The infant and toddler with diabetes: Challenges of diagnosis and management

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Children under three to five years of age with type 1 diabetes comprise a small minority of all those with this disorder: less than 1\% of all children are diagnosed in the first year of life, and less than 2\% of children attending large paediatric diabetes centres fall into the under three-year age group. Nevertheless, recent experience, backed up by epidemiological studies, suggests a significant trend towards diagnosis of type 1 diabetes at a younger age (1).

Infants and toddlers with diabetes pose a series of implications for both the health care professionals involved in their care as well as to their families. At diagnosis, younger children often do not present with classical symptoms of diabetes. Unless health professionals remain alert to the possibility of diabetes being the underlying cause of a child’s illness, the diagnosis may be missed. Once the diabetes has been diagnosed, the major challenge is to set up a treatment regimen that is both reasonable and realistic; in the youngest children, the goal of very tight metabolic control may expose them to episodes of severe hypoglycaemia which may lead to subtle cognitive impairments later in life. The therapeutic regimen must balance the naturally erratic eating and exercise patterns of very young children with the need to maintain adequate metabolic control. Setting a blood glucose target range of 6 to 12 mmol/L usually allows this to be accomplished. Diabetes during early childhood creates a psychosocial challenge to the families of these children. Successful management of infants and toddlers with diabetes depends on a well functioning and educated family, the availability of diabetes health care team experienced in the treatment of these youngsters, and the involvement of the extended family, child care personnel and others who play a role in their daily care.

Key Words: Infants, Metabolic control, Toddlers, Type 1 diabetes

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portant challenges to health care professionals. First, at the time of diagnosis, children often do not present with the classical early symptoms and signs of diabetes. Second, it is difficult to set up an appropriate therapeutic regimen for them. Third, it is a challenge to prevent serious hypoglycemia, which is especially important given hypoglycemia’s potential impact on the developing brain. Finally, from the psychosocial standpoint, there is the impact that a serious chronic disorder can have on the child and family. In this article, we will focus on these major issues, highlighting the need to balance what may be thought of as ideal care in older individuals with diabetes with what is practical and realistic in infants and toddlers.

DIAGNOSING DIABETES IN VERY YOUNG CHILDREN

When a sick infant or toddler presents to their primary care physician, type I diabetes is generally not high on the list of possible diagnoses, given the relatively low incidence of the disease in this age group. Furthermore, the classical symptoms of polyuria and nocturia, polydipsia, polyphagia, and weight loss are often overlooked or ascribed to other causes until the disorder has progressed to frank diabetic ketoacidosis (DKA). Even then the diagnosis may not be made immediately, and other serious illnesses such as bronchiolitis or asthma (because of the ‘heavy’ Kussmaul breathing), or meningitis or septicaemia (associated with obtundation and severe dehydration) may be considered first. The presence of a candida diaper dermatitis (and particularly one that is resistant to therapy) may provide a significant tip-off of the presence of glycosuria.

It is the authors’ clinical impression that many infants and toddlers are seen multiple times by one or more physicians or other health care professionals before ‘the penny drops’. The presence of polyuria and polydipsia may not only be overlooked, but may also be used to reassure the parents that nothing can be terribly wrong if their child is drinking and urinating well. The diagnosis may be one of upper respiratory infection or otitis media, or urinary tract infection if the excess urination is noted. It is not uncommon for children to receive a series of antibiotics for an illness that is not responding to treatment. For this reason, it is recommended that all infants and toddlers presenting to their physician with an illness for which there is not another readily acceptable explanation undergo a simple urinalysis to exclude glycosuria and ketonuria (2). Although diabetes is diagnosed in only a very small minority of such children, its detection prevents the development of severe DKA, the morbidity associated with severe dehydration or shock in an infant or toddler and the need for more prolonged hospitalization.

Of note is that some young children who are given large volumes of fruit juice and other concentrated carbohydrate-containing fluids in response to the polydipsia may present with severe degrees of hyperglycaemia (greater than approximately 350 mOsm/kg). Extreme caution should be exercised in correcting the DKA and hyperosmolar state to prevent a rapid drop in serum osmolality and possible intracranial fluid shifts (3,4).

ONCE THE DIAGNOSIS HAS BEEN MADE

Traditionally, most children with new onset type I diabetes, and particularly the youngest ones, have been hospitalized to stabilize their hyperglycaemia and to provide the initial education of their families. In more recent years, there has been a trend away from hospitalization at diagnosis except under certain circumstances (5,6). The Hospital for Sick Children has found this to be no less true for infants and toddlers than for older children and teens. Indications for hospitalization include the severity of their condition at diagnosis (eg, DKA, hyperosmolality), family living far from the hospital with difficulty attending on a daily basis, or if the responsible physician is not certain that the family understands the significance of the diagnosis or may be unlikely to attend the day care education program. The latter may be due to the presence of a language barrier or part of a severe emotional response to the diagnosis.

The authors’ approach to the immediate postdiagnosis management of these infants and toddlers is as follows. If admitted, children should remain in hospital only as long as their clinical condition demands (usually less than two to four days). If the child is not hospitalized, the family should return on a daily basis for two to four days to the diabetes day care facility: they arrive before breakfast and leave after dinner each day. During this time, parents and/or other primary caregivers are taught the ‘survival skills’ needed to care for an infant or toddler with diabetes, ie, insulin injection technique, blood glucose monitoring, appropriate infant feeding, and recognition and treatment of hypoglycaemia. More complete diabetes education is carried out on an ambulatory basis as the family begins to deal with the diabetes at home; this is invariably accomplished within two to four weeks of diagnosis. Throughout this early phase, general medical care and psychosocial support are provided by a core diabetes team experienced in the care of young patients, including a paediatric endocrinologist, diabetes nurse, diettitian and social worker. It is often beneficial to have home care providers assist the family with the routines after their initial period in day care.

INSULIN

Whether hospitalized or not, infants and toddlers are given very small doses of intermediate- (usually NPH) and fast- or super-fast-acting (either regular or insulin lispro, Humalog, Eli Lilly Canada) human insulins given twice daily. In the youngest infants, particularly those who are still breastfeeding, the injections are given about 12 h apart (about 08:00 and 20:00) and in the older children before breakfast and supper. As the children grow older, they are switched to a three-times daily injection routine...
MONITORING AND THE TARGET RANGE

Blood glucose monitoring is an especially useful tool in the management of the youngest children with diabetes; no longer do parents need to squeeze out their child’s diapers to test his or her urine! The authors have found that the families of most infants and toddlers are willing to test their children’s glucose levels three, four or more times a day to maintain control of the diabetes and to feel confident that the child is safe. The authors’ recommend that this monitoring be performed before meals and at the time of the bedtime snack. Additional testing 2 h after this snack or in the middle of the night (eg, 24:00 to 04:00) is also useful at times to predict and prevent nocturnal hypoglycemia.

Most families find that it is more convenient to use glucose meters than to determine glucose concentrations with visual strips. While most of the meters provide an excellent degree of accuracy and are relatively user friendly, the families of infants and toddlers usually prefer meters that require smaller amounts of blood for test performance and those that can be moved to accept the drop of blood rather than requiring the child’s finger to be in the correct position.

While studies such as the Diabetes Control and Complications Trial (DCCT) have unequivocally demonstrated a close relationship between the level of metabolic control achieved over the long term, and the onset and progression of the chronic microvascular complications of diabetes, none has included a prepubertal cohort (9,10). There are also data that, although still controversial, suggest that the clock does not start ticking (or at least ticks more slowly) in children with diabetes before the onset of puberty (11,12). Furthermore, there are also data (see the section on Hypoglycemia) that demonstrate that infants and toddlers who experience severe hypoglycemia early in the course of their diabetes may be at risk for subtle cognitive impairment later in life (13-15). It is for these reasons that a safe and realistic target range for blood glucose and hemoglobin A1c (HbA1c) levels should be set for young children. It is suggested that a range of blood glucose concentrations from 6 to 12 mmol/L (approximately 110 to 220 mg/dL) before meals and snacks is both achievable and safe in most infants and toddlers. This contrasts with a target of 4 to 10 mmol/L in school-aged children, and 4 to 7 or 8 mmol/L in adolescents. The target should represent the range in which most (perhaps 60% to 75%) of the blood glucose concentrations fall. It is impossible for all values to fall within this relatively narrow range.

Achievement of blood glucose levels in this target range should lead to HbA1c levels below 8.5 to 9% (where the nondiabetic range is 4% to 6%). Levels of 8.5 to 9% should lead to appropriate adjustments in the treatment regimen to improve metabolic control. As diabetic children grow, tighter blood glucose and HbA1c targets be-

with NPH and Regular/insulin lispro at breakfast, Regular/insulin lispro at supper and NPH at bedtime.

The authors usually start with about 0.25 to 0.5 U of insulin/kg body weight per day with the larger dose (about two-thirds) given in the morning, and about two-thirds to three-quarters of each dose given as NPH insulin, the remainder as Regular or insulin lispro. This is preferred to half- or full unit dosages and avoids the need for dilution of the insulin. The dose is slowly but steadily increased (by no more than 1 to 2 U each day) until blood glucose concentrations start to fall into the target range (6 to 12 mmol/L before meals, see below). This approach minimizes the risks of early hypoglycemia events while the family is still learning the ins and outs of diabetes management. Using this approach, the authors are unaware of any severe hypoglycemia episodes occurring in these young children in the first year after diagnosis (7).

Many parents of infants and toddlers with diabetes have concerns about giving insulin before they know how much their child is going to eat. This is especially true in those labelled as ‘picky eaters’. It is in these children that the superfast-acting insulin analogue, insulin lispro, may be most appropriate: the parents can judge the amount of food eaten at the meal and then give the insulin dose immediately afterwards. This approach requires that the parents become quite adept at judging the amount of food eaten and deciding on the appropriate amount of insulin based on an insulin dose algorithm or ‘sliding scale’.

The authors recommend insulin dosage adjustments based on ‘pattern management’. If blood glucose levels exceed the upper limit of the target range for three days in a row, the appropriate insulin dose is increased by 0.5 to 1 U at a time; if the levels are below the lower limit of the target range for two days in a row, the insulin is decreased by a similar amount. While most families use this pattern management approach, many are also taught how to make minor adjustments in the Regular or insulin lispro dose before breakfast and supper, depending on the ambient blood glucose level at that time and, in those receiving postprandial insulin lispro, the size of the meal.

Infants and toddlers require proportionately lower doses of insulin than older children or adolescents do (8). This demands that care be taken when adjusting the dosage of these preparations. For those few infants in whom single or even half unit doses cause hypoglycemia, dilution of the insulin may be necessary to deliver a reproducible amount. There are some data to suggest that diluted insulins may be less predictably absorbed.

In some centres, even infants and toddlers are placed on a multiple daily insulin injection regimen, with small doses of Regular or insulin lispro insulin given before each meal, and NPH either once (at bedtime) or twice (at both breakfast and bedtime) daily. There are no data available as to whether this approach provides improved metabolic control and/or a lower frequency of hypoglycemia. We are concerned about the added burden placed on the child and family by such an intensive approach at such a young age.
MEAL PLANNING

All families should have access to a dietitian who is experienced in infant nutrition as well as in diabetes care. For infants and toddlers with diabetes, the emphasis should be placed, initially at least, on teaching the principles of good infant nutrition with the provision of a variety of foods at consistent times and in fairly consistent amounts. There should also be some limitation put on the amount of concentrated carbohydrate (usually in the form of fruit juices) offered. For the majority of families with infants and toddlers with diabetes, this approach will suffice. Infants and toddlers often have erratic eating patterns: some days they seem to want to eat everything in sight and on other days they are content to pick at the food on their plate. For these families, a more formal diabetes meal plan (based either on an exchange-type diabetes diet or on carbohydrate counting) can be introduced once the child has a more structured lifestyle (eg, when starting school).

Parents should be advised to try not to fight with their children at meal times, and not to try to force feed those who do not finish their portions. Furthermore, parents should also avoid letting meal times drag on indefinitely – they will soon feel that their entire day revolves around food preparation and eating. In general, children will eat when they are hungry. Parents should use the results of blood glucose testing to direct their actions around offering food.

For some families, a more structured meal plan may be beneficial even at a young age, particularly if the family is anxious about the portion sizes that they are providing or if they are adjusting their insulin lispro insulin dose based on the amount of food eaten at the meal. A clearly structured meal plan may sometimes help avoid costly adjustments to the insulin dosage. The presence of an intercurrent illness with high blood glucose concentrations and ketones in the urine is a strong signal for concern.

HYPOGLYCEMIA

There are three issues of importance with respect to hypoglycemia in this age group. First, there are data showing that younger children with diabetes are more likely to experience severe hypoglycemia than are older children and teens (16,17). Second, infants and toddlers are invariably unable to express themselves in such a way that their parents can be certain that their symptoms are those of a hypoglycemic event. Third, repeated hypoglycemic episodes put them at risk for the later development of subtle cognitive or learning impairment (13-15).

The early warning symptoms of hypoglycemia in infants and toddlers with diabetes may be quite subtle: behavioural change (eg, irritability, crankiness, lethargy or floppiness, temper tantrums), sweating, pallor, a ‘different’ kind of cry or waking up at night crying. If not dealt with quickly, this may lead to severe hypoglycemia with coma or convulsion. Because it may be difficult to determine whether a certain behaviour on a specific day represents hypoglycemia, it is imperative that parents or other care providers monitor blood glucose levels at these times to confirm (or reject) hypoglycemia and direct treatment. The presence of a blood glucose level below 6 mmol/L in the presence of symptoms should lead to provision of about 60 to 120 mL of juice. If the episode occurs immediately before a meal, the meal should be started at once and the simple carbohydrate offered first.

Care should be taken not to overtreat mild hypoglycemia: there is often a tendency for parents to want to offer as much food as possible until the symptoms abate. This will inevitably lead to rebound hyperglycemia. Rather, the parent should offer the child 60 to 120 mL of juice and then wait 10 to 15 mins. If the symptoms continue, the treatment should be repeated. Reactions that occur during the night should be treated with a bottle or glass of milk. An alternative is to provide some juice plus a source of complex carbohydrate (eg, cookies) to support the blood glucose overnight.

All families of children with diabetes should have a Glucagon Emergency Kit at home to treat severe hypoglycemia (18). The authors have found that using 0.5 mg Glucagon immediately
PSYCHOSOCIAL ISSUES

Each age and stage of life present a different set of challenges concerning physical and emotional growth and development. The addition of a chronic disorder such as diabetes can increase the magnitude of many of these challenges considerably. Studies of the psychosocial adaptation to diabetes have focused largely on children over eight years of age: Kovacs and colleagues (20-22) and others (23,24) have followed a cohort of children diagnosed between eight and 13 years of age, while Jacobson’s group (23,24) comprised children age nine to 16 years at diagnosis. Both major longitudinal studies of adaptation to diabetes demonstrate that many of these children and their families have considerable difficulties in the immediate postdiagnosis phase, followed by a ‘settling down’ or coping phase and then a significantly increased potential for problems after many years (22,25).

Although it is reasonable to hypothesize that similar outcomes would be found in the very youngest children with diabetes, there are no empirical data to either support or refute this viewpoint.

Experience, supported by a single qualitative study (26), suggests that both medical and psychosocial factors pose an increased burden to the family during infancy and early childhood, and may predispose the family to both family dysfunction and difficulties with achieving good metabolic control in the child. The combined risk of severe hypoglycemia and its impact on the developing brain (13-15), and the erratic eating and activity patterns of infants and toddlers makes adjustment of the treatment regimen more difficult.

From the available studies in older children (20-24), it is clear that diabetes is a significant burden to the family and child: important associations have been reported between maternal and child psychopathology (26) and between maternal and child depression (27). Family behaviours (28) and characteristics, such as organization and cohesiveness, emotional expressiveness, lower levels of conflict and more marital satisfaction in the parents (29,30), have been associated with better metabolic control in the child, particularly in the younger children in these studies. Furthermore, the family environment was strongly related to perceived competence and self-esteem, diabetes adjustment and symptomatology in the older children (31).

There is evidence that periods of major psychological transition are associated with increased vulnerability. Adolescence is such a transition and has been well stud-

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TABLE 1: ‘Sick day’ rules for young children with diabetes

- Check blood glucose concentration and urine ketones every 4 h around the clock.
- Make sure that the child continues to receive fluids and calories; if the child is unable to eat, offer clear glucose-containing fluids (eg, juice, ginger ale, Jell-o or popsicles).
- Do not discontinue insulin: the dose may need to be adjusted.
- Treat the underlying illness. The effect on metabolic control will not be alleviated until the illness resolves or is treated.
- Call the diabetes team immediately or go the nearest emergency room if:
  - the child refuses to eat, drink or vomits more than twice in a short space of time;
  - the blood glucose concentration remains low despite appropriate food intake and insulin doses adjustment; or
  - the blood glucose remains high with positive urinary ketones despite appropriate illness management.

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TABLE 2: Insulin dose adjustment during ‘sick days’

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| Blood glucose remains more than 6 mmol/L but less than 13 mmol/L | Continue the same dose of insulin.
| Blood glucose is greater than 13 mmol/L but less than 17 mmol/L AND ketones are absent | Start the next day to increase dose 10% to 20% per day until target sugars are achieved.
| Blood glucose remains greater than 13 mmol/L AND ketones are moderate or large, OR blood glucose is greater than 17 mmol/L independent of ketones | Give extra Regular/insulin lispro immediately: approximately 10% to 20% of daily dose every 4 h until glucose is less than 13 mmol/L and ketones are negative to small.
| Blood glucose less than 6 mmol/L | Encourage glucose-containing fluids.
| Blood glucose remains more than 6 mmol/L | Continue the same dose of insulin.
| Blood glucose is greater than 13 mmol/L but less than 17 mmol/L AND ketones are absent | Start the next day to increase dose 10% to 20% per day until target sugars are achieved.
| Blood glucose remains greater than 13 mmol/L AND ketones are moderate or large, OR blood glucose is greater than 17 mmol/L independent of ketones | Give extra Regular/insulin lispro immediately: approximately 10% to 20% of daily dose every 4 h until glucose is less than 13 mmol/L and ketones are negative to small.
| Blood glucose less than 6 mmol/L | Encourage glucose-containing fluids.

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ied. On the other hand, the first three years of life are also recognized as a time of rapid change and development with long-lasting implications for the future (32). It would be surprising if diabetes and its management in this period did not have the potential to influence development significantly.

Diabetes and its management impinge on the normal psychological tasks of infancy and early childhood, including developing a sense of one’s own body (which includes appetites and preferences) (33) and establishing a sense of trust and security in one’s caregivers, especially at times of pain distress (34). Parents and other primary caregivers who are needed as sources of security and comfort become agents of pain: the child is subjected repeatedly to insulin injections, finger pricks and an increase in the external control of diet preferences and food intake. Additionally, if parents are distressed by frequent reminders of their child’s diabetes, they may compromise their ability to offer comfort and security to their youngsters when they need it most.

Food intake is a potentially contentious issue for parents and infants or toddlers, even in the absence of diabetes. Up to 25% of all young children may have feeding difficulties at some time (35). In other disorders where feeding is of special interest, such as cystic fibrosis, the rates of feeding disorders are increased (36). Hypoglycemic events cause special concern to parents, given their potential to affect later cognitive impairment (13-15) and because they are hard to identify (25). Thus, it seems likely that parents of infants and toddlers with diabetes will become engaged in struggles over eating at least as commonly, if not more so, than do parents of nondiabetic children.

The authors believe that the onset of diabetes during early childhood poses a definite risk of the development of significant family dysfunction, maladaptive behaviour and poor metabolic control in the children and their families. The authors suspect that the presence and severity of such dysfunction and behaviour depend highly on family adaptation before onset of diabetes and on the early psychosocial responses following diagnosis. It is also suspected that adaption to diabetes will be affected by early experiences such as hypoglycemia and DKA. Clearly, research is urgently needed about the early adaptation of these children and their families, with the aim of finding interventions to lessen the negative outcomes in some families.

HELPFUL HINTS IN COPING WITH INFANTS AND TODDLERS WITH DIABETES

Adopt a ‘matter-of-fact’ approach to the routines (injections, finger pricks and meal times) and maintain an emotionally positive attitude throughout. Young children quickly pick up on the anxieties of their parents and are likely to be distressed in response. Children may show oppositional or withdrawal behaviour even while their parents are trying to reassure them. This may be disconcerting and upsetting for the parents. A vicious cycle may ensue in that the more the parents try to console the child and coax him or her to have an injection or finger prick, the more oppositional or withdrawn the child may become. Parents can learn to master interactions and modulate their own behaviours if they recognize these situations as opportunities to teach their children, and if they understand that their child learns from everything the parents say or do.

Prepare the insulin or blood testing equipment in another room out of sight of the infant or toddler and only involve him or her once everything is ready. This may shorten his or her period of anxiety or upset considerably.

Involve the whole family. Diabetes care is a partnership between the child with diabetes and the whole family. Parents should share the responsibility for the diabetes care to prevent the child from playing one off against the other. In single parent families, enlisting support from extended family members, friends or home care professionals may help to lessen the stress for parents.

If the child is upset by the injections or finger pricks, try distractions, such as signing songs, holding a favourite animal or toy, or watching television while the routine is performed. Then give the child a hug and a kiss, and move on with the day. Find ways to give the child some control over aspects of these otherwise unpleasant procedures, eg, do not give the injection until she or he is holding her or his favourite teddy bear. Provide reassurance throughout and try not to express anger; it is normal for children to refuse or resist needles or finger pricks.

For the really picky eater, set limits on the amount of time for meals and snacks. If they have not eaten in the allotted time, take the food away. Parents should offer healthy foods that their child usually enjoys. Parents must then understand that their child eats best when he or she pays attention to his or her feelings of hunger and satiety. Begging children to eat or force feeding them will interfere with that awareness. Regular blood glucose checks will prevent hypoglycemia.

Use the resources available: the diabetes team, in particular, but also parent support groups, volunteer agencies (eg, the Canadian Diabetes Association), etc.

CONCLUSIONS

The family of the infant or toddler with type I diabetes is faced with a long and seemingly arduous journey through early childhood, the school years and adolescence before the child establishes himself- or herself as an independent young adult. At times this path may seem like a minefield to many parents. They should take heart: the vast majority of children carefully and successfully manoeuvre their way through the age and stage transitions, and learn to cope with and adjust to their diabetes. Success depends on a well functioning and fully informed family, an available and experienced diabetes health care team, and the involvement of the extended family, day care personnel and others who play a role in the child’s day-to-day care. With this support and guidance, the burden of diabetes can be significantly reduced.
REFERENCES


Infants and toddlers with diabetes

Answer the following questions by circling the letter of the correct answer(s). Answers can be found on page 86.

1. Children under three years of age comprise _______ of children less than 18 years of age with newly diagnosed type 1 diabetes:
   (a) less than 2%
   (b) 2% to 10%
   (c) 10% to 25%
   (d) 50%
   (e) almost two-thirds

2. Infants and toddlers are at increased risk for severe hypoglycemia because of which of the following:
   (a) erratic eating habits.
   (b) defective counter regulatory hormone responses.
   (c) nonspecific nature of early warning symptoms of hypoglycemia.
   (d) autonomic dysfunction.
   (e) likelihood of increased period of intense activity.

3. During periods of intercurrent illness, parents should do all of the following except:
   (a) check blood glucose levels every 2 to 4 h.
   (b) withhold insulin in case child does not eat well.
   (c) check for ketonuria.
   (d) attend the emergency room if the child vomits repeatedly.
   (e) avoid using medications that may raise the blood sugar.

4. The long term outcome of early onset diabetes is influenced by:
   (a) adequacy of family functioning.
   (b) frequency of ketonuria.
   (c) occurrence of episodes of severe hypoglycemia.
   (d) presence of associated thyroid dysfunction.
   (e) number of insulin injections provided each day.

5. Hospitalization for infants and toddlers with diabetes is:
   (a) always necessary at the time of diagnosis.
   (b) likely to be frequent because of difficulties with control.
   (c) advisable as soon as an intercurrent illness becomes apparent.
   (d) only indicated if the metabolic disturbance is severe.
   (e) never indicated.