

Diabetes Positive Living; Highlights from Practice in the Gulf Region

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Abstract

Type 1 diabetes is a complex disease with many challenges attached. However, there are many sides of this disease that impact positively on children and families. Behavior of children and young people with diabetes vary according to life style, dietary habits and psychology. Culture of a given area reflects unique features on the disease and affects the impact on life of children and young people with diabetes. It is known that diagnosing a child with diabetes impacts a long-term effect on the child and the family as a whole. Parents (mainly mothers) undergo stages of shock, anger, sadness and even depression. Coping strategies that families adopt are variable with some families being able to cope and adapt quicker than others. Children reaction to the diagnosis and the disease management is also variable with some children refusing injections and testing to others who do not mind them. In this review, the positive side of living with diabetes will be highlighted with special emphasis on the impact of the disease on the families and the positive attitude families and children adopt. Selected life examples will be presented. Overall, diabetes is a complex disease. It requires a long-term adaptation to the management requirements. Some aspects of the disease reflect positively on the patient and the family with a strong impact of culture on its course evolution.

Positive Impact of Diabetes on Children and Families

Families with children with diabetes get counseled on the importance of diet and exercise on diabetes control. As time goes on, families become to know the importance of a healthy life style on diabetes management. Healthy diet is difficult to stick to in the current era of the wide "fast food" industry. Many families, however, adopt a healthier life style for the whole family members following the diagnosis of diabetes in one child. Families become more educated about food contents and food groups component of individual meals. Some acquire the good habit of looking at food labels when shopping and chose the healthiest option to buy.

Diagnosis of diabetes and proper counseling by an expert multidisciplinary team encourages families to include exercise in their daily routine. Simple advices like taking the stairs instead of lifts or walking to the local market store instead of driving make people realize that exercise can be accommodated within the normal life and does not always mean heavy training in a professional gym. Although modern insulins allow flexibility in timings of injections, people become more alert to their meals and snack timings. Knowing that many CHO-containing snacks require additional injection makes people think twice about frequent snacking and encourages them to eat only if they are hungry. In addition, it prompts people to choose healthier snack/meal options.

Positive Impact of Use of Technology on Diabetes Management

There has been a revolution in the use of technology in management of diabetes. Technology is nowadays widely used both in diagnosis and treatment of diabetes. From the diagnostic point of view, children are provided with various glucose monitoring devices which vary in size, shape and function. These devices operate on various softwares with powerful visual impact. When downloaded at home or in clinic, graphs and trends of blood glucose can be displayed in a simple, yet informative way. Children and young people are technology-oriented and get engaged more easily with visual aids. Having these facilities encourages them to look after their diabetes. Use of insulin pump is another face of technology in diabetes treatment. These smart devices enable children with diabetes a more flexible daily routine and improve their quality of life. As with the glucose measuring machines, they

come with powerful software which on downloading transforms data in various forms of graphs and chart that enable easier interpretation and interaction. Insulin pump therapy and multiple daily injection of insulin are proven to be the better choice of treating type 1 diabetes. Both modalities of treatment require knowledge of carbohydrate content of food for proper insulin dose matching. This encourages people to pay particular attention to what they eat.

The Power of Diabetes on Parents with Affected Children

There is no experience better than one's own. No matter how experienced doctors and nurses become in the field of diabetes, parents still have an additional factor that makes their experience more powerful and unique. There are many success stories around the world of parents who became famous advocates for diabetes. Many parents of children with diabetes chose a career in this field and helped hundreds of children and families. Their personal experience added a special spark on their work as they manage every child as their own. Some mothers who have their children diagnosed with diabetes are illiterate. These mothers acquire this immense power of willing to learn. Many mothers receive special tuitions to learn how to read numbers to be able to read her child's blood sugar level. Many mothers and fathers preferred to test insulin pumps on them before fitting them on their children, not only to make sure that their children will be comfortable with it but also to acquire personal experience to apply for managing their children.

Impact of Parents' Life Experience with Diabetes on Further Research and Development

Parents with children with diabetes become eager to study and know

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more about diabetes. Their big dream (which is shared by health care professionals) is to find cure for diabetes. These feelings turn them into “researchers.” Many parents and older children start to regularly follow and search various sources of knowledge and news about diabetes. One particular issue of great importance is the willingness of these parents to participate in research projects and clinical trials. In addition, parents and children are always willing to participate in diabetes campaigns, medical conferences, media interviews and workshops.

The Power of Diabetes in Developing Interpersonal Relationships

Physicians dealing with children with diabetes children share the feeling that these “patients” are special. The disease has a power to connect families and health care professionals. It strengthens the relationship between both parties as it involves various aspects of child’s life and never stops at prescribing a medicine. Clinic visits for diabetes follow up have a special character that is not confined to the medical part. There is always a mix of Medicine and Life in the discussion which gets into more of a “chat” character rather than a formal doctor-patient consultation. Affording the clinic time for health care professionals is crucial to build up this healthy relationship with parents and children and is a major factor in patients’ satisfaction.

The Field of Diabetes and its Impact on Health Care Professional Development

Diabetes is a complex metabolic disease with many remaining mysteries to be solved. This is particularly applicable to type 1 diabetes in which the actual trigger and etiology of the disease is still not fully understood. Due to all the uncertainty surrounding it, there are always valid questions to be answered which open the door to a multitude of research opportunities. We see many young doctors and nurses growing into senior researchers in the field of diabetes due to its richness of scientific challenges. Another factor leading to advancement and development is the use of technology, which has been intensively integrated in diabetes management. Many general nurses acquired the advanced experience of using these technologies and became specialist nurses and certified educators in diabetes.

The Positive Impact on Children lives

Learning money value

Caring for a child with diabetes can be an economic burden on parents. Children and families with no or low insurance cover tend to value provided equipments and diabetes accessories highly. These children learn to look after their possessions well particularly when they believe in its importance. One common example is children offered expensive insulin pumps from charities or donations. They cherish these instruments and look after them well which reflects on them valuing money in general.

Special aspects from the Arab culture

Although children are children and diabetes is diabetes, there are many characters that are unique to the Gulf region. There are many differences in the attitude of families in relation to family routines and food habits when compared to families from other areas in the world. These differences can, sometimes, be attributed to religion but others are more cultural.

Ramadan

Muslims observe the Holy month of Ramadan in which people fast

from Dusk to Dawn. During the fasting period, no eating or drinking is allowed. In “Quran”, it is clearly indicated that children and sick people are not required to fast. However, the definition of sickness is debatable. Many scholars consider diabetes as sickness and advice people with type 1 diabetes not to fast, others, apply sickness for acute illnesses only. It is noticeable that young people with diabetes in the region feel strongly about the importance of fasting. Majority resist advices allowing them not to fast. Older children behave in the same way and insist to fast even when they get into dehydration, high or low blood glucose. Interviewing many people in this scenario concludes that they feel more “normal” if they fast like others. If they are fasting, like anybody else, they will not be discriminated against. The major element to this is their strong believe in Ramadan as one of the 5 main pillars of Islam, in addition, to feeling that they will be underestimated by other people who will see them as “sick” and probably “disabled” if they do not fast.

Herbal medications

The issue of herbal medication in treating diabetes is an interesting area. A good number of families with children with diabetes thought about or used a trial of herbal medication for their children. Cinnamon is a common one but there are many others. The advice on herbal medication use spreads widely through media and the fact that herbs are natural produce encourage people to use them with the belief that they are harmless. It is not uncommon that desperate families go along the path of using herbs and stopped insulin putting their children lives at risk.

Rewarding by food

One noticeable observation in the region is that adults tend to reward children by food. Obviously, reward food is never a healthy option but chocolates and sweets come on the top of list. Giving children sweets is a way to show love and affection. Some close family members particularly older ones (commonly grandparents) find it hard not to offer children these likable rewards despite knowing that it is not good for them. They find it hard to accept “depriving” them and offer others who do not have diabetes. This attitude usually creates a lot of conflict, particularly between mothers and the offering person. Sometimes, it results in frictions between the parents themselves.

Some families try to encourage their children to eat their main meal by rewarding them with a desert at the end. The attitude of telling a child “you can have sweet only if you eat your savory” gives the child the impression and the belief that savory is the bad option for which they need encouragement to eat by giving them the good one afterwards.

Life style and family structure

In the region, there are many accessible grocery shops and outlets. These shops offer cheap confectionery, high sugar-containing juice and energy drink. They offer free and fast delivery to houses. These services encourage children and adolescents to use them to buy the unhealthy option of food. Another observation is the availability of vending machines in public places including some schools and hospitals. Pocket money in a relatively high amount is available freely for children in most families, so shortage of money is seldom the case. Another feature of the culture in the region is living as extended families in close neighborhood or complexes of apartments and villas. The number of family members is considered high compared to the western average families. Mixing of this number of children in these close communities add some burden on controlling a child with diabetes habits of eating. It is common for children to share food and treats which parents might not be necessarily aware of. In these routine circumstances, it will be

almost impossible to supervise a child's every single food/sweet intake. This is particularly the case in school children who resist to be treated differently, so they engage in similar habits of their peers including those related to eating.

Happy Stories with Diabetes

- (1) WT was diagnosed with diabetes when she was 4 months old. She presented to emergency room very sick and required admission in the intensive care unit. She was diagnosed with diabetes and was started on insulin. Due to her very young age, her diabetes management was very difficult. Mother used to give her up to 6 injections per day to control blood glucose which remained fluctuant with highs and lows.

Full assessment of her special case revealed that she has a rare type of diabetes caused by a gene defect (kATP channel mutation). Confirming the gene mutation enabled us to stop her insulin and treat her with pills which not only controlled her blood glucose but transformed the whole family life.

- (2) MA is a 12 year old girl who was diagnosed with diabetes at the age of 7. Prior to diagnosis, she used to live with her father and paternal uncle's 2 bedroom apartment. Her parents are separated and her mother lives abroad in home country looking after a younger sibling with Down syndrome. MA and her father were not able to cope with the demand of diabetes care. She had poorly-controlled glucose profile and required frequent hospital admissions. As time went on, parents realized that uniting the family again is in the best interest of MA and everybody. Parents re-united and shared care of MA who showed marked medical and psychological improvement.

Examples of Children and families with amazing attitudes

FS is a 12 year old young lady who I met recently in clinic. She was diagnosed with cancer (neuroblastoma) when she was 7 months of age. Her treatment involved many chemotherapy courses and radiotherapy sessions at that young age. She miraculously recovered from an aggressive tumor to relapse again at the age of 7 years. Her treatment the second time required extensive surgery involving excision of a big part of her pancreas. By the age of 12, she started to show signs of diabetes and her diagnosis was confirmed when she presented to a hospital with a random blood glucose of over 500 mg.

FS and her family considered her being a life as a "gift of God" and having diabetes gave them all power to accept living with it and perfect its management. Within weeks of diagnosis, she has mastered her carbohydrate counting and had a very good glucose profile with an HbA1c of 6.6%. Father commented that "all we can do is to keep thanking God that she is still with us. We will take diabetes as a gift that reminds us of how kind God is to cure our child from cancer".

Another family had 3 siblings with diabetes. They also have celiac disease, too. Parents have coped beautifully with the double jeopardy of both diseases. They say: we are now so adapted to healthy gluten-free diet for everybody and our shopping became easier.

Medical differences

Although type 1 diabetes has a known etiology as medical facts, its phenotype and natural course in some children from the region is different. One striking feature is that children in the region seem to tolerate higher readings of blood sugar before going into the common complication of diabetes-ketoacidosis. Children may walk into clinic

showing no ill-health symptoms when their blood glucose is well in excess of 400 or even 500 mg. This is also noticeable on downloading these children's meters in clinic during follow up visits. Glucose reading could be excessively high without children showing any symptoms of acidosis or dehydration. Parents discover the high reading only when they check routinely before meals. Although this feature is favorable as going into dehydration and acidosis secondary to high blood glucose can be life threatening, it makes children accept living with higher blood glucose and encourage them to non-compliance with regular insulin injection. This will result in long term accumulation of sugar with predisposition to chronic complications.

Causes of Diabetes; Special Features

Diabetes in children became more variable in terms of its presentation, causative factors and association with other diseases. Although type 1 diabetes remained to be the commonest form of diabetes, other types of diabetes are getting more prevalent. In the Gulf and other Arab countries, there is strong genetic factor to diseases and diabetes is not an exception. The rate of consanguinity is high resulting in high incidence of hereditary diseases. Monogenic diabetes, particularly neonatal diabetes is more prevalent in this region. The monogenic form of diabetes is linked with consanguinity issue which is a common culture in some areas of the region. Some Muslims consider aborting affected embryos with a disease like diabetes forbidden. Accordingly, utilization of antenatal diagnosis for some genetic causes of diabetes is limited. One family with many affected children accepted the concept of pre-implantation genetic diagnosis for conceiving with healthy children as it does not involve termination of pregnancy. They had the first reported child in the literature following this procedure.

Overall Message and Conclusion

Diabetes is a complex disease. It is strongly connected on many vital aspect of one's life. Its management requires not only a multidisciplinary team of professionals but a family and school environment equipped with all the requirement of its demanding management. Some children and families are an inspiration. Many of them make real role models of how to deal with the burden and the challenges of life. Diabetes affects the whole family. It is linked with affected children day and night. They need to consider it during eating, exercising and with almost in all of their life routines. It is a difficult disease to live with but can be a source of power to make children grow into genius adults. Life style and culture are crucial factors in the disease evolution and progress.