



PARENTAL EXPERIENCE OF LIVING WITH A TYPE 1 DIABETIC ADOLESCENT

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ABSTRACT

There are several chronic childhood medical disorders amongst which Juvenile Diabetes is becoming the commonest of them all. In this condition the body's Pancreatic Beta Cells are unable to produce Insulin that is needed to absorb Sugars into the cells of an individual. It requires a lot of metabolic regularity for the child and as a result has a huge psychological impact on the development of the Adolescent and also their parents. Juvenile Diabetes is also called Type 1 Diabetes or Insulin Dependent Diabetes. It is important for such children to take insulin from an external source all their life. Parents play an important role in the monitoring and treatment management of their Diabetes. The aim of the current study was to understand the experiences of parents of adolescents with Type 1 Diabetes. The study involved interviewing parents of adolescents (n=5) with Type 1 Diabetes. The sessions with the parents were tape recorded (each session was for about 30-40 minutes) and transcribed using content analysis. The main themes that emerged were: a) stigma related to the illness b) emotional upheaval for parents c) impact of diagnosis on family d) coping used by the parents e) issues of adherence

with regard to treatment and, f) coping methods used by adolescents. The study revealed similar trends as was seen as in Western studies; that diagnosis of Type 1 Diabetes impacts not only the adolescent but on the family as a whole.

Key Words- Adolescent, Coping, Emotions, Parents, Type1 Diabetes

INTRODUCTION

Diabetes

Diabetes is one of the most common chronic disorders found in children. Juvenile Diabetes is also called Type1 Diabetes or Insulin Dependent Diabetes (Type 1 DM). It is important for these children to take insulin from an external source all their life. Type 1 Diabetes is a ‘*chronic illness*’ (Sudhir et al., 2001). Chronic Illness has a great impact on the life of an adolescent. The illness itself can impact the life expectancy and can result in various complications.

Type 1 Diabetes is mainly an auto immune disorder where there is destruction of beta cells of the pancreas leading to deficiency in the production of insulin. Hence this leads to intense insulin therapy required to survive. Proper treatment and care of a Type 1 Diabetic mellitus patient includes medical therapy, proper diet, regular health check-up, proper nursing, healthy and consistent ‘*parental care*’. When a child or an adolescent is diagnosed with Diabetes, they feel stigmatized. The main reason for this is that an individual with Type 1 diabetes need regular insulin from an external source mainly as multiple injections during the day. Such individuals feel a sense of devaluation as they are dependent on medical treatment for their survival. The treatment regime that they follow that includes regular administering of insulin and specified diet restrictions are very clearly visible to others. This feeling of being stigmatized can lead to poor adherence or non-compliance of medication (Chatterjee, 2013).

Parenting and Chronic Illness

Type 1 Diabetes is a ‘*chronic illness*’ and parents undergo multiple ongoing stresses with a chronically ill child diagnosed with this condition. Stress in families related to the diagnosis could be at different points of time. The stress parents experience could be at the time of diagnosis, during the developmental transition from childhood to adolescence and adulthood, and when the child undergoes exacerbation of symptoms and hospitalizations. When dealing with a

chronically unwell child, it is also equally important for the respective parents to deal with their emotions. If parental coping gets better, then children's adjustment to the illness is also enhanced (Bernadette et al., 2001).

Once the diagnosis of Type 1 is made, parents and adolescents realize that it is something that they have to learn to live and cope with for life. Regular positive communication, emotional support and empathy from the parents all help the adolescents cope better with the illness. Support from the social fabric is also another important factor. When their teachers, family and friends support diabetes affected children, then management of the illness and process of administering insulin improves significantly. Chronic Illness marks children as different from their peers. Their families get burdened with demanding health care responsibilities and may find it difficult to meet the demands (Dharmalingam and Kumar, 2001). Since psychological factors play an important role in lives of children and adolescents with Type 1 Diabetes, psychological management and therapeutic intervention also becomes extremely important and needs to be implemented along with routine medical management.

Parents and Diabetes

In a study carried out on normal children and a group of chronically ill children with an existing diagnosis of Asthma, Anemia, Diabetes and chronic otitis media, it was seen that alleviating the psychological distress of parents was important. Otherwise it resulted in poor parenting skills that also lead to increase in behavioral problems in children (Hoard, 2004; Powers et al., 2002).

In another study that looked at Pediatric Parenting Stress, it was revealed that the stress in parents of a child with Type 1 Diabetes is multifaceted. Stress is related to issues such as parents own confidence in ensuring that their children stick to the diabetes treatment regimen, their responsibility for the dietary management and their fears related to hypoglycemia and other complications. It also highlighted the need for any kind of psychological intervention to help improve the psychological well-being of the parents and the children's health with Type 1 Diabetes (Streisand et al., 2005).

In conclusion it can be stated that parents are actively involved in the management of a Chronic Illness such as Type 1 Diabetes. They undergo a lot of stress and learn to cope with the Adolescents on a day to day basis. The aim of the current study was to understand the experiences of these parents who are living with adolescents with a diagnosis of Type 1 Diabetes.

METHODOLOGY

Qualitative interviews were conducted between January and March of 2015 to understand the experiences of parents of Type 1 Diabetic Adolescents. The interviews were facilitated with the use of a semi-structured interview schedule that was developed for the purpose of this study and validated by five experts (Child Psychiatrist, Clinical Psychologist, Endocrinologist, Counsellor, and Professor in Psychology). The study was approved by the ethical board of the hospital. The center where the study was conducted has a multi-disciplinary team that is involved with the care of parents and adolescents with Type 1 Diabetes. Written informed consent was obtained from the parents who participated in the study.

Sample and setting

The sample was purposively selected from the out-patient clinic. The eligibility criteria were Parents having a child/adolescent aged 10-18years diagnosed with Type 1 Diabetes at least for a year and more. The parents should be fluent in Kannada/English. The research was conducted in an Out-patient Clinic in South Bangalore.

Procedure

Parents were interviewed on various aspects of parental involvement; parental stress, adherence to treatment, coping in treatment and management of Diabetes. All the interviews were tape-recorded. Each interview was done individually and lasted for about 35-40 minutes. The interviews were later transcribed to maintain accuracy in terms of the dilemmas parents face in handling the adolescents. Quotations from the interviews were used in the results section to make the data more reliable and authentic. Once the interviews were transcribed, themes and sub-themes were obtained that facilitated data interpretation and helped in methodological rigor. Data was analysed through content analysis.

RESULTS

The objective of the study was to understand Parental Experience of Living with a Type 1 Diabetic Adolescent. Five parents were selected for the interviews. There were 2 Fathers and 3 Mother. Average duration of diagnosis of Type 1 in the adolescents was 3.3years (1-10 years). The main themes emerged were stigma (society, peer level and inadequate knowledge), emotional upheaval (shift of emotions from negative to positive), impact of diagnosis (parenting practices, monetary impact, life style changes in family, impact on siblings), coping used by the parents (religious, despair to strength), adherence issues (following diabetes regimen), understanding coping used by the adolescent. After conducting the interviews and analyzing the results, various themes that emerged from the interviews have been summarized below:

Stigma and Diabetes

The element of stigma due to the illness is inevitable that a family and an individual has to face from society, extended family and peers. The theme of stigma has emerged accordingly.

As one mother of a 13 year old from a small town stated in the interview ‘.....*In a remote place like ours people are still very illiterate, they have no idea of the disease. If they get to know this then the numbers of children interacting with my child will also come down....*’ ‘.... *I face a lot of negativity from my father- in-law, who keeps scaring us that the illness will lead to a lot of problems will get worse.....*’

Another significant finding was the severe Worry associated with the initial diagnosis of Type I DM and the various misconceptions associated with the disease and its treatment.

One parent of a 12 year old girl reported that ‘it is a *worry for life; I am scared of side effects that can happen due to insulin*’

As one parent of a 13 year old reported ‘ *people do not have adequate information about diabetesI feel that people will not want to mix with my child because of the illness she has developed in the past...*’ ‘.....*See in my family nobody has Diabetes and for me ‘.....if somebody gets diabetes then sooner or later they lose their legs, fingers and hands. That was the only knowledge that I had about diabetes.....*’

Emotional Upheaval in parents

In the interviews, parents have reported a series of emotions. This ranges from disbelief, sadness, depression, helplessness etc. The negative emotions seem to be more at the initial phase of diagnosis. As one father of an 18 year old girl expressed ‘.....*When I heard about the diagnosis I was very sad and depressed and helpless, felt that I must not live but now I see so many children with diabetes, so I have got a lot of strength. I still feel sad that this has happened to my child....*’ ‘.....*Now things are better, we have been counselled many times and have met several families with similar issues and it is a challenge to help our child now...*’

The mother of an 11 year old girl reported ‘....*As a parent I wish this goes away and she leads a normal life....otherwise also we will fight it out. With God’s grace and support from Doctors she will do well I have a lot of faith.....if there is any new research, please inform us...*’ ‘*It is now after repeated counselling sessions and understanding that I have understood more about the illness and a lot of my misconceptions have been cleared....*’

On interviewing the parents, they have constantly reported that taking insulin four times a day is very painful for them to monitor and it hurts them to watch their child take the medication. Some of them have tried alternative therapies e.g. Unani and Ayurveda, but have stuck on to insulin treatment as nothing else was effective. Families are also constantly keeping themselves abreast of any latest research that can replace insulin, in injection form.

‘.....*We started her on Unani medication but her sugars went up to 600 and we tried the medication for 15 days. Then our family doctor advised us that we need to switch to English medicine and now we will follow this till the end..... I feel hopeful that something will come out like a tablet instead of an injection. It helps to produce insulin*’

To summarize the observations, a lot of families have been with negative feelings and confusion in the initial stages of diagnosis. But with regular and frequent counselling and interaction with other families they appear more positive, strong willed, ready to face the situation and determined to go through the medical treatment to be followed in the years to come. Parents and children/adolescents living with diabetes are looking for Hope for alternate treatments to bring down the rigorous treatment protocol that a child has to face when diagnosed.

Impact on Family

As outlined earlier, Type 1 Diabetes has an impact on the family as a whole and certainly not limited to the affected children. Families have to come to terms with the illness and it also brings about a lot of changes that one makes personally, emotionally, financially, socially and professionally. Even dietary changes have been made by the whole family so that the individual can maintain the required dietary intake better.

Parents also have issues in disciplining an adolescent with Diabetes. They feel that by disciplining their children, his/her condition may worsen. The mother of the 13 year old girl reported '*.....as a parent is it difficult to correct her or discipline her because of the illness.....*'. It also impacts other children in the family e.g., '*....My two sons are accommodating....*'. Another mother of a 11 year old girl reported '*.....I have a younger child who hates to come here and she feels that a lot of attention is given to her other sister and that I am softer to her*'.

In the families interviewed, it was gathered that treatment cost would be an issue if not made free. This is yet another important factor to be addressed.

As quoted by father of the 18 year old girl- '*The treatment is acceptable because it is free at this medical centre. If we had to buy insulin then things would have been tough. Since I have three children, management of an illness like Diabetes is tough if medication is not free.*'

Professionally also, changes are being made in order to monitor the illness better. As reported by a mother of an 11 year old who quit her job of seven years to regulate and manage her daughter's Diabetes - '*.... I have now quit my full time job and I am at home to monitor her. She is still not aware to manage her illness by herself....*'

Families have also made dietary changes and adapted in order to cope with the illness as reported by the father of a 10 year old girl '*.....We as a family have changed our eating pattern...we eat ragi (millet), wheat and have decreased our rice intake. We ensure that she eats well and gets healthy food. We would like to give her a lot of organic food but the issue is that it is very expensive; hence in our capacity we ensure healthy food ragi (millet), wheat, fruits vegetables. We have got about a few changes also in our diet and all of us have shifted to using jaggery instead of sugar. Soya is also used by us*'.

Coping By parents from strength to despair

Most of the parents interviewed were worried about the Adolescents' future. Their coping has been in terms of being positive about the future, giving a lot of positive suggestions to the child and in praying.

‘.....I feel bad especially because she is a girl. But I have made my mind very strong I will educate her well make her stand on her feet and she can select her own life partner....’

‘...I pray five times and ask God to take away the illness. I divert my mind by playing with her taking her out. I play with her and distract myself.....’

‘.....We just tell her that people have worse illness and at least yours is manageable. Some people have it worse. Your body does not have enough insulin hence we need to take it from out-side....’

‘my aim is to get my child better.....if she asks for a chocolate I convince her that once better then she can eat anything...we do give things in moderation. My wife works in a cloth shop and we are both hardworking for the children we are strong in front of them and take each day as it comes.’

Adherence to treatment

Parents also play a significant role in a) dietary management, b) exercise routine c) instilling confidence and d) monitoring the insulin intake.

As reported by the father of the 18 year old *‘.....Does not adhere to treatment well, sometimes lazy, misses her walk and careless about diabetes...’*

As reported by the father of the 10 year old ‘.....Her insulin intake is managed by me...at times she was embarrassed to take insulin in school. For two months I would go to school and monitor the same for her. She needed to take it on her arm and her thigh. Now she is used to it...the school is also aware of her illness...’

As stated by the mother of the 13 year old boy ‘.....I make him cycle, walk and his diet is monitored....’

Coping by the Adolescents

Adolescents feel embarrassed to take insulin in front of their friends. They also feel sad and depressed and often appear upset as the treatment is for life. Here again parents play a role in allaying their anxieties and concerns.

As stated by the father of the 18 year old *'.....She does trouble us at times, does not take insulin in school. She would refuse to adhere to treatment due to sadness, the injection is painful...'*

As stated by the mother of the 11 year old boy *'.....There are times when he gets very depressed and he feels that why is it that he has got this illness...I tell him that you are not the only one; there are so many others even three year old children in the center...it is more difficult for them. You manage your treatment properly and you will be better than us in many ways...'*

'...This is the time that she expresses that it is so difficult to inject oneself every day and she asks if this is for life and I feel terribly upset and sorry for her, but at the same time I do not show my sadness I give her a lot of strength...'

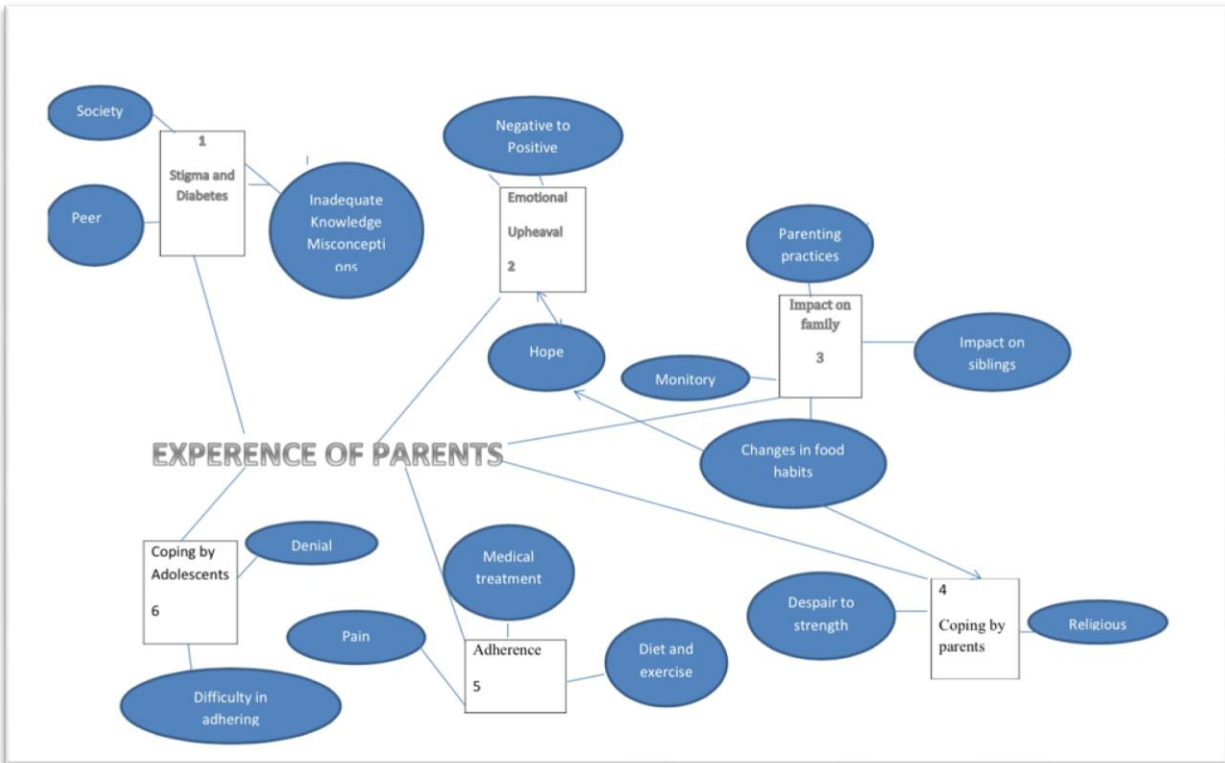


Figure 1: Shows the various themes and subthemes elicited through the interview to summarise the findings.

DISCUSSION

As it can be seen above, various themes and sub themes have emerged from the interviews and re-emphasize the fact that diagnosis of Type 1 Diabetes impacts the family as a whole. Parents and families of children/adolescents with Type 1 diabetes face a lot of negativity from immediate family, peers and society. Affected adolescents struggle to maintain and manage their chronic illness, while negotiating their relationship with their parents and peers (Drew, Berg and Wiebe, 2010). Even among their peers, they feel different mostly because of the treatment requirements (such as insulin intake, dietary restrictions etc.). Peer victimization in this group also makes them more susceptible to depression, social anxiety and loneliness. (Storch et al., 2004). Thus social stigma associated with the illness overall may be subtle but cannot be overlooked. These individuals and families have to face the stigma right from poorer job opportunities and even in delay in marriage (Sudhir et al., 2001). On the other hand, protective factors such as having a positive relationship with the father and mother results in good

Glycemic control (Drew, Berg and Wiebe, 2010). Other protective factors such as self-worth and social support also have a positive effect and mediate the general stress related to Diabetes (Hoard, 2004). These protective qualities need to be encouraged in this group. But the diagnosis such as Type 1 Diabetes leads to a lot of stress in children and often takes away the effects of the protective factors, making the individuals and families more susceptible to maladjustments (Mallik and Koot, 2009).

Apart from this, there is tremendous amount of emotional upheaval that the parents go through right after a diagnosis is made. The routine Diabetes management itself is cumbersome for the parents and the adolescents to deal with. Parents may have a lot of misconceptions regarding the illness. Compared to other parents with healthy children, these parents are more psychologically vulnerable to stress, anxiety and poor mental health. (Moreira et al., 2014; Bhadad et al., 2011). However, with time these negative symptoms fade away. In some parents, depressive symptoms may present as feelings of sadness or hopelessness, changes in sleep, cognitive processing, and decreased energy (APA, 2000). Even after 7-10 years of diagnosis, grief can continue (Seppanen, Kyngas and Nikkonen, 1999). Hence educating the family and adolescents on Type 1 diabetes has to be an ongoing process. The educators or counsellors handling such families must be well equipped themselves. These parents may have adjustment issues due to the illness, anger and grief. At this point important basic survival skills need to be taught. At each stage, involvement of parents in the treatment regimen is important; for preschoolers with the diagnosis parents are the main facilitators of therapy. But with regard to the adolescent group, it is first the adolescents in charge of management and then the parents are involved (Silverstein et al., 2005). Parents also need to learn better coping skills through behavioral intervention (Streisand et al., 2005).

Parent's participation in the management of Diabetes is extremely important for a positive health outcome in the adolescents. Parents have their own coping styles and their own emotional and psychological response in the management process. The six phases of coping have been described in literature as a) disbelief b) lack of information c) guilt d) learning to care e) normalization f) uncertainty and g) reorganization (Seppanen, Kyngas and Nikkonen, 1999). A few of these can be seen in the responses given by the parents in the interviews. Parents use various methods of coping through positive suggestions they give themselves, through prayer

and living with the hope that better treatment options for Type 1 Diabetes will soon be available. Higher family cohesion and warmth from families can lead to better glycemic control in adolescents (Anderson,2004). It has also been seen that the mode of spirituality or divinity may help in terms of coping with illness or recovery (Venning et al., 2007). The family as a whole has to come to terms with the diagnosis of Diabetes. It causes an economic strain, leads to parental distress and affects parenting practices (Yeung,Linver and Brooks-Gunn,2002). Siblings too try to fit into the system of dietary changes, hospital visits and the fear of witnessing medical conditions such as hypoglycemia. They may feel neglected as the diagnosed child receives a lot of personal attention from the parents (Dougherty, 2015).

During Adolescence the individuals experience a lot of hormonal and bodily changes. The impact of a diagnosis such as Type 1 diabetes causes a lot of difficulties with adhering to the strict restrictions. The ramifications of dietary regulations and exercise regimen can be very difficult and intimidating for an individual to follow(Faro,1999). One reality and definite observation is that managing adequate glycemic control during periods of transition are a challenge either from childhood to adolescence or from adolescence to early adulthood (Ferdette,2015). During this phase of transition it is important for the parents and adolescents to find a shared management with regard to diabetes so that parents continue to be involved in the treatment process to maintain good metabolic control (Silverstein et al.,2005).

Studies reveal that in adolescents with Type 1 Diabetes, greater use of primary coping strategies such as problem solving and emotional expression were associated with better quality of life and better metabolic control. The use of disengagement coping strategies such as withdrawal or denial was linked to lower competence or poorer metabolic control (Rosenberg,2006) Parents ability to be emotional, responsive, trust worthy and to able to be supportive and give the adolescents autonomy helps adolescents manage diabetes better (Jaser and White,2011).

In conclusion parents do play a pivotal role in the life of an adolescent with Diabetes. On one hand parents are involved in the treatment, adherence and coping used by the adolescents. On the other hand they need to handle their own emotions, social ramifications of the illness, economic burden and family changes caused by the illness. They also need to develop their own personal coping styles to deal with the illness and its daily demands. Bringing down distress levels in parents helps in the overall management of these patients (Hoff, 2003). Hence it is an important

aspect that clinicians need to give parents and opportunity to give vent to their emotions when it comes to handling an illness like Type 1 Diabetes in their children (Dashiff et al., 2011). Hope is a strong positive theme that has come through, wherein parents develop positive emotions as they go along they are constantly hoping for better treatment, and this would definitely have an impact on these Type 1 Diabetic adolescents. Lack of Hope in parents may lead to an adolescent having a poor sense of security. High hopes in adolescents can lead to boost in parents determination (Yeung, Linver and Brooks Gunn, 2002). While working with these families one has to find a fine balance between these two, inculcate this feeling of Hope to help in the management of the illness.

CONCLUSIONS

One main limitation of the study is its small sample size, however to conclude as seen in the interviews, the whole family changes their set-up in order to cope with the illness. Parents and individuals face challenges at multiple levels personally, professionally and in terms of society and its understanding of the illness. Hence management of the illness is not just in terms of monitoring the sugars and administration of insulin. It must also be in terms of constantly counseling parents and adolescents on various aspects of coping on a day to day basis so that the burden of the illness is made less. However one main limitation of the study is its small sample size.

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