

ORIGINAL ARTICLE

A preliminary evaluation of a novel education model for young people with Type 1 diabetes: the Youth Empowerment Skills programme

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Abstract

Background: Adolescence is a challenging time for young people with Type 1 diabetes, associated with worsening glycaemia and disengagement with care. To improve support, we co-designed with young people a novel psychosocially modelled programme of diabetes education (the Youth Empowerment Skills [YES] programme). This study aimed to estimate the clinical impact and feasibility (recruitment, retention and participant experiences) of this programme.

Methods: A pilot study using mixed-methods was conducted to assess process and outcomes, involving a pre- and post-exposure assessment of glycaemic control, programme participation data, service utilisation and qualitative semi-structured interviews (analysed using Framework Analysis). Participants were recruited from two hospital diabetes centres in Southeast London. The intervention was conducted in local community centres. Participants were young people with Type 1 diabetes aged 15–21 years. The YES programme involves contact with an outreach youth worker and attending a 3-day psychologically modelled course encompassing social learning, peer facilitation and simulation exercises. The primary outcome was change in HbA1c at 6 and 12-months post-intervention. Secondary outcomes included diabetes-related hospital admissions and incident diabetic ketoacidosis (DKA).

Results: Twenty-six young people participated in the programme, mean age 18 (± 1.7) years. Uptake was 34% ($n = 26$) of those approached, with 96% ($n = 25$) programme completion. Pre-exposure (12 month mean) HbA1c was 93.5 (± 29.7) mmol/mol (10.7%), and at 12 months post-exposure, it was 85.1 (± 25.4) mmol/mol (10%) ($P = 0.01$), with 46% ($n = 12$) of participants achieving a reduction in their HbA1c ≥ 5.5 mmol/mol (0.5%). Unplanned hospital admissions and DKA rates reduced by 38 and 30%, respectively. The qualitative data identified positive psychosocial impacts including increased diabetes engagement and activation. Active ingredients were social learning, peer support and experiential learning. Participants emphasised the importance of the youth worker in engaging with the programme.

Conclusion: The evaluation indicates that the YES programme helps improve young people's self-confidence in managing diabetes, enhances diabetes engagement and improves clinical outcomes.

Keywords: *adolescent; diabetes mellitus, Type 1; education; patient; evaluation study*

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Adolescence and early adult life is a challenging period for people with Type 1 diabetes mellitus (T1DM), associated with poor diabetes care engagement, increased risk of diabetes complications and acute events such as recurrent diabetic ketoacidosis (DKA).^{1–5} Furthermore, because this is a period when young people are forming their personal and social identities, diabetes can have a detrimental impact on their

psychosocial development.⁶ Consequently, many young people develop enduring negative emotional constructs about their diabetes and experience frustration regarding the impact of diabetes on their lives.⁷ For some young people, this can lead to the adoption of negative coping styles associated with high risk behaviours and psychological morbidity,⁸ factors that may contribute to the elevated mortality hazard observed in this population.⁹ Socially,

many young people can feel isolated and stigmatised because of their diabetes.¹⁰ Therefore, developing supportive interventions to help young people acquire the psychological and social skills necessary for them to make a positive transition into adult life with diabetes is important.

In response to the ongoing challenge of providing effective education for adolescents, age-appropriate education programmes have been developed.^{11–13} However, these programmes have primarily focussed on diabetes-specific knowledge and skills modelled on adult-based programmes, rather than on diabetes life skills. Whilst these programmes have shown some positive effects on quality of life, few have yielded significant improvements in glycaemic control, suggesting that a different approach may be required. Glycaemic control is important in this population as it is indicative of engagement with diabetes self-management and is a risk marker for both acute and long-term diabetes complications. To address this, we have developed a novel education programme that aims to help young people make positive psychological and social adjustments to how they accommodate diabetes within their lives and improve their orientation to diabetes care and self-management activation.

The Youth Empowerment Skills programme

The Youth Empowerment Skills (YES) programme was co-designed by young people with diabetes and health professionals. Twenty-two young people participated in workshops ($n = 4$) facilitated by a young adult with T1DM and a youth worker, with a further 43 contributing ideas via an online survey. They identified that sessions should be delivered in a youth friendly environment; be interactive, allowing young people to share experiences; and involve peers whom they can relate to as well as professional facilitation. Building on these ideas, we co-designed the programme following three key psychological theories: social learning theory,¹⁴ self-regulatory theory¹⁵ and dual process theory.¹⁶ Respectively, these approaches target self-efficacy, personal identity and personal agency. Drawing on these theories, we constructed a social cognitive learning model that integrates three sets of factors:

- Cognitive factors – considering knowledge, experiences, thinking processes and attitudes.
- Environmental factors – exploring social norms and external factors that mediate behaviour.
- Behavioural factors – developing skills and self-efficacy, with practice, observation and rehearsal.

This model was used to structure programme content and to shape the learning techniques within the programme, which include: experiential and group-based learning; immersive simulations with scenarios such as treating an

episode of severe hypoglycaemia or ketosis, followed by group reflections using a structured debriefing tool; learning together through activities to build self-confidence in challenging situations and through the use of peer-to-peer delivery. As it can be challenging to engage young people in programmes, a qualified youth worker – someone who works with young people to facilitate their personal, social and educational development – was employed to provide outreach work to identify potential participants and encourage attendance. Social media (WhatsApp and Facebook) was used to maintain engagement and provide ongoing peer support. This was moderated by the youth worker. In this paper, we present the findings of a preliminary evaluation of the programme. The programme is fully manualised and Quality Institute for Self-Management Education (QISMET)-accredited.

Materials and methods

The aims of this study were to estimate the impact of the YES programme on glycaemic control and to consider programme feasibility (recruitment, retention and participant experiences). Following the principles of the Medical Research Council (MRC) framework for complex evaluation, we conducted a preliminary evaluation of the YES intervention, to model its impact on diabetes outcomes and to optimise the programme prior to a full feasibility study.^{17,18} The study used a mixed-methods approach with integrated process and outcome evaluations. The process evaluation provided an assessment of programme uptake, attendance and participant satisfaction, and included a qualitative study describing the experiences and perspectives of participants. The outcome evaluation used a pre- and post-test design to estimate the clinical impact of the programme.

Study setting

Participants were identified through diabetes clinics of two large teaching hospitals in inner-London, in areas with high levels of socioeconomic disadvantage and ethnic diversity. The programme was delivered in a local youth centre.

Participants

The participants all attended one of two occurrences of the YES programme. The inclusion criteria for participation were a diagnosis of T1DM and aged 15–21 years. As this was an evaluation of a pilot intervention, a power calculation was not undertaken. However, the sample was sufficient to estimate the effect of the programme, in order to inform a sample size estimation for a future study.

Intervention

The development and theoretical underpinning of the programme is described above. The sessions were

Table 1. The YES curriculum

Session	Learning activity	Facilitators
Day 1		
1	Introductions and warm-up games	Youth worker (YW), peer educator (PE) and diabetes specialist nurse (DSN)
2	How diabetes fits into your daily routine	YW, PE, DSN
3	Psychological impact of diabetes (exploring their feeling about diabetes and building confidence to live with diabetes)	Psychologist (PSY)
4	Away from home and staying safe (going to parties, alcohol, drugs and diabetes)	YW, DSN
5	Preparation for simulation sessions (learning about hypoglycaemia management and sick day rules)	DSN
Day 2 (simulation day)		
1	Ice breaker and warm-up game	YW, simulator staff (SimS), Trained Debriefers (DB)
2	Basic life support on mannequins	YW, SimS, DB
3	Physical limitation simulation – understanding how physical limitation and disability affect function by wearing a disability suit	YW, SimS, DB
4	Role play – to explore what happens during a consultation and how to get more out of a consultation	YW, SimS, DB
5	Role play – sick-day management and explore how they feel about the scenario	YW, SimS, DB
6	Role play – hypoglycaemia management and explore the feeling of managing a 'hypo'	YW, SimS, DB
Day 3		
1	Ice breaker and warm-up game	YW, DSN, PE
2	Relationship issues-peer support, peer pressure, family, healthcare professionals	YW, PE
3	Exploring attitude towards food, eating out and weight	Dietician (DC), PSY
4	Get to know your body – exploring foot care, eye screening, contraception and sexual health	Podiatrist (P), retinal screener (RS), sexual health worker (SHW), diabetologist (D)
5	Exercise and diabetes – activity (e.g. rock climbing)	YW

co-facilitated by the youth worker, a peer educator (young adult with T1DM) and a diabetes healthcare professional. The programme comprised a structured course held on 3 consecutive days from 10:00 to 16:00, access to peer support through social media, a follow-up session. The content of the programme is summarised in Table 1.

Participants were recruited to the programme either through direct referral from members of the diabetes teams or proactive identification from the clinic database. Programme recruitment was co-ordinated by an outreach youth worker, who encouraged participation by building a relationship with the young person and helping them to see the programme as a positive opportunity. The youth worker was then involved in facilitating the 3-day course and fostered ongoing connectivity through social media and get-togethers.

Outcomes and process measures

The primary outcome was change in glycated haemoglobin (HbA1c) pre- and post-exposure. We also considered the proportion of patients exhibiting a reduction in HbA1c ≥ 5.5 mmol/mol (0.5%) as a validated indicator of cost-effective change.¹⁹ Secondary outcomes included

clinical engagement and unplanned hospital admissions. The process measures included proportion of patients recruited, programme completion rate, programme satisfaction and programme usefulness to daily life (0–5 scale, 0 = not useful, 5 = extremely useful).

Data collection

The clinical outcome data were collected from medical records. Baseline HbA1c was mean HbA1c from 12 months pre-exposure (all participants had ≥ 4 readings); post-exposure HbA1c was mean HbA1c recorded at 6 and 12 months. To determine clinical engagement, clinic attendance was taken from medical records in the 12 months pre- and post-exposure, together with hospital admissions, severe hypoglycaemia and DKA.

To explore participants' experiences of the programme, a semi-structured interview schedule was designed in consultation with the clinicians and young people with T1DM (Fig. 1). The interviews were conducted in a non-health care setting, by three independent researchers experienced in working with young people, 6 weeks after the course completion. Interviews were digitally recorded and then transcribed for analysis.

What was life like before doing ‘YES’?
<i>Explore: self-confidence, physical and emotional aspects of diabetes (self-management, social situations, motivation, relationships, interaction with health professionals).</i>
What is life like now, having completed YES?
Have you noticed any changes in how you think or feel about your diabetes and how you manage it?
Did you have any expectations of the YES course?
What encouraged you to attend the course?
What were the most important things for you about the course?
How do you think the course could be improved?

Fig. 1. Topic guide for the semi-structured interviews.

Data on programme usefulness and satisfaction were collected through a post-programme questionnaire.

Data analysis

Descriptive data were compiled detailing participant and non-participant characteristics, programme attendance and completion, life impact and programme satisfaction. Pre- and post-exposure glycaemic control data at 6 and 12 months were compared using repeat measure ANOVA in SPSS v.26. We also calculated the proportion of participants who made a clinically significant improvement in their HbA1c (≥ 5.5 mmol/mol, 0.5%), the observed effect size, and pre- and post-exposure clinic attendance and diabetes-related health events.

The interview recordings were transcribed and analysed thematically using the Framework Method.²⁰ The analysis was conducted in five stages:

- Familiarisation – repeatedly reading the interview transcripts and listening to the recordings.
- Identification – identifying the key concepts to construct codes to express meaning.
- Indexing – all the transcribed data were coded, and each code was indexed within a thematic category.
- Charting – the data were ‘charted’ onto a spreadsheet to generate a matrix relating the data to the thematic categories.
- Mapping and interpretation – similarities and differences between the data were identified, leading to the generation of theoretical concepts and associations relating to the participants experience of the course and its impact.

Patient and public involvement

Young people were involved in designing the intervention and a young adult with T1DM advised on the conduct of the study. From this pilot intervention work, we have established a patient and public involvement (PPI) group of young people and parents who have advised us on the design of a follow-up study.

Table 2. Participant characteristics

Characteristic	Participants (n = 26)	All those approached (n = 76)
Age in years		
Mean (SD)	18 ± 1.7	20.8 ± 2.03
Range	15–22	16–22
Gender		
Male, n = (%)	15 (57%)	32 = (54%)
Female, n = (%)	11 (43%)	27 = (46%)
Ethnicity		
White, n = (%)	17 = (65%)	35 (59%)
Black, n = (%)	7 = (27%)	19 (32%)
Asian, n = (%)	2 = (8%)	5 (9%)
Duration diabetes		
Mean (SD)	7 ± 3.8	8.5 ± 5.4
Range	1–17	1–17
Insulin regimen		
MDI, n = (%)	18 = (69%)	48 (82%)
BD mix, n = (%)	5 = (19%)	2 (3%)
Continuous subcutaneous insulin infusion (CSII), n = (%)	3 = (12%)	9 (15%)
Mean HbA1c		
mmol/mol	93.51 (±29.69)	89.96 (±26.6)
%	10.7	10.4

Ethics

All participants provided a written informed consent to this study, following ethical approval by the NHS Ethics Committee (REC: ref15/WA/0286). Participants aged under 16 required additional written consent of a parent.

Results

Twenty-six young people participated in the programme, with a mean age of 18 (± 1.7 standard deviations [SD]), range 15–21 years, and a mean diabetes duration of 7 (± 3.8) years. Participants were evenly divided by gender and reflected the local socioeconomic demographics (34% [$n = 9$] were of Black or Asian ethnicity). The majority (70%, $n = 18$) followed a multiple-daily insulin regimen, with only 12% ($n = 3$) using an insulin pump and 19% ($n = 5$) using twice daily bi-phasic insulin (BD Mix). Participant characteristics are summarised in Table 2.

Programme uptake and completion

Seventy-six young people were invited to attend the programme, with 26 (34%) attending (see Fig. 2). The characteristics of those who declined were similar to those who accepted (see Table 2), although the non-attenders had a higher level of pump use, a lower level of twice daily mixed insulin and had marginally lower HbA1c. Twenty-five of the 26 (96%) attended at least 2/3 days, and 22 (84%) attended at least one follow-up event.

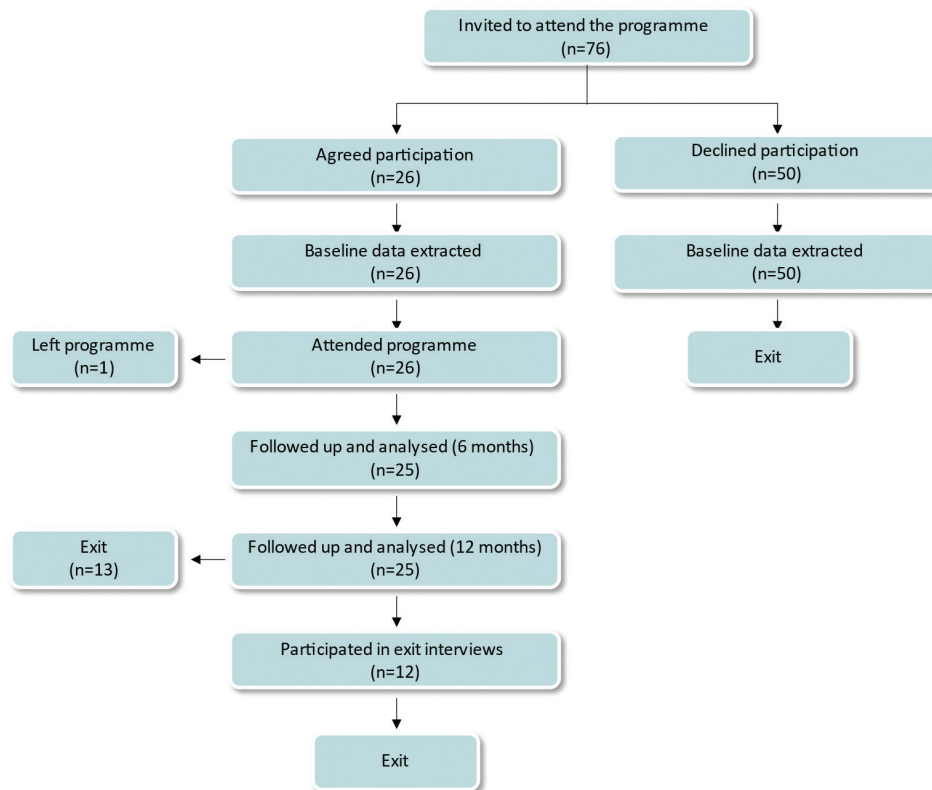


Fig. 2. CONSORT flow chart.

Clinical impact of the programme

Participants showed a mean reduction in HbA1c of 9.4 (± 17.8) mmol/mol (0.8%) and 8.4 (± 15.7) mmol/mol (0.7%) at 6 and 12 months from baseline, respectively ($P = 0.03$; $F = 3.8$) (Table 3). The effect estimates were 0.32 and 0.33 (Cohen's d) at 6 and 12 months, respectively. Overall, 50% ($n = 13$) of participants had a clinically significant reduction in their HbA1c (≥ 5.5 mmol/mol, 0.5%) at 6 months, with 46% ($n = 12$) showing this improvement at 12 months. Three participants had a clinically significant (≥ 5.5 mmol/mol, 0.5%) deterioration in HbA1c, with the remainder showing no clinically important variation. Case level changes in HbA1c at 6 and 12 months are presented in Fig. 3.

There was a 30% reduction in diabetes-related unplanned hospital admissions and a 38% reduction in incident DKA at 12 months, although there was an increase in hypoglycaemia admissions. Additional changes included: three participants going from multiple daily injection (MDI) regimens to insulin pumps; all the participants who were on twice daily mixed insulin changing to an MDI regimen and four participants went onto attend a structured education programme (Dose Adjustment For Normal Eating – DAFNE). There was no significant change in attendance at diabetes out-patient

appointments, although the level of non-attendance at baseline was already low.

Participant perspectives

All participants were invited to a post-exposure interview to elicit their views of the programme, its impact on their lives and how it could be further optimised. Twelve (46%) agreed to participate and data from these interviews are summarised thematically in Table 4, with explanation below.

Impact of diabetes

Participants highlighted difficulties in accepting diabetes and the distress it caused them. Many relayed feelings of social isolation or awkwardness about diabetes. Stigma also featured, with participants feeling judged for what they ate or for their lifestyle, as if they had caused their diabetes.

Reasons for attending and impact of the programme

A desire to build self-confidence, engage more with and learn about diabetes were given as reasons for attendance. In terms of impact, participants identified increased self-confidence, feeling more comfortable with diabetes (normalisation) and increased activation (either taking more interest in diabetes or enacting self-management behaviours).

Table 3. Clinical impact of the programme

Outcome	Pre-programme	6-Month follow-up	12-Month follow-up
Glycaemic control			
HbA1c [§]			
mmol/mol	93.5 (±29.7)	84.1 (±26.9)	85.1 (±25.4)
%	10.7 (±2.7)	9.9 (±2.4)	10.0 (±2.3)
Change in HbA1c [^]			
Reduction ≥ 5.5 mmol/mol (0.5%)	NA	13 (50%)	11 (42%)
Increase ≥ 5.5 mmol/mol (0.5%)	NA	2 (8%)	3 (11%)
Events			
Incident DKA	16	NA	10
Incident severe hypoglycaemia	1	NA	3
Hospital admissions	17	NA	12
Appointments % DNA	17.5%	NA	16.6%

[§]Mean (standard deviation); [^]number (%).

Chart 1. Participant level change in HbA1c

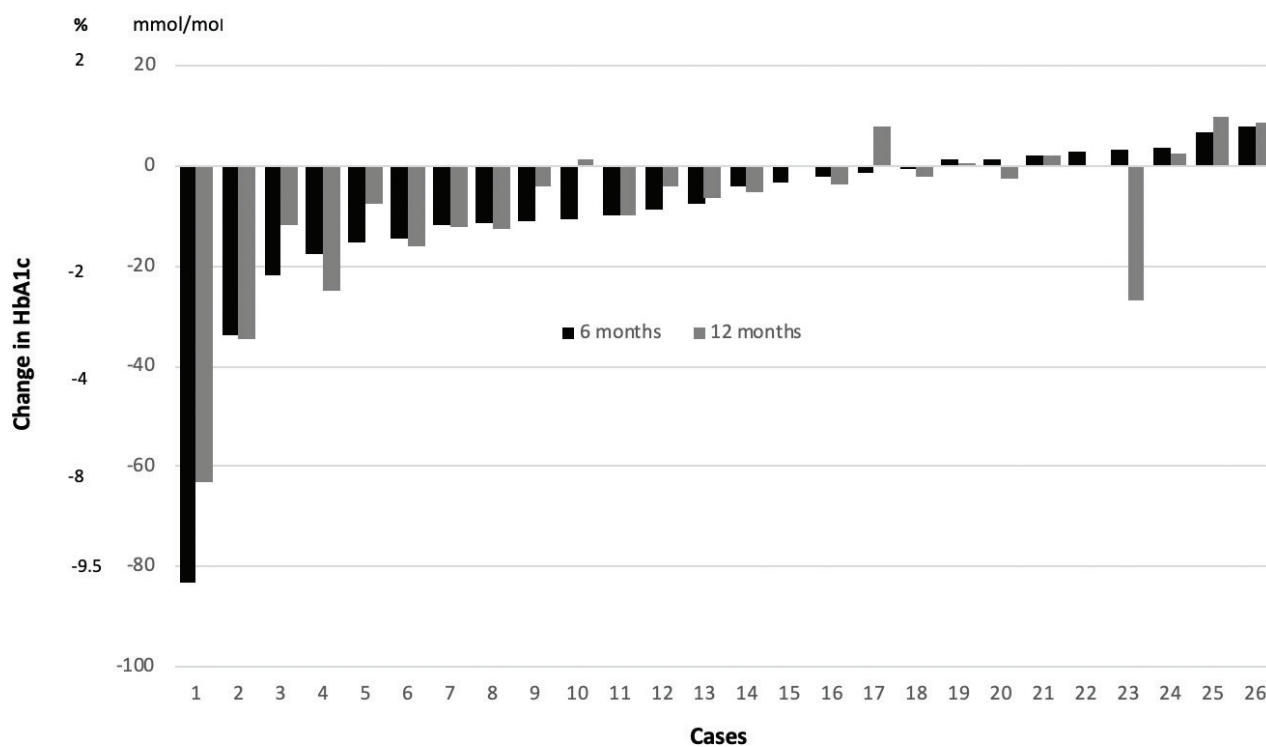


Fig. 3. Participant level change in HbA1c.

Programme Content

Overall, participants related positively to the contents of the programme and described the youth worker as a supportive guide, a co-ordinator and a befriender. Participants also suggested strategies for enhancing the programme, with recommendations for timing and the environment for the programme. It was also suggested that social media could be used to promote the programme to improve uptake.

The patient-centred measures of programme utility and life impact were positive with all participants (n = 26,

100%), indicating that they would recommend the programme to someone else and all rating the usefulness of the programme to their daily lives as *highly relevant* (the maximum level).

Discussion

This study shows that the YES programme can potentially have a positive impact on glycaemic control in young people with T1DM. This finding is important, as previous studies evaluating structured education programmes in

Table 4. Patient perspectives on the programme

Theme	Sub-themes	Participant excerpts
Pre-course views on living with diabetes	Emotional response	'so irritating...I just felt like diabetes was my enemy instead of my friend' 'it changes my moods often... aggressive and, like, annoyed, nervous and all that'
	Social isolation	'deep down I felt lonely because I didn't really know anyone who had Type 1 diabetes...I didn't speak to many people with diabetes'
	Acceptance of diabetes	'can it not just go away...I can't deal with it' 'I just felt like, why?...It didn't feel a part of me'
Motivation for attending programme	Stigma	Interviewer (I): 'Would you tell your friends that you'd got diabetes?' Young Person (YP): 'No, I only tell my friends who I'm really close with, because there's other people, especially in school, that doesn't really understand Type 1 diabetes and they always think that it's because you ate too much sugar or you're too fat or something like that'
	Engage with their diabetes	'Because I think the – from my [CLINIC] appointments, I wasn't really taking my diabetes seriously, so – I think they wanted, like, help me and try find other people who has diabetes, as well, so I can relate to them'
	Increase self-confidence	'I think it's 'cause, as I said before, I'm not – I'm a really shy person, so I thought if I went to this course, it'd sort of bring me out of my shell a little bit, and I'd meet other people with diabetes, as well'
Impact of programme	Learning about their diabetes	'And I just knew that it was something that I had to do, to get through and complete it, because I wanted to know a bit more about my own diabetes and my own experiences, and others', as well'
	Normalising diabetes	'made me realise...I'm not the only one suffering with...my attitude towards diabetes. Everyone else in the group feels the same way, I feel like we've all had the same struggles. Not one of them is like the perfect diabetic. They all have their off days and it just feels good to know that you're not the only one that has those issues, as well' 'It was more free. I felt like I didn't have to feel inferior, like I said before [...] because I was around the same type of people...same type of people as me'
	Enhanced self-confidence	I: 'Since you've been on the course, do you think you're any more open with others about your diabetes?' YP: 'Yeah. Become more confident, 'cause in the college where I go to now – 'cause I'm doing kind of like an active course, they have to know my medical stuff, so – it's not really a good idea not to say that I'm diabetic to anyone, so I've kind of got used to it now' I: 'After coming on the YES scheme, how do you think that's changed you, and your attitudes to your diabetes?' YP: 'I think it changed a lot, because other people around me was always taking their insulin and checking their blood sugars, so it kind of like encouraged me to do it, as well'
Experience of delivery mechanisms	Activation	'It made me more curious about medical stuff. For example, if someone was to have a hypo, and what should I do' 'I feel like listening to how other people's experiences and like attitudes towards it, the diabetes, and like when they inject and where they inject definitely gave me more confidence to just do it. And not like, just like if I need to inject, I'll just inject. Then and there, not try to like, remove myself'
	Social interaction	'it was helpful seeing other people's perspectives and how they deal with it. meet other people and see how they sort of cope with it and share tips'
	Peer support	'the chance that there would be people there around my age, similar age who would know how we felt about certain situations and how we dealt with it and it would give me a chance to make friends there who I could relate my diabetes experiences with' 'there'll be sessions on where you can describe how you're feeling with diabetes, you can talk, and you're mainly around people that's got the same thing as you, so you don't have to feel inferior about saying something you don't want to say around, like, your normal friends'
Social activities and games	Social media	'The WhatsApp group is really, really good 'cause everyone can talk on it and then we can receive messages as well' 'That's been perfect, really. It's just great that you just need to send one message and everyone will get it at the same time. if you're busy, you'll send it later and everyone will get it, so it's quite nice to have a group chat'
	Simulated learning	'Well the round table discussion was quite useful. Another one was where they had like an actor come in, who was like stimulating different, various, like, diabetes conditions, like hypo or hyper, and you had to like, in a group solve their problem, like (using) various techniques' 'There was one point where, if I'd high blood sugars – if it's really high – I used to take a lot of insulin at once, and it was – it turns out it was really dangerous, because I could have – anything could have happened [...] So, like, they had a role play there, as well, who was demonstrating what you should do' 'It made me realise how the doctors, nurses and my mum would feel looking after a patient with diabetes-something I've always taken for granted and never really have put into consideration'
	Youth worker	'I think, 'cause we played activities, as well, which sort of helped with the social side, and make, like, sort of friends, in a way...I still talk to one of the girls [on the course] sometimes [...] so playing the games sort of helped bring [us] out of the shell when doing the scenarios'
		'he generally contacted me through group Whatsapp... he's kind of like a mentor...Really helpful I mean, I'm just trying to find one person that I can kind of go to and explain my problems, and someone that will not judge me, and he's the person that does that he's given me suggestions and ways for me to step forward. He's been a massive motivator'

Table 4. (Continued)

Theme	Sub-themes	Participant excerpts
Ideas for optimising programme	Timing	<i>'I think either after school, around 4 or 5 o'clock would be sort of ideal, or during the summer'</i> <i>'It should be just after exams because I feel like no-one would want to do anything during exam season'</i> <i>'Starting later in the morning'</i>
	Attendance support	<i>'Probably, like, get a taxi again...which was more easier than wasting our time catching a bus'</i> <i>'May be like a YouTube advert...with young people doing it'</i>
	Programme content	<i>'I'd put more activities. Like – not like...I don't mind talking. Maybe replace a bit of the learning with something else'</i> <i>'More interactive activities'</i>
	Programme delivery	<i>'more younger speakers'</i>
	Environment	<i>'the room was OK, but I feel like we needed more space, because we was in there for a long time...somewhere that's like a big space but also has an outside. So you could go and get a bit of air'</i>

this population have often failed to show clinical benefit.^{11,13} The clinical effect observed in our study was larger than that reported in a recent pilot study ($n = 65$) of structured education for young people, which focussed on teaching technical diabetes skills in a youth-friendly setting.¹² In this study, the 12 month follow-up showed a mean reduction in HbA1c of 5.98 mmol/L (0.54%), with an effect size of 0.26 (Cohen's d) compared to the reduction of 8.2 mmol/L (0.7%) with an effect size of 0.33 (Cohen's d) observed in our study. An increase in incidences of hypoglycaemia was also observed after attending YES, which could be a result of participants being more activated in terms of diabetes management, hence taking more insulin and thereby increasing the potential for hypoglycaemia.

Whilst the effects observed in pilot studies must be viewed with caution, the data from an ongoing audit of the YES programme show that this effect has been replicated in future occurrences of the programme. A recent YES audit with 12-month follow-up data ($n = 49$), with pre-programme 12-month mean HbA1c as a baseline showed that mean HbA1c reduced by 7.8 mmol/L (0.7%) and 7.5 mmol/L (0.69%) at 6 and 12 months, respectively ($P < 0.01$). The qualitative data from the study revealed that the programme may also have beneficial effects on psychological and social well-being, such as reduced emotional distress and social isolation and improved diabetes self-identification and self-confidence. These psychosocial effects may help explain the clinical effect, as studies have shown associations between psychosocial factors, self-management performance and diabetes outcomes.^{21,22} The results of this pilot intervention study suggest that psychologically modelled education programmes with a social learning focus may provide an alternative to traditional models of structured education that emphasise teaching diabetes technical skills. This would need to be confirmed in a definitive trial comparing YES with a traditional education programme.

The intervention components of the YES programme included some novel elements, which need to be further

considered. A key feature of the programme was the use of an outreach youth worker to identify and engage the young people in the programme. There are limited data on the use of outreach youth workers in T1DM. One recent small cohort study showed that receiving support from a youth worker for 6 months reduced HbA1c by 11.4 mmol/mol (1.04%) at follow-up in 20 adolescents.²³ The youth worker's role in YES helped to sustain peer relationships within the group and potentially contributed to the high level of participation from ethnic minority groups. This is important, as such groups are at higher risk of disengagement from care and acute complications such as DKA.^{4,24} Another novel component of the programme was the use of simulated learning experiences. Whilst group-based simulated learning is often used in the education of health professionals, its application in patient education has been limited. The results of one recent trial assessing a problem-solving approach for adolescents with T1DM ($n = 53$) showed a significant increase in self-management behaviours and a reduction in HbA1c (6.6 mmol/mol [0.6%]) in those in the problem-solving arm of the study.²⁵ The YES simulations incorporate the DIAMOND debriefing tool,²⁶ which gets the participant to explore the feelings and beliefs that drive their behaviours in the scenarios, so they can consider how to constructively adapt their behaviours. Therefore, considering simulation and problem-solving methods might be useful for future education programmes for younger people.²⁷

The study findings have also provided some valuable suggestions for improving recruitment to future studies. Previous studies have shown that engaging this population in diabetes care or education can be challenging, and young people cite reasons such as 'Had other things to do', 'No time', 'Could not get time off school/college or work', 'Learnt about diabetes from other sources' or 'Feel able to cope on own' for not participating.^{28,29} Suggestions from participants for improving uptake included using social media and/or

videos of the group in action. Participants also emphasised the need to consider school term times, exams and holidays when scheduling the programme. A recent survey of young people to identify factors that increase diabetes education uptake reported the need for pre-programme information and flexible times with local accessibility and shorter course duration.²⁸ Optimal delivery of YES is considered on an ongoing basis, including possible digital delivery of the programme.

Study limitations

It is important to emphasise that this was an evaluation; hence, whilst we have observed a moderate and sustained improvement in HbA1c, in the absence of a control group, we have to interpret that effect with caution. The observed effect may also have been amplified by the relatively high baseline HbA1c levels in the sample, although it should be noted that the average HbA1c level for young people aged 15–19 years in the UK is 75.5 mmol/mol (9.1%). It should also be noted that the YES programme has multiple modalities, as with most complex interventions. Therefore, it is challenging in a small-scale study to isolate the individual effects of any given element of the programme, although some perspectives on the different programme elements were represented in the qualitative data. Finally, it is important to acknowledge that the study did not adequately measure the impact of the programme on the psychosocial functioning. Given that the YES programme aims to mediate this function, this was a missed opportunity. In a future study, we are proposing to use standardised measures targeting behavioural, emotional and psychological constructs. However, this shortcoming was partially ameliorated by the qualitative data, which provided an in-depth insight into how the programme affected the psychological and social functioning of the participants in a way that standardised measure would not have captured.

Conclusions

In conclusion, the central message from our evaluation is that young people want to learn how to live with diabetes positively as much as learning diabetes-specific skills and knowledge. This approach seems to have impacted positively on the psychological and social orientations of the participants. This study has helped us to model the active ingredients in the YES intervention, emphasising the importance of the outreach youth work role, the social context of learning and the use of learning simulations. Overall, the YES programme, which was co-designed with young people, shows encouraging clinical outcomes that will be considered in a larger study with more specific psychosocial measures.

Data availability

Any requests for anonymous source data will be welcome and should be directed to the corresponding author.

Conflict of interest and funding

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