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TRANSITION CHALLENGES IN TYPE 1 DIABETES MELLITUS FROM PAEDIATRIC TO ADULT CLINIC

J. Vella * and L. Grech

Department of Pharmacy, Faculty of Medicine and Surgery, University of Malta.

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Correspondence to Author:
Jonathan Vella

Research Scholar,
Department of Pharmacy, Faculty of Medicine and Surgery, University of Malta.

E-mail: jonathan.vella.93@gmail.com

ABSTRACT: Objectives: Transitioning from a family-centred clinic to a patient-centred clinic is an inevitable and fragile process through which patients and caregivers have to go through. This study aimed to identify transition issues and assess the role of pharmacists during this phase. **Method:** A mixed-method approach combining qualitative and quantitative analysis was used to identify factors that may contribute to uncontrolled diabetes during the transition period. Due to the challenges posed by the COVID-19 pandemic, three online questionnaires were developed, reviewed, and distributed *via* social media to patients, caregivers, and healthcare professionals. **Key Findings:** Concerns were raised about being under the care of a new doctor and not being provided enough support and care during the transition. Participants noticed a shift towards self-management as they moved between clinics. Furthermore, there was strong support for the involvement of pharmacists in the transition process, with participants agreeing that pharmacists could help reduce medication errors. **Conclusion:** A well-structured transition plan can ease the shift from paediatric to adult care. A multidisciplinary approach, involving various healthcare professionals, can better equip patients and caregivers with the skills needed for a successful transition. Identifying specific needs within the patient and healthcare team may allow pharmacists to tailor their interventions to improve patient outcomes during this critical period.

INTRODUCTION: Patients diagnosed with a chronic condition face numerous challenges as they transition through adulthood, in addition to coping with the condition itself and its impact on their lifestyle [1]. Diabetes mellitus is a chronic condition that affects 5-15 % of the total world's population [2]. The rising number of children diagnosed with type 1diabetes mellitus is leading to an increase in patients who must transition from paediatric to adult care. In Malta, in 2014, it was predicted that there would be an annual increase of 25 patients living with type 1 diabetes, which equates to approximately one new patient every two weeks [2].

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Diabetes mellitus is complex and requires ongoing self-management to improve the quality of life for patients living with the condition [3]. As patients grow older and enter adolescence, their needs and priorities shift, making it essential to facilitate a smooth clinical handover and transition of care [4]. Transition of care refers to the gradual shift from supervised care to self-care, which occurs through a planned process that addresses the psychosocial, medical, educational, and vocational needs of teenagers and young adults as they learn to live with diabetes mellitus [5].

The transition phase presents several challenges, including stressful life situations, flaws in the healthcare system, and issues in the transition process itself between paediatric and adult care, all of which lead to an increased risk of loss of motivation and, subsequently poor health and complications [6]. During the transition phase, patients are vulnerable and require both time and assistance to discuss their management plan and access to healthcare providers [4]. However, patients do not receive adequate information regarding transition issues or the transition process [6]. In addition, patients are not given the option to choose the healthcare provided and do not receive care that caters to their daily adulthood life challenges [7]. Furthermore, patients are unaware of or uninformed about who could guide them through the transition [7].

Gaps during the transition period may lead to suboptimal healthcare delivery, deterioration of glycaemic control, increased occurrence of acute complications, the emergence of chronic complications, and psychosocial and emotional changes [8]. This highlights the need for an efficient, individualized transition process to ensure that the patients and caregivers are adequately prepared for the transition. The study aimed to develop tools that could help in identifying issues leading to uncontrolled diabetes in transitioning patients, capture caregiver concerns as their children transition, and explore the perception of the patients, caregivers, and healthcare professionals on the role of the pharmacist during the transition period.

MATERIALS AND METHODS: The methodology was divided into two phases. Phase 1 involved identifying and developing tools to identify predictors that may lead to uncontrolled diabetes mellitus during the transition period, while also capturing the expectations of patients, caregivers, and healthcare professionals regarding the role of the pharmacist. Phase 2 focused on distributing the developed tools to participants in Malta.

Phase 1: Identification, Development, and Validation of Required Tools: Three separate questionnaires were compiled in English and Maltese, each comprising a combination of open- and closed-ended questions. The questionnaires were validated by an expert panel that included an education-based pharmacist, a hospital pharmacist, a community pharmacist, a diabetes education nurse, a paediatric endocrinologist, an adult endocrinologist, a diabetic patient, and a parent of a diabetic patient. The first questionnaire titled: 'Patient Self-management Assessment' addressed type 1 diabetes mellitus individuals, aged 14 to 30. It aimed to capture challenges patients may or have encountered during the transition from paediatric to adult care, assess self-management abilities, and gauge patients' knowledge of diabetes. The 'Patient Self-management Assessment 'contained 46 questions, divided into four sections. Section 1 captured participants' demographics and general patient details.

Questions 1 to 11 were open- and close-end questions, aimed to give an insight into the participants' demographics including their age, how long they have been diagnosed with diabetes, any diabetes-related complications, and current treatment. Section 2 of the' Patient Self-management Assessment' targeted the diabetic care regime where questions 12 to 33 used a 5-point Likert scale (ranging from 5 for" Strongly Agree" to 1 for "Strongly Disagree"). This allowed participants to specify the extent to which they agreed with statements designed to assess their ability to self-control or self-manage their condition. Section 3 of the 'Patient Self-management Assessment' focused on transition issues where questions 34 to 42 used a 5-point Likert scale (ranging from 5 for "Strongly Agree" to 1 for "Strongly Disagree"). These statements addressed transition issues faced during the shift from the paediatric clinic to the adult clinic. Section 4, the final section of the 'Patient Self-management Assessment' dealt with the preparation for the transition. Questions 43 to 46 assessed the participants' readiness for the transition process and featured a checkbox option that allowed participants to select multiple answers simultaneously that best reflected their preferences.

The Second Questionnaire Titled: '*Parents Concern'* was aimed at caregivers of type 1 diabetes mellitus individuals and explored their concerns about the individual's control of the condition during the transition period. The 'Parents Concern 'questionnaire consisted of 39 questions, divided into four sections. Section 1of the' Parents Concern' questionnaire a the red demographic information, including the age of both the caregiver and patient, as well as how long ago the patient was diagnosed with diabetes mellitus. Section 2 of the *'Parents Concern'* questionnaire focused on the caregiver's involvement in diabetes care.

Questions 4 to 24 used a 5-point Likert scale (ranging from 5 for“ Strongly Agree” to 1 for “Strongly Disagree”) and participants were asked to identify the level of agreement with the statements assessing their involvement in the patient’s diabetes treatment and monitoring regimen. Section 3 addresses transition issues with questions 25 to 32 using a 5-point Likert scale (ranging from 5 for“ Strongly Agree” to 1 for “Strongly Disagree”)to assess challenges caregivers face during the transition process. Section 4 of the ‘Parents Concern’ questionnaire dealt with the preparation for the transition phase. Questions 33 to 39 featured a checkbox option that allowed participants to select multiple answers simultaneously that best reflected their readiness for the transition process.

The third Questionnaire Titled: ‘Role of pharmacist’ targeted individuals aged 14 to 30 with type 1 diabetes mellitus, their caregivers, and healthcare professionals. The ‘Role of pharmacist’ questionnaire explored the perception of the respondents regarding the role of the pharmacist during the transition. It consisted of 18 open- and closed-end questions.

Phase 2: Distribution of Developed and Validated Questionnaires: Following approval from the University of Malta Research Ethics Consent (UREC), the questionnaires were distributed between January 2020 and March 2021. Before distribution, participants were provided with an information letter that outlined the study’s purpose, scope, and objectives. Given public health restrictions during the COVID-19 pandemic, the questionnaires were disseminated via Google Forms through social media platforms. Healthcare professionals distributed the questionnaires and liaised with patients and caregivers through specific Facebook groups aimed at the target audiences.

RESULTS:

Validation of the Developed Questionnaires: All members of the expert panel (n=8) agreed that all three questionnaires were self-explanatory, that the information was well presented, and aligned with the aim of the study. **Table 1** shows the minor modifications that were recommended and implemented accordingly.

TABLE 1: RECOMMENDED MODIFICATIONS TO QUESTIONNAIRES

Questionnaire	Modification
Patient Self-management Assessment	To include all insulin products available on the market taking into account both those available on the National Health System as free of charge, as well as those which are available to purchase from community pharmacies.
	To increase the specificity and clarity of the question one question where patients were asked to tick 3 answers was reformatted into 3 separate questions.
Parents Concern	For the question about the ideal age of transition, the “Never” option was changed to “over 18” since patients cannot “never” transition from a paediatric clinic to an adult clinic.
Role of pharmacist	No modifications were recommended.

The main outcomes of the Disseminated Questionnaires: A 95% confidence interval was applied in all questionnaires with a 5% margin of error due to data anomalies. A total of 41 participants completed the ‘Patient Self-management Assessment’, 20 of whom were female. Participants' age ranges from 14 to 30 years, with a mean age of 24 years. The most common insulin regimen used by participants (n=31) was a combination of Lantus® as a long-acting insulin and NovoRapid® as a fast-acting insulin. **Table 2** summarises the insulin taken by the patient cohort.

TABLE 2: INSULIN TAKEN BY PARTICIPANTS

Type of Insulin	Number of patients	Percentage
Lantus® (glargine)	36	87.8%
NovoRapid® (aspart)	37	90.2%
Humulin® M3 (biphasic)	1	2.4%
Humulin® S (soluble)	5	12.2%
Humulin® I (isophane)	1	2.4%
Tresiba® (degludec)	3	7.3%

Complications that required hospitalisation were experienced by 11 participants with the most common complication (n=7) being hyperglycaemia with diabetes ketoacidosis.

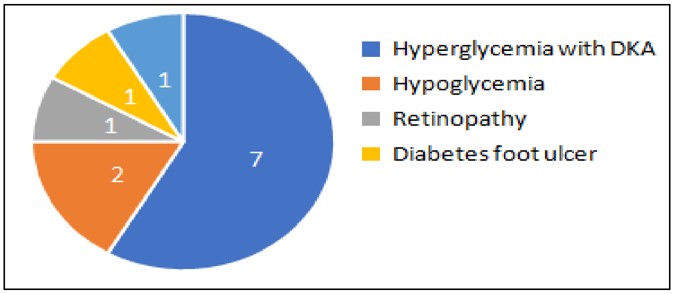

FIG. 1: COMPLICATIONS THAT REQUIRED HOSPITALISATION

Of the 41 participants, 19 strongly agree that they schedule their outpatient appointments, with 10 strongly agreeing that the appointments are scheduled at their convenience. As patients transition to the adult clinic, they are encouraged to attend their outpatient appointments alone. This is reflected in 23 patients who strongly agree to attend by themselves; however, only eight patients strongly agree to attend all appointments. It is noted by 23 patients who strongly agree and 12 patients who agree that outpatient visits tend to become shorter and less frequent in the adult clinic. Additionally, 34 patients strongly agree that outpatient visits focus more on the patient rather than a family-centred approach. Thirteen participants reported that they did not feel prepared for the transition from the paediatric clinic to the adult clinic, and they also noted that they did not openly discuss the transition process. Out of 41 participants, only seven felt that they were fully prepared to transition. The most commonly discussed topics were 'diabetes and alcohol' followed by 'diabetes and insulin misuse' as shown in **Fig. 2.**

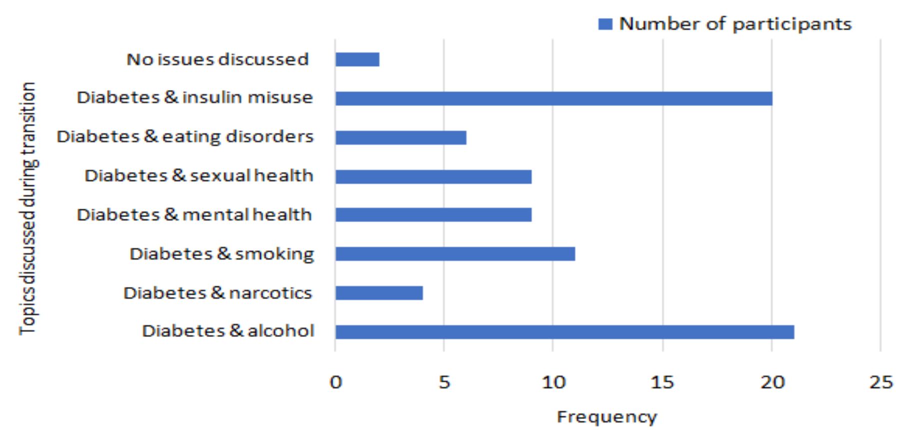

FIG. 2: TOPICS DISCUSSED BY PATIENTS WITH HEALTHCARE PROFESSIONAL

Participants demonstrated a resilient acceptance of their condition, openly informing their peers that they live with type 1 diabetes mellitus and no longer depend on their caregivers to manage their diabetes. Although they felt in control of their condition, participants still expressed several concerns. The most common worry was that after the transition, they would be under the care of a new consultant (n=22), followed by concerns about not receiving enough care and support (n=13) as shown in **Fig. 3.**

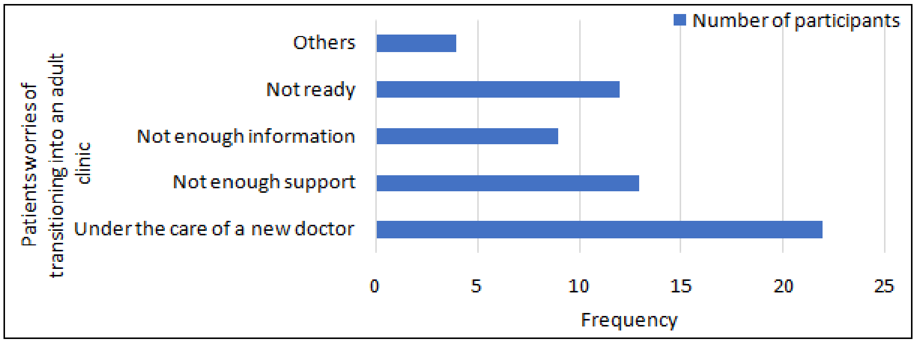

FIG. 3: PARTICIPANTS WORRIES ABOUT THE TRANSITION

The 'Parents Concern' questionnaire was completed by 22 participants (age range: 32 to 56 years; mean= 46 years). The age of the patients they cared for ranged from 10 to 22 years with a mean age of 16 years.

During paediatric care, insulin management and blood glucose monitoring are handled by the caregiver. However, as patients transition to adulthood, they are encouraged to take on self-management of their diabetes. The most common concern expressed by caregivers was that the patient would be under the care of a new doctor (n=15), which aligns with the same concerns voiced by the patients themselves. As the transition period approaches, 11 caregivers strongly agree that they worry about it, with three of them strongly agreeing that they are worried about meeting the new healthcare team. Furthermore, 10 caregivers believe that the patients should begin preparing for the transition at age 15-16, and only nine out of 22 caregivers strongly agree that transition issues have been brought up during outpatient visits.

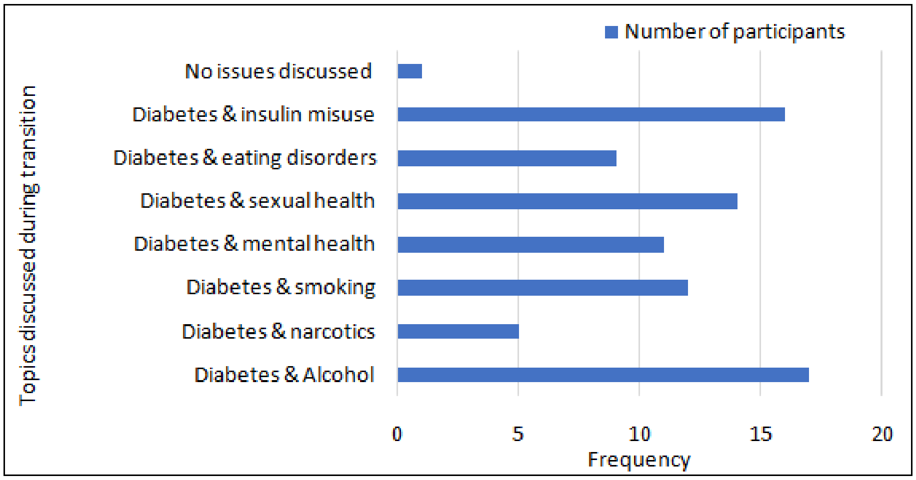

FIG. 4: FREQUENCY OF TOPICS DISCUSSED BY HEALTHCARE PROFESSIONALS

The '*Role of pharmacist'* questionnaire was completed by 35 participants, 27 of whom were female. The youngest participant was 19 years old, and the oldest was 63, with a mean age of 34 years. Seven participants held a post-graduate degree, 12 participants had a bachelor's degree, five participants had completed tertiary level education, and 10 participants had a secondary level of education. Of the 35 participants, 19 strongly believed that the pharmacist should be involved in the transition process, and 18 of them felt that the pharmacist could improve the transition outcome. Participants were also asked about their perceptions of the pharmacists 'qualifications. Twelve strongly agreed and 13 agreed that pharmacists are qualified to be involved in the transition period. However, 16 participants strongly agreed and 11 agreed that specialized training for pharmacists is still necessary.

DISCUSSION: The transition process is an inevitable and challenging phase that both the patient and caregiver must navigate. This phase presents itself with several challenges, including a change in healthcare provider, the shift from a family-based approach to a patient-centred self-management approach, and the need to address psychosocial challenges while trying to maintain a normal daily life [9]. It is not surprising that glycaemic control during the transition period is the worst amongst the age groups of type 1 diabetes mellituspatients [9]. Insulin and medication management for type 1 diabetes mellitus is tailored to the individual patient's needs. With the introduction of new medications and post-market surveillance, pharmacists are qualified to assist in the decision-making process and help identify the best treatment for the individual patient [10]. Home blood glucose monitoring, introduced around 40 years ago, has revolutionized the self-management approach for type 1 diabetes mellitus patients [11]. This innovation has allowed patients to control their blood glucose levels better and take greater responsibility for managing their diabetes [11]. In 1999, the first-ever concept of a continuous glucose monitoring system was introduced, and the accuracy of these devices has improved ever since, further transforming diabetes management [12]. In addition to improved glycaemic control, patients using continuous glucose monitoring systems tend to be more motivated, which empowers their self-management [13]. Continuous glucose monitoring has been recently introduced in Malta, and although patients in the study were using glucose test strips, patients demonstrated compliance towards blood glucose testing without depending on their caregiver but were not compliant with keeping records. With the introduction of continuous glucose monitoring, blood glucose is recorded instantly, and data is stored, contributing to a further decrease in diabetes mellitus deterioration and diabetes mellitus complications.

During the transition from paediatric to adult care, as many as 60% of patients with diabetes may discontinue their outpatient follow-up [14]. This lack of continuity is associated with deteriorating glycaemic control and an increased risk of avoidable hospitalizations [14]. Spaic *et al.* (2019) reported that the number of outpatient appointments increased among patients who participated in an 18-month structured transition process [15]. While most participating patients attended regular outpatient clinics, they did not tend to attend appointments alone. This observation coincides with caregivers' perspectives where 63.6% of caregivers believe that the patient should never visit the healthcare professional alone, even after transitioning to adult care. According to participants, most appointments were scheduled by patients, but not at times that were convenient to them. Recommendations have been made to introduce evening or flexible clinic hours, which have shown an increase in patient compliance towards outpatient attendance [5]. Lack of acceptance in diabetes mellitus management was not only due to the clinic transition but also included psychological, sexual, and intellectual transition [16]. Lack of acceptance in transitioning into adulthood, especially acceptance of diabetes mellitus is found to lead to barriers in compliance towards treatment[17]. Despite this, patients have shown resilient agreement to accepting their condition and educating their peers about diabetes mellitus. In a study conducted by Wysocki and Greco (2006), it was found that peers play a critical role in diabetes and psychological well-being, either by offering support or creating additional burdens [18].

The transition process is not only challenging for the patient but also for the caregiver, whose involvement should not diminish [19]. While patients have shown a strong preference for independence, they still rely on their caregivers to collect their medication from the pharmacy. Family involvement during the transition and the quality of the relationship between the patient and caregiver are critical to optimize diabetes management [19]. Patients and caregivers need to be prepared for the changes that come about during the transition period. Unfortunately, both patients and caregivers expressed feeling unprepared for the changes that occur during the transition period, and they reported a lack of discussion about the transition process with healthcare professionals. This issue is also observed in other transition clinics, where some patients feel confident about transitioning, while others feel anxious [4]. Data suggested that important issues are not always brought up during outpatient clinics, as patients and caregivers tend to rely on healthcare professionals to initiate the conversation [20]. Until 2013, few studies recognized the importance of the relationship between patients, caregivers, and healthcare professionals as a key element of a successful transition, which demonstrated better readiness and prevention of complications [20]. The cut-off age for transition is 16, but many caregivers disagree and suggest that the transition process should begin at 15-16 years of age with the patient fully transitioning by 18.

CONCLUSION: This study highlights gaps in the transition process for patients with type 1 diabetes mellitus and their caregivers as they move from a paediatric clinic to an adult clinic, while also going through lifestyle changes. The issues noticed during the study are of vital importance to be discussed with the healthcare professional and the patients. Seven needs were identified that need to be assessed during the transition process: awareness, self-management, health and lifestyle, undertaking, peer support, psychosocial issues, and the transition itself. Understanding the challenges and concerns faced by patients and their caregivers during the transition phase is essential for optimising a transition plan that ensures a smooth and seamless shift. By identifying the needs of both the patient and the healthcare team, pharmacists can play a crucial role in addressing these needs, ensuring that their interventions evolve to meet the demands of the transition. The study underscores the role of the pharmacist as an integral member of the healthcare team, facilitating the transition for both patients and caregivers. This approach has the potential to enhance the quality of care and improve the overall experience for patients with type 1 diabetes mellitus.

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REFERENCES:

1. Samarasinghe S, Medlow S, Ho J and Steinbeck K: Chronic illness and transition from paediatric to adult care: a systematic review of illness specific clinical guidelines for transition in chronic illnesses that require specialist to specialist transfer. J of Tran Med 2020; 2(1): 20200001.
2. International Diabetes Federation. IDF Diabetes Atlas, 10th edn. Brussels, Belgium: 2021. Available at: https://www.diabetesatlas.org
3. Vaillancourt M, Mok E, Frei J, Dasgupta K, Rahme E, Bell L, Da Costa D and Meranda N: Qualitative study exploring the perspectives of emerging adults with type 1 diabetes after transfer to adult care from a paediatric diabetes centre in Montreal, Canada. BMJ Open 2023; 13: 076524.
4. Zurynski Y, Carrigan A, Meulenbroeks I, Sarkies MN, Dammery G, Halim N, Lake R, Davis E, Jones TW and Braithwaite J: Transition models of care for type 1 diabetes: a systematic review. BMC Health Serv Res 2023; 23(1): 779.
5. Peters A and Laffel L: Diabetes care for emerging adults: recommendations for transition from paediatric to adult diabetes care systems: a position statement of the american diabetes association, with representation by the american college of osteopathic family physicians, the american academy of paediatrics, the american association of clinical endocrinologists, the american osteopathic association, the centers for disease control and prevention, children with diabetes, the endocrine society, the international society for paediatric and adolescent diabetes, juvenile diabetes research foundation international, the national diabetes education program, and the paediatric endocrine society (formerly lawson wilkins paediatric endocrine society). Diabetes Care 2011; 34(11): 2477–85.
6. de Beaufort C, Gomber A, Sap S and Laffel L: From paediatric to adult diabetes care: lost in transition. Lancet Diabetes Endocrinol 2023; 11(7): 446-448.
7. Núñez-Baila MÁ, Gómez-Aragón A, Marques-Silva AM and González-López JR: Lifestyle in Emerging Adults with Type 1 Diabetes Mellitus: A Qualitative Systematic Review. Healthcare 2024; 12(3): 309.
8. Padley N, Moubayed D, Lanteigne A, Ouimet F, Clermont MJ, Fournier A & Racine E: Transition from paediatric to adult health services: aspirations and practices of human flourishing. International Journal of Qualitative Studies on Health and Well-Being 2023; 18(1).
9. Iyengar J, Thomas IH and Soleimanpour SA: Transition from pediatric to adult care in emerging adults with type 1 diabetes: a blueprint for effective receivership. Clin Diabetes Endocrinol 2019; 6(5): 3.
10. Isenor JE, Renaud L, Mathews M, Morrison B, Murphy AL, Bishop A, Bowles SK, Kennie-Kaulbach N, Peddle S, Breton M, Green ME and Marshall EG: Patient perspectives on the vital primary care role of community pharmacists in Nova Scotia, Canada: qualitative findings from the PUPPY Study. Int J Pharm Pract 2024; 32(3):216-222
11. Weinstock RS, Aleppo G, Bailey TS, Bergenstal RM, Fisher WA, Greenwood DA and Young LA: The Role of Blood Glucose Monitoring in Diabetes Management. ADA Clinical Compendia 2020; 2020: (3).
12. Didyuk O, Econom N, Guardia A, Livingston K and Klueh U: Continuous glucose monitoring devices: past, present, and future focus on the history and evolution of technological innovation. Journal of Diabetes Science and Technology 2021; 15(3): 676-683.
13. Kruger S, Deacon E, van Rensburg E and Segal D: Adjustment experiences of adolescents living with well-controlled type 1 diabetes using closed-loop technology. Front Clin Diabetes Healthc 2024; 5: 1445972.
14. Butalia S, McGuire K, Dyjur D, Mercer J and Pacaud D: Youth with diabetes and their parents' perspectives on transition care from pediatric to adult diabetes care services: A qualitative study. Health Science Reports 2020; 3(3).
15. Spaic T, Robinson T, Goldbloom E, Gallego P, Hramiak I, Lawson ML, Malcolm J, Mahon J, Morrison D, Parikh A, Simone A, Stein R, Uvarov A and Clarson C: JDRF canadian clinical trial cctn1102 study group. closing the gap: results of the multicenter canadian randomized controlled trial of structured transition in young adults with type 1 diabetes. Diabetes Care 2019; 42(6): 1018-1026.
16. Leocadio P, Kelleher C, Fernández E and Hawkes CP: Adolescents' experiences of transition to self-management of type 1 diabetes: systematic review and future directions. Sci Diabetes Self Manag Care 2023; 49(6): 477-492.
17. Azar S, Maroun Abou Jaoude N, Kędzia A and Niechciał E: Barriers to Type 1 Diabetes Adherence in Adolescents. Journal of Clinical Medicin. 2024; 13(19): 5669.
18. Núñez-Baila MdlÁ, Gómez-Aragón A and González-López JR: Social support and peer group integration of adolescents with diabetes. International J of Environmental Research and Public Health 2021; 18(4): 2064.
19. Badour B, Bull A, Gupta AA, Mirza RM and Klinger CA: Parental involvement in the transition from paediatric to adult care for youth with chronic illness: a scoping review of the north american literature. Int J Pediatr 2023; 2023: 9392040.
20. Monaghan M and Baumann K: Type 1 diabetes: addressing the transition from pediatric to adult-oriented health care. Res Rep Endocr Disord 2016; 6: 31-40.

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