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Diabetic Medicine Section: Care Delivery

Title: Parent and Adolescent Communication with Health Care Professionals about Type 1 Diabetes Management at Adolescents' Outpatient Clinic Appointments

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What's New?

- Outpatient clinic appointments with 29 adolescents living with Type 1 diabetes and their parents were observed to examine how adolescents and their parents communicate about Type 1 diabetes management with health care professionals (HCPs) in a clinical setting.
- Three patterns of communication were identified (parent-led, collaborative, and adolescent-led).
- Parent and adolescent engagement in communication with HCPs during outpatient clinic appointments may reflect their degree of involvement in daily Type 1 diabetes management.
- By attending to the nature and extent of communication to HCPs by adolescents and/or their parents, HCPs may be able to encourage more effective communication in consultations and support adolescents as their self-management skills develop.

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Abstract

Aim: This study aimed to identify the ways in which adolescents living with Type 1 diabetes and their parents communicate about Type 1 diabetes management with health care professionals (HCPs) in a clinical setting.

Methods: Twenty-nine adolescents (aged 11-17 years) and their parents were purposively recruited from two outpatient clinics for non-participant observations. Outpatient clinic appointments, which consisted of multiple consultations with HCPs, were observed and audio-recorded. Outpatient clinic appointments were categorised based on the nature and extent of communication by the adolescent and their parent(s) in relation to Type 1 diabetes management activities.

Findings: Data from 29 outpatient clinic appointments, consisting of a total of 68 observed consultations, were analysed and a continuum consisting of three patterns of communication was identified (parent-led, collaborative, and adolescent-led). HCPs should attend to the nature and extent of communication by adolescents and their parents in relation to Type 1 diabetes management activities as parent and adolescent engagement in communication during clinic appointments may also reflect their degree of involvement in daily Type 1 diabetes management.

Conclusions: This continuum provides a framework for HCPs to use in order to identify communication patterns in consultations which in turn may allow HCPs to encourage more effective communication about Type 1 diabetes management from adolescents and their parents in clinic consultations. This may have a positive impact on the sharing of Type 1 diabetes management responsibilities and adolescents' developing self-management skills as roles change during this developmental period.

Keywords: Type 1 diabetes, parents, adolescents, communication, self-management, clinic consultations, health care delivery

1. Introduction

Type 1 diabetes is one of the most common chronic conditions in childhood and the prevalence of Type 1 diabetes in childhood and adolescence is increasing internationally, with highest incidence in Scandinavia [1]. The Irish Childhood Diabetes National Registry was established in the Republic of Ireland in 2008 and identified a high incidence of Type 1 diabetes in the Irish population aged under 15 years old [2]. The directly standardised incidence rates of Type 1 diabetes in those under 15 years of age was 27.5 and 26.0 per 100,000 per year in 2008 and 2009 respectively [2].

Treatment for Type 1 diabetes is arduous and requires commitment from parents and adolescents to undertake complex multi-component management activities in order to maintain optimal glycaemic control, e.g. monitoring the impact of food intake and physical activity on blood glucose levels and adjusting insulin doses accordingly. Schilling et al. [3] describe the concept of self-management of Type 1 diabetes in children and adolescents as including three attributes: *process*, *activities*, and *goals*. Notably, along with the numerous Type 1 diabetes self-management activities identified in their review, Schilling et al. [3] describe the *process* involved in Type 1 diabetes self-management. This process includes the shifting and sharing of responsibility between the parent and adolescent, collaboration with HCPs, and shared decision making to achieve treatment goals. This process is daily and lifelong and requires flexibility in relation to Type 1 diabetes treatment.

Monaghan et al. [4] suggest a conceptual model of patient-provider communication for adolescents and emerging adults living with diabetes. The model emphasises the role of paediatric HCPs in supporting adolescents' developing communication and decision making skills, as well as supporting them as they take on an increased level of Type 1 diabetes management responsibility and prepare for transition to adult services. Monaghan et al. [4] note that preparation in paediatric care may contribute to improved outcomes and increased engagement in adult medical care following transition to an adult diabetes service. It is important that adolescents develop the skills for communicating effectively with HCPs and are supported through the process of acquiring Type 1 diabetes self-management skills while attending paediatric care [4]. Yet, minimal attention has been given to describing how adolescents living with Type 1 diabetes and their parents communicate about Type 1 diabetes management activities and goals with HCPs in paediatric settings, and how the process of

attaining effective collaboration between the adolescent and HCPs might be impacted by the adolescent's and parent's contributions in clinic consultations.

Pyörälä [5] explored the participation roles of children and adolescents living with Type 1 diabetes in dietary counselling consultations. Analysis of clinical encounters with an adolescent sample (13 to 15 year olds) indicated that while adolescents often took an active role in communicating with their dietitian in two party consultations (dietitian and adolescent), they often withdrew from conversations in three party consultations (e.g. dietitian, adolescent, and parent) when their parent spoke on their behalf. A case study of a triadic medical interaction with a nurse practitioner reported by Buchbinder [6] suggests that adolescent autonomy may be constrained by parents when considering solutions to Type 1 diabetes related issues, whereas emphasis may be given to adolescents' autonomy when identifying Type 1 diabetes related problems with HCPs. Pyörälä [5] advocates that the adolescent's autonomy in their diabetes care can be supported by beginning a session with the adolescent only and inviting the parent to join at a later point, thereby limiting input from parents. In contrast, Buchbinder [6] suggests that parents can contribute valuable information in consultations which may not be revealed by adolescents themselves. Adolescent and parent communication in clinical encounters about adolescents' Type 1 diabetes management warrants further investigation to explore how the transition of Type 1 diabetes management responsibility might be conveyed in clinic consultations.

ISPAD Clinical Consensus Guidelines [7] recognise that adolescence is a time in which adolescent and parent roles and responsibilities in Type 1 diabetes management change and a gradual transition from full parental responsibility to collaboration with the adolescent is best. Maintaining parental support during adolescence is paramount while also acknowledging the adolescent's increasing need for privacy and confidentiality [7]. Balancing parental involvement in health care for adolescents living with Type 1 diabetes has recently been discussed in the literature and a survey of parents of 12 to 21 year olds found that parents had concerns about adolescents having confidential consultations with HCPs about their Type 1 diabetes care which included not being kept informed, for example about the adolescent's treatment plan [8]. Lowes et al. [9] found that while some carers' reported mixed feelings in relation to their teenager consulting with a doctor alone, some carers found it useful to consult with HCPs without their child.

Parents of adolescents living with Type 1 diabetes are faced with a major developmental challenge in finding a balance between monitoring and enhancing autonomous adolescent diabetes self-management [10]. Adolescents themselves have indicated that they struggle with the complexity of diabetes management and they often feel unable to seek advice and guidance from both HCPs and their parents [11]. A recent review by Young et al. [12] concluded that moving from a directive to a more collaborative approach to parenting and Type 1 diabetes management in adolescence is preferred. Young et al. [12] also advise that parental monitoring may need to increase rather than decrease throughout adolescence depending on the adolescent's abilities. Schilling et al. [13] described changing patterns of self-management in adolescents living with Type 1 diabetes and noted that as the degree of responsibility for self-management increased over time self-management moves from a parent-dominant pattern to a transitional pattern before becoming adolescent-dominant.

In a qualitative study carried out by Dovey-Pearce et al. [14] exploring experiences of diabetes services since diagnosis, young adults living with diabetes identified the need for consultation style to change gradually in line with developmental stage throughout adolescence and the importance of HCPs involving adolescents in communication in consultations. Simms et al. [15] also explored the retrospective accounts of emerging adults living with Type 1 diabetes in relation to their health care communication experiences with their paediatric HCPs. Respondents viewed HCP support for their increasing independence positively; this included HCPs directing the conversation towards the patient rather than their parent and including the young person in shared decision-making processes in relation to their care. Respondents reported that they valued decreased involvement but continued support from their parents in their medical care. Simms et al. [15] suggest that taking a primary role in communication with HCPs during routine appointments is a key aspect of young people taking responsibility for their diabetes care.

HCPs hold a key role in helping parents and adolescents to navigate changes in Type 1 diabetes management throughout adolescence and may be in a position to address difficulties as they arise. Ivey et al. [16] conclude that clinicians can assist families to negotiate a partnership to achieve shared goals for adolescents' Type 1 diabetes management. The communication process that occurs in clinic consultations between HCPs and adolescents living with a chronic disease such as Type 1 diabetes is influenced by many factors, however, previous research has largely focused on the way that HCPs engage with and interact with patients in consultations. As only a few studies have explored how parents

and adolescents communicate with HCPs about Type 1 diabetes management in clinical encounters [5, 6], the present study focuses on the parent-adolescent dynamic as observed in consultations with HCPs during outpatient clinic appointments. To address the gaps in the current literature on parent and adolescent communication about Type 1 diabetes management with HCPs, this study aimed to identify the ways in which parents and adolescents communicate about Type 1 diabetes management with HCPs in a clinical setting, i.e. who engages with HCPs in terms of Type 1 diabetes management and to what extent.

2. Participants and Methods

2.1 Design

This study used a qualitative, exploratory design consisting of non-participant observations [17] of consultations with HCPs at adolescents' outpatient clinic appointments, i.e. the researcher responsible for data collection did not participate actively in the consultations being observed with HCPs at adolescents' outpatient clinic appointments in any way.

2.2 Participants and recruitment

2.2.1 Participants

Eligible participants were purposively sampled according to the study's inclusion and exclusion criteria with the target to recruit a stratified sample representing the following age categories; 11-13 year olds, 14-15 year olds, and 16-17 year olds. Participants were recruited from two national diabetes and endocrine outpatient clinics in the Republic of Ireland (one clinic situated within a children's hospital and one adolescent clinic situated within an adult hospital). Thirty-one adolescents and their parents were approached and invited to participate in the research. Two adolescents and their parents declined participation. Posters were also displayed in the waiting areas of the outpatient clinics with details of the research study and an invitation for adolescents who met the eligibility criteria for the study and their parent(s) to participate. The poster invitation did not yield any additional participants to those who were approached by the researcher (CR). Twenty-nine 11-17 year olds (M = 13.9, SD = 2.0) and their parents participated and were observed during a single outpatient clinic appointment (which consisted of multiple consultations with HCPs). The mean duration of diabetes for the overall group of participants was 6.4 years (SD = 3.4, range = 1-13 years). The mean age of parent participants was 46.5 years (SD = 4.9, range = 35-56 years). See Table 1 for details of

adolescent participants' demographic information and blood glucose monitoring and insulin administration information.

[INSERT TABLE 1]

2.2.2 Inclusion criteria

Adolescents were invited to participate if they were aged between 11-17 years old and diagnosed with Type 1 diabetes for ≥ 6 months which was not secondary to any other illness.

Parent for the purpose of this study was defined as a primary caregiver to the adolescent living with Type 1 diabetes, i.e. biological parent or legal guardian.

2.2.3 Exclusion criteria

Adolescents were excluded if they were attending the outpatient clinic for their first appointment since Type 1 diabetes diagnosis.

2.3 Data collection

Approval was obtained from the Research Ethics Committees at Dublin City University and participating hospitals. On arrival at their routine outpatient clinic appointment eligible adolescents and their parents were invited to participate in the study by the researcher responsible for data collection (CR). HCPs did not play a role in selecting participants for the study. Potential participants were verbally informed of the purpose of the research. After receiving a verbal explanation, adolescents received an age-appropriate information sheet and assent form to help them consider their potential participation; parents received a parent information sheet and consent form and were given time to consider their participation, to discuss participation with their child, and to ask the researcher questions.

Adolescents and parents were observed (by CR) as they attended their outpatient clinic appointment which consisted of multiple consultations with HCPs on a single day. Typically the adolescent living with Type 1 diabetes, their parent(s), and one or more HCP

were present in each consultation. The group of HCPs included a consultant paediatric endocrinologist, non-consultant hospital doctors, a dietitian, diabetes clinical nurse specialists, and health care assistants. HCPs provided written consent to have their consultations observed at the beginning of the study and ongoing verbal consent throughout the data collection period. Data were collected between September 2016 and April 2017 at a weekly diabetes outpatient clinic. A maximum of two families were observed per outpatient clinic.

Clinic appointments typically consisted of an initial consultation with a health care assistant who measured the adolescent's HbA1c, height, and weight, and one/two additional consultations with a doctor (e.g. non-consultant hospital doctor and/or consultant paediatric endocrinologist) in which the HbA1c result was addressed, information was gathered in relation to any Type 1 diabetes management issues which may have arisen between appointments, and any necessary changes to insulin regimen were advised. Six of the adolescent participants also attended a routine consultation with a dietitian on the date of observation; four of these were observed. See Table 2 for a summary of observed consultations at diabetes outpatient clinic appointments for each adolescent participant.

An observation guide was used to gather data in the form of field notes in this study (see Table 3). The researcher recorded where each consultation took place, features of the physical environment, the people who were present for each observation and their roles, and features of the conversational process, i.e. the information exchanged and questions asked by each participant and the way in which participants communicated, e.g. turn taking. Throughout each clinic appointment, the researcher noted who took the lead in communicating Type 1 diabetes management information, i.e. when questions were asked by HCPs the researcher noted whether the adolescent and/or their parent(s) responded and the content of their response. Questions raised by the adolescent and their parent(s) were noted. In addition to the information gathered using the observational guide outlined in Table 3, the researcher responsible for data collection (CR) noted when Type 1 diabetes management responsibilities and family communication were specifically addressed by HCPs, e.g. if more parent-adolescent communication was encouraged, if more support from a parent was encouraged, or if transfer of Type 1 diabetes management responsibility from parent to adolescent was addressed. Clinic consultations were audio-recorded. A reflective journal was completed by the researcher (CR) after each observation to record additional information pertinent to each observation and the overall research aims.

[INSERT TABLE 2 AND TABLE 3]

2.4 Data analysis

Data from 29 audio-recorded outpatient clinic appointments, consisting of a total of 68 observed consultations with HCPs, along with the researcher's field notes were analysed in order to identify the ways in which parents and adolescents communicate about Type 1 diabetes management with HCPs in a clinical setting following the methodology for data management outlined by Halcomb and Davidson [19]. Field notes were taken concurrently by the researcher throughout each observation. Audio-recordings of clinic consultations were not transcribed verbatim but were listened to a number of times by the researcher responsible for data analysis (CR) and reviewed alongside the researcher's field notes. Further notes were taken and added to the observation field notes until a descriptive representation of each consultation was attained. The researcher (CR) then reviewed the notes for each participant and analysed the content of each appointment for common themes pertaining to the nature and extent of input from each adolescent and their parent(s). The researcher's (CR) preliminary analysis was reviewed by the research team and a number of consensus meetings were held as a framework for the continuum of communication patterns was developed. This framework was then applied to the data set and a communication pattern was assigned to each adolescent participant for their overall outpatient clinic appointment. A communication pattern was assigned to each participant (i.e. per outpatient clinic appointment) rather than to each individual consultation to allow for the fact that adolescents may have been more familiar with some of the HCPs than others, in particular they may not have been familiar with the non-consultant hospital doctors and may have been meeting one of them for the first time.

3. Findings

3.1 Patterns of communication observed

A continuum consisting of three patterns of communication was identified; these are described in detail below. Table 4 provides a summary of the adolescent participants whose clinic appointments were categorised within each pattern of communication on the continuum for their outpatient clinic appointment. Figure 1 outlines the key findings relating to observed

communication patterns and the development of adolescents' Type 1 diabetes self-management skills.

[INSERT TABLE 4 AND FIGURE 1]

3.1.1 Parent-led communication with HCPs

During clinic appointments categorised as parent-led, the parent(s) typically led the conversation with HCPs. Adolescents varied in relation to the extent of their input into conversations with HCPs during parent-led appointments. In some cases, adolescents answered a small number of questions requiring straightforward answers, e.g. if they recognise when their blood glucose is low and what this feels like. Other questions answered by adolescents included if they were on any other medication, if they had any bad lows (i.e. instances of hypoglycaemia) since their last appointment, any difficulty with injection or pump sites, and questions relating to Type 1 diabetes management when engaged in physical activity. Some adolescents answered questions indicating that they knew what to do when their blood glucose was low or high but adolescents rarely answered specific questions relating to insulin doses, e.g. reporting basal rates. In parent-led appointments, parents often answered questions in relation to the adolescent's insulin regimen, including bolus doses and corrections, and questions relating to insulin pump management. Parents generally asked HCPs any questions that the family may have had.

In parent-led appointments, the pattern of communication and information shared in clinic consultations suggested that the adolescent's Type 1 diabetes management was led by their parent(s) who seemed to be overseeing or closely monitoring all aspects of blood glucose monitoring and insulin administration, including insulin adjustments for food and physical activity such as bolus and correction calculations. Observations indicated that the adolescents were responsible for some aspects of their Type 1 diabetes management such as blood glucose monitoring when away from their parent(s) and reacting to lows, particularly when involved in sports or activities. Observations showed that some adolescents in this category were responsible for giving bolus doses but there was evidence that this was often prompted or supported by a parent (where the parent advised on the dose) or in some cases the adolescent stated that they had bolused based on experience, e.g. knowing the amount of

insulin to take for foods they frequently ate. Information exchanged in parent-led appointments suggested that the parent was responsible for regimen adjustments and insulin pump management where applicable.

Table 5 outlines two examples of parent-led communication in which a mother expressed frustration in relation to the management of her daughter's blood glucose levels while engaged in sports as well as overnight blood glucose management. Despite HCPs directing questions to the adolescent (P05), her mother took the lead in communicating with HCPs throughout all consultations. This mother's input indicated a high level of involvement in her daughter's Type 1 diabetes management. In the examples provided in Table 5, the conversation was between the adolescent's mother and the doctor as the adolescent's mother had taken the lead in communicating with the doctor since early in the consultation.

3.1.2 Collaborative communication with HCPs

In clinic appointments categorised as collaborative, typically the adolescent living with Type 1 diabetes led some parts of the conversation with HCPs but some adolescents looked for reassurance, input, or clarification from their parent(s), e.g. when confirming insulin doses or bolus and correction adjustments. Some parents in this category interjected to say something that the adolescent may not have been willing to share themselves, e.g. to disclose information about something that was bothering the adolescent. Parents in this category also answered some questions relating to Type 1 diabetes management, taking a lead in parts of consultations. HCPs were asked questions by either the adolescent or a parent on the adolescent's behalf.

The information shared in appointments categorised as collaborative indicated that the adolescent and their parent(s) were working together to manage the adolescent's Type 1 diabetes care. Adolescents in this category were taking on some responsibility for managing their insulin doses; they may have been starting to calculate some bolus and correction doses but may not have appeared confident in this task yet. Some parents stated that they performed night time blood glucose readings where necessary and it seemed that parents in this category were responsible for managing supplies and prescriptions also. This collaborative pattern of communication indicated that the adolescent may still have required a high level of support from a parent in some situations and their parent(s) may have continued to attend their

outpatient clinic appointments with them to provide support but also to actively engage with HCPs in relation to the adolescent's Type 1 diabetes management.

The excerpt outlined in Table 5, from a collaborative communication pattern, illustrates how one mother revealed that her adolescent daughter (P03) did not wish to use a flash glucose monitoring device. The adolescent confirmed that she did not wish to use a flash glucose monitoring device when asked directly by the doctor after the adolescent's mother disclosed this information. The adolescent's mother also disclosed that she disliked using an insulin pump after which the adolescent contributed more information to indicate why she disliked using the flash glucose monitoring device, illustrating a pattern of collaborative communication.

3.1.3 Adolescent-led communication with HCPs

In clinic appointments categorised as adolescent-led, generally the adolescent spoke mostly with HCPs in relation to their Type 1 diabetes management and in some cases HCPs asked questions to confirm that the adolescent living with Type 1 diabetes was capable of adjusting insulin doses etc., e.g. the HCP may have asked 'if eating X amount of carbohydrates how much would you bolus?'. In this category, the adolescent's contribution during the appointment was typically at a higher level than observed in 'collaborative' communication as the adolescent may have discussed actively manipulating insulin doses, e.g. calculations when administering bolus insulin doses or making corrections. Adolescents in this category did not seek reassurance from their parent(s) when answering questions posed by HCPs. Some adolescents answered questions in relation to site changes if using an insulin pump but some parents also mentioned that they assisted with site changes. Adolescents in this category asked the HCPs questions or in some cases a parent may have asked questions on the adolescent's behalf, e.g. questions relating to the renewal of prescriptions. Some parents in this category stated that they carried out night time blood glucose checks where necessary. A parent was not present throughout consultations with one adolescent in this category and parents who were present for consultations had a lower level of input into the conversations about Type 1 diabetes management with HCPs.

This adolescent-led pattern of communication suggested that the adolescent was managing most of their Type 1 diabetes care with support from their parent if and when

required. When present, a parent may have been there to support the adolescent but it was evident that the adolescent was managing most of their Type 1 diabetes care themselves with minimal input from their parent based on the information exchanged throughout the appointment. Data suggested that parent(s) mostly provided emotional support while the adolescent was responsible for all of the physical monitoring and insulin administration activities involved in Type 1 diabetes management. In adolescent-led appointments, observations showed that the adolescent could manage independently if necessary but a parent still attended their appointment with them to provide support.

One example of an adolescent-led communication pattern outlined in Table 5 shows how a doctor questioned an adolescent (P27) in relation to correction calculations which the adolescent answered independently and without hesitation. The second excerpt included in Table 5, for an adolescent-led pattern of communication, is an example of a question raised by an adolescent (P29). Although P29's mother also asked the doctor some questions during the consultation, P29's mother mainly offered emotional support and all questions relating to Type 1 diabetes care were answered by the adolescent who also raised some questions in relation to her Type 1 diabetes management.

[INSERT TABLE 5]

4. Discussion

The present study used a qualitative exploratory approach and based on the findings from non-participant observations a continuum consisting of three patterns of communication in adolescents' Type 1 diabetes outpatient clinic appointments was developed – parent-led, collaborative, and adolescent-led. Information communicated by adolescents to HCPs may reflect the adolescent's level of involvement in their Type 1 diabetes management, i.e. the Type 1 diabetes activities that the adolescent is taking responsibility for. Information communicated by adolescents in parent-led appointments indicated that these adolescents were taking a lower level of responsibility for some Type 1 diabetes management activities, e.g. checking blood glucose when away from their parents and adjusting insulin administration for food intake and physical activity in line with parental instruction or under supervision. In collaborative appointments, data revealed adolescents and parents sharing

responsibility for some Type 1 diabetes management activities and in adolescent-led appointments adolescents were observed to be further along in this process of sharing Type 1 diabetes management responsibilities with their parents.

Part of the process of developing independent Type 1 diabetes self-management in adolescence includes the development of effective communication skills in clinic consultations and collaborative relationships with HCPs to achieve treatment goals [3]. It has been suggested that adolescents should begin preparing for transition to adult diabetes services while in paediatric care [4]; however, only a few studies have focused on parents' and adolescents' participation roles in clinical encounters indicating that parents can aid or impede adolescents' developing communication skills in this context [5, 6]. In the present study the contribution of adolescents in conversations with HCPs may have reflected the pattern of shared responsibility between the adolescent and their parent(s); however, it is possible that the adolescent's role in communicating with HCPs may have been affected by factors relating to their parent(s) or the clinical setting, as well as factors relating to the adolescent. As the sharing of self-management responsibilities changes over time, parent and adolescent roles in communicating about Type 1 diabetes management should also change to reflect this. However, further exploration of the communication roles of adolescents in clinical encounters is warranted and the impact that both parents and HCPs have on facilitating the adolescent's contribution to discussions about their Type 1 diabetes management needs additional investigation.

It was noted in the present study, that despite HCPs efforts to direct questions to adolescents living with Type 1 diabetes, in parent-led appointments, parents often stepped in to answer HCPs questions in relation to their child's Type 1 diabetes care. This may reflect the level of involvement that the parent has in their child's Type 1 diabetes management and may correspond with the adolescent's developmental capability. Where adolescents are at an age close to transition to adult diabetes services and have minimal input in terms of communication in consultations with HCPs, this may flag a delay in the adolescent's uptake of Type 1 diabetes self-management or the reluctance of parents to hand over responsibility to adolescents which HCPs could address. Some parents in the present study actively encouraged adolescents to participate and contribute to the conversation with HCPs in clinic consultations. As previously suggested by Buchbinder [6], HCPs could focus on ways in which adolescents' can be enabled to actively engage with HCPs in the presence of their parent(s) and how parents can support adolescents to communicate about their health care

needs in clinical encounters. A communication tool to prompt discussion about parent and adolescent roles and responsibilities in relation to the adolescents' Type 1 diabetes management and to support shared communication in clinic consultations may provide a useful means for HCPs to encourage communication about shared Type 1 diabetes management throughout this developmental period.

Future research could also elaborate on the non-verbal communication between adolescents, parents, and HCPs which occurs in clinic consultations at outpatient clinic appointments and explore the factors which prevent or discourage adolescents from participating in conversations when consulting with HCPs. In the present study, the age of participants increased across the three patterns of communication identified on the continuum. It may also be useful for HCPs to consider additional factors such as the adolescent's developmental stage, i.e. cognitive and emotional maturity, length of time since Type 1 diabetes diagnosis, and insulin regimen in conjunction with age when thinking of these communication categories and any possible intervention in relation to the transition or sharing of Type 1 diabetes management responsibilities.

In the present study, data were gathered in a busy clinic environment and this gave rise to a number of challenges resulting in some limitations to the findings. The researcher responsible for data collection had the opportunity to speak to adolescents living with Type 1 diabetes and their parents between consultations in some cases but this was not always possible and depended on the flow of patients through the outpatient clinic at the time of data collection. This made it difficult to obtain extra contextual information which may have enhanced the interpretation of data gathered and the conclusions drawn from data collected. Future research could incorporate data pertaining to adolescents' and parents' perceptions of communication with HCPs in clinic consultations by gathering additional interview or survey data from adolescents and parents following clinic consultations at outpatient clinic appointments. Data presented in this study were collected via non-participant observations at a single outpatient clinic appointment with limited information about the adolescents and parents who participated. The proposed continuum of communication patterns and adolescent development of Type 1 diabetes self-management skills does not tell us how adolescents transition or move forward, and/or backwards, along the continuum as they encounter different challenges in their everyday self-management of Type 1 diabetes.

In addition, the HCPs being observed in the present study changed throughout the data collection period, in particular the team of non-consultant hospital doctors who participated, due to the nature of hospital rotas and scheduling and medical training. This meant that adolescents and their parents may have been meeting a new doctor for the first time on the date of observation which may have resulted in a slightly different dynamic than usual due to factors such as the HCPs communication style, familiarity etc. This was taken into account during data analysis and appointments were categorised rather than individual consultations, as participants would have been familiar with other HCPs (e.g. the consultant paediatric endocrinologist, diabetes clinical nurse specialists, and the dietitian).

4.1 Conclusion

The continuum of communication patterns and adolescent development of Type 1 diabetes self-management skills identified in the present study may provide a framework for HCPs to use in order to encourage effective communication from both adolescents and parents when they attend their routine outpatient clinic appointments. This in turn may support the day-to-day sharing and shifting of self-management responsibilities as the process of Type 1 diabetes management changes during the developmental period of adolescence and as adolescents learn to self-manage their Type 1 diabetes effectively. By encouraging communication from adolescents about Type 1 diabetes activities they manage, HCPs will not only help adolescents to develop effective communication skills but they may also impact the process of Type 1 diabetes self-management as responsibility transitions from parent to adolescent. HCPs are in a position to help parents and adolescents as their responsibilities and support needs changes throughout this developmental time. HCPs can promote adolescent autonomy as adolescents' self-management skills develop and help parents to step-back as adolescent and parent roles change over time. This may have implications for health care practice as through supporting adolescents to develop effective skills in communicating their health care needs and goals with HCPs, and supporting effective parent and adolescent communication as adolescents' self-management skills develop, HCPs may help adolescents living with Type 1 diabetes to achieve better biomedical and psychosocial outcomes throughout adolescence and in their transition to adult diabetes services.

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Table 1: Demographic information for adolescent participants

		11-13 years (*n* = 10) *n*	**14-15 years** (*n* = 11) *n*	**16-17 years** (*n* = 8) *n*	**Total** (*n* = 29) *n (%)*
Gender	Male	5	6	6	17 (58.6)
	Female	5	5	2	12 (41.4)
School Level	Primary	7	0	0	7 (24.1)
	Secondary – Junior Cycle	3	10	0	13 (44.8)
	Secondary – Senior Cycle	0	1	8	9 (31)
Blood Glucose Monitoring	Finger Prick	8	8	6	22 (75.9)
	Flash Glucose Monitoring System[a]	2	3	2	7 (24.1)
Insulin Administration	Insulin Pen	3	2	3	8 (27.6)
	Insulin Pump	7	9	5	21 (72.4)
Family History of Type 1 diabetes	Yes	5	2	2	9 (31)
	No	5	9	6	20 (69)
Accompanying Parent(s)	Mother	3	6	5	14 (48.3)
	Father	3	3	2	8 (27.6)
	Both	4	2	1	7 (24.1)
HbA1c[b]	Mean in mmol/mol (%)	65 (8.1)	63 (7.9)	64 (8.0)	64 (8.0)
	Range in mmol/mol (%)	48-101 (6.5-11.4)	49-78 (6.6-9.3)	51-75 (6.8-9.0)	48-101 (6.5-11.4)

Note. [a] FreeStyle Libre. [b] HbA1c at observed outpatient clinic appointment.

Table 2: Summary of observed consultations at adolescents' outpatient clinic appointments

Adolescent's Participant Number	Consultation 1: Healthcare Assistant/Nurse*	Consultation 2: Dietitian**	Consultation 3: Non-Consultant Hospital Doctor***	Consultation 4: Non-Consultant Hospital Doctor/Consultant Paediatric Endocrinologist	Total Number of Observed Consultations
01			✓	✓	2
02			✓	✓	2
03			✓	✓	3
04	✓		✓	✓	3
05	✓		✓	✓	3
06				✓	1
07	✓		✓	✓	3
08				✓	1
09	✓	✓		✓	3
10	✓	✓	✓	✓	4
11	✓		✓	✓	3
12			✓	✓	2
13	✓			✓	2
14				✓	1
15			✓	✓	2
16			✓	✓	2
17			✓	✓	2
18			✓	✓	2
19	✓		✓	✓	3
20	✓		✓	✓	3
21	✓			✓	2
22	✓		✓	✓	3
23	✓		✓	✓	3
24	✓	✓	✓	✓	4
25	✓		✓	✓	3
26	✓		✓	✓	3
27		✓		✓	2
28				✓	1
29				✓	1
Total	15	4	20	29	68

Note. All ticks indicate that a consultation took place and was observed.

*All participants attended an initial consultation with a health care assistant or nurse, 15 of these consultations were observed as indicated above.

**Participants 12 and 14 also attended a consultation with a dietitian which was not observed.

***For participants 6, 8, 9, 13, 14, 21, 27, 28, and 29 no consultation with a non-consultant hospital doctor took place.

Table 3: Observation guide

Dimension	Information Recorded
Place	The environment, i.e. diabetes outpatient clinic (children's/adult's hospital), private consultation room.
Actors	Participants involved in the consultation, i.e. adolescent, parent(s), HCPs. Healthcare profession of each HCP, i.e. health care assistant, nurse, non-consultant hospital doctor, consultant paediatric endocrinologist, dietitian etc.
Objects	Physical elements of the observed environment, i.e. office/clinic furniture, medical-based objects and hospital equipment, as well as personal objects and distractors.
Event	Meeting with multidisciplinary HCPs, i.e. consultation number.
Process	The way in which all participants communicated, i.e. features of the conversational process such as turn taking and who communicated information relating to Type 1 diabetes management.
Message	What participants (i.e. the adolescent, their parent(s), and/or HCPs involved) were attempting to accomplish. Information exchanged and questions asked.
Context	Emotions in particular contexts, i.e. feelings expressed by the adolescent and their parent(s) in particular and the context in which feelings were expressed.

Note. Adapted from Spradley [18].

Table 4: Summary of findings from outpatient clinic appointment observations

Pattern of Communication Observed	Adolescent's Participant Number	Age	Gender	Parent(s) Present	Age when Diagnosed	HbA1c mmol/mol (%)	Mean HbA1c and Range mmol/mol (%)
Parent-led	01	11	M	Both	4.5	51 (6.8)	65 (8.1)
	02	11	M	Both	5	48 (6.5)	
	04	14	M	Father	6	72 (8.7)	48-101 (6.5-11.4)
	05	11	F	Mother	5	61 (7.7)	
	06	14	M	Father	1.75	70 (8.6)	
	09	16	M	Mother	12	51 (6.8)	
	16	11	M	Both	9	64 (8)	
	17	12	F	Father	9	61 (7.7)	
	18	12	F	Both	3	63 (7.9)	
	19	14	M	Both	4	78 (9.3)	
	20	11	F	Mother	9	63 (7.9)	
	22	11	M	Father	3	67 (8.3)	
	23	13	F	Mother	11	101 (11.4)	
Collaborative	03	14	F	Mother	7	58 (7.5)	61 (7.7)
	10	14	F	Mother	5	61 (7.7)	
	12	14	F	Both	8	49 (6.6)	49-70 (6.6-8.6)
	13	13	M	Father	1.5	70 (8.6)	
	15	14	M	Mother	8	53 (7)	
	21	16	M	Mother	15	69 (8.5)	
Adolescent-led	07	15	F	Mother	11	61 (7.7)	64 (8.0)
	08	14	M	Mother	10	52 (6.9)	
	11	15	F	Mother[a]	9	77 (9.2)	52-77 (6.9-9.2)
	14	16	F	Mother	3	75 (9)	
	24	16	M	Father	8	61 (7.7)	
	25	14	M	Father	12	60 (7.6)	
	26	16	M	Father	5	62 (7.8)	
	27	16	M	Both	11	63 (7.9)	
	28	17	M	Mother	6	58 (7.5)	
	29	17	F	Mother	13	69 (8.5)	

Note. [a] Mother was present in waiting area but adolescent attended consultations at their outpatient clinic appointment alone.

Table 5: Examples of parent-led, collaborative, and adolescent-led communication

Communication Pattern	Excerpt from Transcript
Parent-led	*Example 1* **Doctor:** …are your corrections working? **P05's Mother:** I think so. **Doctor:** Would you have corrected her all day here, do you know? **P05's Mother:** Maybe that's the day; you know there was one horrible day where I just couldn't get her down, I changed her set, I tried everything and I couldn't get her down… *Example 2* **Doctor:** Is there anything else you've noticed that you're worried about? It's mainly trying to get the sports right. **P05's Mother:** That's it; it's just getting that a little bit more controlled. **Doctor:** It's so frustrating because you are doing so much hard work, isn't it? **P05's Mother:** You know, it's frustrating in the night time and yeah it's frustrating to see the A1c. **Doctor:** I know, I know. **Mother:** And you'd be half tempted to kind of drop back on sports and I just know that's not the way to go. **Doctor:** No. **P05 (11 years old, female, diagnosed at 5 years old)**
Collaborative	**Doctor:** You are using it, you have it or- **P03's Mother:** She doesn't love it though. **Doctor:** Do you not love it? You just don't like wearing it, is it? **P03:** Yeah. **P03's Mother:** And sometimes the pump is, you know, I think since you went to secondary [school], she doesn't like the pump, so we don't push the Libre but we wear it in between you know. **Doctor:** Yeah, the only thing is if you don't like it at the moment that's ok, you know that kind of way. **P03's Mother:** Yeah…we were going using it for information… **Doctor:** Well you can't get cross with someone who does this much work and does such a fabulous job so, you know what I mean, it's just, I mean it was only a question of if it would make your life easier. You just don't like the idea of people knowing and stuff is it or? **P03:** I just don't like having the arm- **Doctor:** Another thing hanging out of you?

	P03: Yeah another thing plugged into me, so. **P03 (14 years old, female, diagnosed at 7 years old)**
Adolescent-led	**Doctor:** If you said on average - how many lows, once a day, once a week? **P27:** Once a week or twice a week maybe. **Doctor:** It is hard to avoid, like there is always going to be an occasional low, life kind of takes over, you plan for something that doesn't happen. So once or twice a week is probably what most people have. What are you correcting above at? What blood sugars are you correcting off? **P27:** 9. **Doctor:** What do you do when you do your correction? **P27:** Minus 8 divided by 6. **Doctor:** And do you think your corrections mostly work or do you think they kind of work? If you did a correction would you expect your blood sugars to be between 4 and 8 the next time? **P27:** When I correct, when it's really high I use the pen and that brings it straight down but that is over 16, below 16 I just do it with the pump and it comes down again. **Doctor:** And does it come down within two hours, would it be back down to normal? **P27:** Yes. **Doctor:** And you wouldn't have to do a couple of corrections. **P27:** No I do one. **P27 (16 years old, male, diagnosed at 11 years old)**
	P29: Just one more question. If I am going to go on a jog in the mornings should I, like before I go and have breakfast, at 6:30, should I eat before I go or go on the jog and come home and take my Novorapid at normal time? **P29 (17 years old, female, diagnosed at 13 years old)**

Figure Legend

Figure 1: Findings relating to observed patterns of communication and development of adolescents' Type 1 diabetes self-management skills