



Parents' representations and glycemic control among adolescents with type 1 diabetes

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Abstract

Background Parents of adolescents with type 1 diabetes mellitus (T1DM) experience major challenges as they cope with the adolescent-child disease. The current research investigated maternal and paternal representations of parents of adolescents diagnosed with T1DM, specifically, the association between parental representations and adolescents' glycemic control (A1C level).

Methods Seventy-five mothers and fathers of adolescents (13–18 years of age) diagnosed with T1DM (disease onset \geq 12 months) were recruited from a large medical center in Israel. Data were gathered from a demographic questionnaire, a blood test for A1C level, and the Parenting Representations Interview.

Results No significant correlations were found between A1C level and maternal representations or balanced narrative. However, for fathers, a negative correlation was found between A1C level and paternal representations of the self, representations of the child, and positive relationships; and between A1C level and balanced narrative.

Conclusions The association found between paternal positive representations and glycemic control and the lack of any significance association within mothers point to the differences between motherhood and fatherhood in the context of an adolescent with T1DM. Therefore, fathers should be addressed as significant caregivers in treatment at the clinical practice.

Keywords Parenting representation · Type 1 diabetes · Adolescents · A1C

Diabetes mellitus type 1 (also known as type 1 diabetes, T1DM, or juvenile diabetes) is one of the common autoimmune chronic diseases among children: 15,000 children are diagnosed each year in the United States (Juvenile Diabetes Research Foundation [JDRF] 2016). Their total dependence on an outside source of insulin has short- and long-term implications and is a life threat (Edgar and Skinner 2003).

The diagnosis of a chronic disease in a child compels reorganizing the everyday lives of the individual and his/her family (Melamed 2008). Moreover, during adolescence there are major biological, cognitive, and emotional changes that are challenging for adolescents and their parents (Scharf and Shulman 2006; Steinberg and Silk 2002). Adolescents spend less time with their parents and more time with peers (Lam et al. 2012), making it more difficult for parents to keep track and monitor their adolescents' whereabouts. Parents need to

adapt their parenting to support adolescents' growing need for autonomy, individuation, and more mutual relationships with their parents (Wray-Lake et al. 2010).

In the case of adolescents with T1DM, the complex treatment and new lifetime regime affect the routines of both child and parents, confronting the parents with the behavioral and emotional challenges that adolescence poses (Martz and Livneh 2007). Communication about disease management can bring additional and unique sources of conflict that can influence the adolescent's metabolic control (Anderson et al. 2002). An adolescent with T1DM is at risk for the complications of diabetes, which can be exacerbated by his or her need for individualization and independence (Silverstein et al. 2005). Therefore, the ability of parents to maintain positive relationships, based on trust and positive communication with their adolescent child, is important in preventing the acceleration of conflict about disease management and in promoting metabolic control (Ivey et al. 2009). Hence, from the time of receiving the child's diagnosis, parents seem to be at risk for negative affective outcomes (Landolt et al. 2005). Research on the contribution of parents to the quality of their child's diabetes self-treatment has found that parents' emotional support

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of the adolescent, acceptance of the disease, open communication, effective monitoring, and proper conflict resolution are likely to encourage the adolescent's adherence to the treatment regime and thus achieve a better blood-sugar balance (Goldberg and Wiseman 2016; Guill Liles and Juhnke 2008; Hilliard et al. 2013).

There has been greater understanding of mothers' caregiving to adolescents with diabetes; however, the research on fathers' experience of and role in diabetes management is relatively sparse. Paternal involvement has been found to be important in adolescent diabetes management (Shorer et al. 2011) and was associated with poorer glycemic control, with increased involvement of fathers in response to suboptimal glycemic outcomes (Hilliard et al. 2011). Yet, fathers' involvement (like mothers') declines during early adolescence, as their involvement influences or is influenced by their child's self-management (Hilliard et al. 2014). Lower psychological control and higher responsiveness of both fathers and mothers were associated with better treatment adherence during adolescence (Goethals et al. 2017). Finally, fathers' and mothers' stress was associated with depressive symptoms and A1C levels of adolescents with T1DM (Maas-van Schaaijk et al. 2013).

These recent findings may strengthen the need to further explore fathers' contribution to adolescents' outcomes, which may be addressed in clinical practice and within the family setting. Furthermore, the current research suggests that an examination of mothers' and fathers' inner worlds—how they perceive, understand, and interpret themselves as parents, their adolescent child's needs and behavior, and the parent–child relationship—is essential to better understanding their motivation, coping, and parenting practices when parenting an adolescent with T1DM.

Parenting representation

Bowlby (1982), the founder of attachment theory, pointed to two complementary and distinct behavioral systems—the attachment system, or the system by which the infant receives care; and the caregiving system, or the system by which the parent gives care and protection. Bowlby (1982) claimed that the behavioral system is governed by higher processes, namely representations—and, with regard to the caregiving behavioral system, “*parenting representations*.” These representations are expected to include a representation of the child, of the self as a caregiver, and of the parental goals expressed verbally and nonverbally (Bretherton and Munholland 1999). Parenting representations reflect the individual's early experience of being cared for (George and Solomon 2008) and are also influenced by other resources, for example, the child's health. Still, research on parenting representations with respect to adolescence is sparse and tends to focus on maternal

representations. It has been found that mothers' representations are associated with adolescent attachment patterns (Scharf et al. 2015) and predicted adolescents' psychosocial adjustment (Scharf et al. 2015). Moreover, there is a significant research focus on parenting resolution to child's diagnosis as a disease-specific representation and its association with child adjustment (Dolev 2006; Goldberg and Wiseman 2016), but there is little research with regard to general parenting representations in the context of child illness.

Parents perceive and interpret their children through these representations, which also guide the parents in their parenting practices and regulate their responses to and behavior with respect to different parenting situations, not necessarily linked to the disease (George and Solomon 2008). Hence, these representations are essential elements in any interventions developed and implemented with parents of children and adolescents (Scharf et al. 2015), especially for parents of children who have a disease.

The current research investigated maternal and paternal representations of parents of adolescents diagnosed with T1DM, specifically the association between parental representations and adolescents' glycemic control (A1C level). It was hypothesized that the more the parenting is characterized by positive representations, the better the glycemic control (lower A1C level), and that the more the parenting is characterized by negative representations, the poorer the glycemic control.

Method

Participants

The participants were mothers and fathers of adolescents with T1DM. The adolescents ($n = 75$) were 38 boys (50.7%) and 37 girls (49.3%). They ranged in age from 13 to 18 years, with an average age of 14.73 years ($SD = 1.57$). Most of the adolescents were born in Israel (95.8%). The adolescents had all been diagnosed with T1DM at least 12 months prior to their parents' participation in the study, and on average their disease had been diagnosed 6.63 years previously ($SD = 3.47$), at ages ranging from 1 to 16 years ($M = 9.06$, $SD = 3.58$).

Mothers ($n = 75$) ranged in age from 31 to 55 years, with an average age of 46.87 years ($SD = 4.93$). Of these, 70% were born in Israel, 11% were born in the former Soviet Union, and the remaining 19% were born in other countries (e.g., Spain, England, and France). The mothers' education level was heterogeneous: 31% had a high school education, 16% had post-high school education, 23% had bachelor's degrees, 20% had master's degrees, and 10% had doctoral degrees. Most of the mothers (76%) declared their income to be average, 22% said their income was above average, and only 2% said their income was below average.

Fathers ($n = 75$) ranged in age from 38 to 65 years, with an average age of 49.73 years ($SD = 4.85$). Of these, 68% were born in Israel, 5% were born in countries in the former Soviet Union, and the remaining 27% were born in various other countries (e.g., Morocco and Argentina). The education level of the fathers was heterogeneous: 35% had a high school education, 20% had post-high school education, 20% had bachelor's degrees, 14% had master's degrees, and 11% had doctoral degrees. Most of the fathers (54%) declared their income to be average, 42% said their income was above average, and only 4% said their income was below average.

All of the participating families were intact families. Sixty-nine percent defined themselves as religiously secular, 28% as traditional, and 3% as religious. The average number of children per family was 2.13 ($SD = .98$).

Procedure

The Helsinki committee at a large medical center approved the study. Families meeting the inclusion criteria (intact families and disease onset at a minimum of 6 months) were invited by the clinic staff and the Juvenile Diabetes Research Foundation of Israel to participate in the study. After the parents' initial informed consent, the researcher approached each parent. The families were told they would each be interviewed separately about their parenting at their home. Families were informed that their anonymity would be preserved throughout the study, that the data collected would be used for research purposes only, and that their names would remain confidential. They were also assured that they had the right to discontinue their participation in the study at any time, and were offered the option to receive the final general research findings. The parents signed informed consent forms to confirm their participation.

Measures

Demographic questionnaire This questionnaire included information regarding the disease (i.e., onset of T1DM), parents' marital status, gender and age of parents and adolescent, number of children in the family, birth order of the adolescent, parents' education level, and income level.

Glycosylated hemoglobin (A1C) A blood test is administered regularly to test the amount of glucose to which hemoglobin is bound (range in normal population 4–5.9). A1C level serves as an *objective* indication of the degree to which the disease is regulated (stability over time) because it is not affected by one-time deviations from the recommended treatment or regimen or by minor illnesses. The A1C test is commonly used to assess metabolic sugar stability; high levels indicate deficient metabolic stability (Martin et al. 1998). In the current study,

this indication was provided by the child's treatment clinic ($M = 7.95$, $SD = 1.17$) close to parents' scheduled interviews.

The Parenting Representations Interview—Adolescence (PRI—A)

This interview format introduced by Scharf and Maysless (1997/2000) is a semistructured interview designed to arouse memories and emotions with regard to parenting experiences with adolescent children. Parents were asked to give a general description of their relationships with their children and to support this description with specific incidents from childhood and adolescence. The interview included questions about experiences of closeness, pain, guilt, anger, worry, discipline and children's increasing autonomy, and the way parents handle these situations. In addition, parents were asked to describe how they see their children in the future and their anticipated future relationships with them. Interviews, which generally lasted about 60 min, were recorded and transcribed verbatim. Dimensions were coded based on coders' evaluation, using 5-point Likert scales referring to three general domains: (a) representations of the parent (parental competence, self-understanding, and self-sacrifice), (b) representations of the adolescent (trust/confidence in the child's capacities, child's understanding, elaborate perception of the child, and elaborate perception of the child in the future), and (c) representations of the parent-adolescent relationship (secure base, attention to physical needs, positive feelings, partnership and mutuality, granting of autonomy, monitoring, conflicts and power struggles, emphasizing achievement, idealization, indifference, acceptance of parental authority, and the nature of relationship with the child in the future). Qualities of negative emotionality (pain/difficulty, worry/fear, anger, guilt, inappropriate/inadequate boundaries, parentification/role-reversal, and intrusiveness) were also evaluated. Based on ratings of these dimensions, parents' quality of a balanced narrative (i.e., state of mind) was evaluated.

All interviews were coded by a trained coder (trained by Prof. Miri Scharf) blind to questionnaire data and to all identifying information. Ten randomly selected interviews were coded by two coders, yielding an agreement of 100% for classifications. Interclass reliability on the scales ranged from .87 to .98.

Due to high intercorrelation between the representations dimensions ($r = .82-.90$), and corresponding with a previous study (Scharf et al. 2015), the dimensions were aggregated to four major dimensions: *representation of self* (competence, self-understanding, and confidence), *representations of adolescent* (trust, child's understanding, elaborate current and future perception of the child), *positive relationships* (mutuality, granting of autonomy, secure base, monitoring, and positive feelings), and *negative emotionality* (pain, worry,

anger, and guilt). Correlations between maternal and paternal representations ranged from .32 to .45.

Results

No significant correlations were found between age at disease onset, years since diagnosis, and parenting representations and A1C level. Furthermore, no significant correlations were found between education level, parent's income, and the research variables. Therefore, age at disease onset, years since diagnosis, parent education level, and income were not treated as covariate variables while examining the hypothesis.

The research hypothesis was that positive representations would be negatively associated with A1C level, that negative representations would be positively associated with A1C level, and that coherent state of mind would be negatively associated with A1C level. We first performed partial correlations (controlling for adolescents' gender and age) between the study variables. Results of partial Pearson correlation tests showed no significant correlations between maternal representations and A1C level. However, for fathers, there was a negative correlation between A1C level and paternal representations of the self ($r = -.53, p < .001$), representations of the child ($r = -.61, p < .001$), and positive relationships ($r = -.40, p < .01$). Also, fathers' coherent state of mind was negatively correlated with A1C level ($r = -.59, p < .001$). As hypothesized, paternal positive representations and fathers' coherent state of mind are associated with better glycemic control and metabolic stability in adolescents.

Finally, no significant correlations were found between negative paternal emotionality representations and A1C level, as presented in Table 1.

Table 1 Correlations between parents' parenting representations dimensions and A1C Level ($N = 75$)

	A1C level
Mothers	
Representation of the self	.09
Representation of the child	.03
Positive relationships representations	.08
Negative emotionality	.18
Balanced narrative	-.11
Fathers	
Representation of the self	-.53***
Representation of the child	-.61***
Positive relationships representations	-.40**
Negative emotionality	-.08
Balanced narrative	-.59***

** $p < .01$ *** $p < .001$

Discussion

This research examined the association between parents' representations and A1C level (glycemic control) among adolescents with T1DM. The hypothesis suggested that positive representations would be negatively associated with A1C level and that negative representations would be positively associated with A1C level. Parents' quality of a balanced narrative was expected to be negatively associated with A1C level.

No relationship was found between maternal representations and balanced narrative with A1C level. This finding adds to earlier research that demonstrated an association between maternal resolution with disease (i.e., a disease-specific parental representation) and emotional adjustment, but *not* between maternal resolution with disease and adolescents' health or glycemic control (Goldberg and Wiseman 2016). Therefore, the significance of maternal representations during adolescence might be more emotional than physical. Also, parenting representations not only reflect the individual's early experience as being cared for but also are influenced by current experiences with the child's health (George and Solomon 2008). These two unrelated influences on parenting representations may blur any association between maternal representations and glycemic control; for example, positive childhood experience of the parent as being cared for yet, as a caregiver, the poor health of his or her child, and vice versa.

The results for fathers demonstrated, as hypothesized, that paternal positive representations are significantly related to A1C level. It was found that fathers' representations of the self as a parent, representations of the adolescent, positive representations of their relationship with the adolescent, and quality of a balanced narrative are associated with adolescents' better glycemic control. The findings regarding the nature and role of paternal representation add to those of a small number of studies focusing on fathers. Paternal involvement has been found to be important in adolescent diabetes management (Shorer et al. 2011), as fathers increase their involvement in response to suboptimal glycemic outcomes but are not necessarily involved in everyday treatment (Hilliard et al. 2011, 2014).

Yet, because of the current study's cross-sectional design, we cannot conclude that there is a causal effect between paternal representations and A1C. Hence, A1C levels as reflected in the child's health condition might affect the father's representations about himself as a parent, about his child, and about their relationship (George and Solomon 2008), while also influencing paternal stress (Maas-van Schaaijk et al. 2013).

The present findings strengthen the motivation for paternal caregiving to and involvement with the adolescent who has diabetes. A father's positive views of himself as a father, as competent; his understanding of his child's needs and feelings; and his striving to develop positive relationships based

on trust, mutuality, and autonomy minimize the potential high-conflict relationship between the adolescent with T1DM and the parent (Anderson et al. 2002; Silverstein et al. 2005), and might bring the adolescent to a better metabolic balance (Ivey et al. 2009). Furthermore, paternal caregiving representations might also be influenced by the child's health, the child's disease management, and his or her A1C level. Therefore, more balanced T1DM and a healthier child may contribute to a more positive representation of the father and a balanced description of his parenting, his child, and their relationship.

Implications

A small number of studies, most focused on mothers, explored parental representation among parents of adolescents. The current research shed light on the inner world of mothers and fathers of adolescents with T1DM, and addressed the potential bias in the preponderance of studies on mothers' contributions to adolescents' health and adjustment. Furthermore, the association found between paternal positive representations and glycemic control and the lack of any significance association within mothers point to the differences between motherhood and fatherhood in the context of an adolescent with T1DM. Therefore, fathers should be also addressed as significant caregivers in treatment at the clinical practice, and especially by diabetes health care providers.

Regimen adherence problems are common in individuals with diabetes, making glycemic control difficult to attain. Because the risk of complications of diabetes can be reduced by proper adherence, patient nonadherence to treatment recommendations is often frustrating for diabetes health care professionals. To improve patient adherence, it is important to understand why nonadherence occurs and what may contribute to a better adherence, and that parents may also be influenced by it.

Furthermore, health care providers should take into consideration both fathers' and mothers' states of mind and their respective caregiving representations, while trying to involve parents in any treatment targeted at achieving better glycemic control.

Limitations and future studies

Although the contribution of the study is significant, it has some limitations. The study was conducted in Israel, and the generalization of the results to other cultures needs to be explored. No data were collected regarding whether mothers or fathers were primary caregivers of adolescents or whether both were equally involved, or on the nature of treatment regime (e.g., insulin pump or injections). Most important, the current study has a cross-sectional design. Therefore, it is not possible to state any causal conclusions.

Future studies should be conducted in other cultures, expanding the response rate, and examining also the predictive role of parenting representations in the social domains of the adolescents using self-, parents', peers', and teachers' reports. Finally, we suggest designing a longitudinal study to determine whether any causal relationships exist between parenting representations and child health and adjustment.

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Compliance with ethical standards

There was no funding for the current research, and no conflict of interest. This research involves human participants. Hence, a Helsinki committee at a large medical center approved the study (titled: "The health and adjustment of adolescents with type 1 diabetes," protocol number 2357), and all participants signed informed consent forms to confirm their participation. Families were informed that their anonymity would be preserved throughout the study, that the data collected would be used for research purposes only, and that their names would remain confidential. They were also assured that they had the right to discontinue their participation in the study at any time.

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