



## Social Inclusion of Children With Down Syndrome: Jewish and Muslim Mothers' Knowledge, Attitudes, Beliefs, and Behavioral Intentions



Sivia Barnoy, RN, PhD<sup>a</sup>, Anna Biton, RN, MA<sup>b</sup>, Michal Itzhaki, RN, PhD<sup>a,\*</sup>

<sup>a</sup> Nursing Department, School of Health Professions, Sackler Faculty of Medicine, Tel Aviv University, Tel Aviv, Israel

<sup>b</sup> Pediatric Emergency Department, Hillel Yaffe Medical Center, Hadera, Israel

### ARTICLE INFO

#### Article history:

Received 12 November 2016

Revised 26 February 2017

Accepted 28 February 2017

#### Keywords:

Down syndrome

Behavioral intentions

Children

Mothers

Social inclusion

### ABSTRACT

**Purpose:** The current study examined mothers' knowledge, beliefs, attitudes, and intention to socially integrate children with Down syndrome (DS) in the family, with children without disabilities and school system.

**Design and Methods:** A questionnaire based on a descriptive, cross-sectional design was administered to Jewish and Muslim mothers. The questionnaire included demographics, knowledge, beliefs, attitudes, and intention to integrate children with DS. Analysis included a regression test of intention to integrate children with DS and a one-way ANOVA for differences between Jewish and Muslim mothers.

**Results:** Nearly all the Jewish mothers (93.7%) and about half the Muslim mothers (52.8%) had performed screening tests for DS during their pregnancy. All mothers displayed low knowledge level about DS. Being Jewish ( $t = 2.89$ ;  $p = 0.005$ ) and holding more positive beliefs ( $t = 3.39$ ;  $p = 0.001$ ) were associated with a higher intention to socially integrate children with DS. Significant positive correlations were found between beliefs and attitudes ( $r = 0.65$ ;  $p < 0.001$ ) and between attitudes and intention to socially integrate children with DS ( $r = 0.39$ ;  $p < 0.001$ ).

**Conclusions:** This study shows that Jewish and Muslim mothers' beliefs and attitudes towards social inclusion of children with DS are quite positive and the intention to integrate children with DS in the family, with children without disabilities, and in the mainstream school system is high. However, their level of knowledge about DS is low.

**Practice Implications:** Nurses, as a critical source of information about DS, should develop an ethno-cultural sensitivity to diverse populations in order to influence attitudes and beliefs regarding the social integration of children with DS.

© 2017 Elsevier Inc. All rights reserved.

### Background

Down syndrome (DS) is the most common genetic autosomal chromosomal disorder, characterized by a trisomy (three copies) of chromosome 21. Individuals with DS have an increased occurrence of intellectual disability and health complications, including congenital heart malformations, respiratory and gastrointestinal diseases, as well as orofacial problems (Ferreira et al., 2016; Graves et al., 2016; Ivan & Cromwell, 2014). The American National Down Syndrome Society (NDSS) Fact Sheet declares that one in 691 babies in the United States (US) are born with DS and >400,000 people with DS live in the US. As common health conditions in patients with DS are nowadays treatable, the life expectancy of patients with DS has dramatically increased over the last 30 years, from 25 to 60 years (NDSS, 2015).

Invasive diagnostic tests and non-invasive screening tests for DS have been available for over several decades in most Western countries (Lewis, Hill, & Chitty, 2016). Despite screening, the prevalence of babies born with trisomy 21 has increased over the last decade, mainly due to the rising maternal age of pregnant women (Loane et al., 2013). Recently, non-invasive prenatal testing (NIPT) for DS, based on assessing cell-free DNA in maternal plasma, has increased the detection of DS pregnancies with a reduced need for invasive diagnostic testing, though worldwide this technique is expensive and it is available mostly through the private sector (Chitty et al., 2016).

Throughout the world, over the last 20 years the inclusion of children with DS in mainstream education is being encouraged by legislation aimed at providing them with individual support in regular classrooms (De Graaf, Van Hove, & Haveman, 2014; MacFarlane & Marks Woolfson, 2013). In the US, the Individuals with Disabilities Education Act (IDEA), Section 504 of the Rehabilitation Act of 1973 identifies the accommodations and structural framework available for children with disabilities. The Individualized Education Program (IEP), characterized by collaborative meetings of decision-making process

\* Corresponding author: Michal Itzhaki, RN, PhD.  
E-mail address: itzhakim@post.tau.ac.il (M. Itzhaki).

between students, parents, and school professionals, outlines the types of educational services and legally provides adapted public education services. These regulations protect the person with disability from discrimination in their physical and social life (Bray & Lin Russell, 2016; Krahn, Walker, & Correa-De-Araujo, 2015).

In Israel, in 2010–2011, the birthrate of infants with DS was lower among Jews (0.67 per 1000 live births) than among non-Jews (0.83 per 1000 live births), as the detection rate of DS during pregnancy was higher among Jewish women (70.8%) than among non-Jewish women (30%). This was due to the higher rates of prenatal screening for DS among Jews (Grinshpun-Cohen, Miron-Shatz, Ries-Levavi, & Pras, 2014). However, the expected risk of DS at birth was higher among Jews (2.16 per 1000 live births) than among non-Jews (1.11 per 1000 live births), since a higher percentage of Jewish women give birth at an older age, over 35 years (Department of Community Genetics, Israeli Ministry of Health, 2011).

Most children with DS in Israel live at home with their families unless they have complicated health problems requiring residential care (Tenenbaum, Shoshana Aspler, Rorman, Fuchs, & Merrick, 2011). The Israeli Ministry of Education (1988) enacted the Special Education Law under which children with DS are entitled to receive special education services from ages 3 through 21. The law was updated in 2002 and determines that an integration committee is responsible for determining eligibility for integrating children with DS in the mainstream school system in Israel according to their functional level, in regular classrooms with a personal assistant teacher or in special classes in mainstream schools (Israeli Ministry of Education, 2014).

A literature review shows more positive than negative effects of inclusive education. Although the self-confidence of children with special needs attending mainstream schools can be impaired as they compare themselves to children without disabilities, education in segregated special schools can damage their self-esteem due to feelings of rejection (Ruijs & Peetsma, 2009). Inclusion creates a platform for socializing among children with disabilities and children without disabilities and provides an example of role models and normative behaviors. Children with special needs can learn from typically developing children and may be more motivated to achieve better results in the mainstream school system. This experience can be significant for future integration into society, enabling children with DS to lead independent lives as adults, participate in social activities, and work for a living. Additionally, children without disabilities who are exposed to children with DS may become more aware of the differences between people and increase their tolerance towards them. Inclusion prepares them for life in a multicultural world and teaches values of mutual respect and assistance (Dessementet & Bless, 2013; Ruijs & Peetsma, 2009).

Similarly, studies show comparative advantages concerning the integration of children with DS in the family. Although having a child with DS might lead to parental stress and more time is dedicated to caregiving activities, parents of children with DS learn to be more tolerant, accepting, and empathic towards different people; they experience satisfaction with support received from the community; and they are less likely to get divorced (Skotko, Levine, & Goldstein, 2011). However, siblings living with a child with DS might experience negative emotional reactions, such as embarrassment and anger, but they have good relationships with others, have less adjustment difficulties, and develop personal strengths that include sensitivity, patience, and maturity (Mandleco & Webb, 2015).

It is important to examine the perceptions and knowledge of people regarding DS, as negative opinions, low levels of knowledge, and stereotypes might create barriers to social integration. Pace, Shin, and Rasmussen (2010) found that the general US population has negative attitudes towards the social and educational inclusion of people with DS, arising from the belief that students with DS should study in separate special schools since their inclusion is distracting. Other studies present positive attitudes towards the school inclusion of schoolchildren with disabilities, since accepting others increases

tolerance and empathy (Levis et al., 2012; Leyser & Romi, 2008). Knowledge about DS among pregnant mothers or women who are planning to have a child, were examined by Levis et al. (2012) who found misconceptions of DS and a belief that having a child with DS would disrupt their lives. However, most of the studies on the social and educational inclusion of children with DS focus mainly on teachers' and educators' attitudes (Vaughan & Henderson, 2016) or on the perceptions of mothers of children with DS, as their primary caregivers (Choi & Van Riper, 2016), while perceptions of mothers of typically developing children regarding the social inclusion of children with DS were rarely examined. Since mothers are frequently dominant in decision making concerning children's with disability education and social life (Zaidman-Zait & Curle, 2016), it is worth examining mothers' attitudes and intentions towards the integration of a child with DS in these settings.

### *Theoretical Framework*

The theoretical framework of the study was based on Ajzen's Theory of Planned Behavior (Ajzen, 1991). Accordingly, the belief that a specific behavior will yield an assumed result, i.e. the behavioral belief, is associated with attitudes towards the behavior. Assessment of the behavior's outcomes is directly related to attitudes towards the behavior. Attitudes towards the behavior are defined by Ajzen (1991) as the (positive or negative) evaluation of a certain behavior. The theory assumes that behavioral beliefs and attitudes towards the behavior determine the behavioral intention, meaning the inclination that one will carry out a specific behavior. Behavioral intention is the strongest predictor of the actual behavior.

### *Purpose*

The aim of the current study was to examine mothers' knowledge about DS. Furthermore, another aim was to explore their beliefs, attitudes, and intention to socially integrate children with DS: in the family, with children without disabilities, and in the regular education system.

### **Methods**

#### *Design*

A descriptive, cross-sectional design was used.

#### *Setting and Sample*

The questionnaires were distributed among mothers of children hospitalized due to acute conditions (i.e. liquid/antibiotic transfusion or for surveillance), but not to mothers of children hospitalized due to life threatening conditions. Since beliefs, attitudes, and intention to socially integrate children with DS might be linked to parental stress, we chose to study mothers during their child's hospitalization, a situation which raises parental stress (Wray, Lee, Dearmun, & Franck, 2011) and could raise the awareness of mothers towards children's disability. Moreover, as needs and perceptions of parents from various cultures are experienced differently while their child is in hospital (Sanjari et al., 2009), we examined the two main Israeli ethnic groups, i.e., Jews (74.8%) and Muslim Arabs (16.5%) (Israel Central Bureau of Statistics, 2016). As we focused on mothers of children hospitalized due to acute conditions, exclusion criteria were being a parent of a child with Down syndrome or a child with other disability. In addition, mothers of a child admitted with a life threatening condition were excluded.

The sample size was calculated by means of the WINPEPI COMPARE2 program, used to determine power and sample size in cross-sectional designs (Abramson, 2011). The sample size required for achieving a power of 0.80 and 0.05 was 72 participants: 36 in each group of mothers.

Download English Version:

<https://daneshyari.com/en/article/5570104>

Download Persian Version:

<https://daneshyari.com/article/5570104>

[Daneshyari.com](https://daneshyari.com)