

**The Ultra-Orthodox (*Haredi*) Jewish Mother's Experiences
in Caring for a Type 1 Diabetic Child:
With a Special Focus on Disclosure and Concealment**

Ahuva Spitz

Interdisciplinary Studies Unit

The Gender Studies Program

Ph.D. Thesis

Submitted to the Senate of Bar-Ilan University

Ramat-Gan, Israel

September, 2018

The Ultra-Orthodox (*Haredi*) Jewish Mother's Experiences in Caring for a Type 1 Diabetic Child

חוויות האימהות לילדים החולים בסוכרת נעורים במגזר החרדי

Abstract

Background

This study examines the experience of mothering a diabetic child in Israeli *haredi* [ultra-Orthodox] society.

The global prevalence of Type 1 diabetes has been increasing consistently over the past decade, with the corresponding increase within the *haredi* community. Diabetes treatment adherence is difficult, requiring multiple treatment modalities, such as monitoring blood glucose, administering insulin, following a diet, and exercise.

In addition to this complex regimen, *haredi* diabetic patients, and their caregivers, are situated in a specific societal context imposing an extra layer of burden. A prime example involves the dilemma of concealing or disclosing the diabetes, particularly given *haredi* society's extreme sensitivity to health issues in connection with match-making (*shidduchim*). Due to factors such as high rates of misinformation about diabetes, young people with diabetes (as well as their healthy siblings) can face significant obstacles to finding a mate, as well as general social isolation.

Diabetic children require assistance to help them handle ongoing adjustments to the various lifestyle changes in managing the disease. Furthermore; research has shown that youngsters receiving strong family support for diabetes care adhere better to their diabetes regimen. The mother's involvement in the complex care regimen is thus essential to help monitor glucose levels in the blood, preventing extreme conditions as a result of fluctuations in the blood sugar.

The existing literature on mothers of Type 1 diabetic children has highlighted various challenges that mothers face. These have included: new medical knowledge to master; pressure and associated fears of maintaining day-to-day care; juggling pre-existing responsibilities with the additional burden of care; and the psycho-social issues in dealing with children and aspects of chronic illness. However, the literature has yet to discuss the mothers' experiences in delivering care for Type 1 diabetic

children within the *haredi* societal context, especially in relation to the concealment vs. disclosure dilemma mentioned above.

Methodology

In this research, semi-structured qualitative interviews were conducted with 34 *haredi* mothers of Type 1 diabetic children. They shared their experiences about their maternal challenges in handling the diabetes, highlighting the specific social issues they confronted. The interview guide contained questions about diabetes control in general and questions that elicited descriptions of their unique experiences.

The interviews gave the mothers the opportunity to speak about issues that they wouldn't otherwise have considered discussing. Mothers raised the topic of concealment spontaneously, almost immediately; it was clearly an issue that was almost constantly on their minds.

The interviews were taped after permission had been obtained, followed by verbatim transcriptions (with names and identifiers removed or changed). Grounded theory was utilized for data analysis. To validate the data that arose from the text, two sources of data were utilized in addition to the interviews: the researcher designed and led support groups for mothers, and examined articles in *haredi* newspapers describing illness, particularly diabetes. These supplemental data sources helped place in wider context the mothers' reported thoughts and shared experiences in caring for a Type 1 diabetic child, thus facilitating a deeper understanding of the specific societal *haredi* milieu.

Findings

The interviewed mothers shared experiences relating to their maternal roles in raising Type 1 diabetic children. They focused mainly on issues associated with protection of their children, keeping their families intact, and leading their household. The topics that they chose to highlight their stories were not related to the additional burden of a working mother. Rather, they discussed encounters regarding family, social issues of marriage (*shidduchim*), and concealment; these all related to what they considered their main role: that of a mother, which role clearly ranked first for them.

Utilizing qualitative grounded theory methodology, four main themes were extracted from the text: *haredi* society; motherhood; *shidduchim*; and secrecy.