

Serveur Académique Lausannois **SERVAL** serval.unil.ch

Author Manuscript

Faculty of Biology and Medicine Publication

This paper has been peer-reviewed but does not include the final publisher proof-corrections or journal pagination.

Published in final edited form as:

Title: Brief report: Maternal posttraumatic stress symptoms are related to adherence to their child's diabetes treatment regimen.

Authors: Horsch A, McManus F

Journal: Journal of health psychology

Year: 2014 Aug

Issue: 19

Volume: 8

Pages: 987-92

DOI: 10.1177/1359105313482169

In the absence of a copyright statement, users should assume that standard copyright protection applies, unless the article contains an explicit statement to the contrary. In case of doubt, contact the journal publisher to verify the copyright status of an article.

**Brief report: Maternal posttraumatic stress symptoms are related to adherence to their
child's diabetes treatment regimen**

Antje Horsch¹ and Freda McManus²

¹Service Universitaire de Psychiatrie de l'Enfant et de l'Adolescent (SUPEA), Unité de Recherche,
Lausanne, Switzerland

²Oxford Cognitive Therapy Centre, Warneford Hospital, Oxford, UK

Corresponding Author:

Antje Horsch, Service Universitaire de Psychiatrie de l'Enfant et de l'Adolescent (SUPEA), Unité de
Recherche, 25 A, Rue du Bugnon, CH-1011 Lausanne, Switzerland. Email: antje.horsch@chuv.ch

Acknowledgements: We would like to thank all participants.

Abstract

Although research suggests that PTSD symptoms in relation to physical health diagnoses may be related to poor adherence to treatment regimens, so far, whether parental PTSD symptoms have an impact on their child's adherence to IDDM treatment has not been investigated. Using self-report questionnaires, the present study found that children of mothers who have PTSD symptoms in relation to their child's diagnosis of type I diabetes showed poorer adherence to treatment than the children of mothers without PTSD. However, this was only the case for younger children (aged 0-8) where mothers played a more active part in their treatment.

Keywords

diabetes, PTSD, adherence, maternal, child, chronic illness

Brief report: Maternal posttraumatic stress symptoms are related to adherence to their child's diabetes treatment regimen

Introduction

Type I diabetes, or insulin dependent diabetes mellitus (IDDM), is the most common endocrine disorder of childhood (Department of Health, 2007). Parents of children with IDDM are faced with having to learn how to check blood glucose levels several times a day, inject appropriate types and amounts of insulin on a round the clock schedule and continually monitor the child's diet and exercise (Diabetes UK, 2010). Furthermore, parents are expected to acquire a sophisticated understanding of the disease process in order to effectively respond to potentially life-threatening situations, such as hyper- or hypoglycaemia and ketoacidosis. Perhaps unsurprisingly, increased parental and family stress, and lower parental self-esteem, efficacy and satisfaction, have been reported (Helgeson et al., 2012; Lewin et al., 2005; Mitchell et al., 2009; Sullivan-Bolyai et al., 2002). Parents also report posttraumatic stress symptoms triggered by their child's IDDM (Horsch et al., 2007; Horsch et al., 2012; Landoldt et al., 2002).

Recent research has suggested that PTSD symptoms in relation to physical health diagnoses may be related to poor adherence to treatment regimens. For example, Shemesh et al. (2000, 2001) found a relationship between PTSD symptoms and non-adherence in paediatric liver transplant recipients and survivors of a myocardial infarction. Implementation of a trauma-focused intervention successfully treated non-adherence in paediatric patients (Shemesh et al., 2006). The authors argued that patients suffering from PTSD related to their illness may not take the prescribed medication because it serves as a recurrent reminder of the traumatic experience, its complications and associated morbidity (Shemesh et al., 2004). An exception to this is a study of adults with type I diabetes that found that PTSD symptoms were not significantly related to

glycemic control (Myers et al., 2007). Nevertheless, it has been demonstrated that re-exposure of cancer patients to cues associated with the treatment can elicit strong aversion responses, intrusive thoughts, nightmares about treatment, and attempts to avoid reminders of both diagnosis and treatment (Redd et al., 1994). Thus it is possible that parental PTSD symptoms may have an impact on their child's adherence to IDDM treatment.

Factor analyses find five components of adherence in childhood diabetes: eating/testing frequency; exercise; injections; diet type; and diet amount (Johnson et al., 1990). Previous research has shown the following factors to be relevant in predicting treatment adherence in children with IDDM: parenting style; child's age, duration of diabetes, diabetes knowledge, child's health beliefs, and coping strategies; family size, stress, conflict, cohesion and communication (Charron-Prochownik et al., 1993; Davis et al., 2001; Delamater et al., 2001; Hauser et al., 1990; Miller-Johnson et al., 1994; Reid et al., 1994). Glycaemic control is typically assessed by using the HbA_{1C} (Glycosylated haemoglobin A_{1C}) index, which reflects integrated diabetic control over the previous 6-8 week period. Studies commonly find a significant inverse relationship between HbA_{1C} and treatment adherence (e.g. Morris et al., 1997). Although several studies have identified a relationship between parental stress and poor glycemic control for the child (Cameron et al., 2007; Cunningham et al., 2011; Helgeson et al., 2012; Streisand et al., 2005), so far no study has looked more closely at the specific nature of this stress.

Hence, the present study examines the hypothesis that the children of mothers who have PTSD symptoms in relation to their child's diagnosis of IDDM will show poorer adherence to treatment than the children of mothers who do not have PTSD symptoms in relation to their child's diagnosis. Given that children assume greater responsibility for their diabetes care with increasing age (e.g. Keough et al., 2011), the relationship between adherence and maternal PTSD

symptoms is only expected to be present for younger children (where mothers play an active role in their child's treatment) but not for older children (where mothers are less involved).

Method

Participants and Procedure

One hundred fifty mothers of children under the age of 16 who had been diagnosed with T1DM for at least one month and up to five years were contacted. The final sample consisted of 60 mothers who completed a structured clinical interview and self-report questionnaires (participants and methods are described in detail in Horsch et al., 2007).

Measures

Structured Clinical Interview-DSM-IV-PTSD module (SCID; First et al., 1995). The SCID-PTSD module is a standardised diagnostic interview consisting of 17 items, which was used to assess current DSM-IV-TR (APA, 2000) PTSD criteria. Good inter-rater reliability (.85), sensitivity and specificity, and very good diagnostic accuracy (82%) have been found when trained clinicians used the SCID (Ventura et al., 1998).

The Posttraumatic Stress Diagnostic Scale (PDS; Foa, 1995; Foa et al., 1997). The PDS is a 17-item self-report questionnaire measuring PTSD symptom severity as well as PTSD diagnosis according to DSM-IV-TR criteria. It has high internal consistency ($\alpha = .92$) and good test-retest reliability ($\alpha = .74$) (Foa et al., 1997). In this study, participants were specifically requested to rate their current PTSD symptoms in relation to the diabetes-related traumatic stressor that had been identified in the clinical interview (see Horsch et al., 2012 for a detailed description of how the stressor was identified). They were asked to rate how often they experienced each of the PTSD symptoms in the past month, using a 4-point Likert frequency

scale ranging from *not at all or only one time* to *five times per week or almost always*. Total scores range from *mild* (≤ 10), *moderate* (11–20), *moderate to severe* (21–35) to *severe* (≥ 36). A symptom was rated as present when the item corresponding with the symptom was rated 1 or greater (Foa and Meadows, 1997).

Family Responsibility Questionnaire (FRQ; La Greca et al., 1990). The FRQ has six items which measure the degree of the child's and mother's responsibility for the child's diabetes management. Items cover: testing daily glucose, charting daily glucose, measuring insulin, administering insulin, content of diet and scheduling of meals. Mothers complete the FRQ by rating each item from 1 = *mother assumed all responsibility*, through 3 = *the mother and child equally shared responsibility* to 5 = *child assumed all responsibility*. Thus high total scores indicate that the child assumes responsibility for care, whereas low scores indicate that the mother assumes responsibility for care. Good internal reliability in a sample of children with IDDM has been demonstrated, with a Cronbach's $\alpha = .78$ (La Greca et al., 1990).

The Adherence and IDDM interview (AII; Hanson et al., 1987). This 15-item interview measures treatment adherence across the areas identified as crucial by the American Diabetes Association and researchers of adherence behaviours: diet, insulin adjustment, hypoglycaemia and glucose testing (Wing et al., 1986). However, piloting for the present study resulted in the exclusion of two items (regular testing of urine and weighing of food/use of exchanges to regulate the child's diet) as paediatricians reported these practices to be uncommon in the UK. We therefore used a version with 13 items, with higher scores indicating greater adherence to treatment. Thompson et al. (2001) report good internal consistency in a sample of children with IDDM (Cronbach's $\alpha = .70$).

Glycemic control. Information regarding HbA_{1C} was extracted from the children's hospital notes. HbA_{1C} test results are expressed as percentages, with 3.0 to 6.5 per cent considered as normal.

Results

Reporting on the same sample, Horsch et al. (2007) found 10% of mothers to meet criteria for the diagnosis of PTSD, and a further 15% to meet criteria for the partial diagnosis (i.e., two out of three symptom clusters present). The mean total score (frequency) for the PDS was 8.20 ($SD = 8.90$) (see Horsch et al., 2007 for more details). The mean score for the FRQ was 15.71 ($SD = 8.39$). The number of mothers who reported on the FRQ that they assumed full responsibility for different aspects of treatment were: 21 (35.0%) for testing daily glucose levels, 21 (35.0%) for charting daily glucose levels, 23 (38.3%) for measuring insulin, 22 (36.7%) for administering injections, 32 (53.3%) for diet content and 32 (53.3%) for scheduling of meals. As expected, FRQ scores were significantly correlated with the age of the child ($n = 60$; $r = 0.856$, $p < .001$), indicating that, with increasing age, children assumed more responsibility for their diabetes management. The mean total score for the Hanson-IDDMM interview was 25.25 ($SD = 5.64$; range = 12.00 – 35.00) and the mean HbA_{1C} at the time of interview was 8.6% ($SD = 1.29$; range = 6.8% – 11.9%).

Considering the sample as a whole, a non-significant relationship between current PTSD symptoms and treatment adherence, as measured by the Hanson IDDM total score (Pearson correlation: $r = -.115$; $p = .190$) and HbA_{1C} at the time of interview (Pearson correlation: $r = -.160$; $p = .111$) was shown. To investigate the post-hoc hypothesis that maternal PTSD symptoms are related to treatment adherence for the younger but not for the older children, the sample of

mothers of children with IDDM was split into 'older' and 'younger' groups according to whether the child with diabetes was aged 0–8 years ($n = 21$) or aged 9-16 years ($n = 39$), and each age group was analysed separately using Pearson correlations. For the mothers of younger children, maternal PTSD symptoms (as measured by PDS scores) were significantly correlated with adherence as measured by both the AII ($n = 21$; $r = -.519$ $p = .008$) and by the HbA_{1c}, ($n = 21$; $r = .429$ $p = .026$). This was not the case for the older age group where mothers' PDS scores were not significantly correlated with either the AII scores ($n = 39$; $r = .062$ $p = .354$) or HbA_{1c}, scores ($n = 39$; $r = -.080$ $p = .315$). A Mann-Whitney test was performed to test for differences in adherence between mothers with and without a diagnosis of PTSD. A significant difference between mothers with and without a diagnosis of PTSD was found for treatment adherence ($n = 21$; $U = 4.500$, $p = .009$) as well as HbA_{1c}, scores ($n = 21$; $U = 7.500$, $p = .002$) for the younger but not for the older group of children ($n = 39$; $U = 30.500$, $p = .350$ for adherence; $n = 39$; $U = 30.000$, $p = .350$ for HbA_{1c}, scores).

Discussion

The present study is the first to examine the relationship between PTSD symptoms/diagnosis in mothers and adherence to their child's diabetes treatment regime. Consistent with previous research, results confirmed that mothers' responsibility for the diabetes management significantly decreased with the age of their child. With regard to the impact of maternal PTSD on adherence, a non-significant relationship between current PTSD symptoms and treatment adherence in the sample as a whole was found. However, PTSD symptoms were significantly negatively correlated with treatment adherence measures for the younger (aged 0–8) but not for the older children (9-16). Thus, a positive relationship between mothers' PTSD

symptoms/diagnosis and treatment adherence was only found for younger children where mothers assumed more responsibility for the management of their child's diabetes.

The results add to the findings by Shemesh et al. (2000), who reported that adherence problems in children who had received a liver transplant were significantly correlated with their PTSD symptoms and with avoidance symptoms in particular. However, they somewhat contradict the findings by Myers et al. (2007) who reported that PTSD symptoms in adults with type I diabetes were not significantly related to glycemic control.

When considering the results of the study, attention has to be paid to the fact that the relationship between mothers' PTSD symptoms/diagnosis and treatment adherence was only established on the basis of correlational analyses and non-parametric significance tests. Other study limitations are the small sample size, the relatively low response rate (42.4%) and the neglect of the role of fathers in their child's diabetes management. Furthermore, the Adherence and IDDM Interview is a subjective measure of adherence and its validity with only 13 items has not been tested. However, the results of this study suggest that identifying and offering help to mothers who develop PTSD symptoms in relation to their child's IDDM might be one avenue to improve their adherence to their child's treatment regimen, particularly for younger children. Future research could helpfully replicate current findings in a larger cohort and include the perspective of fathers.

References

American Psychiatric Association (2000) *Diagnostic and Statistical Manual of Mental Disorders* (4th edn; DSM-IV-TR). Washington, DC: American Psychiatric Association.

- Cameron, LD, Young, MJ and Wiebe, DJ (2007) Maternal trait anxiety and diabetes control in adolescents with type I diabetes. *Journal of Pediatric Psychology*, 32, 733-744.
- Charron-Prochownik, D, Becker, MH, Brown, MB, Liang, WM and Benn, S (1993) Understanding young children's health beliefs and diabetes regimen adherence. *Diabetes Education*, 19, 409-418.
- Cunningham, NR, Vesco, AT, Dolan, LM and Hood, KK (2011) From caregiver psychological distress to adolescent glycemic control: The mediating role of perceived burden around diabetes management. *Journal of Pediatric Psychology*, 36, 196-205.
- Davis, CL, Delamater, AM, Shaw, KH, La Greca, AM, Eidson, MS, Perez-Rodriguez, JE and Nemery, R (2001) Parenting styles, regimen adherence, and glycemic control in 4- to 10-year-old children with diabetes. *Journal of Pediatric Psychology*, 26, 123-129.
- Delamater, AM, Jacobson, AM, Anderson, BJ, Cox, D, Fisher, L, Lustman, P, Rubin, R and Wysocki, T (2001) Psychosocial therapies in diabetes: report of the Psychosocial Therapies Working Group. *Diabetes Care*, 24, 1286-1292.
- Department of Health (2007) *Making every young person matter*.
www.diabetes.org.uk/Documents/Reports/MakingEveryYoungPersonMatter.pdf
- Diabetes UK (2010) *Diabetes in the UK: Key statistics*.
http://www.diabetes.org.uk/Documents/Reports/Diabetes_in_the_UK_2010.pdf
- First, MB, Spitzer, RL, Gibbon, M and Williams, JBW (1995) *Structured Clinical Interview for DSM-IV Axis I Disorders – Patient Edition (SCID-I/P, Version 2.0)*. New York: Biometrics Research Department of the New York State Psychiatric Institute.

- Foa, EB (1995) *The Posttraumatic Diagnostic Scale (PDS) Manual*. Minneapolis: National Computer Systems, Inc.
- Foa, EB, Cashman, L, Jaycox, L and Perry, K. (1997) The validation of the self-report measure of posttraumatic stress disorder: The Posttraumatic Diagnostic Scale. *Psychological Assessment, 9*, 445–451.
- Foa, EB and Meadows, EA (1997) Psychosocial treatments for posttraumatic stress disorder: A critical review. *Annual Review of Psychology, 48*, 449–480.
- Hanson, CL, Henggeler, SW and Burghen, GA (1987) Model of associations between psychosocial variables and health-outcome measures of adolescents with IDDM. *Diabetes Care, 10*, 752-758.
- Hauser, ST, Jacobson, AM, Lavori, P, Wolfsdorf, JI, Herskowitz, RD, Milley, JE, Bliss, R, Wertlieb, D and Stein, J (1990) Adherence among children and adolescents with insulin-dependent diabetes mellitus over a four-year longitudinal follow-up. *Journal of Pediatric Psychology, 15*, 527-542.
- Helgeson, VS, Reynolds, KA, Siminerio, L, Escobar, O and Becker, D (2008) Distribution of parent and adolescent responsibility for diabetes self care: Emerging impact of shared responsibility. *Journal of Pediatric Psychology, 33*, 497-508.
- Helgeson, VS, Becker, D, Escobar, O and Siminerio, L (2012) Families with children with diabetes: Implications of parent stress for parent and child health. *Journal of Pediatric Psychology, 37*, 467-478.

- Horsch, A, McManus, F and Kennedy, P (2012) Cognitive and non-cognitive factors associated with posttraumatic stress symptoms in mothers of children with type 1 diabetes mellitus. *Behavioural and Cognitive Psychotherapy*, 40, 400-411.
- Horsch, A, McManus, F, Kennedy, P and Edge, J (2007) Anxiety, depressive and posttraumatic stress symptoms in mothers of children with type I diabetes. *Journal of Traumatic Stress*, 20, 881-891.
- Keough, L, Sullivan-Bolyai, S, Crawford, S, Schilling, L and Dixon, J (2011) Self-management of type I diabetes across adolescence. *Diabetes Educator*, 37, 486-500.
- La Greca, AM, Follansbee, D and Skyler, JS (1990) Developmental and behavioural aspects of diabetes management in youngsters. *Children's Health Care*, 19, 132-139.
- Landolt, MA, Ribbi, K, Laimbacher, J, Vollrath, M, Gnehm, HE and Sennhauser, FH (2002) Brief report: posttraumatic stress disorder in parents of children with newly diagnosed IDDM. *Journal of Pediatric Psychology*, 27, 647-652.
- Lewin, AB, Storch, EA, Silverstein, JH, Baumeister, AL, Strawser, MS and Geffken, GR (2005) Validation of the Pediatric Inventory for Parents in mothers of children with type I diabetes: An examination of parenting stress, anxiety, and childhood psychopathology. *Families, Systems & Health*, 23, 56-65.
- Miller-Johnson, S, Emery, RE, Marvin, RS, Clarke, W, Lovinger, R and Martin, M (1994) Parent-child relationships and the management of insulin-dependent diabetes mellitus. *Journal of Consulting and Clinical Psychology*, 62, 603-610.

- Mitchell, SJ, Hiliard, ME, Mednick, L, Henderson, C, Cogen, FR and Streisand, R (2009) Stress among fathers of young children with type I diabetes. *Families, Systems and Health*, 27, 314-324.
- Morris, AD, Boyle, DIR, McMahon, AD, Greene, SA, MacDonald, TM and Newton, RW (1997) Adherence to insulin treatment, glycaemic control, and ketoacidosis in insulin-dependent diabetes mellitus. *Lancet*, 350, 1505-1510.
- Myers, VH, Boyer, BA, Herbert, JD, Barakat, LP and Scheiner, G (2007) Fear of hypoglycemia and self reported posttraumatic stress in adults with type I diabetes treated by intensive regimens. *Journal of Clinical Psychology in Medical Settings*, 14, 11–21.
- Redd, WH, Dadds, MR, Futterman, AD, Taylor, KL and Bovbjerg, DH (1994) Nausea induced by mental images of chemotherapy. *Cancer*, 73, 756.
- Reid, GJ, Dubow, EF, Carey, TC and Dura, JR (1994) Contribution of coping to medical adjustment and treatment responsibility among children and adolescents with diabetes. *Journal of Deviant Behavioral Pediatrics*, 15, 327-335.
- Shemesh, E, Shneider, BL, Stuber, ML (2000) A pilot study of symptoms of posttraumatic stress disorder and non-adherence in pediatric liver transplant recipients. *Pediatrics*, 105, 1-7.
- Shemesh, E, Rudnick, A, Kaluski, E, Milovanov, O, Salah, A and Alon, D (2001) A prospective study of posttraumatic stress symptoms and non-adherence in survivors of a myocardial infarction. *General Hospital Psychiatry*, 23, 215-222.

- Shemesh, E, Yehuda, R, Milo, O, Dinur, I, Rudnick, A, Vered, Z and Cotter, G (2004) Posttraumatic stress, nonadherence, and adverse outcomes in survivors of a myocardial infarction. *Psychosomatic Medicine*, 66, 521-526.
- Shemesh, E, Koren-Michowitz, M, Yehuda, R, Milo-Cotter, O, Murdock, E, Vered, Z, Shneider, BL, Gorman, JM and Cotter, G (2006) Symptoms of posttraumatic stress disorder in patients who have had a myocardial infarction. *Psychosomatics*, 47, 231-239.
- Streisand, R, Swift, E, Wickmark, T, Chen, R and Holmes, CS (2005) Pediatric parenting stress among parents of children with type I diabetes: The role of self-efficacy, responsibility, and fear. *Journal of Pediatric Psychology*, 30, 513-521.
- Sullivan-Bolyai, S, Deatrck, J, Gruppuso, P, Tamborlane, W and Grey, M (2002) Mothers' experiences raising young children with type 1 diabetes. *Journal of the Society of Pediatric Nursing*, 7, 93-103.
- Thompson, SJ, Auslander, WF and White, NH (2001) Comparison of single-mother and two-parent families on metabolic control of children. *Diabetes Care*, 24, 234-238.
- Ventura, J, Liberman, RP, Green, MF, Shaner, A and Mintz, J (1998) Training and quality assurance with the Structured Clinical Interview for DSM-IV (SCID-I/P). *Psychological Research*, 79, 163-173.
- Wing, RR, Epstein, LH, Nowalk, MP and Lamparski, DM (1986) Behavioural self-regulation in the treatment of patients with diabetes mellitus. *Psychological Bulletin*, 99, 78-89.