Coping with children with diabetes: Is this burden too great for parents to bear?

“So, here is a question to all mothers who are raising children with diabetes. As mothers, we try to be as healthy as we can and to teach our children a healthy lifestyle. When does it get too much? When do we say that we are not perfect and we can’t always make the right choices for our children when it comes to food? Everywhere, we read that we must use less sugar, less fat, less salt, no preservatives, no colorants, no processed food, no this and no that! I can’t afford to shop at Woolworths all the time, and being a working mother, I really struggle to keep the children balanced. Sometimes I feel like such a failure when I read about everything they shouldn’t eat, and I think: ‘You know what? I just can’t! I try and do healthy living as much as possible, but I just can’t get everything right. Do other mothers also feel like this, or am I the only one? I love my children and would do anything for them, but food choices sometimes get me down!’

This is a comment that was made by a mother at a diabetes forum for mothers on facebook, called “Kids powered by insulin” in February 2013. The mothers’ responses to the question: “Do other mothers feel like that, or am I the only one?” was met with an overwhelming response of: “No, you are not the only one. We all feel like that sometimes!”

When a child is diagnosed with type 1 diabetes, good management thereof mean keeping the blood glucose levels as near to normal as possible. This is challenging at the best of times. Usually, the challenge sits squarely on the shoulders of the parents, most often the mother of the child. According to the International Society for Pediatric and Adolescent Diabetes, “psychological factors are the most important influences that affect the care and management of diabetes”. While this is entirely true of children with diabetes, it is also true that the psychological health of parents is equally important.

The passage of diabetes through childhood and adolescence is constantly changing and is no easy task. The mother has to learn to live with a higher-than-usual, ongoing state of anxiety.

Is this burden too great for mothers to bear? It is easy for anxiety to become overwhelming, and if a mother or main caregiver feels this way, the management of the child’s diabetes will be in jeopardy.

Why do parents become anxious?

Very young children cannot speak about how they are feeling, so the mother has to interpret every move, change and response that the child makes in terms of the diabetes. She has to “feel” the symptoms of the child. The responsibility to do so lies exclusively with the parents or caregiver.

Schoolchildren are immature and rely heavily on their mothers to supervise their diabetes management, even if they can do some of it on their own. The mother has to help school teachers to cope with her child’s diabetes. This is an added challenge that must be dealt with, especially if the teacher is reluctant to accept it. When the child stays overnight at a friend’s house, the friend’s parents have to cope with the diabetes and mothers have to teach them how to manage. Grandparents and babysitters need guidance on how to manage diabetes while the child is in their care. Parents struggle to decide whether or not to let their child play at a friend’s house after school, in case no one is there to help with the lunch time food and insulin. They debate how much responsibility the child should have in managing his or her own diet and blood sugar levels. Parents are sometimes afraid to sleep because their child might experience a life-threatening low overnight.

Teenagers want to manage their diabetes on their own, but often they are not emotionally ready to take on such responsibility. The mother has to gauge how much to stand back, and how much to be involved. This is a balancing act that constantly changes. Teenagers still need the support of their parents, but they need to gradually take over management of their own condition. They often develop a negative attitude about their diabetes in their teen years. If the teen is not managing his or her diabetes successfully, the mother will become anxious.

The parents’ own psychological state plays a part in the anxiety. Anderson et al found that high stress in parents was associated with:

- The parents’ beliefs about their ability to manage their child’s illness, i.e. self-efficacy.
- The level of the parental responsibility for, or involvement in, the daily care of the child.
- Parental fear of hypoglycaemia.

Up to one third of parents’ stress was associated with these three factors. It seems likely that parents who have a fear of hypoglycaemia will also experience increased frequency of stress, because with tightly controlled blood glucose levels, hypoglycaemia is a constant possibility.
When do parents become anxious?

The period after diagnosis appears to be the most stressful. Many mothers have psychological problems after the diagnosis. Approximately one third of mothers showed significant levels of depression in the first few months. Usually this was resolved by one year. One study showed that 24% of mothers and 22% of fathers experienced post-traumatic stress disorder roughly six weeks after diagnosis.

Bowes et al explored parents' long-term experiences of having a child with diabetes. They concluded that after seven years, parents had adapted to the needs of diabetes management, but most had not come to terms with the diagnosis completely. Although they didn’t feel sad most of the time, they experienced a resurgence of grief, anger and guilt during critical times, such as hospitalisation, adolescence, injections and transitions.

Family interactions also have a significant impact on how much tension is experienced with regard to diabetes. Alan Delamater noted that many research papers demonstrated that “family factors are integral to the management of diabetes in children”.

Families with high levels of conflict, diffusion of responsibility and regimen-related conflict had less success with glycaemic control of the child.

By contrast, families with high levels of family cohesion, agreement about diabetes management responsibilities, supportive behaviour and who practised collaborative problem-solving coped better and achieved better glycaemic control in the child. The words “cohesion”, “agreement”, “supportive” and “collaborative” suggest that a “burden shared is a burden halved”.

What of the single mother? Handling the daily care of her child on her own can be overwhelming. Single mothers cannot do it all without serious help and support. That means that the diabetes healthcare team should always be available to support parents throughout the period that they are parenting the child.

Recent findings indicate that responsibility for diabetes management falls heavily on mothers. The majority of families do not receive outside child care assistance and report feeling overwhelmed. Parents experience high levels of stress, difficulties, as well as moderate symptoms of anxiety.

What are the consequences of high stress levels in parents?

Stress affects parents in the following ways:

- There is potential impairment of parents’ ability to learn illness-management skills when they are too stressed or depressed.
- High stress in parents gives rise to increased stress in the child.
- Landolt et al found that psychological maladjustment in fathers predicted poor glycaemic control in children five years after diagnosis. It is likely that fathers also experience considerable stress, although their stress may differ in quality and quantity to that of mothers.

Kovaks et al followed the psychological correlates of mothers managing children with type 1 diabetes and found the following:

- Mothers’ adjustment shortly after their children were diagnosed was a strong predictor of their long-term emotional symptomatology. For instance, a mother who was highly anxious in the beginning was likely to experience ongoing anxiety in the long term.
- Both maternal depression and overall emotional distress after the first year of diabetes decreased slightly as the length of the duration of the illness increased.
- The higher the mother’s overall levels of emotional distress, the more bothersome and difficult it was for her to manage at any given point in time.

Intervention

To return to the question posed at the beginning of this article: “Is this burden too great for parents to bear?” The answer is: “At times, yes, it is”. We all assume burdens that are difficult and which we manage for a short while, but there comes a time when they become too heavy, and we feel that we cannot continue without added support. The temptation is to either relinquish the burden and give up trying to carry it, or to find someone else to help us carry it. Parents do not have the option of giving up. Their only option is to find the help that they need to enable them to carry on. With the best will in the world to do the right things, mothers cannot do it all without serious help and support. That means that the diabetes healthcare team should always be available to support parents throughout the period that they are parenting the child.

What interventions are helpful?

Written information should only serve as a back-up to personal interaction with parents. Parents’ anxiety can cloud the information they read, so that they still feel very afraid and helpless.

After diagnosis, parents should be provided with only as much information as they need to begin managing the diabetes at home. The support should be enhanced with written information. Usually, parents are still reeling from shock in the first few days, and the amount of information
that can be absorbed is very limited. Be available to the parents on a daily basis so that any questions or crises which arise can be dealt with immediately. Being available to parents continuously throughout the parenting years is desired.

Parents should be evaluated for post-traumatic stress disorder in the early weeks and months after diagnosis, or at any other time when they show signs of high stress levels. The Problem Areas in Diabetes questionnaire is a useful tool to screen for high stress in the parents. If parents have high scores, further questions should be asked about their emotional state.

The following questions, based on the Diagnostic and Statistical Manual of Mental Disorders criteria (fourth edition) for post-traumatic stress disorder will help:

- Do you have recurrent and intrusive distressing feelings about the diabetes?
- Do you have recurring nightmares about the diabetes?
- Do you revile the diagnosis and trauma around the condition of your child at the time of diagnosis?
- Do you feel intense psychological distress upon exposure to the diabetes, or an aspect of it?
- Do you try to avoid thinking about, or dealing with, the diabetes?
- Are you more forgetful lately?
- Have you lost interest in activities that you used to enjoy?
- Do you sometimes feel detached from others?
- Do you find that you are unable to have loving feelings for anybody?
- Do you have difficulty falling or staying asleep?
- Are you more irritable than usual?
- Do you have more difficulty concentrating than usual?
- Do you find you are hyper-alert all of the time?

If a parent has experienced four or more of these symptoms for a period of a month or longer, they need professional help (a psychologist or psychiatrist) to help them to deal with their distress.

Parents with a fear of hypoglycaemia will benefit from additional diabetes education and counselling, as well as the offer of ongoing support, to bolster their self-confidence and to better prepare them to manage hypoglycaemic episodes. Doing so could help to alleviate stress and improve parent mental health and child health outcomes ultimately.

Parents will learn a lot as they gain experience managing the diabetes, together with their support team and with the help of education material. The more experience they have, the more they can compare their own experiences with the information that they read. They also gain confidence as they realise how things work and how to avoid pitfalls. According to Kwok and Wong, “when parents have more knowledge and feel more confident about handling the daily care of the diabetes, their stress is moderated”.13 Parents’ readiness to absorb and carry out what they read depends largely on how stressed they are. Sullivan-Bolyai et al14 found that fathers tend to move quickly from sadness to action. They begin with shock and awe at the time of diagnosis, and then quickly progress to learning to care for the needs of their child.

Coping resources significantly contribute to mothers’ diabetes self-efficacy. Mothers with good internal and external coping resources feel more confident in managing their children’s diabetes.15 Allow parents to discuss their feelings about managing the diabetes. Having someone understand their anxieties with empathy and without judgement makes a significant contribution to the reduction of anxiety. According to Bowes, Lowes, Warner and Gregory, “during interviews, mothers were far more likely than fathers to talk about their feelings. Mothers discussed their emotions and identified how specific events incurred continuing feelings of sadness”.7 Encourage parents to share information with grandparents, school teachers and others who will be involved with the child. Sharing information helps parents to consolidate their own knowledge.

When parents are in conflict with each other about the diabetes management, it helps if you can persuade them to work together. If they cannot do that, as is often the case with divorced parents, they need to be referred to a psychologist to help them to resolve their differences. They need to put aside their dissimilarities in order to help the child.

When parents are making unrealistic demands of a child, help them to adjust their parenting skills to adjust to managing the diabetes in a tolerable way.

Establish support groups for mothers and parents. Having contact with other parents who are dealing with diabetes makes them feel less isolated and they can learn from each other. Social media, such as facebook, lends itself to making support available to parents at the time of their need. “Kids powered with insulin” is an excellent example of a facebook support group for parents.

Caring for a child with diabetes is a daunting task for parents. The diabetes care team should have an understanding and non-judgemental attitude towards the parents. Each healthcare worker should do his or her best to:

- Listen to their difficulties.
- Boost their self-confidence by highlighting what they are doing right.
• Tactfully correct them when they are on the wrong track.
• Give them the information needed to master management of the diabetes.
• Allay their fears when their anxiety is unfounded, and encourage them to seek help when their anxiety or depression interferes with care of the child.
• Encourage them to become part of a support group.

This type of attitude towards, and input into, the parents of children with diabetes will make a significant contribution to ensuring that management of the diabetes is successful.

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References