

OBSTACLES ENCOUNTERED BY THE PARENTS ATTENDING TO CHILDREN WITH DIABETES PROBLEMS

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Abstract: The incidence of diabetes in young children (age >6 years) is rising. Diabetes management guidelines offered by the American Diabetes Association and health care teams understandably place a high burden of responsibility on caregivers to check young children's blood glucose levels, administer insulin, and monitor diet and physical activity with the ultimate goal of maintaining tight glycemic control. Unfortunately, this tight control is needed during a vulnerable developmental period when behavior is unpredictable, children in diabetes can be physiologically difficult to control, parenting stress can be elevated, and caregivers are strained by normal child caretaking routines. Despite the potentially different management needs, specific education and clinical services for managing diabetes in young children are rarely offered, and behavioural research with this young child age group has been limited in scope and quantity. Diabetes management in young children can be challenging for a variety of reasons, including physiological factors such as increased insulin sensitivity and a potentially shortened honeymoon period. Daily children with diabetes management is further complicated by young children's cognitive, behavioural, and social-emotional development. The data collected with respect to understand the obstacles encountered by the parents attending to children with diabetes problems. The results revealed that Problems and stress observed by the parents are following High level of expectation, Excessive emotional involvement, Problems related to long term treatment, Patient's refusal to drug use, Lack of understanding about illness symptoms, Lack of understanding about the importance of medicine, Fear of social stigma, Unable to attend to family functions.

Keywords: parents, children with diabetes

INTRODUCTION:

Youth with Diabetes must adhere to a complex and time-consuming lifelong daily medical regimen to delay or prevent the onset of acute and chronic Diabetes related complications such as seizure, coma, diabetic ketoacidosis, cardiovascular disease, retinopathy, nephropathy, and neuropathy (Bade-White PA, Obrzut JE. 2009).

Parents of young children with T1D are responsible for their child's daily diabetes management, including frequent blood glucose (BG) monitoring, insulin administration, and diet/physical activity regulation (Sullivan-Bolyai S, Deatrick J, Gruppuso P, Tamborlane W, Grey M. 2002).

Goals include maintaining BG levels between 100-200 mg/dl and HbA1c levels below 8.5% (equivalent estimated average glucose [EAG] <197 mg/dl), monitoring BG levels at least 4x/day, and engaging in healthy eating habits with adequate intake of vitamins and minerals. These relatively conservative glycemic goals recognize the developmental challenges of increased insulin sensitivity, unpredictable diet/physical activity patterns, and resulting glycemic variability in this population.

The (ISPAD) International Society for Pediatric and Adolescent Diabetes is less conservative and does not specify tailored treatment goals for young children, recommending that all youth with type 1 diabetes achieve an A1c <7.5% and maintain euglycemia as much as possible while avoiding hypoglycaemia (Rewers M, Pihoker C, Donaghy K, Hanas R, Swift P, Klingensmith GJ. 2009)

However, both the ADA and ISPAD-suggested treatment goals can be difficult to achieve and clinical behavioral T1D management programs do not typically offer tailored patient education/counseling services specifically designed to meet the young child or his/her family's individual needs.

Diagnosis, approximately 69% of young children experience a temporary restoration of beta cell function (i.e., honeymoon period) as a result of insulin therapy, during which less insulin is required. Yet, 90% of young children no longer fall into this category 12 months post-diagnosis (Abdul-Rasoul M, Habib H, Al-Khouly M. 2006).

Thus, parents must quickly adapt to a new diabetes regimen and changing physiological needs. Young children also exhibit increased insulin sensitivity, susceptibility to hypoglycemia, and potentially long-term neuropsychological effects due to difficulties meeting treatment goals and longer disease duration. The burden of diabetes management and

resulting parental worry about acute and chronic complications likely contributes to daily BG management challenges and parent stress.

Research on the neurocognitive consequences of early-onset diabetes and related glycemic variability is emerging. Recently, the DirecNet research group published several papers comparing brain structure and neuropsychological functioning in a group of young children (ages 4-<10) with T1D to age-matched healthy controls. Using structural magnetic resonance imaging, Marzelli and colleagues found that young children with diabetes with a history of significant hyperglycemia evidenced decreased gray matter volume as compared to healthy control participants in key brain regions associated with cognitive capacities (Marzelli M, Masaika P, Barnea-Goraly N, Hershey T, Tsalikian E, Tamborlane W, et al. 2014).

The association between glycemic variability, particularly hyperglycemia, and cognitive function was more pronounced in young children with earlier onset and longer duration of diabetes, further highlighting the vulnerability of the developing brain in this age group (Barnea-Goraly N, Raman M, Mazaika P, Marzelli M, Hershey T, Weinzimer SA, et al. 2014).

In this same sample from the DirecNet study, Cato and colleagues reported trending associations among executive functioning, learning/memory, and hyperglycemia, suggesting that structural brain changes in youth with diabetes have a subtle, yet measurable, impact on cognition as soon as two years after the onset of diabetes. Additional research on the long-term cognitive impact of T1D and hyperglycemia in early childhood is needed (Cato M, Mauras N, Ambrosino J, Bondurant A, Conrad A, Kollman C, et al. 2014).

The very young age at diagnosis during a critical period of rapid neurological growth contributes to significant concerns regarding hypoglycemia as well. For a variety of reasons, including lack of expressive language skills and cognitive immaturity, young children may be unable to reliably detect and/or report early symptoms of hypoglycemia (Sullivan-Bolyai S, Deatrick J, Gruppuso P, Tamborlane W, Grey M. 2002).

Parents may struggle to discriminate between behavioral cues signifying a low or high BG level and normal developmental (mis)behavior such as temper tantrums, which can interfere with proper T1D management (Hilliard ME, Monaghan M, Cogen FR, Streisand R. 2011).

Further, young children's cognitive capacities make it difficult for them to grasp complex, higher-order concepts typically associated with formal, logical thought, including time and cause and effect. Given the concrete reasoning skills and limited problem-solving abilities of young children, adherence to the diabetes treatment regimen may, in fact, seem like punishment (Hatton DL, Canam C, Thorne S, Hughes AM. 1995).

The young child's limited cognitive ability to cope with daily regimen demands may also lead to aggression, resistance to BG checks or injections/site changes, or somatic complaints (Wysocki T, Huxtable K, Linscheid TR, Wayne W. 1989).

RESEARCH METHOD:

It focused on children (3 to 15 years). The main focus of the study was to study “Obstacles Encountered by the Parents Attending to Children with Diabetes Problems”

Sample: N= (60)

Research Findings and Discussion:

Open-ended check list to find out the obstacles encountered of parents includes 10 Areas: Physical care, Health, Career, Losing support, Financial, Social and psychological - Embarrassment/ Ridicule, Relationships, Sibling effect.

Obstacles encountered by the parents attending to children with diabetes problems (n=60)

S.no	Area	Category based on Mean ± SD	Male (n=21)		Female (n=39)		Total (n=60)	
			F	%	F	%	F	%
1	Physical care	Mild level	1	5	2	5	3	5
		Moderate level	9	43	17	43	26	43
		Severe level	11	52	20	51	31	52
2	Health	Mild level	5	24	4	10	9	15
		Moderate level	7	33	16	41	23	38
		Severe level	9	43	19	49	28	47
3	Career	Mild level	2	10	3	8	5	8
		Moderate level	8	38	16	41	24	40
		Severe level	11	52	20	51	31	52
4	Losing support	Mild level	1	5	4	10	5	8
		Moderate level	12	57	15	38	27	45
		Severe level	8	38	20	51	28	47
5	Financial	Mild level	3	14	6	15	9	15
		Moderate level	9	43	20	51	29	48

		Severe level	9	43	13	33	22	37
6	Social	Mild level	4	19	5	13	9	15
		Moderate level	7	33	15	38	22	37
		Severe level	10	48	19	49	29	48
7	Psychological	Mild level	1	5	2	5	3	4
		Moderate level	8	38	20	51	28	46
		Severe level	12	57	17	43	29	48
8	Embarrassment/ Ridicule	Mild level	2	10	4	10	6	10
		Moderate level	10	48	16	41	26	43
		Severe level	9	43	19	49	28	47
9	Relationship	Mild level	8	38	15	38	23	38
		Moderate level	7	33	13	33	20	33
		Severe level	6	28	11	28	17	27
10	Sibling effect	Mild level	2	9	5	13	7	12
		Moderate level	6	28	15	38	21	35
		Severe level	13	62	19	49	32	53

The above table presents the list of obstacles encountered by the parents attending to children with diabetes problems. Physical care deals with attending to the physical needs of the child such as - bathing, feeding, dressing, brushing, grooming, lifting and carrying the child, medicating and toilet needs. In this area 52 per cent of the caretakers faced problems of severe level, 43 per cent with moderate level and 5 per cent faced with mild problems in attending to the Physical care of the child.

With regard to parent's health problems such as - asthma, high blood pressure, headache, mental worries, 47 per cent faced severe level of health problems, 38 per cent faced moderate problems and only 15 per cent had mild health problems due to child's ill health.

The third area Career deals with readjusting job timings, taking up a less paying job, in ability to take up a job, and seeking transfer. In this area, 52 per cent had severe problems, 40 per cent moderate level and only 8 per cent faced mild problems in this area.

The fourth area deals with losing support from spouse, family, in-laws, relatives, friends, neighbours. In this area 47 per cent of the caretakers faced severe problems due to lack of support, 45 per cent moderate and only 8 per cent of the caretaker's has very little problem in this area.

The next area deals with financial problems - visit to doctors and other professionals, transportation, medical investigation, aids, appliances / equipment, visit to traditional healers. In this area, 48 per cent had moderate problems and 37 per cent had severe problems and 15 percent had mild problems.

Social category deals with attending to social functions, indulging in recreational activities, pursuing an interesting hobby. In this area only 48 per cent faced severe level of problems, 37 per cent moderate level and 15 per cent had mild problems.

Further with psychological problems such as mood swings, irritability, resentment, feeling of powerlessness, low self esteem, low self worth, lack of interest in activities, anxiety and depression. In this category 48 percent faced problems of severe problems, 46 per cent had moderate psychological problems and only 4 had mild problems.

Embarrassment deals with reaction of family members, relatives, neighbours and community. With regard to facing relationship problems with spouse, family members, in laws, relatives, friends, neighbours, 47 per cent faced severe problems and 43 per cent faced problems of moderate level and 10 per cent of the caretakers felt mild embarrassment with people's reactions.

With regard to facing relationship problems with spouse, family members, in laws, relatives, friends, neighbours, 38 per cent faced severe and mild problems and 33 per cent faced problems of moderate level.

Sibling effect deals with parents spending less time with other children, studies getting affected, having added responsibilities, being teased by neighbours and community, feeling isolated, and worrying about future. In this area, 53 per cent faced severe problems, 35 percent faced moderate problems and 12 percent faced very mild problems.

The results revealed that 38 per cent of the parents faced relationship problems in spending time with the siblings, i.e. getting less time to talk, having added responsibilities, recreation needs being compromised, sometimes being teased by the community, feeling isolated, and worrying about the future as the care takers were spending most of the time with the sick child and attending to the medical needs and physical needs.

More than half of the parents faced problems in child's physical care, and 33 per cent of the parents belonged to low income group and were 48 per cent illiterates. Most of them were from rural areas.

As the children suffering from diabetes experience the sick effects such as nausea and vomiting, dizziness or light-headedness, sweating, shortness of breath, pale coloration of the skin, indigestion, heart rate increase - Seeing them in such situation, most of the parents generally develop signs of depression, anxiety, irritability, resentment, powerlessness, low self esteem and low self worth.

CONCLUSION:

The data collected with respect to understand the obstacles encountered by the parents attending to children with diabetes problems. The results revealed that **Problems and stress observed by the parents are following** High level of expectation, Excessive emotional involvement, Problems related to long term treatment, Patient's refusal to drug use, Lack of understanding about illness symptoms, Lack of understanding about the importance of medicine, Fear of social stigma, Unable to attend to family functions.

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