Developing a video intervention to improve youth question-asking and provider education during paediatric diabetes clinic encounters: The Promoting Adolescents Communication and Engagement study

Sinead Pembrokeb,c, Edna F. Rochec,e, Betsy Sleathf, Maria Brennerb, Carol Hilliardd,e, Declan Coby, Imelda Coyneb

b School of Nursing and Midwifery, Trinity College Dublin, the University of Dublin College Green, 24 D'Olier Street, Trinity College Dublin, Dublin 2, Ireland
c Department of Endocrinology and Diabetes, Children’s Health Ireland, Tallaght, Dublin 24, Ireland
d Department of Diabetes and Endocrinology, Children’s Health Ireland, Crumlin, Cooley Road, Dublin 12, Ireland
e School of Medicine, Trinity College Dublin, the University of Dublin College Green, Dublin 2, Ireland
f University of North Carolina at Chapel Hill, Chapel Hill, NC, United States

ARTICLE INFO

Article history:
Received 29 July 2020
Received in revised form 27 November 2020
Accepted 9 February 2021

Keywords:
Diabetes
Adolescents
Patient-HCP communication
Engagement
Video
Intervention

ABSTRACT

Background: Research on long-term health conditions indicates that adolescents are not actively involved during their medical visits. Active involvement is essential because this can help adolescents learn how to self-manage their treatment plan.

Objective: To co-design a video intervention to improve youth question-asking and provider education during paediatric diabetes visits.

Patient Involvement: A participatory-led approach was used to co-design the video, through a combination of interviews/focus groups and the establishment of a Youth Advisory Group.

Methods: First, focus groups and one-to-one interviews were held with adolescents, parents and healthcare providers. Second, two workshops were held with the Youth Advisory Group, Parent Advisory Group and stakeholders on script design. Finally, an iterative development of the video took place between the research team, videographer, both advisory groups and the steering committee. There were three rounds of feedback before the video was finalised.

Results: Adolescents’ content preferences included: 1) message of empowerment; 2) managing your diabetes so you can get on with the fun stuff in life; 3) Promoting independence; 4) Reasons for not speaking at clinic visits and reassurance; 5) Becoming comfortable to speak and ask questions at clinic visits; 6) Practical advice on how to ask questions. Formatting preferences included that the video should be short, divided into segments, with adolescents with diabetes acting in it, and speaking directly to the camera.

Discussion: Identifying and reflecting adolescents’ needs and preferences for engagement with healthcare providers was critical in the development process. Adolescents’ participation in the co-design process was pivotal to the acceptability of the intervention for adolescents with diabetes.

Practical value: The intervention may increase adolescents’ participation in communication and interactions with healthcare providers, which may help them to be more active in the self-management of their condition.

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1. Introduction/ background

Transitioning to diabetes self-management is a challenging time for adolescents [1], often associated with disengagement from healthcare services and increased risk of complications [2,3]. There are greater expectations of self-advocacy and communication skills [1,5,6] and this added pressure can negatively impact on self-management and health-related outcomes [7]. Structured education, and age-appropriate self-advocacy appear to be important factors in determining both clinical outcomes and quality of life for adolescents [8]. Therefore, interventions that promote self-management skills [9] and help adolescents to communicate with their healthcare providers are important [10].

https://doi.org/10.1016/j.pec.2021.02.021
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Active participation in decision-making [11] is an essential skill that adolescents need to lead an independent life with diabetes [5,12]. Enhanced diabetes self-efficacy, a central component of Social Cognitive Theory (SCT), has been linked to improved diabetes self-management and glycaemic control [37–40].

Current diabetes guidelines emphasise that adolescents need to be empowered to manage their diabetes [13,14] and that this process should start early (about 11 years) and be youth focused and developmentally appropriate [15]. Studies examining provider-patient communication have reported difficulties in engaging adolescents to actively participate in diabetes clinics [4,16], with adolescents reporting that they felt their needs for managing diabetes were poorly understood [17]. Research on long-term conditions has found that adolescents are not actively involved during their medical visits and that adolescents may not receive education about how to assume a more active role in condition management [18,19]. Yet, adolescents view effective communication as essential to achieving good self-management and glycaemic control [20,21]. Active involvement is important, because interactive discussions with providers can help adolescents learn how to self-manage their condition and treatment plan [22,23].

Literature on interventions to educate and promote treatment adherence in children and adolescents with type one diabetes is extensive [24–26]. However, interventions that encourage self-management and self-advocacy are needed [27]. Recent systematic reviews concluded that only a small number of trials have been carried out on such interventions for young adults, and quality was low [2,28]. Video interventions have the potential to encourage and empower adolescents [29–31] and have been used with other chronic conditions [32,33]. Sleath and colleagues found that providing a question prompt list with a video intervention increased adolescents’ engagement and provider education in asthma clinics [34]. Video interventions have also been designed to optimise adolescents’ (with type one diabetes) self-management [35].

This paper reports on the co-development of an educational video, which is one part of an intervention to improve youth question-asking and provider education during paediatric diabetes visits with stakeholders. The objective was to identify adolescent, parent and provider perspectives to encourage adolescents with type one diabetes to ask more questions. A participatory-led approach was integral to the design of the video [41–44]. Other studies that employed similar participatory-led approaches have been positively received, particularly in developing interventions for adolescents with a chronic condition, because the content, format and terminology resonated with the target audience [34,44,47–49].

2. Methods

2.1. Research design

The participatory-led approach involved three stages of user-led input (see Fig. 1). First, adolescents, parents and healthcare providers were recruited for one-to-one interviews and focus groups to investigate content preferences for the video (see Table 1 for topic guide). Recruitment and interviews took place over three months and continued until data saturation was reached.

Second, adolescents were recruited to form a Youth Advisory Group, and their parents were recruited to form a Parent Advisory Group. Both advisory groups were part of the video development team, which comprised the research team, a videographer, and the steering committee made up of academics with expertise in adolescent communication, content, diabetes and psychology. Both advisory groups were involved in the co-design, formatting, filming and editing of the video (see Table 2 for recruitment details).

2.2. Analysis

Interviews were recorded and transcribed verbatim. Data was managed using qualitative analysis software package NVivo 11.0 (QSR International Pty Ltd., 2017), and transcripts were analysed using thematic analysis. A coding framework was generated through an inductive process of data analysis. Interview transcripts were coded line by line into descriptive codes, until patterns emerged into thematic codes. Three members of the research team were involved in the coding process and independently analysed the data. Discrepancies that arose were discussed and resolved by consensus. The Youth Advisory Group and the Parent Advisory Group also provided input by prioritising the themes they felt were important for the video. This was discussed amongst the research team and the steering committee until consensus was reached.

![Fig. 1. Phases of the study.](image-url)
2.3. Ethical considerations

Ethical approval was obtained from the Research Ethics Committees of both participating hospitals, and informed written consent was obtained from all participants.

3. Results

3.1. Sample

A total of 13 adolescents with type one diabetes (aged 11–17 years), 14 parents, and seven healthcare providers participated in one-to-one interviews or focus groups. In total 24 interviews and three separate focus groups took place, (three adolescents, three parents and four healthcare providers). Of the 13 adolescents, ten were female. Nine were using an insulin pump and four injection therapy. Mean age was 14 years and mean diabetes duration was 5.7 years. Most parents were female (93%). Healthcare providers included four nurses and three consultant endocrinologists. Most healthcare providers were female (86%) and working in clinical practice at least ten years.

3.2. Phase one: investigating content preferences for video

The data analysis of interviews and focus groups revealed six themes that should be included as key messages for adolescents in the video content to improve youth question-asking and provider education during paediatric diabetes clinic encounters (see participants comments in Table 3).

3.2.1. Message of empowerment

Most participants suggested that a positive message should be included in the video content to empower adolescents with diabetes. The message should convey that although diabetes does require close management, it is still possible to engage in activities similar to young people who do not have diabetes.
3.2.2. Managing your diabetes so that you can get on with the fun stuff in life

The second theme addressed the importance of adolescents taking control in managing their diabetes, and the role of clinic visits and healthcare providers in supporting adolescents to achieve this. The message should convey that moving towards self-management is important for the adolescent and that the clinic visit will help them do that.

3.2.3. Promoting independence

Another theme was the importance of promoting independence for adolescents with type one diabetes. By asking questions, adolescents can learn and in turn the healthcare provider can also learn how to help them. Participants articulated this as a necessary step for adolescents before they transition to adult services. This does not involve exclusion of parents as they could continue to have a supportive role during this gradual process.

3.2.4. Reasons for not speaking at clinic visits and reassurance

Participants suggested that the video intervention should highlight reasons why some adolescents do not speak and engage with healthcare providers. Some of the challenges included, feeling under pressure and nervous about their blood glucose level (HbA1c), being shy, a parent responding and not giving the adolescent an opportunity to speak, a desire to get the appointment over quickly, and fear of asking a stupid question.

Participants also spoke about the importance of reassuring adolescents about speaking and asking questions at clinic visits. Reassurances are important as adolescents attending the clinic can feel that they are being criticised, which exerts pressure on them.

3.2.5. Becoming comfortable to speak and ask questions at clinic visits

Participants suggested that adolescents require practical advice on the following: talking with parents about how they feel; talking to healthcare providers about topics other than diabetes to develop trust and relationships; and a reminder that healthcare providers are there to help and that nothing bad will happen if they ask a question. It was also suggested that with time, adolescents will get to know the healthcare provider and feel more comfortable.

3.2.6. Practical advice on how to ask questions

Participants highlighted the need for practical advice for adolescents and parents about how to ask questions. Practical advice included, thinking of questions to ask before the clinic and writing them down, and starting small, for example, thinking of two questions to ask at the visit. Participants also highlighted that parents have a major role in encouraging their son/daughter to ask questions, and they can do so by having conversations with their son/daughter beforehand.

3.3. Phase two: Script design consultation with stakeholders

Both advisory groups worked closely with the videographer and the research team throughout the script-writing process. However, the Youth Advisory Group had the final say on the content and formatting of the video. The Youth Advisory Group consisted of three female and two male adolescents, who also acted in the video. The PAG consisted of four mothers and one father.

The research team and the videographer discussed the themes, video style and formatting choices with both advisory groups in two separate workshops (see Table 4). The steering committee was consulted in a separate meeting for their feedback. This formed the basis of an initial draft script written by the videographer, which was reviewed and revised by the advisory groups and research team before the final script (see Fig. 2) and style was approved, and filming could commence.

3.4. Phase three: Iterative development of the video

Five members of the Youth Advisory Group volunteered to be actors in the video intervention. A further three adolescents were recruited through a diabetes support group. When filming was completed, the videographer produced a rough edit of the video for the advisory groups and research team to view and critique. This iterative process involved three rounds of feedback and revision of the video (see Table 1 for details about the iterative process).

4. Discussion and conclusion

4.1. Discussion

Studies have shown that attitudes and behaviours developed during adolescence influence health behaviours into adulthood [36,45,46]. Therefore, the objective was to increase patient engagement and communication with healthcare providers to prepare adolescents to self-manage type one diabetes into adulthood. The themes resulting from the interviews and workshops focussed on various aspects of clinic engagement, with the aim of giving informative, supportive and practical advice to other adolescents in an engaging user-friendly video format.

Empowering adolescents with type one diabetes was an important message throughout the video. However, it was also important for the methodology to be empowering. The adolescent participatory-centred approach ensured that adolescents with type one diabetes were central to the design and development of the video intervention. Consequently, where discrepancies arose between the views of adolescents and adult stakeholders (parents, healthcare providers and the videographer), the adolescents were given the final say. This ensured that the video was relevant to the target population.

Table 4

| Feedback from advisory groups on video content, formatting and design. |
|--------------------------|---------------------------------------------------------------------|
| **Youth Advisory Group** | It should be short.                                                |
|                         | It would be good if the video was divided into short sections so that you can go back to it later if you want. |
|                         | Speaking directly to the camera and dramatisations.                |
|                         | Jokes and a bit of humour should be used in the video and spoken in our language. |
| **Parent Advisory Group** | Young people with type one diabetes should be in the video.         |
|                         | The video should start with someone famous or a sports role-model with type one diabetes to show that it is possible to live a normal life and succeed with diabetes. |
|                         | It is important to start and finish the video with a positive message. |
|                         | They are more likely to believe what other people their age have to say than from an adult or a healthcare professional. |
|                         | There should be scenes throughout the video of teenagers with diabetes doing ordinary things, like hanging out with friends and checking their blood sugars. |
|                         | There should be advice in the video on how parents can encourage their child. |
Adolescents, parents and healthcare providers felt the message should be delivered by adolescents with type one diabetes instead of actors. Studies have shown where the message is delivered by adolescents’ peers, the impact is more powerful [32,49]. Studies have also revealed the significant influence of online peer-to-peer videos on adolescents [50]. Therefore, it was important that adolescents spoke their own words directly to the camera, rather than using a script. This also allowed for adolescents to speak using terminology familiar to their peer group. As Brannen (p. 177) pointed out, children and adolescents “need also to be conceptualised as exerting agency in respect of research especially when it concerned the representation of their own views” [51]. Decisions on formatting, such as the length and segmenting the video, were also important considerations that were identified by all stakeholders involved. Similarly, Sleath et al. recommended that a video intervention for adolescents should be brief and succinct [32].

Promoting independence was an important theme identified by adolescents, parents and healthcare providers. Prior research on adolescents with type one diabetes has established difficulties associated with becoming independent, which can be discouraging [1]. Participants felt that explaining why it is important to communicate and ask questions at a clinic visit should be an essential component of the video. Within this, it was felt that promoting independence to self-manage diabetes care should be communicated and encouraged. This is consistent with SCT and promoting self-efficacy in managing diabetes, which has been linked to improved self-management and glycaemic control [38,39].

Both adolescents and parents highlighted that barriers to communicating and asking questions often arose due to feeling under pressure about their blood sugar results, shyness, fear of asking a stupid question and a parent responding on their behalf. Previous research has also confirmed difficulties arising for adolescents communicating with healthcare providers at diabetes clinics [20,35]. All participants agreed and emphasised that the key message was to provide reassurance that the healthcare provider was there to help support them, the adolescents. Another theme was that parents should encourage and allow their child to speak more and ask questions at clinic visits. Adolescents will have to learn to manage their condition, in preparation for transition to adult services and adulthood. Yet prior research has found that parents often respond and ask questions on behalf of their child, rather than allowing time to respond [19]. This message is important because it is linked to handing over more responsibility to adolescents so they can transition to adult services more effectively [22,23].

In developing a video intervention to encourage adolescents to engage with their healthcare providers some limitations were experienced. The demographic profile of interview and focus group participants was largely female. However, the demographic profile of the Youth Advisory Group had an equal number of males and females. Parents were also largely female, and only one father was involved. The video was developed with adolescents who identified as Irish and white Caucasian and reflected sport and music in Ireland. Therefore, the video style may not appeal to other cultural groups. However, this theory-based intervention has several strengths. Using SCT [36] as a theoretical framework enhanced the study because it promotes patient involvement in their care, which is the main objective of this intervention. Patient and stakeholder involvement were central to the intervention design; thus, the target audience were instrumental in co-designing the video. Informal feedback from adolescents, parents and healthcare providers involved in co-designing the video intervention was positive. Adolescents reported feeling empowered by the experience of participating in all aspects of the research. This will be evaluated formally in future research.

4.2. Conclusion

To our knowledge, this is the first type of intervention developed to increase adolescent engagement during diabetes clinic encounters using a video designed by adolescents for adolescents. Video interventions have been found to have the potential to empower, inform and influence positive change in self-management routines in adolescents with long-term conditions [29,31]. A similar intervention developed for adolescents with asthma indicated a positive effect on clinic engagement [32,34]. We are currently conducting a pilot randomised trial to evaluate
whether this intervention improves clinic engagement, provider education, self-management, and other health-related outcomes for adolescents with type one diabetes.

4.3. Practice implications

Supporting adolescents’ development of self-advocacy and communication skills is essential and emphasised in international guidelines for diabetes clinics in children’s services [12,13]. Increasing adolescent engagement is important, because two-way exchange of information with healthcare providers can encourage adolescents to self-manage their long-term condition [22,23]. Adolescents have expressed a need for more technology-based resources that address their educational and psychosocial needs to prepare them for transition to adulthood [51], and video interventions are one means of empowering adolescents [29–31]. With increasing numbers of adolescents living with long-term conditions and needing to acquire the skills for self-management, we need to develop more technology-based resources with adolescents’ input to promote their engagement and communication with healthcare providers.

Funding

Provided by the National Children’s Research Centre, Ireland.

CRediT authorship contribution statement

Sinead Pembroke: Methodology, Validation, Formal analysis, Investigation, Data curation, Writing - original draft, Visualization, Supervision, Project administration. Edna F. Roche: Resources, Writing - review & editing. Betsy Sleath: Validation, Writing - review & editing. Maria Brenner: Validation, Investigation, Writing - review & editing. Carol Hilliard: Writing - review & editing. Declan Cody: Resources, Writing - review & editing. Imelda Coyne: Conceptualization, Methodology, Validation, Formal analysis, Investigation, Resources, Writing - review & editing, Supervision, Funding acquisition.

Declaration of Competing Interest

The authors report no declarations of interest.

Acknowledgement

The project is funded by the National Children’s Research Centre, Ireland [Grant number: C18/13]. The funding source had no such involvement in the study design, in the collection, analysis and interpretation of data, in the writing of the report and in the decision to submit the article for publication.

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