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Encouraging adolescents' participation during paediatric diabetes clinic visits: Design and development of a question prompt list intervention

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ABSTRACT

Aims: To investigate adolescents' communication with healthcare providers (HCPs) and co– design a question prompt list as one part of an intervention to increase patient participation and communication at diabetes clinic visits.

Methods: Using an adolescent-led co-design approach we conducted interviews and focus groups with adolescents, parents, and healthcare providers (HCPs) and held workshops with both a Youth Advisory Group (YAG) and a Parent Advisory Group (PAG).

Results: Adolescents and parents identified challenges categorised into four themes: negative experience communicating with HCPs, lacking patient education leading to disinterest, low self-confidence out of fear of being wrong and forgetting to ask question(s). Adolescents identified that a Question Prompt List (QPL) could help them to ask questions, be more confident and participate more. The design process was an iterative development that engaged all stakeholders. Parents and HCPs assumed adolescents had greater knowledge about diabetes than they had in reality.

Conclusions: Divergence in perceptions between adults and adolescents regarding patient knowledge of diabetes care demonstrates the importance of encouraging adolescents to ask the questions that matter to them. The QPL could be a useful means of supporting adolescents to actively participate in clinic encounters with healthcare providers.

1. Introduction

Adolescence can be a challenging stage for those with type 1 diabetes, as they come to terms with learning to take more responsibility to self-manage their condition[1,2]. An important skill required to successfully navigate this period is self-advocacy, an aspect of which involves actively participating in clinic visits[3]. It is through active participation that adolescents with type 1 diabetes can be supported and empowered to undertake more of their diabetes care routine on their own[4,5].

Parents play an important role supporting their child and are usually present at the consultation. Studies examining provider-adolescent communication reported challenges communicating with adolescents were largely due to adolescents reporting that they felt it was directed at their parent [11,22]. Previous studies have also found that parents often interjected before their child had a chance to ask/answer a question[5]. These factors can make transitioning to adult services more challenging as adolescents must learn self-advocacy[4,7]. A shared responsibility approach can help, where a parent plays a more supportive role, whilst allowing their child to self-manage type one diabetes[20]. This includes sharing responsibility when communicating with HCPs at the clinic[21].

International guidelines on diabetes care delivery stress the need for these services to be patient-centred, and to have a strong focus on enabling and empowering adolescents to ask questions and make decisions related to their diabetes care[8]. Although good practices exist, healthcare professionals often fail to acknowledge and address adolescents' development and health-related needs in clinic encounters and inadequately involve them in decisions about their care[29] and

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adolescents' discussion needs go unmet[30]. Consultations that take account of the adolescents' agenda could lead to more meaningful and relevant discussions between healthcare providers (HCPs) and adolescents[29–30], ensure more effective education and encourage adolescents to take an active role in their diabetes management[6]. A good relationship between the adolescent and the healthcare provider is linked to positive health outcomes[7].

Interventions that promote clinic engagement and communication skills between adolescents and HCPs can play an important role in encouraging adolescents' active participation during clinic visits[9,10]. However, not only are there few interventions to encourage adolescent engagement[11–14], the quality of those interventions that have been evaluated, were found to be low[15].

This paper reports on an adolescent-led co-development of a question prompt list intervention to increase patient communication and provider education during paediatric diabetes visits. This is one part of a wider intervention programme that also included an educational video [16]. An adolescent participatory-led approach was central to the design of the Question Prompt List (QPL)[17–19]. This was important to ensure that adolescents with type 1 diabetes were actively involved in partnership with the research team at all stages of the design process. This has been a positive approach for other studies developing interventions for adolescents with a chronic condition because the content resonated with their peers[19].

2. Methods

There were two phases 1) thematic analysis investigating adolescents' communication experiences with HCPs and evaluating new insights on the potential use of a question prompt list at the diabetes clinic and 2) co-design of a question prompt list together with a Youth Advisory Group (YAG) and Parent Advisory Group (PAG) (please see Fig. 1).

2.1. Phase one

Phase one involved interviews and focus groups with adolescents, parents, and HCPs, to investigate adolescent clinic engagement at the diabetes clinic, and content preferences for the intervention. Participants could choose to take part in either an interview or focus group session. The reason for offering a choice was that some adolescents found it more beneficial to take part in an interview rather than a focus group. Reasons included that they were shy, that they had never spoken about type one diabetes with their peers before, and that they felt self-conscious speaking in a group setting. For adult participants who opted for a one-to-one interview, reasons were largely due to conflicting schedules (for example, child-care and work commitments). This flexible approach encouraged adolescents, parents, and HCPs to take part in the study. There were no discernible differences between the data gathered in interviews or focus groups; as participants had chosen the approach that made them feel most comfortable, this led to a more open dialogue between the participant(s) and the researcher, thus richer quality of data was gathered for the analysis.

Altogether, three separate focus groups (four HCPs, three parents and three adolescents) and 24 one-to-one interviews took place (ten adolescents, 11 parents and three HCPs). Parent and adolescent interviews/focus groups were held concurrently but conducted separately. Participants received a 20-euro voucher to cover their travel expenses.

Participants were recruited directly by the lead researcher, from two tertiary urban children's hospitals in Ireland, each with an established multidisciplinary diabetes service. Recruitment criteria included adolescents aged 11 to 17 with type 1 diabetes, who previously attended the diabetes clinic at least once, the parent or legal guardian of an adolescent with type 1 diabetes who attended the clinic, and HCPs employed in either of the two diabetes clinics where recruitment took place. Recruitment continued until data saturation had been reached. Informed, written consent was obtained from all participants. Ethical approval was received from both participating hospitals and university research ethics committee.

A topic guide was used, and a short demographic survey was administered to each participant. Topic guide questions included: 1. *How do you feel about speaking with the doctors? 2. What questions would you like to ask during your clinic visit? 3. How would you feel about using a Question Prompt List during your visits?* A sample Question Prompt List based on a literature search was shown to participants and the questions that followed included: 4. *Can you tell me what questions do you think are helpful? 5. What questions are missing?*

2.2. Phase two

Phase two involved separate workshops with a Youth Advisory Group (YAG) and a Parent Advisory Group (PAG), as part of an iterative design process. An advert was placed on a national diabetes' charity website and on Facebook support groups for type 1 diabetes. Inclusion criteria were the same as phase one. There were two in-person workshops with both advisory groups, held separately but on the same days and times. The YAG was chaired by the lead researcher and the PAG was chaired by another member of the team. The first workshop discussed questions to be included in the QPL, based on a list of questions identified during phase one. Workshop two focussed on discussions around formatting, the total number of questions to include, the sequencing of questions and other design elements of the QPL.

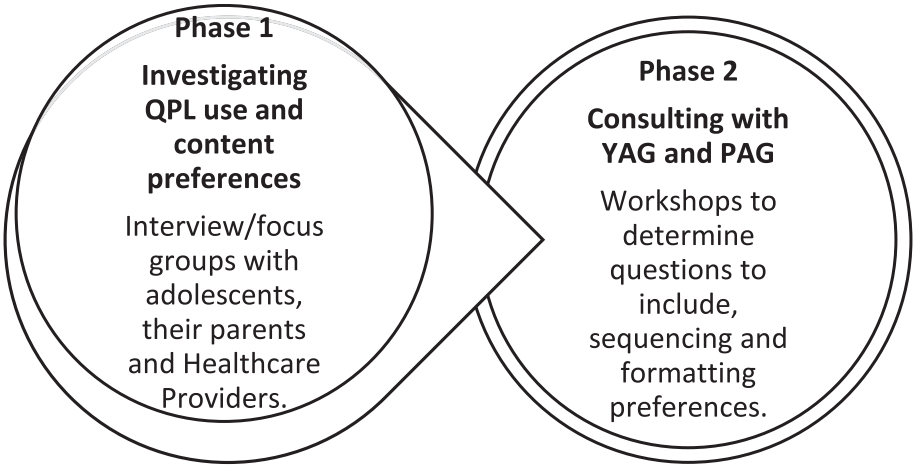

Fig. 1. Research design process for Question Prompt List.

2.3. Sample

In phase one, 34 participants took part in interviews or focus group sessions with a member of the research team. Of these, 13 were adolescents, 14 parents and 7 HCPs (see Table 1. for a breakdown of sample demographics for phase one).

In phase 2, five adolescents with type 1 diabetes and their parent were recruited to be part of a Youth Advisory Group and a Parent Advisory Group, to inform the design of the QPL. A total of five adolescents (three females and two males), and five parents (four females and one male), were recruited.

Table 1
Phase 1 sample demographics.

Gender
Parents
Female: 13
Male: 1
Adolescents
Female: 10
Male: 3
Method of insulin delivery
Continuous Subcutaneous Insulin Infusion: 9
Multiple Daily Injection (MDI): 4
Age and diabetes duration
Mean Age: 14 years' old
Mean diabetes duration: 5.7 years
HCPs
Female: 6
Male: 1
Consultant endocrinologists: 3
Nurses: 4
More than 10 years in clinical practice: 7

2.4. Data analysis

A thematic analysis was conducted of phase one's one-to-one interviews/focus group sessions, which had been audio-recorded and transcribed verbatim. Transcripts were analysed using qualitative analysis software package NVivo. The first stage of the analysis began with coding transcripts line-by-line into descriptive codes. The second stage involved assimilating descriptive codes into thematic codes when patterns emerged.

In phase 2, a separate analysis was conducted of field notes taken from the workshops with the YAG and PAG. This informed the iterative design process of the QPL. Like phase 1, descriptive codes were assimilated into themes. There was a two-stage process to reaching consensus: three members of the research team were involved in the thematic analysis process, and any discrepancies were discussed and agreed by consensus. The results were shared with the YAG and PAG to ensure that the summary reflected their views. Where preferences varied, the Feedback from the YAG was prioritised in the co-design process.

Table 2
Themes from thematic analysis of phase one's interviews and focus group sessions.

Themes	Sub-themes	Quotation examples from interviews and focus groups
Adolescent disengagement with HCPs at the diabetes clinic	Negative experience communicating with HCP	*When you get HbA1c that's a bit higher you should just like be nicer to the person and stop like blaming them because I feel like when that happened to me. I felt really bad like when I was in the clinic because I felt like I couldn't really say anything because they would just like give out to me (Adolescent 2).* *They don't really give me an answer they just kind of ask me why was I asking that, like did I do something wrong or like what happened, what did you do when that happened (Adolescent 2).*
	Lacking patient education leading to disinterest	*They just have no interest in it. They don't see any benefit of going; they don't learn anything new. (Parent 11)*
	Low self-confidence out of fear of being wrong	*I don't really like asking questions, like if it would be wrong or something (Adolescent 10).*
	Forgetting to ask questions	*When I am living my life, I have a lot of questions because sometimes things happen and I don't really know like what to do about it, but when I am in the clinic, I just forget them (Adolescent 2).*
Positivity around using a question prompt list at the clinic visit	Aiding adolescents when forgetting the questions, they want to ask	*I think it would be very good, because if someone can't remember a question, it might remind them of the question they wanted to ask…I probably would use that (Adolescent 12).*
	Encouraging adolescents to ask questions that they may not have thought of asking before	*I think it's a really good idea because you'd definitely read this and you'd be like I didn't think of that question, but it would be a really good question to ask…I don't know an answer to that, I definitely need to know that. (Adolescent 11)*
	Easing the pressure of communicating with a HCP	*It would be easier because, the questions are there for you already. And then for freezing on the spot, you're not as much under pressure for writing down things. (Adolescent 13)*
	Giving confidence to adolescents to ask questions	*I'd feel like that would help me because I feel like when I get shy, I get nervous and it's like, "did you have any questions?" And I did but I just kind of went blank and forgot them. So, I end up always saying no even if I do end up remembering. So, I feel like if I had them written down or printed out, I would be better off asking questions. (Adolescent 4).*
Adolescent v Parent v HCP views on content for Question Prompt List	Adolescents favoured informational questions (questions that lead to explanations of medical terminology on type 1 diabetes)	*I would feel that I'd know less about highs than lows because when you're low you can kind of feel it coming on. (Adolescent 1).* *Maybe what is the HbA1c because lots of people are curious about that. (Adolescent Focus group).*
	Parents favoured lifestyle questions	*She's not allowed drink, but I'd like her to know. (Parent 1).* *Is it okay to skip some meals if you don't feel hungry? Excellent question. (Parent 13)*
	HCPs favoured diabetes-care related questions	*How do I adjust my insulin, because a lot of them don't actually know - because the mams and dads do all that. (HCPs focus group)* *Avoiding hypoglycaemia would be another good one. (HCP 2)*

3. Results

3.1. Phase one: Investigating insights on question prompt list use and content preferences

Three themes emerged from the data analysis of one-to-one interviews and focus groups sessions: 1) Adolescent disengagement with HCPs at the diabetes clinic 2) Positivity around using a question prompt list at the clinic visit 3) Adolescent v Parent v HCP views on content for QPL. Table 2 lists the themes, subthemes and examples of quotations taken from phase one interviews and focus group sessions.

3.2. Phase two: Consulting with the Youth Advisory Group (YAG) and Parent Advisory Group (PAG)

The Youth Advisory Group and Parent Advisory Group were consulted in the next stage of the design process. Both groups were shown a list of twenty-five questions that were extracted from the analysis of interviews and focus groups conducted in phase one (please see Table 3).

A difference emerged in the types of questions the PAG and YAG felt should be prioritised. Similar to the first phase, parents largely favoured lifestyle questions, whereas adolescents largely favoured informational questions. As this was an adolescent-led iterative design process, it was their feedback that took precedence when deciding on the questions to be included in the QPL.

Both Advisory Groups also advised on formatting style of the QPL itself and suggested editing of the wording in the chosen questions. The YAG were particularly instrumental in this because they knew what terminology their peer group would understand. The feedback included: 1) The initial list presented to the YAG had 25 questions. However, consensus was reached in relation to the number of questions; 16 questions was considered optimal, as too many questions might be "information overload" for the adolescent using the QPL. 2) Should there be a question the adolescent wanted to ask but that was not on the sheet, a space should be provided so they can write down their questions. 3) The flow of the questions was recommended to start with informational questions and questions related to day-to-day diabetes care, followed by lifestyle questions, and the insulin pump questions should go last, and separated from the other questions as these only affect people who have the pump or who are at the stage where they are getting a pump. 4) Colour should be used to make the QPL more eye catching. Table 4 outlines the final questions selected for the QPL.

Table 3
List of questions discussed and edited during deliberations by both Advisory Groups.

List of questions
1What does HbA1c mean and what does it measure? 2.How do I adjust my insulin? 3. How many times a day do I measure my blood glucose? 4.What are ketones? 5.When should you test for ketones? 6.What are the warning signs if my blood sugar is too high?7.What are the warning signs if my blood sugar is too low? 8.How do I avoid a hypo?9.What should I do when I feel sick or unwell? 10.What do I need to do to manage my blood sugars when I get my period? 11.What is an insulin pump? 12.Do I have to check my blood sugars when using an insulin pump? 13.How long can I disconnect my insulin pump for? 14.If I tried an insulin pump before and it wasn't for me can I try it again? 15.How does food affect my blood sugar? 16.Are there any foods I cannot eat? 17.How do I count carbs when I am eating out or at a party? 18. How do I manage exercise? 19.How does exercise affect my blood sugar? 20.Is it ok to drink alcohol? 21.Is it ok to skip meals if you don't feel hungry? 22.How do I manage my diabetes during my exams? 23.What should I do when I am away on holidays/school trip to manage my diabetes? 24.How do I tell people I have diabetes? 25.Can you tell me more about transitioning into adult services?

Table 4
Final questions selected by YAG and PAG for Question Prompt List.

Final Question Prompt List
1. What is HbA1c and what does it measure?
2. How do I change my insulin?
3. What are ketones and when should you test for ketones?
4. What are the symptoms if my blood sugar is too high or too low?
5. What should I do if I feel sick?
6. What do I need to do to manage my blood sugars when I get my period?
7. How do I count carbs when I am eating out or at a party?
8. How does exercise affect my blood sugar and how do I manage it?
9. Is it ok to drink alcohol?
10. Is it ok to skip meals if you do not feel hungry?
11. How do I manage my diabetes during my exams?
12. What should I do when I am away on holidays/school trip to manage my diabetes?
13. Can you tell me more about changing to the adult clinic?
14. What is an insulin pump?
15. Do I have to check my blood sugars when using an insulin pump?
16. How long can I disconnect my insulin pump for?

4. Discussion

Previous studies have highlighted the challenges faced by adolescents as they assume greater levels of responsibility in the management of their diabetes, including communicating with HCPs[1–3]. Research examining provider-patient communication during clinic visits reported sub-optimal levels of involvement of adolescents, which has repercussions when it comes to preparing them to assume a more active role in diabetes management[5,7]. Therefore, the objective was to investigate adolescents with type 1 diabetes' communication experience with HCPs, insights into the use of a QPL at the diabetes clinic and co-designing a QPL as an intervention to increase adolescent communication with HCPs.

Previous studies have shown that communication from the adolescent can often be limited to responses to questions from the healthcare provider as there is a focus on clinical outcomes in the consultation rather than on the person's needs as a whole[7]. Participants in this study identified reasons for adolescent disengagement when communicating with HCPs. These can be categorised into four themes: negative experience communicating with HCP, lacking patient education leading to disinterest, low self-confidence out of fear of being wrong and forgetting to ask question(s).

Previous studies have highlighted how clinical consultations between the parent and HCP can stifle adolescent engagement in the diabetes clinic[20–21]. Parents have a role in managing their child's diabetes, and sometimes this can lead to HCPs directing questions to parents or parents responding on behalf of their child[5,11,22]. While studies have highlighted parents' supportive role in advocating and managing their child's diabetes[1], it is necessary to nurture adolescents' independence so that they can self-manage and advocate for themselves when they transition to adult services[28]. The shared responsibility model is promoted in diabetes care, where responsibility levels in self-management increases with the caregiver playing a more supportive but subordinate role[20–22]. The findings of this study indicate that a bespoke intervention could be a novel way of supporting adolescents in assuming responsibility for engagement with HCPs. Participants in this study felt positive about using a QPL during their consultation and identified several ways this intervention could support adolescents to communicate better with HCPs. Firstly, adolescents identified that it could increase self-efficacy in asking questions, secondly it could encourage provider education as the question prompt list would act as a trigger to ask questions they had not thought of before, and finally it could help ease the pressure of communicating with HCPs. Prior to the clinic visit, it could be a useful tool to help adolescents to think about the topics that they wish to discuss, which they could share with their doctor/nurse so that the consultation meets their needs and

preferences. Because adolescents' needs evolve over time, the QPL could serve as a tool to encourage adolescents to identify their own individual questions and topics so that the consultation is structured according to their agenda. This agenda-setting approach promotes a person-centred individualised approach in consultations[29–30].

Adolescent-centred psychosocial interventions have been shown to be successful for enabling self-management of type 1 diabetes[11–14]. Interventions designed to increase adolescent communication with HCPs in other chronic conditions have also been shown to be effective [23,24]. For example, Sleath et al. trialled a Question Prompt List and video intervention which was reported to have increased engagement and provider education on adolescents in asthma clinics[24].

Interventions have largely focussed on healthcare provider communication, such as motivational interviewing[15]. However, in the long term, existing interventions have not been successful, because they do not empower adolescents to communicate and self-advocate for themselves[9]. The principal aim of this intervention was to encourage behavioural change in adolescents with type 1 diabetes rather than the healthcare provider. Thus, this intervention seeks to increase self-efficacy in adolescents to engage with HCPs. Interventions that promote self-efficacy in adolescents to self-manage type 1 diabetes have been successful because self-efficacy is central to increasing levels of responsibility in diabetes management among adolescents[25].

Parents, adolescents, and HCPs provided feedback on questions that should be included in the QPL. There were three categories of questions: lifestyle, informational and diabetes care. Notably, a difference emerged between parent and adolescent content preference. Adolescents largely favoured informational questions (for example what the HbA1c is, how to detect a high or low), whereas parents veered towards lifestyle questions. Parents and HCPs assumed adolescents had greater knowledge about diabetes, which was in contradiction with adolescents' own perceptions. This translated to parents, HCPs and adolescents diverging in the types of questions they felt should be included in the QPL. This divergence demonstrates the importance of adolescent clinic engagement taking precedence with HCPs[3,4,7,21].

The design process was led by adolescents with type 1 diabetes. This was an iterative development that engaged adolescent, parent and healthcare provider stakeholders throughout. This was important to ensure that the QPL was relevant to the target population[17–19]. Previous studies have shown the value of adolescents involved in research, as it provides a direct voice, ensuring data analysis reflects their interpretation[26,27]. Consequently, when there were discrepancies over question content, sequencing, and format, it was the adolescents' views that took precedence.

4.1. Limitations and strengths

Some limitations were experienced in the study. First, the sample interviewed in phase one was largely female. However, the YAG had equal numbers of male and female adolescents. The intervention was one QPL designed to target a broad age group (11 to 17 years). Therefore, the relevance of some questions depended on the adolescent's age. Furthermore, the QPL had to be relevant to both adolescents who were newly diagnosed and adolescents who were already living with diabetes. Consequently, some questions might be considered basic to some adolescents and relevant to newly diagnosed only.

The QPL was intended as a tool to encourage adolescents question asking at a clinic visit, and not as an intervention to address psychosocial issues such as feeling blamed for a high HbA1c. While we acknowledge that the QPL does not address this, other methods/interventions are warranted, including educating healthcare providers, and raising their awareness of how their consultation style of questioning causes some adolescents to feel criticised. While some of the questions are related to the treatment of type one diabetes, there were also lifestyle and quality of life questions. The QPL also provides space for adolescents to write their own personal and individual questions as it was not possible to cover all possible questions and needs can vary over time.

However, the study was strengthened by being adolescent-led, and patient and stakeholder input were central to the co-design process. As the design process was adolescent-led, decisions on what questions to include, was left up to the adolescents who participated in the study. The Youth Advisory Group (YAG) had the final say on the QPL. As this was central to the design process, the questions that were picked were determined by them to be the most relevant for their peers.

5. Conclusion

This study is relevant to HCPs and researchers in diabetes and other chronic conditions who are working towards a shared responsibility model of providing healthcare to adolescents. It is also of interest to HCPs who want to encourage adolescents to take more control of their condition and participate actively in communication exchanges at their clinic visits. The QPL is one part of an intervention, which also included a video to encourage adolescent engagement at the diabetes clinic[16]. Currently, a pilot randomised control trial is underway to evaluate whether this intervention improves several outcomes, including clinic engagement, provider education, and self-efficacy. This study illustrates the importance of co-designing a healthcare intervention with adolescents so that it resonates with their needs.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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