Do close relative marriages contribute to the Causes of Autism among ethnic groups in Jordan, psychological effect on society? Umm Al Quttain village and Abdali area a case study

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Abstract

This field survey aims at investigating and if possible prove that close relative marriages are considered to be one of autism causing factors among ethnic groups in Jordan. To achieve this purpose author conducted a Field survey in two areas in Jordan, where the ethnic group of Duruz live: Umm Al Quttain in northern Jordan and Al Abdali area in Amman, the capital city. Ten families were chosen from these areas to be experimental group, and other ten families from mainstream population in Amman were chosen to be a control group. A brief questionnaire was developed to be use simultaneously with the experimental group and control group.

Results revealed that Duruz ethnic group practice widely relative marriages and there many autistic children within the duruz families member in the study. The study puts forward several recommendations, most importantly is to stay away from marrying relatives, and initiate awareness programs to show the negative consequences of relative marriages.

Keywords: Autistic children, the ethnic group of Duruz, Umm Quttain area, Abdali

Introduction:

When asked what causes Autism? One may receive several different responses. Ordinary person would not know what to answer, Autism in its regular definition, autism spectrum, Asberger syndrome or any other illness that has to do with problems in social interaction and unusual responses to the environment.

Others may say that the cause of autism is congenital (Zuriaqat, 2010) which means, that children were born with it. However, with the progress of medical technology, we know now many things about autism such as children seem develop autism in the first years of life. Other scientists claim that autism is associated with intellectual disability while others reject this logic by claiming that autism is not associated with mental retardation because children do well on some parts of intelligence quotient (IQ) test. (Kanner, 1943).

Some other psychologists blamed parents in the cause of autism. Even Bruno Bettelheim of the University of Chicago advocated "removing children from the home in an attempt to address what he saw as the fundamental problem". (Hallahan et al 2009).

With overtime, it has become clear that autism has a strong genetic aspects. Unfortunately, scientists still unsure of that, however they agreed that "the best evidence suggests that autism is a brain- based disorder with a very strong genetic components". (Zuraiqat, 2010).

Susan Folstein and Michael Rutter (1977) have extensive studies in the genetics of autism. In 2005, Rutter, has detailed discussion which can be summarized as following.

Genetics of Autism

Strong role for genetic factors suggested by:

- "High rates of concordance in identical twins (if one twin has it, the other one is very likely to have it).
- Increased risk for autism in siblings. (2-10%) this is significantly greater than the population rate" (Rutter 2005)
- Studies and research are taken place every single day in order to discover new aspects of autism, on the hope to have a cure and save thousands of children around the world whom deprived the joy of healthy life this study comes with the hope to attribute little into the autism literature, through the study of the effect of relative marriages (first, second cousins) which is a common occurrence in Jordan.

The problem of the study:

Marrying a blood relative (first and second cousins) is a common occurrence in Jordan, and is part of society's culture.

Furthermore, it has been noticed that certain ethnic groups like the "Duruz" in Jordan- and due to their religious beliefs- forbid any marriage from a non-Durzi-young woman, nor giving their daughters for marriage to foreigners. Furthermore, this ethnic group has the highest rate of autism in Jordan (D of S reports 2000) Thus, the problem of the study lies in exploring the relationship between marriages among cousins and autism. To achieve this purpose the study will answer the following questions.

- achieve this purpose the study will answer the following questions.
 - 1- To what extent cousin marriages take place among Duruz in Jordan?

2- What can be done to decrease the practice of cousin marriages among Duruz?

Importance of the study:

- 1- This study considered to be important because it discusses an important issue which is the relationship between relative marriages and autism especially among people who practice this tradition significantly such as Duruz ethnic group in Jordan.
- 2- To the best of the author's knowledge there is no even one study discusses the relationship between relative marriages while targeting a group of people such as this study.

Definitions

- Duruz: a group of people live mainly in Lebanon, Syria and Jordan. They have their own religious beliefs, culture including traditions and customs which differ from the culture of mainstream Jordanians.
- Relative marriages: is marriages within the extended families in Jordan. It is a common practice to marry one with his/her first cousin. However, this practice decreased significantly in the last few decades among Jordanians
- Autism: A developmental retardation which is characterized by isolation, cognitive short comings, language difficulties, self tantrums, starts before 30 months of age.
- Asberger syndrome: is characterized by normal cognitive and language development, however, child is slow in motor development and social and reaction retardation, As is one of autism spectrum.

Literature Review

This author is determined to make use of the massive and rich literature relevant to autism and autism spectrum, and other disorders have relation to autism, in order to obtain new ideas and to keep up with recent research development in this regard. However, and unfortunately, autism in Jordan is under-studied. There are very few Jordanian authors with fewer publications and studies. Most of these studies discuss autism: Types, characteristics and other features mostly taken from western resources. For example, Dr. Zuraiqat, Ibrahim (2010) published a book entitled "Autism: Behavior, Diagnosis and Treatment. Author discusses almost all information about autism but from a Westerner's perspective, no chapter in the book discusses autism in Jordan".

Even the name of children he uses as example are Western names. Nothing wrong with that but people nowadays have the opportunity to obtain any information with a touch of PC key board, about autism or anything else anywhere in the world via accessing the internet. Thus, there is no need to accumulate general knowledge in a book.

Another book by authors Dr. Imam, M. and Jawaldeh, F (2010) entitled Autism and Theory of mind. It is no 4 in their series.

In this book authors discuss autism with all of its features, aspects types, theories, characteristic and so forth. Again all information in the book is from Western sources. Which are available on the internet, even definitions they used are "according to National Autistic society UK or Autism society of America (ASA)". Nothing mentioned about autism in Jordan what so ever; Matter of fact, it is quite natural taking information from outside sources, however, to ignore Jordanian autistic children and suffering parents is a sign of failure from the authors side.

In contrast, there are several authors who indulge into the core of autism problem in Jordan, such as Dr. Deeb, sheikh Raed, who has several publications in this regard in which he gives accurate statistics which is the fruit of serious and field surveys: such as:

There is about 7500-8000 autistic children in Jordan, mostly stay with their families for the lack of proper treatment; while others are institutionalized in mental health centers.

Most autistic children suffer from marginalization, absence of proper care treatment, and rehabilitation they need. The cost of minimum level of care is sky rocketing which most families cannot afford (800 J.D a month). That is why families with autistic children keep their autistic children home.

Dr Deeb adds that, there is no public centers specialized in treating autism, no one center in Jordan. The private sector centers are very expensive. While there is no cure for this disease however early diagnosis is vital (Deeb,2007).

In Sum, There is ample of publications about autism in the developed countries, unfortunately, autism in the developing countries is understudied Jordan included.

Methodology

Study model

We have two types of variables: dependent and independent as it is shown in the study model below

independent variables

dependent variables



Sample

Sample of the study consists of twenty families or 40 father and mother of each. Sample is divided equally into two groups:

1- Experimental group consists of families from Duruz ethnic group resides mainly in umm Quttain village and Al Abdali area. Those people are known by marrying blood relatives such as first and second cousins and have a high rate of autistic children.

control group consists of 20 couple in ten household's mainstream Jordanians.

Data collection

- Primary data: A questionnaire is developed to be the main instrument to collect data from sample members in both groups, through structured interviews.
- Secondary data. Author relied heavily on relevant literature, magazines and statistics from governmental and UN agencies.

Questionnaire used in structured interviews with study's sample

1	How old are you?	Yes	No	Other
2	Are you married?			
3	How long you have been married?			
4	Does your wife/ husband relate to you ?			
5	What is the degree of this relationship?			
6	Do you have children ?			
7	How many? How old are they? And their gender?			
8	Have you had medical test prior to marriage? Both of you			
9	What type were they?			
10	Your kids, are they healthy and normal children?			
11	If the answer is no, then what kind of problems they have?			
12	Do they receive any medical help? How and what ?			
13	Do you receive any support? Or is there any support group in your			
	area			
14	What is your advice to the young people who are planning to get			
	married?			

Items: 7,9,11,12,13,14 are open ended questions.

Qualitative approach is used in conducting interview and data analysis.

- Study Hypotheses
 - This study attempts to test the following hypothesis :
 - H1- there is strong correlation between relative marriages and Autism especially among Duruz H2- there is no strong correlation between relative marriages and Autism among Duruz

Study's Limitation

- Participants: small sample from Duruz ethnic group and main stream Jordanians. This necessitates further studies in order to generalize the results
- Place: Umm Quttain village, Al Abdali area

• Time: April: 2015

Procedures:

Author visited the area of Umm Quttain to meet families there, for the purpose of the study. With the help of a nurse works at a public health care center, 10 families were located and ready for interview. Most men were working, thus the mothers answered the questionnaire

The same procedure took place with the control group, in areas similar to the Duruz areas

Data Analysis and discussion:

Control group:

Q1- the age of women respondents between 28-52 years. 35 years over average age

Q2- All Women respondent are married. Author intentionally chose married women with children as criteria to participate in the study.

Q3- between 3-21 years of marriage

Q4-8 respondents answered with no while 2 answered with yes.

Q5- Degree of relationship is "far relative not first or second cousin".

Q6- yes by all respondents

Q7- between 2-5 children. Between 1-35 years old. 16male/14female

Q8- yes we did especially thesalemia test.

Q9- Routine pre marriage medical test by the ministry of Health.

Q10- yes they are by all respondents

Q11- Three children suffer from hearing impairment and five from sight impairment.

- Q12- yeas, from health care centers
- Q13- NIA

Q14- There are many advice, one of them is not marrying from close relative

Questionnaire used in structured interviews with study

Experimental Group

No.	Item	Yes	No	Other
1	How old are you?			22-51
2	Are you married?	1		
3	How long you have married?			3-15
4	Does your wife/ husband relate to you?	√		
5	What is the degree of this relationship?			First and second cousin
6	Do you have children?	√		
7	How many? How old are they? And their gender?			3
				2-21 17-14
8	Have you had medical test prior to marriage? Both of you	√		
9	What type were they?	-		MOH Routine test
10	Your kids, are they healthy and normal children?		\checkmark	Some are some are not
11	If the answer is no, then what kind of problems they have?			Diagnosed with Autism
12	Do they receive any medical help? How and what ?	√		Sedatives From health care center
13	Do you receive any support? Or is there and support group in your area	1		
14	What is your advice to the young people who are you planning to get married? to a relative			Never be married

Psychological effects and challenges

Faced by families of Autistic children

During the author's visit to the town of Umm Qutain, and her meeting with families of autistic children, author was told by the mothers of autistic children that: they were not familiar with such disease called autism spectrum disorders (ASD) until late around when some clinics in large cities start using autism diagnostic tests such as Diagnostic and statistical Manual of mental Disorders (DSM-s) in diagnosing their children with autism- related disorders. As a results, families have found that they are facing substantial challenges and psychological impact especially after noticing the impairments in multiple areas in their children such as: social interaction, communication and behavior and the disorder is associated with disruptive antisocial behavior. Thus parents

with ASD children have to live in extreme difficulties and burdens with multiple facets and aspects such as: dealing with their autistic child's behavior, teaching their children to communicate, especially there is no such rehabilitation centers in Jordan to teach such children basic life skills.

Parents spend most of their time guarding their child recurrence risks, misconception and assumptions.

Moreover, families feel of guilt and blame regarding their child. In addition such families face discrimination for their autistic child and the family is seen as a part of the illness.

What makes thing worse is that, families have no support by government and there is no support groups at the community level.

Results / Recommendation

Experimental group showed a significant relationship between close relatives marriages and autism, whereas, each family of the experimental group has one child at the minimum suffers from autism, in comparison with control group whose families has no autistic children what so ever. This results makes one wonders why there are so many autistic children among Duruz families. In Al Abdali area there are 7 autistic children 3 siblings in one family.

In regard to the study's hypotheses, the null hypothesis is rejected while the hypothesis, there is strong correlation between relative marriages and Autism especially among Duruz without conduction serious medical tests.

The study recommends:

- 1- Initiate awareness programs and national campaigns showing the negative impact of relative relatives.
- 2- Provide health care to autistic children and the support to their families

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