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# Egyptian students' guardians knowledge, attitude and predictors of negative attitude of epilepsy in Assiut city



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#### **KEYWORDS**

Knowledge; Attitude; Epilepsy; Students' guardians; Predictors; Egypt **Abstract** *Background:* Epilepsy is very prevalent in Egypt, approaching 6.98 per 1000 population. This study was designed to assess the knowledge and attitudes towards epilepsy among guardians of Egyptian high school students.

*Methods*: A cross-sectional study was made among guardians (parents/guardians) of high school students in Assiut city, Egypt. A 15-item questionnaire was self-administered by 1257 students' guardians who were randomly selected.

Results: All recruited parents/guardians of high school students had heard about epilepsy. Families with a patient with epilepsy (PWE) had significantly better information about epilepsy and its aetiology than other families. The predictors of negative attitudes towards PWE were: age group ranging from 40 to 49 years, no work, skilled work, male sex and incorrect knowledge.

Conclusion: Having a patient with epilepsy is a predictor to having greater knowledge and a better attitude towards epilepsy. However, people still have a concept that PWE are stigmatized and are different from others. Raising awareness about epilepsy and its aetiology will increase the knowledge and improve the attitudes towards PWE. © 2013 Ministry of Health, Saudi Arabia. Published by Elsevier Ltd. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).

#### 1. Introduction

Seizures result from a sudden and recurrent excessive disordered discharge of cerebral neurons. They

are unpredictable, uncontrollable, and distressful to the sufferer, and thus arouse fear [1]. Epilepsy is the most serious, highly stigmatizing condition and a prevalent non-communicable neurological disorder [2,3]. Its prevalence worldwide ranges between 2 and 10 per 1000, with considerable variation between different countries [4—6]. In Egypt, the prevalence was estimated to be 6.98/1000 [7].

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The perception of this condition in the world varies depending on the regions and the cultures of the people studied [8]. Several studies have shown the influence of culture and the people's lifestyle on their attitudes and practices with respect to epilepsy in developed countries [8—11].

Stigma is a major factor associated with the burden of patients with epilepsy [12]. For many patients, the fear of stigma makes them keep their disorder a secret. They refrain from discussing it openly and try to minimize their difficulties. Such people seek treatment from traditional healers or faith healers [13].

The aim of this study is to assess the knowledge and attitude of guardians of the Egyptian high school students (families with or without a student with epilepsy) towards epilepsy and patients with epilepsy.

### 2. Methodology

Prior to this study, a formal approval to implement the study was taken from the local representatives of the Ministry of Education at Assiut city and the ethics committee of the faculty of medicine, Assiut University, Egypt. Written consent was obtained from all participants. No incentives were given for the study participants. Confidentiality of data was preserved throughout the study period.

#### 2.1. Studied area

This cross-sectional study was carried out to analyze the knowledge of and attitude about epilepsy among Assiut city students' guardians in selected secondary schools. Assiut city is the largest town in Upper Egypt and lies about 375 miles South of Cairo.

### 2.2. Participants

The surveyed participants comprised of 1257 guardians (parents/responsible person). The data were collected from the guardians of students attending secondary schools in Assiut city. Visits were made to all 24 secondary schools in Assiut city, including 14 government schools, 7 private schools and 3 vocational schools; 50% of all students in the selected school year were included by using the systematic random sampling technique. The study was conducted during the school year 2011–2012. The choice of guardians of secondary school students as a representative sample of the populations was made for two reasons: first, for the direct responsibility and experience of the students' guardians in dealing with adults and

children. Second, this sample is controllable and is a responsible group with a good chance that the questionnaires will be returned, which in turn ensures a high response rate. The inclusion criteria for the respondents were: (1) age is 30 years old or more; (2) should be able to understand, read, speak or write in the Arabic language; and (3) capable to answer the questions in written form. An information sheet about the study was distributed to the respondents for clarification about the aim of the study. A signed written consent was taken from the participants.

### 2.3. Survey methods

The questionnaire was sent to the guardians (parents/persons who are taking care of the students) in addition to the written consent. The purpose of the study was explained by one of the investigators (the authors and three well-trained data collectors) to the guardians at the parent meeting in school. Teachers were responsible for collecting the completed questionnaires on the second day, in addition to reminding students who forgot to bring it back within two weeks. The guardians who refused to participate were revisited by one of the data collectors to convince them to participate in order to get a higher achievable sample size.

### 2.4. Questionnaire

A 15-item questionnaire in the Arabic language was used. Data were collected by a simplified structured self-administered questionnaire that was pilot tested. The pilot study was carried out among 100 clerics and workers at the Assiut University hospital. They were chosen randomly from different educational levels among the employees and workers of both sexes. Its aim was to assess the questionnaire and to identify the difficulties in understanding the questions which may arise and how to deal with them. The required changes were minimal because the questionnaire was translated from other studies and was tested before. Only a few changes were required, such as wording modifications and the rearrangement of the order of the questions to be more easily understood by all educational levels.

It was thought that a self-administered questionnaire would offer participants greater freedom to express their knowledge and attitudes when compared with a personal interview approach [14]. A standardized Arabic questionnaire had been adapted from previous studies [15,16] in Egypt, as well as other studies conducted in Malaysia [17],

Vietnam [18], Jordan [19], United Arab Emirates [20], Kuwait [21], Hong Kong [22], North Batibo Health District and South-West region-Cameroon [2,23], and Turkey [24].

The study questionnaire (appendix 1) consists of 15 items divided into four categories. The first part included questions about some demographic data such as age, sex and occupation. The second part included general information about an epileptic person in the home, such as: Does he/she take regular treatment? How was this person with epilepsy diagnosed? And, what is the effect of the presence of an epileptic patient among the family? The third part was designed to assess the knowledge about epilepsy such as: Do you think that epilepsy is a contagious disease or a psychiatric illness? And, what do you think about the aetiology of epilepsy and giving ten options to choose from, such as genetic, high grade fever or God's punishment. Correct knowledge about epilepsy would be considered if the answer was brain disease, genetic, head trauma, result of drugs, fever, more than one correct response or any reasonable answers such as brain tumour, or infections (Table 3). Incorrect answers were considered when the answer about the aetiology of epilepsy was described as God's punishment, evil spirits, a form of insanity, as a result of depression and anxiety, contagious, psychiatric, a form of mental retardation, a nontreatable illness or unknown.

The final section was designed to assess the perception of epilepsy as a social stigma which consisted of eight questions. The respondents' answers were categorized as yes, no or I do not know. Respondents were required to answer the question or choose the answer from a list provided. Negative attitudes were considered as: refusal to marry a PWE; if married, he/she should not have children; a PWE was unable to think; a PWE cannot judge well; and cannot drive a car; refusal to have a friendship with a PWE; refusal to employ a PWE; and will not go away with a PWE. The significant predictors were age, sex, occupational status. Positive attitudes were considered as opposite to these previous negative attitudes.

### 2.5. Statistical analysis

Data were recorded in a questionnaire and data entry was performed using the Excel program. Descriptive statistics (mean, SD, and percentages) were calculated using the SPSS software package for windows, version 16. Frequencies were noted and associations were determined using the Pearson Chi-Square test (X2 test) to examine the association between responses of families with a PWE

and other families without a PWE in a univariate analysis. Results were analyzed using independent-sample T test that did not assume equal variances. The Pearson correlation coefficient was used to examine the impact of correct knowledge about epilepsy on positive attitude towards a PWE. Significance level was set at  $p \leqslant 0.05$ . Multinomial Logistic Regression was performed to analyze predictors for negative attitudes.

### 3. Results

### 3.1. Demographics and characteristics of the students' guardians

Out of 2500 questionnaires distributed, 1257 were satisfactorily completed with a response rate of 51.56%. Families who had a PWE represented 32 out of 1289 (2.48%). Demographic details of the two studied groups are summarized in Table 1. Occupations were classified into: not working (including housewives), skilled workers (including workers, farmers or drivers) and professionals (doctors, teachers or engineers). Thirty-two families (2.5%) had at least one family member with epilepsy. Their medical and burden of disease data are presented in Table 2.

### 3.2. Awareness and knowledge about epilepsy among students' guardians

All students' guardians (families with a PWE and families without a PWE) were aware of epilepsy. There was significantly more knowledge about epilepsy among families with a PWE (Table 3). It was surprising that the wrong way of thinking about the aetiology of epilepsy as God's punishment is higher among families with a PWE than families without a PWE (15.6%; 3%, respectively).

### 3.3. Attitude towards epilepsy among populations

There were five attitude aspects that were significantly better among parents/guardians of a PWE than families without as shown in Table 4. These attitudes were acceptance of their kids marrying, playing, befriending, working or going outside and being seen with a PWE.

### 3.4. Independent predictors of negative attitudes

To detect the predictors for negative attitude towards a PWE, multinomial logistic regression was done as shown in Table 5. The significant predictors

| Criteria                          | Families without PWE | Families with PWE | P value |
|-----------------------------------|----------------------|-------------------|---------|
|                                   | N = 1257             | N = 32            |         |
| Age (mean ± SD)                   | 49.13 ± 6.32         | 46.062 ± 4.74     | 0.005   |
| Gender                            |                      |                   |         |
| Males                             | 697(96.7%)           | 24(3.3%)          | 0.030   |
| Females                           | 560(98.6%)           | 8(1.4%)           |         |
| Occupational categories           |                      |                   |         |
| Non workers (include house wives) | 709(98.9%)           | 8(1.1%)           | 0.001   |
| Skilled workers                   | 136(94.4%)           | 8(5.6%)           |         |
| Professional workers              | 412(96.3%)           | 16(3.7%)          |         |

| Criteria                       | Total (32) |
|--------------------------------|------------|
|                                | N(%)       |
| PWE receives regular treatment | 29(90.6%)  |
| Method of diagnosis            |            |
| Doctor                         | 7(21.9%)   |
| Doctor and EEG                 | 7(21.9%)   |
| Doctor, EEG and CT             | 18(56.2%)  |
| Its burden on families         |            |
| Psychic burden                 | 7(21.9%)   |
| Economic burden                | 2(6.2%)    |
| Both                           | 23(71.9%)  |

for negative attitude were guardian age from 40 to 90 years, not working, skilled jobs as workers or farmers, and male sex.

### 3.5. Impact of knowledge about epilepsy upon attitude towards PWE

To examine the impact of incorrect knowledge about epilepsy on negative attitude of population towards a PWE, a score of one was made for the incorrect knowledge and a score of zero for the correct answer. The incorrect knowledge about epilepsy was: epilepsy is contagious or a non-treatable illness and the aetiology of epilepsy is evil spirits, or a punishment from God. A good attitude answer was given a score of one and a score of zero was given for a negative attitude answer. So, every student's guardian had a summation for all his/her answers. Pearson correlation coefficients test was performed between the two scores of the incorrect knowledge and attitude. There were significant negative correlations between incorrect knowl-

edge and thinking that a PWE can think and judge well (r = -0.086, P = 0.002), accept your son or daughter playing with a PWE (r = -0.055, P = 0.049), accept to have a friendship with a PWE) r = -0.099, P = 0.000, accept working with a PWE (r = -0.088, P = 0.002) and accept going away and being seen with a PWE (r = -0.062, P = 0.027).

### 3.6. Comparison of the study results with other studies

Table 6 compares some incorrect knowledge and negative attitude towards a PWE in Egypt and other countries.

### 4. Discussion

The main objectives of this study were to assess the level of knowledge about epilepsy and to determine the predictors of negative attitudes towards a PWE among the students' guardians in Assiut city in

| Questions                                 | Families without PWE | Families with PWE | Pearson Chi-Square |  |
|---|----------------------|-------------------|--------------------|--|
|   | N(1257)              | N(32)             |                    |  |
| Have you heard or read about epilepsy     | 1257 (100%)          | 32(100%)          | NC                 |  |
| Do you think that epilepsy is:            |                      |                   |                    |  |
| Contagious                                | 5(0.4%)              | 0                 | 0.008*             |  |
| Psychiatric                               | 355(28.2%)           | 13(40.6%)         |                    |  |
| A form of mental retardation              | 44(3.5%)             | 4(12.5%)          |                    |  |
| Non-treatable illness                     | 25(2.0%)             | 2(6.2%)           |                    |  |
| Blood disease                             | 8(0.6%)              | 0                 |                    |  |
| Unknown                                   | 789(6.2.8%)          | 11(34.4%)         |                    |  |
| More than one answer                      | 31(2.5%)             | 2(6.2%)           |                    |  |
| Do you think that the aetiology of epilep | sy is                |                   |                    |  |
| Genetic                                   | 73(12.2%)            | 1(3.1%)           | 0.001*             |  |
| Evil spirits                              | 10(1.7%)             | 0                 |                    |  |
| A form of insanity                        | 6(1.0%)              | 0                 |                    |  |
| As result of depression and anxiety       | 189(31.5%)           | 8(25.0%)          |                    |  |
| As a result of fever                      | 18(3.0%)             | 0                 |                    |  |
| As result of drugs                        | 6(1.0%)              | 1(3.1%)           |                    |  |
| As God punishment                         | 18(3.0%)             | 5(15.6%)          |                    |  |
| As result of head trauma                  | 36(6.0%)             | 1(3.1%)           |                    |  |
| More than one correct response            | 36(6.0%              | 2(6.2%)           |                    |  |
| Unknown                                   | 119(19.8%)           | 10(31.2%)         |                    |  |

Values under the question columns represent number and percentages of participants with a ''yes'' response to the question; Pearson Chi-Square represents *p* value. PWE; people with epilepsy. More than one correct answer include (genetic, fever, drugs or head trauma).

<sup>\*</sup> The significance is not a true biological significance due to low prevalence of families with PWE and very small subdivision under this category with cells less than 5.

| Questions   | Families<br>without PWE | Families<br>with PWE | Pearson<br>Chi-Square |  |
|---|-------------------------|----------------------|-----------------------|--|
|   | N(1257)                 | N(32)                |                       |  |
| Do you think that PWE should not marry?                   | 303(24.1%)              | 7(21.9%)             | 0.232                 |  |
| Do you think that PWE if marry, should not have children? | 288(22.9%)              | 8(25.0%)             | 0.178                 |  |
| Do you think that PWE can think and judge well?           | 399(31.7%)              | 18(56.2%)            | 0.178                 |  |
| Do you think that PWE can drive a car?                    | 165(13.1%)              | 6(18.8%)             | .075                  |  |
| Do you accept that your son/daughter can marry a PWE?     | 121(9.6%)               | 8(25.0%)             | 0.010                 |  |
| Do you accept your son or daughter to play with a PWE?    | 280(22.3%)              | 14(43.8%)            | 0.015                 |  |
| Do you accept to have a friendship with a PWE?            | 353(28.1%)              | 18(56.2%)            | 0.000                 |  |
| Do you accept to work with PWE?                           | 340(27.0%)              | 16(50.0%)            | 0.002                 |  |
| Do you accept to go away and to be seen with a PWE?       | 306(24.3%)              | 14(43.8%)            | 0.042                 |  |

as numbers (percentage). Statistical significance at P < .05 using Pearson Chi-Square; PWE: person with epilepsy.

Upper Egypt. The knowledge of and attitude towards epilepsy vary in different countries and in different studied groups as shown in Table 6. In this study, the results of this study were compared with those studies conducted in Egypt [15,16] and other countries [2,8,15,16,18–20,23,25–27]. The results revealed that 100% of the respondents had heard or read about epilepsy in Egypt. The general knowl-

edge and awareness about epilepsy showed by this study were more commonly believed to be caused by psychiatric illness, a form of professional retardation, non-treatable illness or blood disease among those families with a PWE or those without; both groups have no clear idea about epilepsy aetiology. In comparison with previous studies [15,16] in Egypt, one of the incorrect answers about

|  | S              | OR    | 95% CI |       |  |
|--|----------------|-------|--------|-------|--|
|  |                |       | Lower  | Upper |  |
| Thinking that PWE should not marry     |                |       |        |       |  |
| Age group ranged 40-49 years           | 0.047          | 1.44  | 0.72   | 2.867 |  |
| Not working                            | 0.037          | 0.599 | 0.371  | 0.969 |  |
| Skilled workers                        | 0.021          | 0.561 | 0.344  | 0.916 |  |
| PWE if marry should not have children  |                |       |        |       |  |
| Not working                            | 0.024          | 0.575 | 0.305  | 0.929 |  |
| Skilled workers                        | 0.006          | 0.501 | 0.501  | 0.822 |  |
| PWE cannot think and judge well        |                |       |        |       |  |
| Skilled workers                        | 0.000          | 0.284 | 0.165  | 0.489 |  |
| Male sex                               | 0.000          | 0.447 | 0.295  | 0.676 |  |
| Refuse that your son/daughter can mar  | ry a PWE       |       |        |       |  |
| Not working                            | 0.002          | 0.504 | 0.326  | 0.778 |  |
| Male sex                               | 0.008          | 0.571 | 0.377  | 0.863 |  |
| Refuse that your son or daughter can p | lay with a PWE |       |        |       |  |
| Not working                            | 0.000          | 0.388 | 0.242  | 0.621 |  |
| Skilled workers                        | 0.001          | 0.411 | 0.238  | 0.710 |  |
| Male sex                               | 0.001          | 0.494 | 0.328  | 0.743 |  |
| Refused to have a friendship with a PW | /E             |       |        |       |  |
| Skilled workers                        | 0.007          | 0.477 | 0.279  | 0.814 |  |
| Male sex                               | 0.031          | 0.601 | 0.402  | 0.899 |  |
| Refuse to work with a PWE              |                |       |        |       |  |
| Not working                            | 0.008          | 0.530 | 0.331  | 0.850 |  |
| Skilled work                           | 0.004          | 0.447 | 0.259  | 0.722 |  |
| Male sex                               | 0.004          | 0.544 | 0.359  | 0.824 |  |
| Refuse to go outside and to be seen wi | th a PWE       |       |        |       |  |
| Skilled work                           | 0.005          | 0.468 | 0.276  | 0.793 |  |
| Male sex                               | 0.009          | 0.581 | 0.387  | 0.873 |  |

| Study/year                     | Study population                     | Epilepsy is contagious | MR   | Accept you or<br>your son or<br>daughter to<br>marry PWE | Accept<br>friendship<br>with PWE | Accept to<br>work with<br>PWE |
|--------------------------------|--------------------------------------|------------------------|------|--|----------------------------------|-------------------------------|
| Egypt 2012 (recent study)      | Population                           | 0.4                    | 3.7  | 10   | 28.8                             | 27.6                          |
| Egypt 2010 [15]                | Teachers                             | 1.6                    |      | NA   | NA                               | NA                            |
| Egypt 2011 [15]                | Students                             | 0.9                    | 4.8  | 8.1  | 31.1                             | 30.2                          |
| Italy 2010 [25]                | Population                           | 25.5(as viral)         | 56.1 | 53.8   | 61.3                             |                               |
| Cameroon 2009 [23]             | Population Batibo<br>health district | 32.7                   | 20.1 | 24.2   | 57.3                             | 35.1                          |
| Cameroon 2009 [8]              | Populations Badissa village          | 23.8                   | 67.3 | 67.1   | 84.1                             | 55.5                          |
| Cameroon 2009 [2]              | Populations<br>South-West<br>region  | 45.2                   |      | 31.3   | 48.6                             | 41.6                          |
| Jordan 2007 [19]               | Population                           | NA                     | NA   | 11.5   | 52.41                            | 43.66                         |
| China 2006 [18]                | Populations                          | NA                     | 24.2 | 44   | 81.3                             | 57.9                          |
| United Arab Emirates 1998 [20] | Populations                          | 46.2                   | 12   | NA   | 93                               | 90                            |

Values under the respondents' answer columns are percentages of Yes responses to questions. PWE: patient with epilepsy; NA: not available; MR; mental retardation.

epilepsy (as being contagious) was found more among teachers, followed by students, than guardians. This can be explained as guardians are of older age and have had more experiences than younger generations. In addition, epilepsy is not a recent disease. As regards the incorrect knowledge towards epilepsy among other countries, these results were better than what was found in Cameroon [2,8,23] and the United Arab Emirates [20]. These results can be attributed to different methods between studies.

The attitudes of families with a PWE were better than families without a PWE except with regard to the acceptance of the epileptic patients to have children. This can be explained by their fear of the genetic aetiology of epilepsy. In addition, epilepsy itself leads to cognitive impairment, depressymptoms, aggression, and different personality traits such as neurosis, extroversion introversion, psychosis, and lying, especially among adult patients [28]. The results of good attitude of the population towards a PWE, such as the acceptance to marry, to have a friendship and to work with a PWE, were among the students in Egypt [16]. Also, these results matched with Spatt et al. [11] who reported that familiarity with epilepsy was an independent predictor for a positive attitude towards epilepsy. Otherwise, the results of positive attitude were less than other countries such as United Arab Emirates 1996 [20], China (2006), Jordan (2007) and Cameroon (2009) [2,18-20]. This was due to the lack of available information about epilepsy and lack of education programs. In addition, the sources of information of all respondents are the movies about epilepsy, which could provide non-scientific information but in a traditional framework.

Background and stigma against a PWE, especially among community populations, compromises their treatment and quality of life [29]. Therefore, this study is important in providing baseline information about how epilepsy is perceived within the region and may help in the design of education programs targeted to certain groups in the future.

There was no significant difference in the level of awareness and knowledge based on gender among the respondents in this study. It could also mean that both males and females experience the same exposure to community beliefs and lack of heath education programs to provide the correct knowledge for both sexes with regard to the disease in Egypt. This particular finding was supported by Neni et al. [17] and Lim et al. [30] who reported that gender did not have a significant association with the awareness or familiarity of epilepsy. As

regards independent factors for a negative attitude towards a PWE, males reported negative attitudes towards epilepsy. This agrees with Neni et al. [17] who reported that negative attitudes towards employment was more from males, while females were found to harbour negative attitudes towards marriage to a PWE.

In this study, the respondents who do not work or those having skilled work have a negative attitude towards a PWE. This means that professionals had significantly better attitudes towards epilepsy than other respondents. This finding suggested that people could probably improve their attitudes and perceptions towards epilepsy through their higher educational levels and employment. Also, employment added knowledge about epilepsy through dealing with a PWE at work rather than in families. This finding was in concordance with Neni and his colleagues [17]. However, the results of this study are not consistent with the results of a study in Hong Kong [31] which illustrated that employed respondents with medically-related occupations, such as doctors, nurses or pharmacists, showed more negative attitudes towards epilepsy. Another study conducted among Omani physicians suggested that many doctors in Oman are worryingly harbouring negative attitudes towards people with epilepsy [32]. These two studies suggested that employment or higher levels of education had a positive impact upon the attitudes towards epileptics. Again, the differences in findings showed that attitude towards epilepsy with respect to employment varied among different communities in different countries, probably due to different socio-demographic backgrounds and cultural values.

In this study it was reported that incorrect knowledge, such as epilepsy is a contagious disease, a mental illness or a non-treatable condition, was negatively correlated with positive attitudes towards a PWE. This agreed with Spatt and his colleagues [11] who reported that misconceptions of epilepsy as a form of insanity independently predisposes people to a negative attitudes towards epilepsy. Therefore, knowledge about the aetiology of epilepsy seems to be a very important protector against negative attitudes towards epilepsy [11]. This could be explained as a lack of awareness and knowledge that might lead to negative attitudes towards epilepsy and could be a factor explaining stigma [17]. Hence this study was a crucial tool in obtaining accurate information about the public attitudes towards epilepsy, which has often been subjected to misconception, stigmatization and social misunderstanding, ultimately affecting the overall quality of life of a PWE and their families more than the disease itself. Furthermore, this study provided a preliminary insight on predictors of the negative attitude towards epilepsy among Egyptian communities. This could be a very important basis to formulate an epilepsy educational tool for the public. This was supported by a study conducted in Malaysia [17] which claimed that the low level of knowledge and misconceptions found among respondents demonstrated the need for educational programs.

### 5. Conclusion

Incorrect knowledge of epilepsy, not having a PWE, skilled workers, or being without work and male sex were independent factors for negative attitudes towards epilepsy. Increasing the awareness about epilepsy and its aetiology will raise the level of knowledge and improve the attitude towards a PWE.

### 6. Ethical publication

"We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines."

#### 7. Disclosure of conflicts of interest

None of the authors has any conflict of interest to disclose.

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### Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at http://dx.doi.org/10.1016/j.jegh.2013.09.006.

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