

Uncontrolled diabetes: A difficult mother or a mother in difficulty?

Amir Babiker^{1,2}, Bothainah Alaqeel², Mohammed Alsaeed², Ghadeer Aljahdali², Abdulrahman Almunif², Sundeep Sandhu³

¹Department of Pediatrics, King Abdullah Specialized Children Hospital, Ministry of the National Guard - Health Affairs, Riyadh, ²College of Medicine, King Saud bin Abdulaziz University for Health Sciences, Riyadh, Saudi Arabia, ³Neonatal Unit, York Hospital NHS Foundation Trust, York, United Kingdom

ABSTRACT

Young children with diabetes (YCD) are a particularly vulnerable group because they are reliant on adult carers in their management. Diabetes treating teams (DTT) have a responsibility towards YCD targeting good glycemic control (GC) to improve quality of life and reduce risk of complications. It can be difficult, however, in occasions to balance between providing support for struggling families and considering safeguarding YCD who are not well looked after by carers in their management. We report a 6-year-old girl with type 1 diabetes with HbA1c ranged between 10.7% and 15.7%. A number of social factors have influenced her diabetes control including parental separation, maternal mental health concerns and lack of family support. Each time, these issues have been addressed, and also when grandparents were involved, a transient short-lived improvement in GC was observed. However, there were always ongoing concerns about mother's lack of engagement with the DTT. Similar cases continue to pose significant challenges for DTT, worldwide. A balance should be kept between providing adequate support for such families against a possible need for safeguarding YCD. Using a patient centered approach, if there is no improvement in GC despite taking all measures to support mothers or families who struggle with their YCD management, it becomes difficult to justify not involving the safeguarding team and social services.

Keywords: Diabetes team, safeguarding, social services, uncontrolled diabetes, young children

Introduction

Young children with diabetes (YCD) are a particularly vulnerable group because they depend on adults to deliver their management. Several social factors might influence the glycemic control (GC) of these patients. Children who have irregular attendance in diabetes clinics are more prone to have acute complications of diabetes and poor GC.^[1]

Address for correspondence: Dr. Amir Babiker, King Abdullah Specialized Children Hospital, King Saud Bin Abdulaziz University for Health Sciences, Ministry of National Guard Health Affairs, P.O. Box 22490, Riyadh 11426, Saudi Arabia. E-mail: babikeram1@ngha.med.sa, babikeramir@hotmail.com

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Schools have a responsibility for the health and safety needs of YCD.^[2] Various studies have shown parent's concerns about the awareness and levels of support available at schools for their children, particularly in case of an emergency.^[3] Parental divorce can be a major disruption in the life of an YCD.^[4] It has been reported that children living in single parent households demonstrated persistent deterioration in GC.^[4,5] Primary care physicians, who provide comprehensive care of YCD, have a responsibility to identify deficiencies in the management of these children. It can, however, be difficult to balance identifying families that need additional support and considering when to involve children safeguarding team.

Detecting obscure hints in a patient's course of management may be missed in large hospitals, while in a primary care setting, the

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opportunity of identification of struggling patients or children in need for safeguarding is more attainable.^[6] Early identification is key for effective collaboration with specialized diabetes and social services. YCD should always be in the heart of our service. Our attention should extend to include YCD families to optimize their care. We present the example of YCD at an early age that had problematic GC since diagnosis with a complex social background to elaborate further on different dimensions of similar cases.

Case Report

Amy (a pseudonym) presented with Diabetic Ketoacidosis (DKA) at the age of 2.5 years. Her family initially seemed to cope well with the diagnosis of diabetes. Amy was discharged home on a twice-daily insulin regime and a plan of follow-up in the clinic. Educational sessions were planned to train the nursery Amy attended to support her condition. Amy was noted to have a high glycated hemoglobin (HbA1c) level at the subsequent review. Later on, parental separation affected Amy's condition [Figure 1]. In a subsequent visit, a discussion was carried out with Amy's mother regarding her compliance to medication. The option of insulin pump (CSII) therapy was explored. It was proposed that the inclusion of social services might be in Amy's best interest. During the following visits, Amy's mother reported having panic



Figure 1: Sequence of events and challenges faced in Amy's management

attacks affecting her functioning at work and with caring for Amy. Grandparents stepped in to help. Unfortunately, despite the efforts of the diabetes team and family support, Amy's mother continued to have difficulties.

Continuing problems

Persistently high HbA1c levels necessitated further discussions with Amy's mother 3 years after the diagnosis. She was not following advice to alternate injection sites and was not testing Amy's blood glucose frequently. Worryingly, she was also calculating insulin doses, correction insulin boluses and carbohydrate counting incorrectly, even though the diabetes team had repeatedly and properly explained this to her. Again, there was a transient improvement in Amy's HbA1c levels following further discussions, but this had worsened at the next reviews. At this point, mum became upset with the diabetes team. She reported disliking attending clinic because she was constantly reminded about the risks of complications and despite trying hard; she always felt criticized.

Discussion

Managing YCD can be challenging for both parents and healthcare professionals. Proper parent's education is essential for the optimal delivery of treatment. Preschool children have unpredictable habits especially in terms of activity and caloric intake, which results in varying insulin requirements. In addition, increased insulin sensitivity and greater risk of hypoglycemia poses further problems. Hence, causes parents to experience various degrees of stress.^[7] Therefore, parents may get overprotective, not allowing their child out of their sight and may scold them for exploring. Children spend a considerable amount of their time at school. Which demands a certain degree of responsibility towards YCD medical needs on school systems.^[2] HbA1c has a significant impact on education and cognitive ability of children especially in YCD diagnosed before seven years of age.^[8] Successful management requires collaboration between parents, treating teams and schools. Difficulties arise however when, despite continued efforts, a patient has persistently high HbA1c levels.

Parents may fail to engage with provided services that care for YCD. This is attributed to three main barriers: physical, practical and social stigma.^[9] In the UK, Gardner *et al.* found that many parents preferred services provided by voluntary organizations to those provided by social services because of easy accessibility.^[10] Contact with social workers was not an experience to contemplate with ease. Social workers were viewed as those who "checked up" on families and were strongly associated with investigating allegations of child abuse.^[11]

On numerous occasions, healthcare professionals were concerned about Amy. Factors arising concerns included persistent poor GC, failing to attend clinic appointments, missing school, frequently missing blood glucose level tests and maternal health problems. Despite these concerns, social services were never involved. To our knowledge, there is no evidence in the literature to suggest benefits of early involvement of social services in similar situations. However, if the mother's struggles were identified earlier, this might have allowed prompt additional support and consequently an improvement in Amy's GC. It is our duty to prevent further complications of diagnosed conditions. This means appropriate GC to prevent the risk of developing long-term complications.^[12] However, we feared that the involvement of social services would have led to further deterioration in the relationship between Amy's family and the diabetes team, which might have negatively impacted her medical care. Through additional support from extended family, we hoped that we would be able to improve Amy's HbA1c level. Amy's case highlights that involvement of safeguarding team in the management of YCD should be individualized.

Conclusions

Safeguarding children may include providing further support to their families who struggle with their care. In occasions, it can be difficult to differentiate the struggling families from those who are neglecting their YCD.

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Conflicts of interest

There are no conflicts of interest.

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