

# Diabetes Distress and Marriage in Type-1 Diabetes

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## Abstract

**Background:** In spite of the large number of people with Type-1 diabetes mellitus (T1DM) in India, India is not a diabetes-friendly society. The society suffers from lots of myths regarding diabetes and insulin use. This review highlights challenges faced by young people living with T1DM with regards to marriage, associated diabetes distress, and suggests potential solutions. **Methods:** PubMed, Medline, and Embase search for articles published up to October 2017, using the terms “marriage” (MeSH Terms) OR “diabetes distress” (All Fields) OR “depression” (All Fields) AND “diabetes” (All Fields). The reference lists of the articles thus identified were also searched. The search was not restricted to English-language literature. **Results:** Misconception regarding social, occupational, marital abilities, fertility, genetics, quality of life, sexism in young people living with T1DM raises major barriers to marriage, resulting in significant diabetes distress, depression, and psychological issues in them. People with T1DM are wrongly assumed to be sick, disabled, dependent persons, unsuitable for marriages, and likely to have complicated pregnancies with the possibility of having children with diabetes. Counseling at the level of individual, spouse, family, and society can help in obviating such issues. **Conclusion:** Diabetes distress and psychological issues are major problems related to marriage in young people with T1DM. Counseling of patients, family, relatives, prospective spouse, and increasing social awareness regarding diabetes through mass communication are the keys to their resolution.

**Keywords:** Challenges, counseling, India, marriage, relationships, spouse, Type 1 diabetes

## INTRODUCTION

The prevalence of diabetes and prediabetes in India is believed to be 10% and 15%, respectively.<sup>[1,2]</sup> The large majority of this is Type-2 diabetes mellitus (T2DM). It must be highlighted that according to the International Diabetes Federation 2015 report, India, comes second among the top three countries in world with people living with T1DM.<sup>[3]</sup> It is estimated that India is housing approximately 97,700 children with T1DM.<sup>[4]</sup> A 3%–5% per annum increase in the incidence of T1DM has been reported.<sup>[5]</sup> In India, the average prevalence of T1DM is believed to be 10.20 cases/100,000 persons each year.<sup>[6,7]</sup>

In spite of the large number of people diabetes living in India, India is not a diabetes-friendly society. Significant myths exist in persons with diabetes, their family members and general public about the disease, its impact on their health and their capacity to perform day-to-day activities in society. Moreover, India continues to be a “prick sensitive” society. There are lots of misconceptions with the use of insulin injections. It is

almost a shock for the patient as well as for the family when the person is prescribed insulin therapy for managing diabetes.<sup>[8]</sup> The aim of this article is to highlight these issues and suggest potential solutions to them.

## METHODS

PubMed, Medline, and Embase search for articles published up to October 2017, using the terms “marriage” (MeSH Terms) OR “diabetes distress” (All Fields) OR “depression” (All Fields) AND “diabetes” (All Fields). The reference lists of the articles thus identified were also searched. The search was not restricted to English-language literature.

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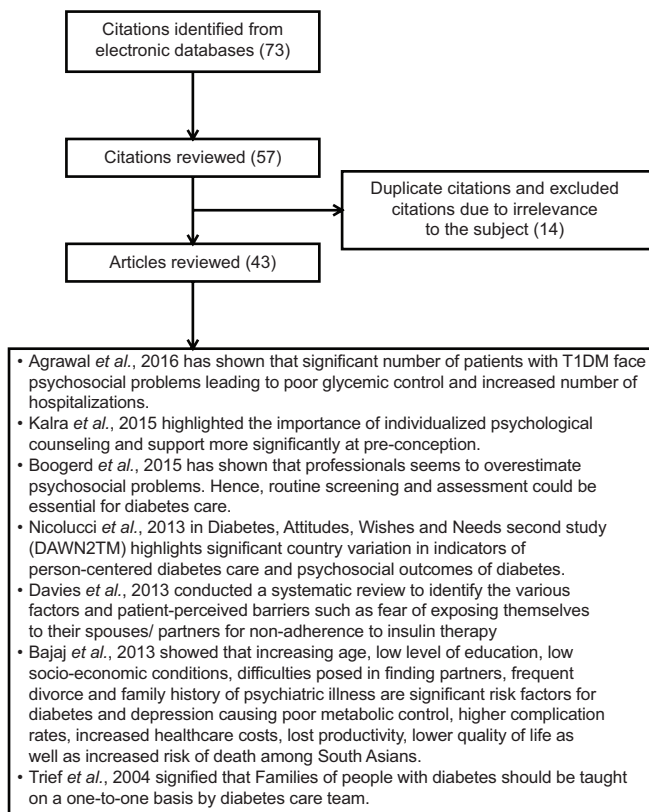
## RESULTS

Thirty-six numbers of articles were reviewed, which included, 21 original work, 9 review articles, 1 book chapter, and 1 systemic review. The key information obtained from these articles has been summarized in Figure 1.

### Social challenges of Type-1 diabetes mellitus management in India

There remain unique social challenges of managing T1DM in South East Asian countries like India, for patients, for their family members as well as for diabetes care team. Family members generally avoid disclosing the disease state among relatives and society due to social stigma and fear attached to T1DM. This is more so for the female patients due to marital concerns.<sup>[8,9]</sup> Furthermore, persons living with diabetes on insulin therapy do not feel comfortable to inject insulin in public places such as social function/gathering. Patients from their early childhood and teenage tends to develop a negativity and start becoming socially isolated.

Psychosocial problems are observed in almost 20% of children with T1DM in India, which are often ignored in clinical practice and responsible for poor glycemic control and increased number of hospitalizations.<sup>[10,11]</sup> The gaps between the expectations in life and reality, the resistance faced in the society, the associated mental agony, contributes to “diabetes distress” which has an adverse impact on glycemic control and overall quality of life of an individual living with T1DM.



**Figure 1:** Study protocol and flow of articles reviewed

### Transitional phase: childhood to adulthood

Adolescence age other than physical and pubertal growth is marked with an understanding of physical or emotional changes and making social relationships, including relationships with parents/caregivers, friends, and romantic partners. Most young adults experience multiple transitions during this developmental period while shifting relationships with family members, friends, and intimate partners.<sup>[12]</sup> Such changes in persons with diabetes may affect overall glycemic control with potential short- and long-term complications.<sup>[13]</sup>

Many young adults with diabetes lack normal aspects of peer relationships which hampers the smooth transition to adulthood, especially among females.<sup>[14]</sup> Persons with diabetes experience more negative social experiences in forming close relations. In addition, the absence of supportive relationships may impact diabetes management.<sup>[15]</sup> The diabetes attitudes, wishes, and needs second study (DAWN2) highlights significant country variation in indicators of person-centered diabetes care and psychosocial outcomes of diabetes.<sup>[16]</sup>

### Marital challenges

Persons with T1DM face many marital challenges, which may be disease related, social or psychological factors<sup>[17]</sup> [Table 1]. The people with diabetes face disparities in finding a good match for marriage.<sup>[8,9]</sup> A girl with diabetes is not preferred owing to wrong beliefs regarding physical and reproductive health.<sup>[9]</sup> People with Type 1 diabetes are wrongly perceived as sick, disabled, dependent persons with reduced life expectancy, unsuitable for marriages and likely to have complicated pregnancies with the possibility of having children with diabetes.<sup>[8,18,19]</sup> Many persons with diabetes prefer to remain single and unmarried especially if marriage is planned late. They may have a fear of exposing themselves to their spouses/

**Table 1: Marital challenges for persons with type 1 diabetes**

A. Disease-related
Poor glycemic control
Nocturnal hypoglycemias
Diabetes complications
Sexual dysfunction/hypoactive sexual desire/erectile dysfunction
Issues with fertility
Pregnancy complications
B. Social/family related
Disclosing diagnosis
Social discrimination/isolation
Job discrimination
Financial burden
Nonacceptance by society
Difficulty in finding suitable partner/match as per expectation
Poor family support
C. Psychological
Fear of disease acceptance by spouse/family members
Fear regarding satisfactory sexual life
Fear of hypoglycemia during intimate moments

partners regarding day-to-day challenges such as necessity of using syringes, hypoglycemic incidences, and complications.<sup>[20]</sup> The chances of unsuccessful marriages are also high in case of arranged marriages, especially among girls.<sup>[9]</sup>

### Risk in offspring

An important misbelief among society is that offspring of T1DM persons are likely to suffer T1DM, especially for females with T1DM. The key point to be highlighted is that the absolute risk is actually very small. In fact, studies have consistently shown that most persons (>85%) with T1DM do not have a first degree relative with disease.<sup>[21]</sup> In addition, the eugenics of T1DM is contrary to societal belief,<sup>[22]</sup> as the risks of having a child with T1DM are higher if the father is suffering from T1DM (4.6%) as compared to the mother (2%); although the absolute risk is small in both the cases. The risk increases further if both parents are having T1DM (10%). These issues need to be discussed and highlighted while counseling persons with T1DM, their partners and family members.

### Planning marriage and postmarriage

Lack of understanding about disease may result in couples' reluctance to collaborate and conflicts and may increase anxiety and negative experiences,<sup>[23,24]</sup> and further impacts collaborative management and marital relationships in persons with T1DM. Further emotional aspects and sexual concerns may cause fear and anxiety about future, and fluctuations in mood.<sup>[25]</sup>

Many persons with T1DM may be suffering from sexual dysfunction especially those with long-standing disease, or with associated hypertension or neuropathy. Several studies have indicated a higher prevalence of sexual dysfunction among both men and women with T1DM as compared to healthy age-matched controls. There is established relationship between marital relation, sexual dysfunction, and depression.<sup>[26]</sup> It is very important to look for depressive symptoms, partner-related factors, and individual perception of sexuality.<sup>[27,28]</sup> Persons with T1DM and their spouses should be evaluated and counseled properly to discuss and report their sexual problems. Most issues can be resolved smoothly such as biomedical treatment of atrophy and lubrication difficulties, as well as treatment of comorbidities and/or sex therapy.

### Counseling

Diabetes care team has very important role in counseling of persons with T1DM, their spouses and family members as well as in the society. Creating more awareness and discussion can resolve many queries and change the lives of many persons with T1DM. Counseling needs to be modified based on educational level, life stage, and religious and cultural beliefs.<sup>[29]</sup>

### Individual level

Counseling related to relationship and marital issues should be an integral part of diabetes education and should be started early in life at an appropriate age in a social-friendly manner.<sup>[30]</sup> The young adults should be counseled to become aware of their own capacities, shortcomings, emotional reactions, and reflections.<sup>[31]</sup> They should be taught to manage day-to-day

stressful situations and counseled about the ways to live well with this disorder especially after marriage.<sup>[9]</sup>

### Family/spousal level

The DAWN2 study necessitates the involvement of family members for the improvement of glycemic control.<sup>[32]</sup> The family involvement and responsibility for diabetes care significantly determines metabolic outcomes in people with diabetes.<sup>[33]</sup> Families of people with diabetes should be taught on a one-to-one basis by diabetes care team.<sup>[34]</sup>

Future partners should be acknowledged about the problems and management of diabetes. Both partners should fully understand diabetes, its complications and management. The spousal support and responsibility about the disease and its management has shown better treatment adherence, illness adaptation, and blood glucose control among patients.<sup>[35]</sup> Satisfied marital relationships also overcome the feeling of physical illness, decrease diabetes-specific emotional distress, and improve quality of Life.<sup>[36-38]</sup>

Health-care providers should counsel patients, their partners and their families about planning pregnancy and prepregnancy care in a positive and supportive manner.<sup>[39]</sup> and should be reassured that a person with diabetes have proper sexual and reproductive development and women with T1DM can have normal pregnancy and lead a normal life thereafter with proper care.<sup>[9]</sup> The patient, partner and family should be emphasized the importance of good glycemic and metabolic control prepregnancy and throughout pregnancy. The risks associated with pregnancy for maternal and fetal health needs to be discussed.<sup>[40,41]</sup>

### Society level

The societal acceptance of diabetes is influenced by the culture in which people live.<sup>[42]</sup> In South Asian countries like India, knowledge and awareness about T1DM in general population is very poor. Awareness in society can be promoted through mass educational aids such as media, seminars, pamphlets, posters, and small group discussions.<sup>[9,28]</sup> Studies have shown that, peer group intervention approaches and involvement may positively influence adolescents' diabetes care and self-perception through social adjustment and support.<sup>[43]</sup>

## CONCLUSION

Diabetes care professionals should counsel T1DM patients, their families and prospective spouses about marriage and impact of T1DM on married life in a supportive manner.

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## REFERENCES

1. Dutta D, Mukhopadhyay S. Intervening at prediabetes stage is critical to controlling the diabetes epidemic among Asian Indians. *Indian J Med*

- Res 2016;143:401-4.
2. Dutta D, Mukhopadhyay S. Comment on Anjana *et al.* Incidence of diabetes and prediabetes and predictors of progression among Asian Indians: 10-year follow-up of the Chennai urban rural epidemiology study (CURES). *Diabetes care* 2015;38:1441-1448. *Diabetes Care* 2015;38:e146.
  3. International Diabetes Federation. IDF Diabetes Atlas. 7th ed. Brussels, Belgium: International Diabetes Federation; 2015. Available from: <http://www.diabetesatlas.org>. [Last accessed on 2018 Aug 08].
  4. Kumar KM. Incidence trends for childhood type 1 diabetes in India. *Indian J Endocrinol Metab* 2015;19:S34-5.
  5. Das AK. Type 1 diabetes in India: Overall insights. *Indian J Endocrinol Metab* 2015;19:S31-3.
  6. Kalra S, Kalra B, Sharma A. Prevalence of type 1 diabetes mellitus in Karnal district, Haryana state, India. *Diabetol Metab Syndr* 2010;2:14.
  7. Praveen PA, Madhu SV, Mohan V, Das S, Kakati S, Shah N, *et al.* Registry of youth onset diabetes in India (YDR): Rationale, recruitment, and current status. *J Diabetes Sci Technol* 2016;10:1034-41.
  8. Kesavadev J, Sadikot SM, Saboo B, Shrestha D, Jawad F, Azad K, *et al.* Challenges in type 1 diabetes management in South East Asia: Descriptive situational assessment. *Indian J Endocrinol Metab* 2014;18:600-7.
  9. Bajaj S, Jawad F, Islam N, Mahtab H, Bhattarai J, Shrestha D, *et al.* South Asian women with diabetes: Psychosocial challenges and management: Consensus statement. *Indian J Endocrinol Metab* 2013;17:548-62.
  10. Agrawal J, Kumar R, Malhi P, Dayal D. Prevalence of psychosocial morbidity in children with type 1 diabetes mellitus: A survey from Northern India. *J Pediatr Endocrinol Metab* 2016;29:893-9.
  11. Boogerd EA, Damhuis AM, van Alfen-van der Velden JA, Steeghs MC, Noordam C, Verhaak CM, *et al.* Assessment of psychosocial problems in children with type 1 diabetes and their families: The added value of using standardised questionnaires in addition to clinical estimations of nurses and paediatricians. *J Clin Nurs* 2015;24:2143-51.
  12. Trast J. CE: Diabetes and puberty: A glycemic challenge. *Am J Nurs* 2014;114:26-35.
  13. Monaghan M, Helgeson V, Wiebe D. Type 1 diabetes in young adulthood. *Curr Diabetes Rev* 2015;11:239-50.
  14. Helgeson VS, Mascatelli K, Reynolds KA, Becker D, Escobar O, Siminerio L. Friendship and romantic relationships among emerging adults with and without type 1 diabetes. *J Pediatr Psychol* 2015;40:359-72.
  15. Pyatak EA, Sequeira PA, Whittlemore R, Vigen CP, Peters AL, Weigensberg MJ, *et al.* Challenges contributing to disrupted transition from paediatric to adult diabetes care in young adults with type 1 diabetes. *Diabet Med* 2014;31:1615-24.
  16. Nicolucci A, Kovacs Burns K, Holt RI, Comaschi M, Hermanns N, Ishii H, *et al.* Diabetes attitudes, wishes and needs second study (DAWN2™): Cross-national benchmarking of diabetes-related psychosocial outcomes for people with diabetes. *Diabet Med* 2013;30:767-77.
  17. Joensen LE, Almdal TP, Willaing I. Associations between patient characteristics, social relations, diabetes management, quality of life, glycaemic control and emotional burden in type 1 diabetes. *Prim Care Diabetes* 2016;10:41-50.
  18. Jaacks LM, Liu W, Ji L, Mayer-Davis EJ. Type 1 diabetes stigma in china: A call to end the devaluation of individuals living with a manageable chronic disease. *Diabetes Res Clin Pract* 2015;107:306-7.
  19. Abdoli S, Abazari P, Mardanian L. Exploring diabetes type 1-related stigma. *Iran J Nurs Midwifery Res* 2013;18:65-70.
  20. Davies MJ, Gagliardino JJ, Gray LJ, Khunti K, Mohan V, Hughes R, *et al.* Real-world factors affecting adherence to insulin therapy in patients with type 1 or type 2 diabetes mellitus: A systematic review. *Diabet Med* 2013;30:512-24.
  21. Rjasanowski I, Vogt L, Michaelis D, Keilacker H, Kohnert K. The frequency of diabetes in children of type 1 diabetic parents. *Diabetes Metab* 1993;19:173-7.
  22. Atkinson MA. Type 1 diabetes mellitus. *Williams Textbook of Endocrinology*. 13<sup>th</sup> ed., Vol. 13. Elsevier Saunders, Philadelphia, PA; 2016. p. 1451-83.
  23. Ritholz MD, Beste M, Edwards SS, Beverly EA, Atakov-Castillo A, Wolpert HA, *et al.* Impact of continuous glucose monitoring on diabetes management and marital relationships of adults with type 1 diabetes and their spouses: A qualitative study. *Diabet Med* 2014;31:47-54.
  24. Helgeson VS, Palladino DK, Reynolds KA, Becker DJ, Escobar O, Siminerio L, *et al.* Relationships and health among emerging adults with and without type 1 diabetes. *Health Psychol* 2014;33:1125-33.
  25. Kalra B, Gupta Y, Baruah MP. Renaming gestational diabetes mellitus: A psychosocial argument. *Indian J Endocrinol Metab* 2013;17:S593-5.
  26. Enzlin P, Mathieu C, Van den Bruel A, Bosteels J, Vanderschueren D, Demyttenaere K, *et al.* Sexual dysfunction in women with type 1 diabetes: A controlled study. *Diabetes Care* 2002;25:672-7.
  27. Nowosielski K, Skrzypulec-Plinta V. Mediators of sexual functions in women with diabetes. *J Sex Med* 2011;8:2532-45.
  28. DiFazio D. Divorce and children with chronic disorders: Diabetes as an exemplar. *J Pediatr Nurs* 2013;28:311-2.
  29. Stein HF. The many-voiced cultural story line of a case of diabetes mellitus. *J Fam Pract* 1992;35:529-33.
  30. Anderson BJ, Wolpert HA. A developmental perspective on the challenges of diabetes education and care during the young adult period. *Patient Educ Couns* 2004;53:347-52.
  31. Sparud-Lundin C, Ohrn I, Danielson E. Redefining relationships and identity in young adults with type 1 diabetes. *J Adv Nurs* 2010;66:128-38.
  32. Kovacs Burns K, Nicolucci A, Holt RI, Willaing I, Hermanns N, Kalra S, *et al.* Diabetes attitudes, wishes and needs second study (DAWN2™): Cross-national benchmarking indicators for family members living with people with diabetes. *Diabet Med* 2013;30:778-88.
  33. Cameron FJ, Skinner TC, de Beaufort CE, Hoey H, Swift PG, Aanstoot H, *et al.* Are family factors universally related to metabolic outcomes in adolescents with type 1 diabetes? *Diabet Med* 2008;25:463-8.
  34. Trief PM, Ploutz-Snyder R, Britton KD, Weinstock RS. The relationship between marital quality and adherence to the diabetes care regimen. *Ann Behav Med* 2004;27:148-54.
  35. Sandberg JG, Trief PM, Greenberg RP, Graff K, Weinstock RS. He said, she said: The impact of gender on spousal support in diabetes management. *J Clin Educ Interv* 2005;5:23-42.
  36. Varghese RT, Salini R, Abraham P, Reeshma K, Vijayakumar K. Determinants of the quality of life among diabetic subjects in Kerala, India. *Diabetes Metab Syndr Clin Res Rev* 2007;1:173-9.
  37. Trief PM, Wade MJ, Britton KD, Weinstock RS. A prospective analysis of marital relationship factors and quality of life in diabetes. *Diabetes Care* 2002;25:1154-8.
  38. Trief PM, Himes CL, Orendorff R, Weinstock RS. The marital relationship and psychosocial adaptation and glycemic control of individuals with diabetes. *Diabetes Care* 2001;24:1384-9.
  39. Spence M, Alderdice FA, Harper R, McCance DR, Holmes VA. An exploration of knowledge and attitudes related to pre-pregnancy care in women with diabetes. *Diabet Med* 2010;27:1385-91.
  40. Graber AL, Christman B, Boehm FH. Planning for sex, marriage, contraception, and pregnancy. *Diabetes Care* 1978;1:202-3.
  41. Kalra B, Gupta Y, Kalra S. Pre-conception management of diabetes. *J Pak Med Assoc* 2015;65:1242-3.
  42. Patel N, Stone MA, McDonough C, Davies MJ, Khunti K, Eborall H. Concerns and perceptions about necessity in relation to insulin therapy in an ethnically diverse UK population with Type 2 diabetes: A qualitative study focusing mainly on people of South Asian origin. *Diabet Med* 2015;32:635-44.
  43. Greco P, Pendley JS, McDonnell K, Reeves G. A peer group intervention for adolescents with type 1 diabetes and their best friends. *J Pediatr Psychol* 2001;26:485-90.