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

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Background
The practice of marriage between close relatives increases the risk of genetic disease. The Bedouin population in southern Israel is a tribal, traditional, Arab-Muslim cohort that is characterized by high consanguinity. Because of this, autosomal recessive genetic diseases are prevalent in this community, causing high infant mortality rates. Over thirty genetic diseases are known among this population, and many of them can be identified through surveys and diagnostic carrier tests.

The Bedouin population is offered the genetic screening tests free as part of the Israeli public health services. Whereas until 2010 genetic screening tests were offered to only some of the tribes in the Negev, beginning November 2010, all women of childbearing age were offered carrier screening for hypothyroidism – retardation – dysmorphism syndrome (HRD), as well as for tribe-specific diseases. In recent years there have been efforts to increase access to genetics prevention programs and adapt them to the population.

The main change is the introduction of a community nursing genetic services (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 to do so after counseling. In this study we examine the efficiency and 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.

While in 2011 genetic carrier testing was done at the genetics institute at Soroka Medical Center, the outreach program was effectively implemented in 2012, making nurse-mediated carrier testing services available the community clinics. We analyzed differences between various parameters of the cohort tested in the community in the year 2012 and the cohort tested at the genetic counseling clinic in Soroka Medical Center in 2011; we examined what are the factors that influence the decision to carry out or refuse to perform the carrier testing, and to undergo medical diagnostic prenatal tests.

Research objectives
1. To assess 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 in the year 2012, compared to the provisions of services only in Genetics Institute (2011).
2. To examine the factors affecting compliance for further genetic counseling and testing when both spouses are carriers (genetic counseling at the 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 Bedouin visitors in the community/nursing genetic services (CNGS) in 2012 and all Bedouins attending genetic carrier testing services at the Genetics Institute at Soroka Medical Center in 2011.

Data were analyzed using SPSS version 26.0. Univariate analyses include tests for comparison of means (or Mann-Whitney tests as appropriate) for numerical variables and chi-square tests for nominal variables.

Factors associated with uptake of genetic screening test – results from a multivariate logistic regression analysis

Conclusions
The study highlights the efficacy and importance of - making genetic services available to the public in rural areas; - promoting specialized nursing expertise/services in genetics, targeted at specific population at risk; - enhancing genetics aspects in nursing educational programs, enhancing public health and awareness in genetics-related issues.

Keywords: Prenatal genetic screening, prenatal diagnosis, culture, the Bedouin sector, genetic diseases, inbreeding, polygamy, making a decision, genetics community.