

Premarriage Counseling in Type 1 Diabetes

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Abstract

Type 1 diabetes is a challenging illness and needs lifelong diabetes self-care. At the same time, there is a significant stigma associated with it, especially with relation to marriage. There are concerns related to premarriage disclosure, marital relationship, ability to procreate, risk during pregnancy in women, and the risk of disease in children. In this document, we discuss the issue of disease-related stigma which may become a significant challenge for a prospective spouse and the impact of type 1 diabetes on marital relationships and procreation. We also highlight the need for premarriage counseling to ensure long-term success in achieving both individual and interpersonal well-being.

Keywords: Counseling, interpersonal relationships, marriage, procreation, social stigmatization, type 1 diabetes

INTRODUCTION

A diagnosis of type 1 diabetes brings with it significant challenges and hurdles for the individual and his/her family. It translates into a lifelong commitment to adhere to lifestyle changes, self-monitoring of blood glucose, daily multiple insulin injections or insulin pump use, regular investigations and visits to the health-care provider. In addition, there is an impending risk of hypoglycemia, weight gain, and long-term complications. The psychosocial aspects of type 1 diabetes and its impact on the quality of life, however, remain largely ignored. One of the greatest challenges for individuals living with type 1 diabetes relates to marriage, especially so in developing countries such as India, which has its own complex and unique sociocultural considerations with regards to the institution of marriage.^[1,2]

It has been reported that marriage rates are significantly lower among type 1 diabetics in various communities.^[3-5] In a study of 1013 Japanese type 1 diabetics, 354 men and 659 women, both men and women were less likely to be married and to procreate compared to age-matched controls.^[6] This may be due to reduced prospects for marriage as well as a lower intention to marry among these individuals. Females are more affected as was observed by Goenka *et al.*, who reported that families preferred to choose a healthy wife with no hindrances in bearing children.^[5] In an exploratory study from South India, 86% females with type 1 diabetes were worried that they will not be able to have children, while

100% were concerned about the risk to the child.^[7] Another study from Iran reported that discrimination against type 1 diabetics as a potential spouse was high, with disease burden, pregnancy-related risk, and risk to offspring being the prime concerns.^[8] Premarriage counseling is required for individuals living with type 1 diabetes and their families and should involve a focused discussion of specific concerns which are enumerated in Table 1.

PSYCHOSOCIAL CONSIDERATIONS

Self-esteem and patient attitude

Stigmatization refers to the social process whereby an individual or a group may be devalued and discriminated against due to real or perceived differences. Disease-related stigma is a widely reported phenomenon with relation to several chronic illnesses such as obesity, diabetes, mental illness, epilepsy, sexually transmitted diseases, and HIV/AIDS.^[9,10] Type 1 diabetic individuals are quite prone to disease-related stigmatization due to the higher visibility of the condition –multiple daily injections, monitoring of blood glucose, dietary considerations, hypoglycemic episodes, and weight gain, that make them socially identifiable.^[11] This contributes to diabetes stigma, and the individual may suffer from negative feelings of anxiety,

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Table 1: Concerns related to marriage in individuals with type 1 diabetes

Domain	Common concerns
Disease disclosure and acceptance	Whether the prospective spouse and his/her family would be accepting of the diagnosis and supportive toward long-term diabetes care?
Marital relationship	Whether there would be an impact on interpersonal and sexual relationships?
Procreation	Whether the individual can bear healthy children?
Pregnancy	Whether pregnancy would be safe in a woman with type 1 diabetes?
Risk to offspring	Whether there is any risk of congenital disorders, growth abnormalities or diabetes in children?

rejection, exclusion, guilt, low self-esteem, and depression.^[12] About 76% of type 1 diabetics reported perceptions of stigma in an online survey assessing the psychosocial impact of diabetes in 12,000 type 1 or type 2 diabetics in the US. The rates were higher in females with type 1 diabetes and among parents of type 1 diabetic children.^[13]

Diabetes stigma affects emotional life, social life, and diabetes self-management. On the one hand, it can lead to poor diabetes care, suboptimal metabolic control, a higher risk of complications, and poor quality of life.^[14] On the other hand, there may be a sense of insecurity, embarrassment, and guilt and families may try to hide the diagnosis from relations and friends.^[3] It also leads to significant difficulties in finding a marriage partner, especially for females, adding further to the stress of the individual and the family.^[15]

Type 1 diabetes management requires a high degree of patient involvement, self-efficacy, and self-decision making ability. Health literacy, patient empowerment, and a positive patient attitude are vital to achieving good outcomes and are associated with significantly less diabetes-related distress and perceived stigmatization and improved quality of life.^[16-19] A well-motivated individual feels more confident and in control of every situation, including social interactions and interpersonal relationships. Therefore, health-care providers should encourage patient education and patient autonomy. It is important to reassure individuals with type 1 diabetes that it is all a matter of perception. Individuals with type 1 diabetes can have successful careers and interpersonal relationships.

“You are not defined by your disease, but by your spirit!”

Disease disclosure and acceptance

In South Asia, most marriages are arranged by parents and relatives, and the dilemma is often whether to disclose the disease to the prospective spouse and his/her family before marriage. Disclosure of diabetes was considered problematic in the context of marriage prospects among type 1 diabetic people of South Asian origin in the UK.^[20] Diabetes health-care providers must emphasize that disclosure of disease must be done to avoid later problems. Diabetes is a disease with high visibility and nondisclosure may lead to not just a breach of trust, but also compromised self-care: There may be skipping of

glucose monitoring, delaying, or skipping of insulin doses and succumbing to social pressure to eat unhealthy food. Successful diabetes self-care would require support and involvement of the spouse and the in-laws family.^[21]

Attitude of potential spouse

A strong relationship is based on trust and transparency and with that comes greater intimacy and support from the spouse. The need to adjust to a chronic illness like diabetes requires significant life adaptations for both the patient and the spouse. The family will often need to adjust their eating patterns and food choices and pay attention to treatment. When this occurs within an intimate and supportive marriage, the couple will work as a team and support each other. However, when these adjustments must occur within a distant and less satisfying relationship, the conflict that can develop may contribute to a poorer adjustment to the illness for the patient and poorer quality of life.^[22] It is not surprising that the quality of marriage with regards to intimacy and adjustment were strong predictors of glycemic control and diabetes-related quality of life in a study involving couples with a type 1 diabetic partner.^[23] It may be worthwhile to schedule a session with the future spouse of the type 1 diabetic and clear any misconceptions they have with regards to the condition. At the end of the day, one must remember that *“Love conquers all.”*

MARITAL RELATIONSHIP

Type 1 diabetes has an impact on several aspects of marital life, including sociocultural participation, financial considerations, sexual relationship, and procreation. A diagnosis of diabetes is associated with implications for the couple and the entire family as well.

Sociocultural and financial considerations

Changes need to be made in various areas of the family's life, including food habits, activity, and social interactions. There may be concerns with regards to the individual's ability to participate in family feasts and celebrations, social gatherings, festivals, religious fasting, or vacations. Diabetes has often been regarded as a barrier in social relationships.^[24] However, Ahlfield *et al.* reported that most spouses are supportive and reported significantly less impact of the disease on family activities than the diabetics themselves.^[25] There is a need to reiterate that diabetes does not compromise a person's ability to be a productive member of the family unit or the society. Some adjustments need to be made with regard to diet, monitoring, and insulin injections, but they are as capable of having meaningful and fulfilling lives as any other individual.

There may also be financial concerns emanating from the recurring cost of monitoring, insulin, periodic evaluation, and health-care visits. Shobhana *et al.* estimated the direct cost of type 1 diabetes care among Indian families in 2002 as 16% of the annual family income.^[26] In most Indian families, women take up the “caretaker” role and often ignore their own health issues over other family priorities. The gender discrimination is further compounded if they have low levels of education, are

not earning and belong to lower income groups.^[27] Since these women are “housewives” and are essentially “nonpaid,” any health-care expense may be regarded as an additional financial burden, and they may be dependent on the husband for access to treatment. There is a compelling need to change society’s attitude to realize the vital role played by women and empower women with education and vocational training.

Diabetes care

Spousal support is the key to long-term success in diabetes care. Spouses are typically involved in many aspects of healthcare – keeping track of and administering medications, buying and preparing food, exercise, blood glucose monitoring, doctor visits, and health check-ups. Adjustments in family meals need to be made to accommodate the dietary needs of type 1 diabetic individual. A concurrent diagnosis of celiac disease may add further to diet challenges. However, there is a need to emphasize that the meal plans are not deficient or lacking in nutrients or flavor. Rather, the meals are more balanced and nutritious for the entire family. Similarly, physical activity is more likely to be adhered to if the individual has the support of friends and family and involve recreational fun activities. Therefore, family members are frequently encouraged to exercise together. Newer technologies, such as insulin pumps and continuous glucose monitoring have been shown to promote collaborative diabetes care and increase disease understanding in the spouse.^[22,28] However, at the same time, the spouse needs to be careful and not be overprotective or nagging. Participating in the care can actually help families become closer and improve the health of other members of the family.

There is a need to achieve and sustain tight glycemic control in these individuals to reduce the risk of long-term complications. It is prudent to maintain glycated hemoglobin (HbA1c) as close to normal as possible without an undue increase in risk of hypoglycemia. Multifactorial risk management targeting overweight or obesity, dyslipidemia and hypertension, and periodic screening for microvascular and macrovascular complications should begin at diagnosis of diabetes.

Sexuality

Type 1 diabetics, both men and women, are often stressed if they can have a healthy married life. Sexual dysfunction is an important concern. In a study assessing 51 couples with a type 1 diabetic partner (23 males and 28 females), 23 couples reported sexual problems, most commonly arousal problems. While peripheral neuropathy was correlated with sexual dysfunction in diabetic men, a stronger predictor was the couple’s acceptance of diabetes.^[29] The diabetic partner more often complained of fear and anxiety about the future and fluctuations in mood and found daily life more challenging.^[30] In a population-based cohort study, 10-year cumulative incidence of reported erectile dysfunction in men ≥ 21 years, with young-onset (<30 years age) diabetes, was evaluated to be 25%. The risk factors were increasing age, long disease duration, untreated hypertension, and history of smoking.^[31] More recent studies suggest that

sexual dysfunction in women with type 1 diabetes who maintain better glycemic control is not more common than healthy age-matched controls.^[32] The overall prevalence of female sexual dysfunction in diabetic and control women was 20% and 15%, respectively. Those on insulin pump scored better than those on multiple daily injections, suggesting that better glycemic control reduces the risk of sexual dysfunction. In addition, the individual must be reassured that most individuals do not have sexual dysfunction or have only mild, easily treatable forms of sexual dysfunction. Moreover, there have been significant advances in the management of erectile and sexual dysfunction.^[33,34]

Procreation

There is often a misconception that type 1 diabetes is always associated with infertility, leading to significant psychological distress. While type 1 diabetes may be associated with autoimmune polyendocrinopathies and hypogonadism, this association is rare.^[35] In a review of records of 352 type 1 diabetic patients aged 40 and above, 73% women and 81% men were married, while 35% women and 8% men had no offspring. About 43% women and 61% men had >1 offspring.^[36] In the Norwegian Mother and Child Cohort study, the adjusted odds ratio for fecundability was reduced by 24% in type 1 diabetic women but was more significantly reduced (36%) in type 2 diabetic women.^[37] It needs to be understood that fertility is not necessarily affected in type 1 diabetes and people with type 1 diabetes, including women, can have successful pregnancies and healthy children. And even in otherwise healthy individuals, both men and women, there may be several other unidentified factors which can reduce fecundability.

Pregnancy

There are several misconceptions about pregnancy in type 1 diabetes. While women with diabetes can have healthy pregnancies, there is an increased risk of adverse maternal and fetal outcomes due to uncontrolled hyperglycemia at the time of conception and during pregnancy. Most women and couples do not understand the increased risk at the time of conception, and therefore, counseling must focus on preconception care. In fact, the American Diabetes Association recommends that preconception counseling for girls should begin at puberty.^[38] However, three-fourths of the women (76.2%) who were well-educated reported that they did not receive preconception counseling from health-care providers in one recent study.^[39] The scenario is likely to be much worse in women with lower rates of literacy and self-sufficiency.

Preconception counseling should involve a discussion with women of reproductive age about pregnancy and contraception and should be reiterated periodically. An important area of discussion should be contraception to ensure that unplanned pregnancies can be avoided.^[40] Low dose oral contraceptives or intrauterine devices can be used. Both partners should understand the need to improve glycemic control before conception and the impact of poor control on both maternal and fetal health. There is a need to assess the status of long-term

complications before conception and counsel the women regarding the possibility of progression of complications such as nephropathy and retinopathy.^[41] Women should be empowered in diabetes self-management, and this would ensure greater self-efficiency and healthier pregnancies. Preconception care and intensive glycemic control at the time of conception and throughout pregnancy significantly improve the outcomes. Glycemic control should be intensified in the preconception period to maintain HbA1c <6.5% or as close to normal as possible. Continuous subcutaneous insulin infusion and continuous glucose monitoring can help to achieve intensive glycemic control with less risk of hypoglycemia before and during pregnancy.^[42] In addition, thyroid function status must be assessed periodically and before conception, and folic acid supplementation should be started.

HEALTH OF OFFSPRING

General

There is increased risk of congenital malformations and adverse fetal and neonatal outcomes, but this is largely attributed to maternal hyperglycemia. Intensive glycemic control and optimization of health before conception and during organogenesis can significantly reduce the risk of birth anomalies. Continuing intensive control through pregnancy reduces the risk of growth retardation, macrosomia, birth trauma, perinatal mortality, neonatal hypoglycemia, and other adverse neonatal outcomes.^[41]

Risk of diabetes

One of the main concerns related to marriage in type 1 diabetics is the perception that diabetes is hereditary and there is a high probability that the children may also develop diabetes. The overall risk for developing type 1 diabetes varies from 1% to 15% in siblings, parents, and offspring of type 1 diabetic individuals compared to 1.2/1000 of the general population.^[43] However, this risk is small and approximately 85% type 1 diabetes cases occur in individuals with no family history. The lifetime risk of type 1 diabetes in offspring has been shown to be higher with a type 1 diabetic father (6%) than with a type 1 diabetic mother (1.3%).^[44] Moreover, environmental factors play a significant role in the progression of disease process in the background of an underlying genetic susceptibility. The risk of type 1 diabetes in offspring of parents with type 1 diabetes is much lower than the risk of type 2 diabetes in offspring when one or both parents have type 2 diabetes (15% when one parent has type 2 diabetes and 60%–75% when both parents have type 2 diabetes).^[40,41,44]

THE WAY FORWARD

Premarriage counseling of individuals with type 1 diabetes should encompass a discussion about the various biomedical and psychosocial concerns involved as outlined in Table 2. To improve the physical, mental, and psychosocial health of type 1 diabetic individuals, intervention is required at several levels. We discuss the following strategies to improve self-esteem and

reduce diabetes-related stigma among type 1 diabetics and increase awareness in the society. These are enlisted in Table 3.

Patient driven approach

Interventions should focus on improving self-efficacy and empowering type 1 diabetic individuals and their families to confidently manage their diabetes. Patient empowerment focuses on dissemination of information regarding lifestyle

Table 2: Points of discussion in premarriage counseling

Areas of concern	Points of discussion
Biomedical	Patient empowerment about type 1 diabetes (etiopathogenesis, management, long-term care) Need for intensive glycemic control Blood pressure target <130/80 mm Hg LDL cholesterol <100 mg/dl Cardiovascular risk assessment Contraception Preconception care Screening for thyroid dysfunction
Preconception care	HbA1c <6.5% or as close to normal as possible Less stringent targets in individuals with recurrent hypoglycemia, severe hypoglycemia, hypoglycemia unawareness or at increased risk of hypoglycemia Discontinue teratogenic drugs (ACE inhibitors, angiotensin receptor blockers, statins) Use of folic acid
Psychosocial	Coping skills training Couple counseling Family communication Financial management

LDL: Low-density lipoprotein, ACE: Angiotensin converting enzyme, HbA1c: Glycated hemoglobin

Table 3: Improving individual and societal attitude toward type 1 diabetes

Focus group	Strategy
Patient driven approach	Diabetes education-etiopathogenesis, need for insulin, risk of complications, benefits of intensive control Patient empowerment and self-efficacy-lifestyle, blood glucose monitoring, carbohydrate counting, insulin technique, dose titration, hypoglycemia care, sick day guidelines Psychosocial considerations-self-esteem, positive coping skills, positive attitude, productive member of society, education and vocational training Marriage and procreation-disclosure and spousal support, preconception counseling, need for optimal control in pregnancy
Physician driven approach	Pay attention to psychosocial aspects of the illness Diabetes educators and counselors to off-load the health-care provider Group activities with type 1 diabetic families Use of social media to reach out to larger number of individuals and improve awareness in society
Society driven approach	Patient registries and support groups for type 1 diabetes families Matrimony websites for type 1 diabetes Use of mass media like newspapers and television and social media to create awareness about diabetes, reduce diabetes-related stigma, and dispel any misconceptions

changes, carbohydrate counting, monitoring, insulin technique, hypoglycemia management, sick day guidelines, long-term complications, and preconception counseling. While patient empowerment mostly focuses on disease management and health-related behavior, there is a need to identify and address psychosocial concerns such as disease stigma, self-esteem, interpersonal relationships, concerns about marriage and pregnancy, and other sociocultural factors. Psychological interventions and development of positive coping skills would improve outcomes. It is also important to encourage individuals with type 1 diabetes, including women, to attain educational and vocational skills and strive to attain financial independence. Prospective spouses should be fully aware of the problems and management of diabetes.

Physician driven approach

The obvious challenge in diabetes clinics relates to high patient load and lack of time and adequate resources to counsel patients individually. The greatest emphasis is laid on disease management-related skills and often the psychosocial aspects of the illness are left unattended. It is important for all health-care providers to understand that health is not merely an absence of disease but a state of complete physical, mental, and social well-being. Therefore, holistic care must involve the mental and psychosocial domains as well. Group activities and use of social media may assist them in reaching out to a wider audience. Diabetes educators and counselors have an important role to play as well.

Society driven approach

Several patient registries and support groups have been formed for type 1 diabetics and they provide a platform for them to discuss their concerns and find possible solutions. Sharing of knowledge with those who have lived a similar experience can increase the confidence of the individual and the couple in their ability to live wholesome lives. This may also be an opportunity for the health-care provider to address a larger number of people in a smaller amount of time. In addition, mass-media, online networks, and social media can be utilized to create awareness about type 1 diabetes in the society and reduce the stigmatization associated with it. Celebrities with type 1 diabetes can be important role models for these families. This would help reduce myths and misconceptions associated with the condition, including those pertaining to marriage and pregnancy.

CONCLUSION

Health-related quality of life is a multi-dimensional construct. It is determined by well-being in several domains – physical, psychological, social, and interpersonal. Improvements in health-related quality of life should be an important end-point of management in chronic conditions such as type 1 diabetes. Marriage is an often neglected area of discussion, and premarriage counseling is not practiced in most diabetes clinics. The marital relationship can be a significant support or turn out to be a stressor. Therefore, counseling of the individual and the

couple before marriage is essential. Preconception counseling including contraception should also begin early and needs to be emphasized regularly. A successful marriage is based on trust, understanding, support and respect and turns out to be a win-win situation in every aspect of life, including healthcare.

“Coming together is a beginning, keeping together is progress and working together is success.”

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Conflicts of interest

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