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Characteristics Factors Affecting Utilization Patterns of Prenatal Genetic Services in the Bedouin Population

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Purpose: This work focus in examine what is the efficiency of accessibility of the community genetic services and their impact on uptake of genetic carrier screening in community health clinics among the Bedouin population in the Negev,to assess the response rates to genetic carrier screening test when they are made available in the community (2012) compared the provision of services only in Genetics Institute (2011); furthermore, to examine the factors affecting compliance for further genetic counseling and testing when both spouses are carriers (genetic counseling Genetic Institute, performing prenatal diagnosis through chorionic villus sampling / amniocentesis) and the resolutions adopted following the diagnosis of a disease

Methods: The study population: All Bedouins Visitors in the community nursing genetic services (CNGS) by the 2012 and all Bedouin attended genetics carrier testing services at the Genetics Institute at Soroka Medical Center in 2011. Order to obtain advice about genetic screening and uptake the tests in 2011. The information is based on data collected by genetic nurses, genetic information data from Genetics Institute.The statistical analysis compare the main outcome variables in both groups (2011 and 2012) ; At the same time, we examined for each of the relationship between compliance and the demographic characteristics, prenatal history, family history of genetic diseases. Following the one-variable analysis we performed multivariate analysis to identify the characteristics that affect the behavior and decision-making in each of the outcome variables.

Results:

most of the women who carried out the test for HRD were younger average age 26.2, compared with those who did not, average age 27.8. The average number of pregnancies to women who do the test is 3.5 compared to women who did not 4.5 pregnancies per woman; the average number of children is 3 for women who underwent testing as compared with an average of 3.9 children per women for those that chose not to be tested. With the introduction of the community outreach program there was an increase in the percentage of women who carried out the tests: 1164 (14.9 %) of women in 2011, compared to 1871 (22.3 %) in 2012. The number of mutation carriers detected grew accordingly: 121 (10.3 %) in 2011, compared with 169 (9.0 %) in 2012.

In 2011, 28 women underwent chorionic villus sampling identifying seven affected fetuses, with termination of pregnancy in five of them (71.0 %). In comparison, 14 women underwent amniocentesis. Of those cases only three fetuses' identified affected and only one (33.3 %) pregnancy was discontinued. In 2012, 43 women were chorionic villus sampling 12 embryos were found to be affected, and ten (83.3 %) of those pregnancies were discontinued. In 2012, only 9 women underwent amniocentesis, only two fetuses were found to be affected through this procedure, and just one (0.50 %) of those pregnancies was terminated. The majority of women who came to CNGS in 2012 were pregnant women 93.1 %. The average week of pregnancy, number of children and number of pregnancies, 3, 1, 18 respectively. Of those women, 61.6 % were in consanguineous Marriage of any degree: 32.8 % of them first cousins marriage. Only 10.8 % of those women refused to perform a genetic screening test. Of those women attending the CNGS in 2012, 44.6 % completed primary school, only 10.1 % were employed, for most of those women (81.8 %) it was their first visit to CNGS. most came alone and 59.9 % were followed regularly during their pregnancy by the gynecologist in primary health clinic. Of the women attending the CNGS in 2012, 39.1 % were referred for genetic counseling at Soroka medical center-only about half of them actually complied and attended the genetic counseling. The main reasons for referral were family

history of genetic disease and problem detected in the testing during pregnancy. The main factors that correlated with women carrying out a genetic screening test were: knowledge of the Hebrew language, arrival in early week in pregnancy, the presence of a family history of genetic disease in the family, the explanation about the purpose of the test, and the number of children per woman. Factors affecting women's compliance with referral to genetic counseling: the presence of family history of genetic disease in the family, clear explanation about the purpose of the referral, previous contact of the women with the CNGS / genetic counseling teams, termination of pregnancy or still birth in the past and the woman's age.

Conclusion: The study pointed that genetic services should be made available to the public, to promote nursing experts in genetics targeted to specific population especially at risk to genetic diseaeses.to considers genetics aspects in the nursing academic programs, enrich population health knowledge in genetics issues.

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Abstract Summary:
Genetic nurse services in public health clinic targeted to population at risk for autosomal genetic diseases directed to promote health by education and performing genetic screening test to detect couples at risk and recommend further follow up. Service aims to decrease mortality and morbidity in infant.

Content Outline:
Marriage between close relatives increases the risk of genetic disease. This kind of marriage is the preferred pattern in the Bedouin population. The Bedouin population is a tribal, traditional, Arab; Muslim cohort is characterized by high level of consanguinity rate. Because of that autosomal recessive genetic diseases are prevalent in this community causing high infant mortality rate. Over thirty genetic diseases are known among this population and many of them can be identified through surveys and diagnostic tests. Bedouin population offered the genetic screening test free of charge, as part of the health services.

Whereas until 2010 genetic screening test were offered to only some of the tribes in the Bedouin population, beginning November 2010, all women of childbearing age were offered carrier screening test for hypothyroidism-retardation-dysmorphism syndrome (HRD). As well as for tribe specific diseases. In recent years there have been efforts to increase access to genetic prevention programs and adapt them to the population. The main change is the introduction of a community nursing genetic service (CNGS) in the health care system, targeting all couples of reproductive age, to effectively disseminate information on genetic screening tests, and facilitate implementation of testing for those who choose after counseling.

Implication: The study pointed to promote nursing experts in genetics targeted to specific population especially at risk to genetic diseaeses.to considers genetics aspects in the nursing academic programs. Promoting

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Author Summary: I am a PhD nurse working in public health clinic as genetic nurse also manger position. Am teaching in department of nursing in Ashkelon academic collage. The first nurse started to providing genetic services and educating the Bedouin population. Education intended to decrease consanguinity rate. Am 28 years working as a nurse dealing with various health problems like chronic illness.