

Review Article

Socio-cultural aspects of type 1 diabetes in Egypt: Where are we and where do we need to be?

Hanan Hassan Aly

Doctorate Degree in Pediatrics, Postgraduate Diploma in Diabetes, Lecturer of Pediatrics, Ain Shams University, Cairo, Egypt

ABSTRACT

Socio-cultural factors play a pivotal role in the control of type 1 diabetes in children and adolescents, especially in developing countries like Egypt. The financial burden of this chronic illness, together with the modulations needed in lifestyle affect the family and school dynamics, adding further stress on the diabetic individual and his/her family. The key to improved outcome (not only in terms of glycemic control but also quality of life) has two arms. The first one is having a diabetes team with a psychologist skilled in this area for clear and positive communication with both the family and school from the time of diagnosis. The second one is the implementation of government laws to enforce the rights of diabetic children and adolescents.

Key words: Children and adolescents, Egypt, family, government laws, psychologist, school, socio-cultural aspects, type 1 diabetes

INTRODUCTION

Type 1 diabetes in children and adolescents is known to affect and be affected by many aspects of their daily life. It is clear that the blood sugar levels are affected by not only the insulin dose but also the daily activity/exercise level and dietary intake. An important aspect that is commonly overlooked in the developing countries is the socio-cultural factors. To put it in simple terms, the social interactions at home, school, and in the general community may add to the burden on the diabetic individual and impair diabetes control.

Size of the problem in Egypt: Prevalence of type 1 diabetes, national health expenditure and literacy level

The International Diabetes Federation 2012 statistics show Egypt to be on top of all the countries in the Middle East and North Africa (MENA), with a prevalence of diabetes reported as 15.27% in adults,^[1] and in 2010, it

showed that almost quarter of all the diabetic children in the MENA region under the age of 15 years are in Egypt with a prevalence of 12.6%.^[2] On the other hand, in 2010, the mean health expenditure (in US\$) per person with diabetes in Egypt was shown to be 116, just above that of Iraq, Yemen, Afghanistan, and Pakistan.^[3] Given that around 25% of the population lives below the poverty line,^[4] the impact of having a child or adolescent diagnosed with diabetes on families and the financial stress associated with this chronic illness may be better understood. Given also the relatively high illiteracy level in Egypt (with the illiteracy rates among young women in Upper Egypt reported to be 24%),^[5] the existence of many socio-cultural myths about diabetes and barriers to good diabetes health education and self-management can be explained.

Current structure of diabetes care teams in Egypt

The diabetes team in Egypt is typically found at the main university hospitals, and includes besides the pediatric diabetologist, a dietitian or dietetic nurse. Occasionally, a social worker is included (e.g., Ain Shams University Childrens' Hospital Diabetes Clinic in Cairo). Given the limited resources for practical training and for regularly updating the knowledge of dietitians and social workers in these hospitals, it is clear that the social impact of diabetes on the children in Egypt and other similar countries will be more than that in the more developed affluent countries.

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Corresponding Author: Dr. Hanan Hassan Aly, 35 Naguib Mahfouz St, Nasr City, 8th Region, Cairo, Egypt. E-mail: hanan_hassan_aa@yahoo.com

The socio-cultural impact of type 1 diabetes on the family

At the family level, several problems exist. It is well known that upon diagnosis of a child with diabetes, the family passes through several emotional reactions and stages of grief from anger and denial to depression and finally resolution. In USA where good family support exists with a psychologist included in the diabetes management team from diagnosis, this process is estimated to take 6-9 months for school-aged children and 9-12 months for their parents.^[6] This is an adjustment that families with diabetic children make on their own in Egypt, with some religious values helping in the adjustment, such as attributing everything to the will of God and taking it as a test in life. Some families though never regain normal functioning. It is the lack of a clear understanding of the normal phases of these emotions at diagnosis that simply needs to be outlined to them, together with some support from other families with a diabetic child (to convey on practical grounds the message that “you are not alone” and “it will be fine”). The financial burden of the problem adds to the daily struggles, and together with any dysfunction in the family dynamics (divorce, separation, unemployment) they affect the family, the child, and diabetes control, resulting in higher blood sugar levels.^[6] Simple issues concerning child raising and discipline policy may become very troublesome. In our society, there exists the idea that “it is enough that the child has diabetes, parents should not be against him as well, one hit is enough” resulting in spoiling kids with diabetes. A myth that follows is that “disciplining them may raise their blood sugar because of putting them under stress” and this can be so devastating, especially in the context of a chronic illness, especially when such an illness requires self-management and especially as the patients become teenagers. In more developed countries like USA, psychologists bring about open discussion of such issues when they meet the family at the disease onset, so things run through the right course from the start. This is something we unfortunately lack in our care systems.

The socio-cultural impact of type 1 diabetes on school life

When it comes to school, a clear communication between the school and the diabetic team is indispensable for optimum care. In Egypt, it is on behalf of the parents to explain the situation at school, perhaps request to allow the child or adolescent drink 15 g of sugar, which they provide, when signs of hypoglycemia exist. Sometimes they also ask a person at school to keep an eye on the child’s diet. School nurses do not take responsibility for injectable drugs. The team-school communication may happen when problems come up, and is usually through sending a report mentioning the child’s diagnosis, the insulin treatment the child receives, and perhaps the self-

monitored blood glucose (SMBG) plan, and the risk of hypoglycemia and its’ management. However, what the child needs is different. First is the problem of having the kids around learn that he/she is diabetic. This entails that he/she is “different,” something naturally hard to face. In addition, the cultural myths and the “labeling” associated with them, especially among adolescents, are also hard to face. Second, there is the problem of school discipline and to what degree it is acceptable or required, and the access to water and bathroom. Some teachers in our communities are too harsh no matter what the child has and some become too loose or treat the child “different from others” when they learn the child has diabetes. Thirdly, there is the problem of receiving insulin at school. This means that as children consume food during their recess time at school, they need to do so without exogenous insulin administration, unless the child is old enough to do that on his/her own or a mother is willing to go there and give the injection herself. Fourth, there is the stress and peer pressure associated with having some diet restriction and not eating freely with peers, especially at birthdays and school parties. Given that schools in Egypt rarely offer healthy snacks, the social effect of this is more detrimental. Fifth and above all, children need flexibility, whether regarding diet or exercise, at home or at school.

What should we do to improve the situation at our schools and is the picture different in more developed countries like USA? Even though the literacy level in USA is 99% and the health education of the general community about diabetes in children is better, giving smaller room for myths, quite a number of children and adolescents hold back from telling friends as they do not want to “be different.”^[6] Yet, two major differences exist, which we need to implement: The presence of laws that detail the rights of children with diabetes at schools and a different form of communication between the school and diabetes team. The US law details who to care for the child with diabetes at school, what accommodations and services are needed and how to request them, what academic modifications should be provided, and how diabetes affects the child’s discipline.^[7] Moreover, the American Diabetes Association outlines school-health team communication and the school plan^[8] that should be provided by the team. In this position statement, it details the responsibilities on schools, parents, and the diabetes team members with regards to five main areas: Blood glucose targets and monitoring at school, insulin administration, meals and snacks, exercise and sports, treating hypo- and hyperglycemia, and even testing for ketones when needed and the appropriate action that should follow.

Unfortunately, studies in the area of the socio-cultural impact of type 1 diabetes in Egypt are still in their infancy. Several studies have addressed the quality of life and glycemic control in relation to a diabetes health education program,^[9] but none published so far have tackled community myths, school-specific problems, discipline issues, or the grief response.

CONCLUSION

In conclusion, it is of extreme importance to tackle the psychosocial issues related to diabetes from the disease onset for a smoother diabetes control and improved quality of life of both the diabetic individual and his/her family. It is important to note that such issues vary according to the local community, by virtue of the variable literacy level, structure and wealth of the health care system, and the community values of sharing and support. Yet, whatever the culture and the wealth, a psychologist is needed among the diabetes care team and local government laws that protect the rights of diabetic children and adolescents at schools are indispensable for normal functioning and for optimum glycemic control.

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