43%)	811 (3.80%)	−0.37	−0.72 to −0.02	0.041
Divorced	1322 (6.12%)	827 (3.88%)	2.24	1.83 to 2.65	<0.001
Separated	1957 (9.05%)	1118 (5.24%)	3.81	3.33 to 4.30	<0.001
Never married	11 463 (53.03%)	8283 (38.82%)	14.20	13.27 to 15.13	<0.001

Our findings also showed higher scores in controls than in cases at baseline and at each subsequent attempt.

Multi-variable analysis

The maximum scores at attempt 4 were significantly higher than baseline scores by an average of 1.3 points (−14.98, 95% CI −1.46 to −1.12). See table 4.

Supplementary data

The supplementary data contains country specific mean scores, baseline scores for each item (online supplemental figure 3), overall highest scores for items 1–10 (online supplemental table 1), highest scores by case and control (online supplemental table 2) and highest score by country (online supplemental table 3). The country specific data requires a much deeper analysis, including the comparison by language of administration as well as the study site. This data also requires extensive language validation.

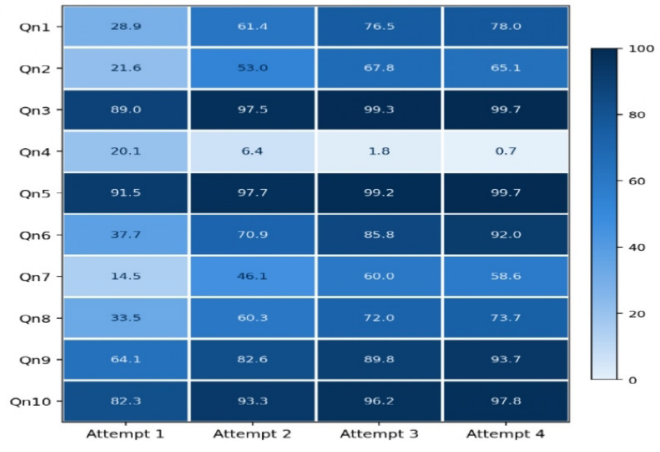

Figure 1 Overall scores of the items 1–10.

DISCUSSION

The main findings of this study were (1) that UBACC scores increased with each administration, (2) that greater education, lower age, being a control and male sex were predictive of scoring 20 on the UBACC.

Overall item scores

With a mean baseline score of 13.27 (<14.5 cut off), our findings indicate that the study participants were not able to fully understand the contents of the consent form at the first attempt— however, the mean scores significantly improved with every attempt. Our findings, supported by previous literature,[14] emphasise that the consent process should not be a one-off event, but an iterative process between research staff and potential participants as a means of understanding the content of the consent form and the overall process before being enrolled. As expected, with such discussion, UBACC scores increase, indicating more fully informed consent. Over and above the understanding of the questions, the possibility of practice effect as an explanation in the increase in scores should be considered; given the fact that the same



Figure 2 UBACC score; questions 1–10 (cases vs controls at baseline and attempt 4).

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Table 2 Mean scores for the overall sample, difference by attempts

Attempt 1	Attempt 2	Difference	95% CI	P value
13.27 (SD=3.5)	16.83 (SD=3.0)	3.56	−3.55 to −3.43	<0.001
Attempt 2	**Attempt 3**	**Difference**	**95% CI**	**P value**
16.83 (SD=3.0)	18.10 (SD=2.2)	1.27	−2.70 to −2.60	<0.001
Attempt 3	**Attempt 4**	**Difference**	**95% CI**	**P value**
18.10 (SD=2.2)	18.37 (SD=1.63)	0.27	−1.83 to −1.76	<0.001

instrument is administered to the same person who gets asked the same question during the iterative process.

Scores by item

The UBACC assesses understanding (questions 1, 3, 7 and 8), appreciation (questions 4–6 and 10) and reasoning (question 2). Our results indicate that overall, participants struggled with questions from each domain, with most participants having difficulty understanding the concept of voluntary participation in a study (question 4). It is possible that the participants simply did not understand the concept of the risk of participating in research—it is also possible that some of the participants were taking part in their first research project. Furthermore, there is a possibility that participants had limited knowledge about the concept of data privacy or data loss. One way of addressing this concern would be to rephrase question 4 about the risk associated with participation in research, and make it culturally and contextually relevant to the SSA setting as a way of spelling out the risks involved in research. It is worth noting that challenges in determining voluntariness may reflect a communal rather than purely individual framing of decision-making across some African settings; best practice therefore may require engaging community-level permission and engagement with individual informed consent, as shown in Kenyan fieldwork and genomics guidance from Human Heredity and Health in Africa (H3Africa).[17–19]

Demographic factors associated with UBACC scores

Age, sex, psychosis condition (cases) and level of education were significantly associated with UBACC scores. These findings are in keeping with previous literature. In South Africa, Campbell *et al*[14] reported statistically significant associations between UBACC scores and a diagnosis of schizophrenia (compared with controls); similarly, findings from two studies that compared individuals with cognitive deficits against controls reported significantly lower UBACC scores among cases.[12 13] The low scores among individuals with psychosis in our study could be a result of the poor cognitive functioning, which has been documented in earlier studies. [20 21]However, given the fact that we did not assess for cognitive deficits, this finding needs to be cautiously explained. More work is needed to examine the reasons for this particular result.

Our findings also show that participants with low levels of functional education had lower mean scores. The association between low UBACC scores and level of education was reported in previous literature by Campbell *et al*.[14] However, other studies have not documented associations between level of education and UBACC scores[12 13]—it is worth noting that these studies[12 13] were conducted in HIC where both functional and mental health literacy levels are higher than those in SSA.[22–25]

Our findings raise the important distinction between formal education and functional understanding in assessing decisional capacity. Evidence from African and international contexts demonstrates that functional literacy, including health literacy, does not consistently correlate with years of schooling and may more accurately predict comprehension in consent processes.[26 27] Functional understanding can diverge sharply from formal education level, particularly among patients with cognitive or catatonic impairments, whose decisional capacity fluctuates dynamically.[28] These findings suggest that beyond education level, functional, iterative and context-sensitive assessments should guide ethical inclusion in psychiatric research.

We found that females were more likely to have lower scores than males. The association between low UBACC scores and female sex needs further scrutiny. There are other plausible explanations that could include education inequalities, socio-demographic factors and site-specific recruitment differences as well as residual confounding.

Table 3 Mean scores for the cases and controls-attempts 1-4

Attempt	Cases	Controls	Difference	95% CI	P value
Attempt 1	12.53 (SD=3.5)	14.01(SD=3.4)	−1.49	−1.56 to −1.43	<0.001
Attempt 2	16.25 (SD=3.2)	17.42 (SD=2.8)	−1.17	−1.23 to −1.11	<0.001
Attempt 3	17.82 (SD=2.3)	18.44 (SD=2.1)	−0.62	−0.67 to −0.57	<0.001
Attempt 4	18.23 (SD=1.7)	18.58(SD=1.6)	−0.35	−0.40 to −0.30	<0.001

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Table 4 Multivariable analyses

Variables	T score	Coefficients	95% CI	P value
Max scores per individual				
Attempt				
2	1.75	0.15	−0.02 to 0.32	0.080
3	−0.11	−0.01	−0.18 to 0.16	0.909
4	−14.98	−1.30	−1.46 to −1.12	<0.001
Case	−16.91	−0.18	−0.20 to −0.16	<0.001
Age at interview	−2.57	−0.001	−0.002 to −0.003	0.010
Male Sex	2.07	0.02	0.001 to 0.04	0.038
Secondary or Higher	29.14	0.35	0.33 to 0.38	<0.001

These explanations will need to be examined further including in country-specific contexts.

Strengths and limitations

A key strength of this study is the large sample size, researched across four different countries. A key limitation is the lack of quantitative and qualitative assessment specifically undertaken to assess how well participants understood the questions and what kind of meaning they attached to them as well as ways of improving some of the aspects of the questions. Another limitation worth considering is the limited rigour in the translation of the instrument across the nine different languages.

CONCLUSION

The finding that a large number of participants had high scores on the UBACC is reassuring in indicating that when consent is undertaken in one's home language, many in SSA are able to provide fully informed consent. The association of socio-demographic variables with high UBACC scores reflects in part ongoing inequities in SSA.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting or dissemination plans of this research.

Patient consent for publication Consent obtained directly from patient(s)

Ethics approval This study involved human participants and was approved by The NeuroGAP–Psychosis study was approved by the Institutional Review Board at Harvard T.H. Chan School of Public Health (#IRB17-0822) in the USA and by the following ethics committees: Addis Ababa University College of Health Sciences (#014/17/Psy) and the Ministry of Science and Technology Ethics Committee (#3.10/14/2018) in Ethiopia; Moi Teaching and Referral Hospital Ethics Committee (#IREC/2016/145), Kenya National Council of Science and Technology (#NACOSTI/P/17/56302/19576), KEMRI Centre Scientific Committee (CSC# KEMRI/CGMRC/CSC/070/2016) and KEMRI Scientific and Ethics Review Unit (SERU#KEMRI/SERU/CGMR-C/070/3575) in Kenya; the University of Cape Town (#466/2016) and Walter Sisulu University (#051/2016) Ethics Committees in South Africa; the Makerere University School of Medicine (SOMREC #REC REF 2016-057) and the Uganda National Council for Science and Technology Ethics Committee (UNCST #HS14ES) in Uganda. Participants gave informed consent to participate in the study before taking part.

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