

Understanding of insulin pump therapy among parents of children with type 1 diabetes

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ABSTRACT

Purpose: The study aimed to analyze the level of awareness among parents of children undergoing therapy using a personal insulin pump and focus specifically on those elements of treatment that create problems for caregivers.

Materials and methods: The study was carried out in a group of 110 parents of children with type 1 diabetes undergoing personal insulin pump treatment. The primary research method was a diagnostic survey conducted using a survey technique. The proprietary survey questionnaire consisted of 69 questions.

Results: Ninety-three percent of parents participated in diabetes education led by qualified personnel. Most subjects (90%) correctly indicated the factors that influence the volume of the primary infusion. Twenty-five percent of respondents pointed to the incorrect answer on the injection site of the infusion set. Nearly all subjects (97%) knew administering a

combined bolus. Forty-four percent of parents chose the incorrect answer to the question concerning the management of hypoglycemia, i.e., the consumption of only simple carbohydrates. Respondents incorrectly identified the symptoms of ketoacidosis: excessive motor activity (15%), decreased volume of urine excreted (10%). Every fourth respondent wrongly indicated an increased dose of insulin as the cause of ketoacidosis. Moreover, 15% of subjects reported excessive motor activity as the cause of ketoacidosis.

Conclusions: The respondents were most knowledgeable about handling an insulin pump, principles of self-control, caring for the injection site, and proper nutrition rules. The caregivers proved least informed about ketoacidosis, choosing the injection site, and managing hypoglycemia.

Keywords: insulin pump, type 1 diabetes, therapeutic education

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INTRODUCTION

The diagnosis of diabetes raises many doubts and questions in every patient. Over the last 30 years, there has been an approximately fivefold increase in the incidence of diabetes among children in Poland. Due to the chronic nature of the disease and the extensive involvement of the patients and their families in therapy, the treatment principles should be fully known and accepted by everyone. Currently, it is considered the best method of treating type 1 diabetes in children, continuous subcutaneous infusion of insulin using a personal insulin pump is considered. This method reflects insulin secretion under physiological conditions [1].

A child's illness poses an enormous challenge for the whole family. It is the caregivers who must acquire the appropriate knowledge to care for their children without difficulty. They make decisions about insulin dose, food preparation, and response to difficult situations daily. That is why therapeutic education and re-education are so critical throughout the course of the disease. Current literature lacks

research on therapeutic education and parents' knowledge of treating their children using a personal insulin pump.

The study aimed to analyze the level of awareness of non-pharmacological and pharmacological treatment of diabetes and management of acute diabetes complications among parents of children undergoing therapy using a personal insulin pump.

MATERIALS AND METHODS

The study was conducted in 2017. The 150 questionnaires were given and sent to parents. Seventy-three percent of questionnaires were completed correctly. The study group consisted of 110 people (80 women and 30 men), aged 20 to 60, who are parents of children with type 1 diabetes treated with personal insulin pumps. Most respondents were between 20 and 30 years old. More than half of the respondents declared cities with more than 150,000 inhabitants as their place of residence (Table 1).

Table 1. Characteristics of the studied group

STUDIED CHARACTERISTIC	Number (n)	Percentage (%)
SEX		
Female	80	73
Male	30	27
AGE		
20 – 30 years of age	44	40
31 – 40 years of age	35	32
41 – 50 years of age	19	17
51 – 60 years of age	12	11
PLACE OF RESIDENCE		
Village	10	9
City population of up to 50 thousand	16	15
City population over 50,000 up to 150 thousand	12	11
City population over 150,000 up to 300 thousand	51	46
City population over 300,000	21	19

The vast majority of people surveyed (94%) had no diabetes. Almost two-thirds of parents had only one child. In 2% of families, more than one child was ill. More than half of cases of diabetes were diagnosed before four years of age. The majority (70%) children of the subjects had diabetes for up to 2 years. The introduction of insulin pump treatment occurred in more than half of cases up to 4 years of age, while the duration of pump treatment in 70% of cases lasted two years.

The method of research was a diagnostic survey carried out with the use of the questionnaire technique. Some of the questionnaires (87%) were obtained via the Internet, the remaining 23% via direct. The research tool was a questionnaire that consisted of 69 questions, checking the parents'

knowledge of the essence of the disease, the basics of insulin pump treatment, and self-control.

RESULTS

The assessment of the quality of diabetes education among families and children with type 1 diabetes.

Almost 2/3 of the respondents (63%) attended diabetes clinics 3 to 4 times a year with their children. Thirty-one percent came to the clinic 5 to 8 times a year. A small percentage of parents (6%) participated in 1 to 2 follow-up visits a year. Most (93%) participated in curricular diabetes education conducted by authorized personnel.

Over half of the respondents (66%) confirmed that the format of the diabetes instruction was adapted to their needs. Twenty-five percent of parents found the course partially incomprehensible, and 10% found it completely unintelligible. The respondents listed the following as the main reasons: hard to understand medical language inadequate to students' abilities, insufficient time allowed to complete exercises, or too broad a scope of knowledge too hard to learn.

The hospital was the most commonplace for leading the education program (85%), followed by a diabetes clinic (15%). None of the respondents listed the sick child's district clinic as a place of therapeutic education.

Individual therapeutic education was more prevalent. Forty-four percent of individuals listed group education, most of which were groups up to 5 people (92%).

All individuals who participated in the study confirmed they had received educational

materials in class that helped them organize and deepen their knowledge.

In ninety-three percent of respondents, the therapeutic team consisted of a nurse trained to teach therapeutic education. A little above a quarter of the respondents had a diabetologist in their group of educators. In contrast, less than 9% of the survey participants mentioned a primary care physician and a psychologist.

Fundamental elements of diabetes treatment, i.e., the principles of insulin therapy, diagnosis and management of hypoglycemia and hyperglycemia, were part of education for all surveyed individuals. Ninety-three percent of respondents learned the principles of self-control, while 84% were instructed on the rules of proper nutrition in diabetes. More than half of the caregivers were trained to deal with technical problems resulting from personal insulin pump therapy. Only 29% of the respondents learned about the correct principles of undertaking physical activity by their children (Table 2).

Table 2. Elements and topics included in the education plan of the patient and his family

EDUCATION ELEMENTS	Percentage (%)
Principles of insulin therapy - use of boluses	100
Symptoms, management of hypoglycemia	100
Symptoms, management of hyperglycemia	100
Self-control - taking measurements with a blood glucose meter	93
Nutrition in diabetes mellitus - calculation of exchangers	84
Technical problems when using an insulin pump	58
Replacing infusion sets	46
Care of the injection site	43
Taking up physical activity	29

* Multiple choice question. The respondent could provide more than one answer

Assessment of parents' knowledge of self-control

All respondents indicated that they monitor their child's daily blood glucose levels. Most reported that they could interpret glycemic values, monitor body weight, and check insulin pump

hardware. About a quarter of the parents asserted that they controlled the blood pressure of their children (Table 3).

Table 3. Activities performed by parents with their children included in self-control

ACTIVITIES	Percentage (%)
Taking and recording blood glucose measurements with a blood glucose meter	100
Drawing conclusions from the obtained results	93
Bodyweight control	81
Checking the equipment in the treatment kit with an insulin pump	56
Monitoring for the presence of ketone bodies and glucose in the urine	52
Monitoring blood pressure	27

* Multiple choice question. The respondent could provide more than one answer

About 3/4 of the parents reported monitoring their children's glycemia 2 to 3 times a day. Eleven percent declared that blood glucose levels were checked up to 5 times a day, and 16% measured glucose levels in children only once a day. Most parents (55%) used a blood glucose meter to measure their child's blood glucose levels which worked with an insulin pump. Only 18% of respondents used the convenience of a continuous glucose monitoring system. Most respondents knew the recommended injection sites, but a quarter of the caregivers incorrectly indicated the scapula area.

Ninety-one percent of respondents had a good knowledge of the duration of the injection. Most of them indicated five correct answers regarding the situations in which the injection site should be changed. Seventy-nine percent of parents reported that they had washed the injection site with Octenisept, and 16% had cleansed it with water. Over 90% of the respondents knew the situations in which it was necessary to disconnect the pump, i.e., in the state of hypoglycemia, before bathing, and before imaging tests (Table 4).

Table 4. Caregivers' awareness of injection issues

INJECTION SITE TOPICS	Percentage (%)
INJECTION SITE	
Abdomen	100
Thigh	95
Buttock	86
Arm	75
Shoulder blade area – incorrect answer	25
MAXIMUM HOLDING TIME FOR TEFLON INJECTION	
Up to 72 hours or whenever necessary	91
Up to 96 hours – incorrect answer	6
Up to 24 hours – incorrect answer	3
SITUATIONS IN WHICH AN INJECTION SITE MUST BE CHANGED	
The period of the injection used is near its end	100
Skin complications developed	100
Infusion set is blocked	98
Blood appeared in the drainage system	92
Hyperglycemia occurs despite the applied correction	72
DISINFECTANT USED TO CLEANSE THE INJECTION SITE	
Octenisept	79
Water	16
Water with soap	5
Not cleansed with anything	0
SPECIAL SITUATIONS IN WHICH THE INSULIN PUMP CAN BE DISCONNECTED BY THE CAREGIVER	
In a state of hypoglycemia	100
When performing electromagnetic field treatments	95
Before tests such as CT, X-rays, or MRI	94
Before the planned bath	90
Before exercising, when it may get damaged	66
During sleep - wrong answer	3
In the state of hyperglycemia - wrong answer	0

* Multiple choice question. The respondent could provide more than one answer

A vast percentage (85%) of the respondents declared that they knew the hotline telephone number to seek advice in the event of technical problems.

The vast majority (93%) of study participants indicated in the survey that they used bolus calculator settings while using a personal insulin pump. All subjects selected bodyweight as a value influencing the size of the basal infusion. However, 10% of respondents chose the wrong answer - meal size as a factor that influences the volume of the basal infusion. Eighty percent

indicated a correct response regarding the timing of administration of insulin analogs before a meal. The vast majority (96%) of the study participants correctly defined the concepts of a regular, complex, and extended bolus. All respondents knew the type of insulin used in an insulin pump, and 94% of respondents showed knowledge of the body's increased need for insulin during an infection. The levels of knowledge on what data is needed to calculate meal boluses and corrective measures (insulin action time, glycemic range we want to achieve, meal index, and insulin sensitivity) varied.

Most of the respondents identified the duration of action of insulin and the range of blood glucose levels as information necessary for the determination of boluses. Seventy-five percent of respondents provided the meal index. A percentage of 14% indicated body weight. Most of the respondents (95%) knew the correct definition of the meal index, i.e., the necessary amount of insulin for the carbohydrate exchanger. All subjects were aware of the need to reduce the insulin dose when doing physical activity, almost all of them during diarrhea or vomiting (98%). The majority (67%) mistakenly believed that the insulin dose should be reduced during long journeys. Most of the respondents (90%) knew about the need to increase the dose of insulin during the disease and during treatment with steroids. Ninety-four percent of respondents correctly defined the carbohydrate exchanger, the glycemic index, and the protein-fat exchanger.

Parents' level of knowledge about the states of hypoglycemia.

All caregivers participating in the study unanimously stated that their children developed a state of hypoglycemia during the disease. According to parents' reports, the state of hypoglycemia occurred in more than 2/3 of children up to 2 times in the last three months. In 3% of children, the state of hypoglycemia occurred much more often, even up to 10 times. The primary symptoms of hypoglycemia mentioned by the respondents were: difficulty thinking and association (98%), anxiety (97%), increased heart rate (95%), irritability and nervousness (90%), increased sweating (85%), increased appetite (80%), trembling hands (46%). Three percent of caregivers incorrectly indicated excessive sleepiness as the initial symptom of hypoglycemia.

All respondents believed that the cause of hypoglycemia was skipping a meal after administering insulin and too much insulin administered in a simple or combined bolus. Other causes of hypoglycemia included excessive physical effort without insulin reduction (83%), incorrect handling of the insulin pump (72%), incorrect replacement of the insulin reservoir (59%), and hormonal disorders of the thyroid gland (43%). In the event of hypoglycemia in children, almost all caregivers considered it necessary to reduce or temporarily stop the dose of the basal infusion (99%). Most of the respondents believed that the intramuscular administration of glucagon (95%) and the use of an extended bolus before a protein-fat meal (85%) were appropriate in severe hypoglycemia. Nearly half (44%) of the respondents considered it necessary to treat hypoglycemia to supply only simple carbohydrates for consumption, and 15% of the respondents incorrectly stated that the correct action is to use a complex bolus extended before a protein-carbohydrate meal.

Parents' level of knowledge about the states of hyperglycemia.

All respondents unanimously admitted that hyperglycemia occurred in their children. According to 80% of the respondents, the state of hyperglycemia was experienced by children between 3 and 5 times. Two percent of them indicated that their children endured such a state ten times within three months. All respondents indicated that the main symptoms of hyperglycemia were increased thirst and polyuria. Slightly fewer people identified fatigue (92%), drowsiness (85%), malaise (84%), and dry mouth (71%). Thirty-seven percent of parents incorrectly suggested a child's excessive physical activity as a symptom of hyperglycemia. All parents indicated insufficient insulin dose, missed bolus, or underestimation of insulin concerning the meal taken by the child as the possible main reasons for the development of hyperglycemia. Other causes of hyperglycemia included increased insulin requirements caused by accompanying diseases (94%), pump failures (85%), improperly conducted insulin therapy (85%), extensive time to disconnect the pump (66%), underestimation of the number of consumed carbohydrate exchanges (63%), increased insulin requirement in the morning (56%), and substantial reduction of insulin doses before exercise (46%). None of the caregivers pointed out the erroneous causes of hyperglycemia. All respondents declared the use of a correction bolus in the event of hyperglycemia. A high percentage (83%) of parents also indicated the injection assessment, checking the tightness of the infusion set and the insulin reservoir (79%), and replacement of the injection if necessary (63%). Ketoacidosis occurred in 2% of children of the surveyed parents. Each caregiver indicated a perceptible smell of acetone from the mouth as the classic symptom of ketoacidosis. Other symptoms identified by caregivers include abdominal pain (98%), either-or nausea vomiting (92%), and rapid breathing (85%). Fifteen percent mistakenly reported excessive motor activity and a 10% decrease in urine volume. Most respondents indicated insulin therapy discontinuation (95%) and infections (92%) as the primary causes of ketoacidosis. The percentage of 25% chose the wrong answer, i.e., increased insulin therapy, and 15% chose excessive physical activity.

The level of knowledge of skincare around injection sites among parents and caregivers.

All respondents confirmed that their children had skin-related complications with the presence of an injection of a personal insulin pump set. The largest group were children with skin complications from 3 to 5 times within three months. Complication indicated by all respondents was the non-adherence of the patch to the skin and infections. Other frequently occurring complications included

pain while moving (67%) or during bolus administration (56%). A percentage of 35% indicated blood in the drain as a complication that occurred during insulin pump therapy. Symptoms of infection reported by all respondents included increased body temperature, increased skin warming, pain, increased glycemia, reddening of the skin, and the presence of purulent discharge, which were identified by over 90% of respondents. Seventy-five percent suggested the feeling of lumps beneath the skin's surface as signs of infection. A small percentage incorrectly pointed to reduced glycemia (6%) and cold skin (1%).

DISCUSSION

Abnormal metabolism of carbohydrates, fats, and proteins of various etiologies are characteristic of diabetes. In-depth knowledge of diabetes helps choose the best solution to the problems in daily life with the disease. Children and adolescents often find it hard to come to terms with the condition. They do not understand the reasons for the development of diabetes and the principles of proper treatment. That is why systematic therapeutic education of parents and guardians is so crucial. They are in charge of their children's treatment in the first stage of the disease. Parents with a large body of knowledge are more likely to make the right and correct decisions that will improve the quality of their children's lives. In the presented study, it was found that the level of knowledge of parents and guardians is satisfactory or better. Most of the respondents had basic knowledge about the nature of the disease and treatment methods. Other authors who studied 50 young people and their caregivers treated with the pump and intensive insulin therapy came to similar conclusions. They found that the children's and caregivers' level of knowledge was satisfactory. The patients' knowledge about treatment with multiple injections was more extensive when compared to patients treated with personal insulin pumps [2].

Education is a fundamental component of holistic diabetes care. Properly conducted treatment is inseparable from model self-control, and this, in turn, requires a constant deepening of knowledge. Therefore, therapeutic education should be carried out by trained professionals and should be an ongoing process. It is also paramount to prepare valuable educational materials in an accessible form to use in education in the home environment. In their publications, Otto-Buczowska E. and Marciniak-Brzezińska M. drew attention to the essential role played by didactic materials. Apart from traditional books or brochures, they suggest modern aids such as computer programs or games children and adolescents [3] find interesting. In the study by Trojanowski A. et al., it can be concluded that children's and adolescents' knowledge about diabetes

is insufficient. The study was conducted in a group of 100 12–16-year-olds with type 1 diabetes. Children were most knowledgeable about the principles of proper nutrition, the essence of the disease, its causes and symptoms, and the correct glucose levels. They were least knowledgeable about self-control related to the principles of insulin supply, diagnosis of hypoglycemia, management of hyperglycemia, and foot care [4]. According to Trojanowska, it is crucial to properly convey knowledge to parents and guardians to pass the acquired knowledge and skills to their children. From the presented study, it can be concluded that almost all parents and caregivers participated in diabetes education conducted by qualified personnel. The therapeutic team mainly consisted of nurses who took over the role of the principal educator. Similar conclusions can be found in the study conducted by Kosicka B. and Wrońska I. aimed at assessing the role of a nurse in the process of diabetes education. The results of this study indicate that the group of patients educated by nurses had proper and satisfactory knowledge compared to the groups educated by other members of the therapeutic team. Nurses provided a wide range of knowledge about the essence of the disease, treatment, and self-care in diabetes [5].

Basic principles of insulin therapy, i.e., the use of boluses, identifying the symptoms of hypoglycemia and hyperglycemia, and the ways to manage them, are among the topics discussed at all diabetes education meetings and presented in this research.

Moreover, a significant number of the respondents learned about the principles of self-control and proper nutrition. In the study by Kosicka and Wrońska, patients learned the most about the nature of the disease, symptoms, and causes of hypoglycemia and hyperglycemia, monitoring glycemia, and nutrition rules. Contrary to the research by Kosicka and Wrońska, the most limited knowledge related to issues concerning undertaking physical exercise [5]. Another author, in a study conducted with a group of 30 parents of diabetic children treated with an insulin pump, the most crucial elements of education was the ability to dose insulin and the correct handling of the infusion set. Dietary training caused the most difficulty in the education process [6]. In the presented study, almost all respondents participated in education on the principles of healthy eating and the principles of bolus supply. Only half of the respondents were educated on solving technical problems related to the pump and the infusion set replacement, which according to Janota's work, is one of the most crucial pump therapy skills. Parents and caregivers demonstrated sufficient understanding of insulin pump use, accessories, and the principles of bolus administration. Over 80% of the study participants correctly indicated the method of handling the

equipment and bolus selection. The study conducted by Ratajczak P. et al. on 107 patients with type 1 and 2 diabetes or LADA type diabetes indicated that subjects had insufficient knowledge about nutrition [7]. All caregivers indicated that they measured blood glucose and kept a self-monitoring diary, but only 93% drew conclusions from the obtained measurements. The vast majority (75%) measured blood glucose two to three times a day in this research. According to Tobiaszewska et al., [2], most respondents performed at least four measurements a day. This difference may be due to the varying sizes of the studied groups. In addition, Tobiaszewska's study also included people treated with multiple insulin injections. Tobiaszewska also points out that the respondents did not have correctly controlled glycemia [2].

The Continuous Glucose Monitoring System is intended to improve and facilitate diabetes control and provide you with a sense of security. In our research, such a facility was used by only 12% of the people under our care. In the studies by other authors, 60% of respondents did not know this technological solution [2]. That proves that there is little interest in this method of measuring glucose or the high costs of self-monitoring. In the research Tabor A., et al. found that the use of pump therapy with additional elements such as a continuous glucose monitoring system reduces the incidence of hypoglycemia. At the same time, the psychological comfort of the patient and his or her family improved [8]. One of the elements of self-monitoring is measuring blood pressure. That is a significant part of self-care because people with diabetes have a higher risk of developing cardiovascular complications than the rest of the population. However, in many cases, this activity is omitted in prophylaxis. Only 27% of the respondents made these measurements in their children. Other authors came to similar conclusions, noting that the percentage of 66% performed sporadic blood pressure measurements [2]. Another essential part of self-care is controlling the presence of ketone bodies and glucose in the soak. In the presented study, this activity is performed by 52% of respondents. Tobiaszewska et al. achieved a similar result in their work [2]. Most parents or guardians of children treated with an insulin pump knew the basic principles of self-control, the amount of time after which the injection should be replaced, and cases where this can be done sooner. The dominant part of the caregivers was able to indicate the events before which it is necessary to disconnect the insulin pump on their own or locate the injection sites of the personal insulin pump set.

Hypoglycemia or hyperglycemia are the most common complications affecting diabetic patients' quality of life. Proper treatment aims to minimize fluctuations in blood glucose levels. According to the reports from parents or guardians,

all children developed a state of hypoglycemia, less than 3/4 of sick children up to 2 times in the last three months. The subjects knew the main symptoms of hypoglycemia. Most people indicated impaired concentration, irritability, anxiety, fast heart rate, nervousness, and increased appetite. All the respondents admitted to administering too much insulin or skipping a meal after administration of insulin as the most common cause of hypoglycemia. Other reasons often indicated were excessive physical activity and errors in the use of the insulin pump. Other authors who studied 140 diabetic patients reached similar conclusions. Food restriction, insulin overdose, hypoglycaemic drugs, and excessive exercise were the primary causes of hypoglycemia [9]. To counteract hypoglycemia, the respondents indicated an insulin dose reduction in the basal infusion, the use of a combined bolus before meals consisting of protein and fat, and in the case of extreme hypoglycemia, administering glucagon intramuscularly. In the study conducted by Pastwe K., the respondents stated that the essential activities they undertook in the state of hypoglycemia included eating one teaspoon of sugar, drinking a sweet drink, eating sweets or a sandwich [10].

In the research, hyperglycemia occurred in all children. In over 80% of them, 3 - 5 times in the last three months based on the reports from parents or caregivers. All participants listed increased thirst and polyuria as the main symptoms of hyperglycemia. Over 80% of respondents also indicated fatigue and dryness in the mouth and skin problems. Likewise, other authors listed polyuria, dry mouth, somnolence, and, additionally, abdominal pain and vomiting as the most common symptoms of hyperglycemia [10]. The reasons for the increase in glucose were the administration of insufficient insulin dose, omission of a meal bolus, infectious conditions of the body, pump failure, and improperly conducted insulin therapy. In the works of Kalinowski et al. and Pastwe, too high a dose of carbohydrates in a meal, low physical activity, insufficient insulin dose, and an accompanying disease were all considered the principal causes of hyperglycemia [9,10]. In the study, the respondents regarded the corrective bolus administration to be appropriate in the case of hyperglycemia. Next, they focused on the need to look for the cause of increased glucose concentration by, among other things, assessing the injection and checking the tightness of the entire infusion set. In the Pastwe study, the respondents first checked their glucose and acetone levels in urine, administered short-acting insulin, and consumed a glass of salted fluid to reduce the level of hyperglycemia [10]. The differences stem from different methods of treating patients in the study compared with the studies by other authors. This study tested parents' or guardians' knowledge about skincare in the area of the infusion set site. That is a

common problem because each respondent confirmed the instance of this complication in their children. Most respondents concluded that this problem appeared in the cared-for children about 3-5 times within three months.

About 90% of the respondents knew the correct symptoms of the infection. Diabetes, as a chronic disease, imposes certain limitations in everyday functioning. Modern methods of treatment that would improve the quality of life of sick people are continually being sought. Parents and caregivers should have extensive knowledge to freely conduct pump therapy and increase the quality of life for their children and themselves. In the work of Kubicz A. et al., the authors emphasize the beneficial effect of pump treatment on the quality of life of children and adolescents with type 1 diabetes [11]. Czechura J. compares patients' quality of life treated with multiple subcutaneous insulin injections with the quality of life of patients treated with a personal insulin pump. Pump treatment provides the patient with better metabolic balance, gives the patient a sense of independence and flexibility, and improves quality of life [12].

CONCLUSIONS

The quality of the diabetes courses conducted was good, and the scope of the topics covered mostly corresponded to the needs. Therapeutic education requires periodic re-education and expansion with added elements related to physical effort. The respondents were most knowledgeable about insulin pump control, principles of self-control, caring for the injection site, and proper nutrition principles. Parents were least knowledgeable about ketoacidosis and the principles of taking up physical exercise.

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Conflicts of Interest

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