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Gender differential in inclination to donate brain for research among Nigerians - the IBADAN Brain Bank Project.

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Abstract

Background: Laboratory - based studies of neurological disease patterns and mechanisms are sparse in sub- Saharan Africa. However, availability of human brain tissue resource depends on

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Conflict of Interest: All the authors declare no conflict of interest

Ethical approval: All procedures performed involving human participants in this study were in accordance with the ethical standards of the University of Ibadan/University College Hospital Institutional Review Committee in Ibadan, Nigeria and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent: Informed consent was obtained from all individual participants included in the study.

willingness towards brain donation. This study evaluated the level of willingness among outpatient clinic attendees in a Nigerian teaching hospital.

Methods: Under the auspices of the IBADAN Brain Bank Project, a 43 – item semi - structured interviewer – administered questionnaire was designed to evaluate knowledge, attitude, and beliefs of individuals attending Neurology, Psychiatry and Geriatrics Outpatient clinics regarding willingness to donate brain for research. Association between participants characteristics and willingness towards brain donation was investigated using logistic regression models. Analysis was conducted using Stata SE version 12.0.

Results: A total of 412 participants were interviewed. Their mean age was 46.3 (16.1) years. 229 (55.6%) were females and 92.5% had at least 6 years of formal education. Overall, 109 (26.7%) were willing to donate brains for research. In analyses adjusting for educational status, religion, ethnicity, marital status and family setting, male sex showed independent association with willingness towards brain donation OR (95% C.I) = 1.7 (1.08 – 2.69), p = 0.023. Participants suggested public engagement and education through mass media (including social media) and involvement of religious and community leaders as important interventions to improve awareness and willingness towards brain donation.

Conclusion: The survey revealed low willingness among outpatient clinic attendees to donate brain for research, although men were more inclined to donate. It is imperative to institute public engagement and educational interventions in order to improve consent for brain donation for research.

Keywords

Willingness; Brain donation; Brain banking; Nigeria; Africa; LMIC

1. Introduction

African populations are ageing rapidly in keeping with trends in other low and middle income countries (LMIC). Concomitant with this is a projected increase in the prevalence of ageing – associated cerebrovascular and neurodegenerative disorders. Among the latter, Alzheimer's and Parkinson's diseases are relatively common(Akinyemi *et al.*, 2014; Dotchin *et al.*, 2013; Kalaria *et al.*, 2008).

Post - mortem studies of the human brain are vital components of longitudinal research on ageing and neurodegenerative diseases for providing data to further understanding of prevalence, pattern, and mechanisms of disease.(Allan *et al.*, 2011; Bennett *et al.*, 2006a; Bennett *et al.*, 2006b) They are indeed critical to unravelling associations with risk factors, discovering new treatment and preventative approaches, and exploring unique ethnic/racial neuropathological variations in brain structure and function.(Barnes *et al.*, 2015) However, laboratory – based histopathological and neurochemical studies of brain disorders are sorely lacking in sub-Saharan Africa due to lack of infrastructure, relevant skills and brain tissue resource from declining autopsy rates.'(Akinyemi *et al.*, 2018a; Akinyemi *et al.*, 2018b)

Biobanking is an emerging research field which is critical to personalized medicine.(Hewitt, 2011) With the declining autopsy rates in hospitals, organized brain donation initiatives have

come up as an innovative intervention to ensure supply of brain tissue for relevant research, and they are often components of longitudinal studies.(Kretzschmar, 2009) Success, however, depends on optimal awareness of brain donation, autopsy, diagnostic and research utilization of brain tissue as well as willingness to provide consent among research participants, patients attending clinics for brain disorders and their caregivers, as well as the general public.(Boise *et al.*, 2017b; Jefferson *et al.*, 2011; Jefferson *et al.*, 2013)

In the last three decades, researchers in western countries have explored awareness and willingness towards brain tissue donation among volunteers in longitudinal ageing and dementia research programmes.(Boise *et al.*, 2017a; Boise *et al.*, 2017b; Jefferson *et al.*, 2011; Jefferson *et al.*, 2013) Findings from these studies suggest that educational attainment and culturally-shaped perceptions, attitudes, values and beliefs may influence willingness to participate in longitudinal brain research programmes or be a brain donor. Ethnic/racial backgrounds also often influenced willingness to participate in research and/or enlist as a potential brain donor.(Boise *et al.*, 2017a; Boise *et al.*, 2017b; Lambe *et al.*, 2011)

Biobanking is growing in Africa but organized brain banking is virtually non - existent.[1,] (Akinyemi *et al.*, 2018a) Public understanding of brain biobanking in the context of unique culture, language, and belief systems has never been examined in Africa. The aim of this study was to determine willingness towards brain donation for research purpose among attendees of neuroclinics in an African teaching hospital. We hypothesized that there would be low willingness towards brain donation for research purpose among the study participants.

2. Methodology

2.1. Setting

The IBAdan Dementia, Ageing and Neurodegeneration [IBADAN] Brain Bank Project is a multidisciplinary pilot project that aims to determine awareness and willingness to donate brain for research purpose, establish a pilot brain bank and evaluate the immuno-histochemical features of ageing – associated degenerative and vascular pathologies in brain tissue from a pilot cohort of adult/ older Nigerians.[1] It is funded by the Research and Innovation Management Unit of the College of Medicine, University of Ibadan, Nigeria. (Imam and Akinyemi, 2016)

The current study was undertaken in the Neurology and Psychiatry Clinics as well as the Chief Tony Anenih Geriatric Centre (CTAGC) of the University College Hospital Ibadan (UCH), southwestern Nigeria. UCH is the premier academic teaching hospital in Nigeria that was established 60 years ago. It receives referrals from all over Nigeria and is well established as a center of excellence in Neurosciences, particularly stroke, ageing and dementia research. The CTAGC is the premier purpose built geriatric centre in Nigeria which caters for individuals 60 years and older.

2.2. Sample

Using a cross - sectional study design, four hundred and twelve consenting adults aged 18 – 85 years were recruited from the outpatient clinics of the neurology, psychiatry and

geriatrics departments of the University College Hospital Ibadan, Nigeria. Trained interviewers conducted face-to-face interviews with consenting study participants using a semi-structured questionnaire.

Patients were identified during their routine presentation for follow-up at the respective Geriatrics, Neurology and Psychiatry clinics at the study site. Consenting patients who were adults (>18 years of age); non – demented, mentally stable and capable of participating in discussion were recruited.

2.3. Survey Development

Survey data were collected using a 43 – item interviewer administered semi – structured questionnaire which was categorized into sections including socio-demographic characteristics, awareness of brain disorders, willingness towards brain donation, and facilitators and barriers of brain donation. Questions on sociodemographic characteristics gathered include age, gender, race/ethnicity (Yoruba, Igbo, Hausa or other), marital status (single, married, widowed, separated, divorced), family setting (“monogamous”, “polygamous”) and educational status (no formal education, primary school, some secondary but failed to graduate, secondary school graduate, some university or 2-year degree, 4 -year university graduate or more).

Awareness of brain diseases focused on perception of what brain diseases are and types of brain diseases. The statement ‘do you think brain disease can be cured?’ had responses coded as ‘yes’ or ‘No’. This statement was followed by a probing question requesting open ended responses on ways in which brain diseases can be cured. These responses were later coded.

Respondents’ willingness towards brain donation for research purpose was assessed with a “yes” or “no” response. To highlight reasons for unwillingness towards brain donation, participants responded to the following statements: ‘I cannot donate my brain because of medical reasons”, “this is against my religion”, “I am afraid to donate because it is possible for a brain-dead person to recover from his/her injuries”, “I do not want my body cut up or disfigured”, “I don’t trust the health system”, “I don’t like the thought of it as such thoughts increase the chances of death”, “never thought about it”, “I want my body maintained whole as my parents gave birth to me”. Participants also responded to questions on why they were willing to consent to brain donation : “I think that after I die, I do not need my organs anymore”, “I like the idea that after I die, the findings from the examination of my brain can save someone’s life”, “I think if I die, my family would find solace in the idea that results of examination on my brain examination is helping someone else live”, and any other reasons.

The questionnaire was developed, revised, reviewed and presented to study investigators for their comments and grammatical edits. This was subjected to another level of validation by experts in neurology, neurosurgery, pathology, mixed methods research who advised the team on arrangement, flow and presentation of questions to enhance eliciting responses from various cohorts.

After the survey instrument was finalized in English, it was translated into Yoruba language by a bi -lingual professional translator who worked in a community-based research support organization. Back translation was provided by a second bi-lingual professional translator at the same translation service. Discrepancies between the English version and the back translated version were reviewed and reconciled by an independent reviewer. The draft questionnaire was pretested among ten research subjects from a different patient population within the University College Hospital, Ibadan. Findings and comments from the pre-test were used to refine the questionnaire to ensure language appropriateness, coherence, clarity and reduction of completion time.

Ethical consideration—All procedures for data collection and analysis for the questionnaire survey phase of the project were reviewed and approved by the University of Ibadan/University College Hospital Institutional Review Committee in Ibadan, Nigeria and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in the study.

Data collection procedures—Prior to commencement of data collection, a team comprising of eight field staff and volunteers were trained by experts from the Faculty of Public Health of the University of Ibadan on the requisite skills for collecting data using the semi-structured questionnaire and informed consent process.

Data collection commenced in the second week of June 2017 and lasted for a period of three weeks. The information was collected by the trained interviewers from qualified and consenting participant by 8am on Mondays, Tuesdays, Thursdays and Fridays in a week at the Psychiatry, Neurology and Geriatric clinics respectively..

Data analysis procedure—Data from the completed copies of the questionnaire were entered and analyzed using the Stata SE version 12.0. Categorical variables were summarized using frequencies and percentages while mean (SD) was computed for continuous variables. Association between categorical variables and willingness towards brain donation was investigated using the Chi square test. Logistic regression models were fitted to estimated unadjusted and adjusted Odds Ratio (with their 95% Confidence Interval) for factors associated with willingness towards brain donation and adjusting for educational status, religion, ethnicity, marital status and family setting.

Results

A total of 412 participants completed the questionnaire survey of which there were 183 males (44.4%). Their mean age was 46.3 9 (SD=16.1) years (Table 1). Thirty-one (7.5%) had no formal education while 50.2% attained tertiary education. The commonest religious affiliation and ethnic group were Christianity (70.6%) and Yoruba (92.7%) respectively. Majority were married (64.6%) and monogamy (79.1%) was the predominant form of marriage.

Three hundred and fifty-nine participants (87.1%) were aware of brain disease (Table 2). Among these, response to question on their perception about brain disease included: madness (13.3%), mental disorder (24.8%), brain malfunction (21.1%) and abnormality (21.1%). When asked about how they would approach the management of brain disease, medical treatment (66.0%) was the commonest response. Others were: spiritual intervention (20.1%) traditional healers (6.2%), psychiatrist attention (2.4%) and psychologist attention (4.1%).

Overall, 109 (26.7%) of respondents were willing to donate brains for research purpose. Table 3 shows the association between socio-demographic characteristics and willingness towards brain donation. There was no difference in the mean age of those willing (mean= 46.1years) and not willing (46.4 years). Males (33.5%) were significantly more willing to donate brains than females (21.2%). Similarly, the proportion of those willing to donate increased progressively with higher educational attainment, although this failed to attain statistical significance. Willingness to donate brains did not vary across religious grouping, ethnicity and marital status. In contrast, participants from monogamous families were 1.9 times (OR= 1.91, CI: 1.04–3.49) more willing to donate brains than participants from polygamous settings. Awareness of brain disease was not associated with willingness towards brain donation. Multivariable logistic regression revealed that male sex (OR=1.70, CI: 1.08–2.69) was the main independent predictor of willingness to donate brains.

Table 4 summarizes the reasons for willingness (or lack of) towards brain donation for research purpose. The commonest reason for lack of willingness was that participants did not want their bodies disfigured after death (43.5%) while 39.4% never thought about it. The most common reason for willingness to donate brains was a respondent’s knowledge that research done with his/her brain after death could help save lives (73.4%).

Participants were further asked about suggestions on how to promote brain donation. Suggestions provided were: mass media publicity (302, 73.8%), educational programmes (258, 63.1%), involvement of religious and community leaders (196, 47.5%), social media (151, 36.9%) and legislation (47,11.5%).

Discussion

This study which was aimed at investigating the barriers and facilitators of willingness to donate brain among Africans found that well over a quarter of participants were willing to donate brains with men having two-times the odds of willingness to donate brains. Participants in this study suggested public engagement using mass media and inclusion of religious and community leaders in these programmes as important interventions to improve inclination towards brain donation. Respondents who were willing to donate brain for research gave such reasons as the fact that they don’t need the brain or other organs after death, research done using their brains might contribute to medical progress and saving others and that their families would love the idea that they donated brain for research. Barriers to brain donation identified by the respondents include fear of body disfigurement from autopsy, mistrust of the health system, religious belief, and belief that a brain – dead person might recover.

A high level of awareness about brain diseases was expected in this study sample given the fact that a very good proportion was recruited from neuroclinics. The varying perceptions expressed regarding brain diseases however could be due to the differing levels of education, and the religious and cultural perspectives held by respondents regarding the sort of conditions on account of which the respective clinics were visited. Indeed, cultural beliefs and practices particularly influence the approach to the diagnosis and management of brain disorders in sub- Saharan African climes.(Adekson, 2016; Osuntokun, 1975) These factors also influenced the suggested approaches to the treatment of brain disorders wherein spiritual treatment was suggested following medical treatment. Respondents also suggested the involvement of community and religious leaders as measures to improve awareness towards brain donation. The strong influence of religious beliefs on the perceived causation of illnesses, health choices and practices have been variously explored in diverse settings among indigenous Africans(Hurst *et al.*, 2015; Jenkins *et al.*, 2016), African Americans(Jefferson *et al.*, 2011; Lambe *et al.*, 2011) and Caucasians(Jefferson *et al.*, 2011).

Only about one third of respondents in this study indicated willingness to donate brains for research purposes despite the claims of high level of awareness of brain disorders. Willingness to donate was recorded in less than 50% of elderly African Americans whereas 75% of elderly Caucasians consented in a previous study(Jefferson *et al.*, 2011) Although we have specifically explored ethnicity in this current study, evidence from literature suggest that minority populations of African ancestry tend to exhibit lower willingness towards brain donation compared to their Caucasian counterpart.(Boise *et al.*, 2017b; Jefferson *et al.*, 2013; Lambe *et al.*, 2011)

Understanding that the brain and other body organs are no more needed after death and appreciation of the need for contribution to research in order to facilitate new discoveries and medical progress have been identified as key facilitators of willingness to donate brain for research in previous studies.(Jefferson *et al.*, 2013; Lambe *et al.*, 2011; Oluwasola *et al.*, 2009) This is usually a key message of brain donation enlistment programmes when volunteers join longitudinal research projects or during public engagement programmes related to such researches.(Arulogun *et al.*, 2016)

Fear of disfigurement has been identified in several studies as a barrier to donation of brain and other organs.(Lambe *et al.*, 2011; Oluwasola *et al.*, 2009) It has its foundations in cultural and religious beliefs and practices that a deceased's body needs to be kept 'whole' in order to enable him function well in the after life, upon re-incarnation or because of religious demands.(Boise *et al.*, 2017a; Boise *et al.*, 2017b) A similar reason was found as a barrier to autopsy among Nigerian patients and caregivers in a previous study.(Oluwasola *et al.*, 2009) On the other hand, mistrust of the health system could be a reaction to perceived wrongs suffered in the past(Lambe *et al.*, 2011) or an expression of dissatisfaction of quality of healthcare received by the deceased person while alive.

Educational programmes using the traditional media have been used with success to enlighten the public and patient populations and raise awareness about health issues including the benefit of participating in research involving donation of biological materials in life or death.(Akinyemi *et al.*, 2018a; Jefferson *et al.*, 2013; Jenkins *et al.*, 2016; Moodley

and Singh, 2016) Engaging community and religious leaders has also been an effective strategy in enhancing research participation and dealing with issues unique to specific populations with peculiar beliefs and practices.(Wells *et al.*, 2004; Wight *et al.*, 2016) This strategy, in particular, has been useful in engaging minority population such as African Americans in the United States.(Jefferson *et al.*, 2013) Social media, mobile telephony and other emerging mHealth platforms(Sarfo *et al.*, 2016) are particularly useful approaches for reaching the younger generation, and will be strategic for the future of neurobiobanking initiatives.[27]

Strengths, Limitations and Future Directions

This study, to the best of our knowledge, represents the first attempt to study willingness towards brain donation for neurobiobanking in Nigeria with implications for other low and medium income countries (LMICs).[27] The study process provided an opportunity to engage potential brain donors for the Ibadan Brain Bank Project. Individuals attending neuroclinics were studied, hence the findings may not be generalizable to the general population with non-neurological conditions or disorders. This could have potential implications for the accrual of control brains in a neurobiobank, but hopefully public engagement programmes suggested by the study participants could also enhance awareness and inclination towards brain donations in the general population without neurological morbidities. Nevertheless, findings from this study offer unique insight into the barriers and facilitators of willingness towards brain donation and provides strategies for developing intervention strategies to educate and engage potential brain donors to enlist in programmes for establishing neurobiobanks in sub- Saharan Africa.

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Table 1:

Sociodemographic characteristics of study participants (N= 412)

Variable	Total: 412(100%)	Male: 183(44.4%)	Female: 229(55.6%)	p-value
Age				
Mean age (years): mean(sd)	46.3 (16.1)	44.3 (16.8)	48.0 (15.4)	**0.0195***
Education				
No formal education	31 (7.5)	5 (2.7)	26 (11.4)	
Primary	71 (17.2)	29 (15.9)	42 (18.3)	
Secondary	103 (25.0)	47 (25.7)	56 (24.5)	**<0.001***
Some tertiary	85 (20.6)	31 (16.9)	54 (23.6)	
Graduate or more	122 (29.6)	71 (38.8)	51 (22.3)	
Religion				
Christianity	291 (70.6)	122 (66.7)	169 (73.8)	
Islam and others	121 (29.4)	61 (33.3)	60 (26.2)	0.114
Ethnic group				
Yoruba	382 (92.7)	169 (92.4)	213 (93.0)	
Non-Yoruba	30 (7.3)	14 (7.6)	16 (7.0)	0.066
Marital status				
Single	107 (26.0)	64 (35.0)	43 (18.8)	
Married	266 (64.6)	114 (62.3)	152 (66.4)	**<0.001***
Widowed/separated/divorced	39 (9.4)	5 (2.7)	34 (14.9)	
Family setting				
Monogamous	326 (79.1)	157 (85.8)	169 (73.8)	
Polgygamous	86 (20.9)	26 (14.2)	60 (26.2)	0.858

Table 2:

Awareness, perception and knowledge of brain disease

Item	Total: 412(100%)	Male: 183(44.4%)	Female: 229(55.6%)	p - value
Aware of brain disease	359 (87.1)	161 (88.0)	198 (86.5)	0.648
Perception about about brain disease **				
Madness	53(13.3)	21 (13.5)	32 (17.3)	0.452
Mental disorder	99 (24.8)	46 (29.7)	53 (28.6)	0.638
Brain malfunction	84 (21.1)	45 (29.0)	39 (21.1)	0.058
Neurological disorder	6 (1.5)	5 (3.2)	1 (0.5)	0.093^{f}
Loss of memory	8 (2.0)	8 (5.2)	0 (0.0)	**0.001***^{f}
Mental retardness	7 (1.8)	3 (1.9)	4 (2.2)	1.000
Brain damage	10 (2.25)	4 (2.6)	6 (3.2)	1.000
Abnormality	84 (21.1)	30 (19.4)	54 (29.2)	0.072
Disease in the brain	22 (5.5)	10 (6.5)	12 (6.5)	0.919
Others	26 (6.5)	13 (8.4)	13 (7.0)	0.554
Approach to management of brain diseases				
Medical treatment	309 (66.0)	134 (63.8)	175 (67.8)	0.457
Spiritual intervention	94 (20.1)	44 (21.0)	50 (19.4)	0.595
Traditional healers	29 (6.2)	9 (4.3)	20 (7.8)	0.104
Psychiatrist attention	11 (2.4)	9 (4.3)	2 (0.8)	**0.027***^{f}
Psychologist attention	5 (1.1)	3 (1.4)	2 (0.8)	0.663^{f}
Care from relations	19 (4.1)	11 (5.2)	8 (3.1)	0.346^{f}

** Multiple response items

^{f}: Fisher Exact test

Table 3:

Association between socio-demographic characteristics and willingness towards brain donation

			Unadjusted			Adjusted		
Variable	**Yes**	**No**	**OR**	**95% Cl**	**P-value**	**OR**	**95% Cl**	**p-value**
Age (years): mean (SD)	46.1 (16.5)	46.4 (16.1)	0.99	0.98–1.01	0.895			
Sex								
Male	61 (33.5)	121 (66.5)	1.88	1.21–2.93*	**0.005***	1.7	1.08–2.69	**0.023***
Female	48 (21.2)	179 (78.8)	1.00			1.00		
Education								
No formal education	4 (13.3)	26 (86.7)	1.00			1.00		
Primary	17 (23.9)	54 (76.1)	2.05	0.63–6.69	0.236	1.65	0.49–5.49	0.415
Secondary	28 (27.5)	74 (72.6)	2.46	0.79–7.68	0.121	1.84	0.58–5.90	0.303
Some tertiary	23 (27.1)	62 (72.9)	2.41	0.76–7.66	0.136	1.88	0.58–6.09	0.294
Graduate or more	37 (30.6)	84 (69.4)	2.86	0.93–8.79	0.066	1.89	0.59–6.06	0.282
Religion								
Christianity	79 (27.4)	209 (72.6)	1.15	0.70–1.87	0.582			
Islam and others	30 (24.8)	91 (75.2)	1.00					
Ethnic group								
Yoruba	102 (26.9)	277 (73.1)	1.21	0.51–2.91	0.67			
Non-Yoruba	7 (23.3)	23 (76.7)	1.00					
Marital status								
Single	32 (29.9)	75 (70.1)	1.00					
Married	68 (25.8)	196 (74.2)	081	0.49–1.34	0.415			
Widowed/separated/divorced	9 (23.7)	29 (76.3)	0.73	0.31–1.71	0.465			
Family setting								
Monogamous	94 (29.0)	230 (71.0)	1.91	1.04–3.49	**0.037***	1.62	0.86–3.04	0.137
Polygamous	15 (17.7)	70 (82.4)	1.00			1.00		
Awareness of brain disease	99 (27.7)	258 (72.3)	1.61	0.78–3.34	0.199			

Table 4:

Reasons for willingness (or lack of) towards brain donation for research purpose

Reasons	Total: n(%)	Male: n(%)	Female: n(%)	p - value
Lack of willingness to donate brain (n=300) [++]				
Medical reasons	13 (5.1)	7 (7.5)	6 (3.8)	0.312
Religion	35 (13.8)	11 (11.7)	24 (15.1)	0.254
Afraid because brain-dead person can recover	17 (6.7)	9 (9.6)	8 (5.0)	0.276
Don't want body disfigured	110 (43.5)	40 (42.6)	70 (44.0)	0.288
Don't trust medical system	24 (9.5)	11 (11.7)	13 (8.2)	0.567
Thoughts about higher chances of death	34 (13.4)	14 (14.9)	20 (12.6)	0.915
Never thought about it	100 (39.4)	38 (40.4)	62 (38.8)	0.56
1 want my body whole	34 (13.9)	12 (13.2)	22 (14.4)	0.525
Reason for willingness to donate brain (n=109) [++]				
I don't need it after death	60 (61.9)	36 (65.5)	24 (57.1)	0.348
Findings from my brain examination can safe a life	80 (82.5)	43 (78.2)	37 (88.1)	0.439
My family will be pleased that examination of my brain safe life	33 (34.7)	25 (46.3)	8 (19.5)	**0.006***

[++]Multiple response items

Table 5:

Suggestions to promote willingness to donate brain for research purpose (n=409)[++]

Suggestion	Total: n(%)	Male: n(%)	Female: n(%)	p - value
Media publicity	302 (73.8)	144 (79.1)	158 (69.6)	0.131
Education	258 (63.1)	128 (70.3)	130 (57.3)	**0.028***
Legislation	47 (11.5)	24 (13.2)	23 (10.1)	0.417
Involve religious and community leaders	196 (47.9)	92 (50.6)	104 (45.8)	0.578
Educate people on social media	151 (36.9)	83 (45.6)	68 (30.0)	**0.003***

[++]Multiple responses