



Children's and young People's diabetes services: What works well and what doesn't?

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ABSTRACT

Objectives: The first year of care, post diagnosis, is pivotal for children and young people diagnosed with type 1 diabetes. This study evaluated a paediatric type 1 diabetes intervention, the 'First Year of Care', designed to maximise the care that newly diagnosed children and young people received.

Study design: An observational mixed methods approach, underpinned by the Influencer Framework.

Methods: A purposeful, non-probability sample of children and young people with type 1 diabetes and their families, and healthcare professionals were invited to take part. Data were collected through medical records of thirty-two newly diagnosed children and young people, plus thirty seven semi-structured interviews and exposure to six concurrent sources of influence through a questionnaire.

Results: For many participants, HbA1c levels were within the optimal range by the time of their first clinic visit post-diagnosis and continued to stay within this range throughout the first year of care. Healthcare professionals prioritised the 'First Year of Care' intervention. Positive practices included: a cohesive and collaborative approach; patient-centred care; latest health technology and embedded structured education. Unusually, different multidisciplinary team members were located in one place.

Data indicated statistically significant differences in total sources of influence score ($t [35] = 2.331, p = 0.026$); healthcare professionals' scores were higher compared to children. This suggests that children and young people have less social capital to self-manage their diabetes effectively. Greater encouragement and assistance from healthcare professionals and social networks may be needed.

Conclusions: This paper identifies contemporary issues in practice and highlights the strengths and challenges for a paediatric diabetes intervention. The findings confirm the potential of layered approaches to behaviour change in managing type 1 diabetes across multiple domains of influence. Our study strongly suggests enhancing social motivation among children, young people and families to support successful long-term engagement in a paediatric diabetes intervention. Findings demonstrate healthcare professionals are key in delivering the intervention, along with opportunities to improve patient care, experience and outcomes.

1. Introduction

Early and intensive blood glucose control is now recognised as the gold standard for people with type 1 diabetes (T1DM), helping them to live healthier and longer lives. Two major research programmes, the Diabetes Control and Complications Trial (DCCT) and the follow-up study, Epidemiology of Diabetes Interventions and Complications

(EDIC), demonstrate that early metabolic control, achieved through intensive diabetes therapy, reduces the subsequent development and progression of long-term complications associated with T1DM, and mortality [1,2]. Evidence from both studies indicate that effective diabetes management in childhood tracks into adulthood [3]. Further, public health guidance recommends offering children and young people with diabetes and their families (CYPF) an ongoing integrated package

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of care provided by a multidisciplinary paediatric diabetes team [4].

Recognising the importance of early metabolic control and integrated care, the diabetes team in the Children’s and Young People’s Diabetes Service at St James’s University Hospital, Leeds, located in England, developed an intervention known as the ‘First Year of Care’, designed to maximise the care that CYPF received during their first year following diagnosis and to improve diabetes outcomes. At the same time as intervention development, the National Institute for Health and Care Excellence (NICE) introduced new guidelines recommending a HbA1c target level of 48 mmol/mol or lower, rather than the previous 58 mmol/mol, as ideal to minimise the impact of T1DM on the future health of children and young people (CYP) [4]. These revised recommendations were incorporated in the intervention.

The authors were commissioned by the Children’s and Young People’s Diabetes Service at St James’s University Hospital to conduct an evaluation of the ‘First Year of Care’ intervention. The importance of thoroughly evaluating interventions is widely recognised [5]. Evaluation includes not only the impact, but also the process of implementation. This means highlighting what works well, identifying which parts of the intervention work less well and the reasons for this and what needs to be done to improve the intervention. The aim of this study was to evaluate the intervention, with a focus on: (I) experiences of care from the perspective of CYPF, concentrating on those within one year of diagnosis and to investigate what CYPF wanted in respect of their care in the first year and in the future and (II) experiences of healthcare professionals (HCPs) and other members of the diabetes team, in respect of the ‘First Year of Care’ intervention.

2. Methods

2.1. The intervention

The ‘First Year of Care’ intervention consisted of the following: (i) educating and training the children’s diabetes team to deliver as appropriate, the CYP T1DM Model of Care, a new model adapted from the German Model of Care and regarded as one of the global ‘gold standards’ of care for CYP with T1DM [6,7]; (ii) adherence to the Best Practice Tariff, which incorporated predetermined criteria that addressed all aspects of high quality care, including providing a tailored, structured education programme [8]; (iii) the adaptation of the ‘Goals of diabetes education’ programme [9], aligned to the latest guidelines [4] and designed to facilitate patient-centred learning and enable CYP to gradually take control of their diabetes and (iv) the utilisation of Dig-iBete [10], a digital platform designed to facilitate T1DM self-management education amongst CYPF.

2.2. Design and overarching evaluation framework

The evaluation aimed to evaluate the ‘First Year of Care’ intervention received by CYP diagnosed with T1DM between April 1, 2017 and the March 31, 2018. As part of this, and to meet the overall aim, the objectives for this work were:

1. To collect quantitative data on CYP with T1DM within one year of diagnosis;
2. To investigate children’s, young people’s, families’ and professionals’ qualitative experiences of current provision and education tools during the first year of care following diagnosis;
3. To evaluate the care provision for those CYPF with T1DM within one year of diagnosis.

In facilitating evaluations, there has been a call for using an approach that embraces a holistic and social-ecological perspective when designing, implementing and evaluating interventions [11]. With this in mind, the evaluation was underpinned by the Influencer Framework, which was used to shape the instrumentation and processes for the

collection, analysis and interpretation of data, as per previous evaluations of community health improvement programmes [12]. The Influencer Framework suggests that intervention success is influenced by design, implementation and the host system [13]. Therefore, even for simple initiatives, interactions resulting from the key agents in these systems can be highly complex. Understanding how they work in practice is vital to building a functional evidence base that can enhance practicality and the likelihood of translating the research findings into practice. Nevertheless, practitioners have few, if any, methods to assess the integration and implementation of such work into routine practice [14,15]. Equally, evaluators and researchers need designs and practical solutions to assess influence across the necessary constituent parts [5].

The Influencer Framework facilitates the needs of both these groups. The framework proposes that behaviour is influenced by changing motivation and ability across three layers, leaving six areas of influence (personal motivation, personal ability, social motivation, social ability, system motivation [see Fig. 1] and system ability) [16]. It seeks to clarify measurable results and find preferred approaches, while confirming the scale of influence of its six respective domains. Importantly, the framework relies on the concept of ‘over determining change’, which entails on-going prevention of relapse and/or dropout. Fundamentally, because of the risk of falling engagement, programme success relies on sustaining the most powerful individual, combined and sequential influences on behaviour, even when they may not seem necessary [17].

2.3. Instrumentation and sampling

In this evaluation, data was collected using three approaches: (i) by accessing the medical records of CYP diagnosed with T1DM between April 1, 2017 and the March 31, 2018 through the Diabetes Management System (DMS). This provided the baseline information relating to demographics, HbA1c levels, diagnosis and other clinical measures, needed to evaluate the intervention; (ii) a brief questionnaire completed by a sample of CYPF and the diabetes team working in the Children’s and Young People’s Diabetes Service at St James’s University Hospital, the purpose of which was to explore the degree to which the intervention would be integrated into routine behaviour and practice and (iii) semi-structured interviews with a sample of newly diagnosed CYPF and members of the diabetes team to investigate strengths and weaknesses of intervention delivery, in order to enable recommendations to be made regarding refinement of the intervention.

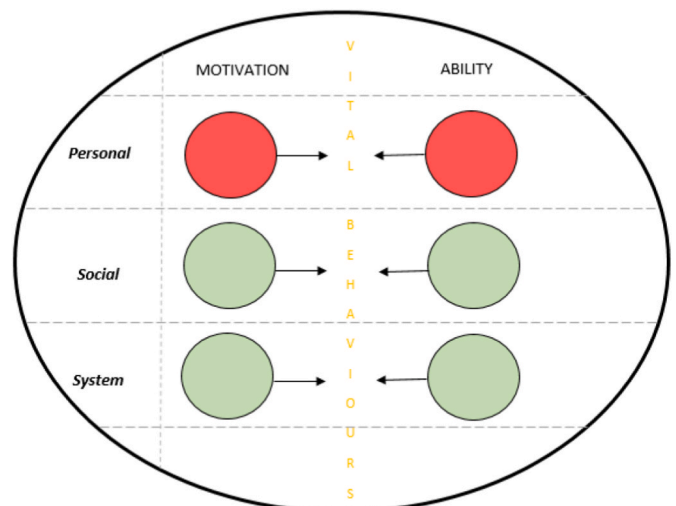


Fig. 1. The Six Sources of Influence Adapted from Grenny et al. (16).

2.4. Participants

Following Research and Development approval for the evaluation from Leeds Teaching Hospitals NHS Trust and ethical approval from Leeds Beckett University research ethics committee, potential participants were invited to participate in the evaluation by letter sent by post. All participants were provided with an information sheet which highlighted the voluntary nature of participating in the evaluation alongside assurances of confidentiality and anonymity. Prior to formally engaging in the evaluation, participants were required to provide informed consent and were made aware that they could withdraw at any time without giving a reason and informed how they could withdraw.

2.5. Data collection and analysis

2.5.1. Quantitative data

The medical records of CYP provided baseline and follow-up data to assess the impact of the 'First Year of Care' intervention. The questionnaire contained demographic questions and a modified 12-item Sources of Influence (SOI) questionnaire to assess perspectives on motivation and competencies across three powerful behavioural domains (9). Two questions addressed each domain, scoring responses 1 (Strongly Disagree) to 5 (Strongly Agree). SOI items have positive phrasing, meaning that high scores indicated strong coverage of a theme; these were scored (i) individually, (ii) socially, (iii) structurally and (iv) overall. Descriptive statistics were used to describe information from the DMS and responses from the short SOI questionnaire. In addition to generating descriptive statistics, inferential analyses were conducted (where appropriate) to explore the relationship between variables of interest. For all inferential tests, a p value of < 0.05 was taken to be statistically significant. All quantitative analyses were undertaken using IBM SPSS Statistics v24.

2.5.2. Qualitative data

The topic schedule for the semi-structured interviews was developed to sit alongside the survey around the Influencer Framework and included the same topic areas for the CYPF and HCPs and members of the diabetes team. Semi-structured interviews were digitally recorded and transcribed verbatim and participants were given pseudonyms. The semi-structured interviews were used to explore participants' experiences of the intervention, in particular, in-depth accounts of the barriers and facilitators that CYPF faced when adopting health enhancing behaviours [18] and HCPs faced when promoting lifestyle behaviours with CYP with diabetes [19]. Please see the results for more details. All data were primary-coded in relation to the SOI framework by looking at both the semantic and latent content of the data; that is, considering both the surface and deeper meaning within the accounts given [20]. This coded data was then collated into potential themes. The researchers then met to refine the specifics of each theme and an initial thematic framework was generated. Throughout this and the writing process, the coding, collating and refining of themes occurred with reference to previous conceptual and empirical work in an iterative way.

3. Results

3.1. Quantitative data

3.1.1. Participants medical records

There were $N = 32$ CYP diagnosed with T1DM between April 1, 2017 and the March 31, 2018 at the diabetes service. Among this sample, there were an equal proportion of boys and girls and the average age was 10.4 (± 3.84) years, ranging between 4.3 and 18.2 years. Boy's average age at diagnosis was 9.2 years compared to 11.7 years for girls. In terms of ethnicity, data were obtained for $n = 24$ participants, of these, 70.8% were white British and the next largest ethnic group was Pakistani which accounted for 12.5% of respondents.

Overall, the average HbA1c value at diagnosis was 104.6 mmol/mol (± 22.63), and values ranged from 48 mmol/mol to 149 mmol/mol. The average blood ketone value at diagnosis was 3.1 mmol/L (± 2.45), and values ranged from 0.1 mmol/L to 6.4 mmol/L. There were 59.1% ($n = 13/22$) who presented with values above 3 mmol/L, suggesting that they required emergency medical treatment. For most CYP, their HbA1c levels at diagnosis were outside the optimal range (see Fig. 2). However, for many, their HbA1c levels were within the optimal range by the time of their first clinic visit post-diagnosis and continued to stay within this range at subsequent visits. For those CYP who were outside this optimal range for most of their pathway, other complications with their general health were, in part, attributed to irregular HbA1c values.

In relation to education around diabetes for newly diagnosed CYP, 49 sessions were listed on DMS. On average, this sample had undertaken and completed 17.4 (± 8.27) educational sessions since diagnosis, ranging from 2 to 33. 'Explanation of diabetes' (78.1%, $n = 25/32$) and 'Monitoring and AGP (Ambulatory Glucose Profile)'; taking control: Blood glucose targets' (78.1%, $n = 25/32$) were the two most frequently recorded educational sessions. 'Introduction to the team and philosophy of care', 'Injections: Timing – MDI (Multiple Daily Injections)', 'Monitoring and AGP; taking control: Technique', were the next most frequently recorded sessions (68.8% $n = 22/32$). Social support is likely to play a large part in living functionally with T1DM. For CYP, outside of the family environment, schools provided a great opportunity for support. In terms of education recorded in relation to support, schools were contacted for 34.4% of children ($n = 11/32$), school care plans were agreed for 12.5% ($n = 4/32$), school update reviews for 6.3% ($n = 2/32$) and other support, such as Diabetes UK (DUK) and Juvenile Diabetes Research Foundation (JDRF) local support for 15.6% ($n = 5/32$).

3.1.2. SOI questionnaire

In total, $N = 37$ CYPF and HCPs completed the SOI questionnaire and were interviewed. Regarding the newly diagnosed CYPF who were surveyed and interviewed, the total sample was $N = 19$, of which there were 14 parents and 5 children or young people from twelve different families. In relation to the $n = 18$ HCPs at the Children's and Young People's Diabetes Service that were surveyed and interviewed, 94.7% were female; the average age was 39 (± 10.4) years and average length of service was over 9 years. In addition, 78% of HCPs were educated to degree level or higher. Nurses (47%), doctors (21%) and dietitians (16%) were the most common job roles. This suggests that these participants were highly educated and experienced in the field of T1DM.

Table 1 shows participants mean scores on the SOI questionnaire. From a maximum of 60, the average score for all participants was 50.16 (± 4.20). Data indicated statistically significant differences in total SOI score (t [35] = 2.331, $p = 0.026$), with HCPs reporting higher scores compared to CYPF. Total scores comprised values of 17.70 (± 1.19) at the personal level, 16.68 (± 2.29) at the social level and 15.78 (± 2.24) at the system level. HCPs scored higher at all three levels compared to CYPF and there were statistically significant differences in scores at the social level (t [35] = 2.595, $p = 0.014$). Motivation scores (26.03 \pm 2.42) were higher than ability scores (24.14 \pm 2.25) for all participants, with motivation being significantly higher in HCPs compared to CYPF (t [35] = 2.556, $p = 0.015$). Across all six SOI's, HCPs scored higher than CYPF, yet, social motivation was the only layer where there was a statistically significant difference (t [35] = 2.844, $p = 0.007$). System motivation was the lowest scoring item for all participants and by HCPs and CYPF, while personal motivation was the highest scoring item.

3.2. Qualitative data

Qualitative data was focused on implementation characteristics and aligned to the domains of the Influencer Framework (personal motivation, personal ability, social motivation, social ability, system motivation and system ability).

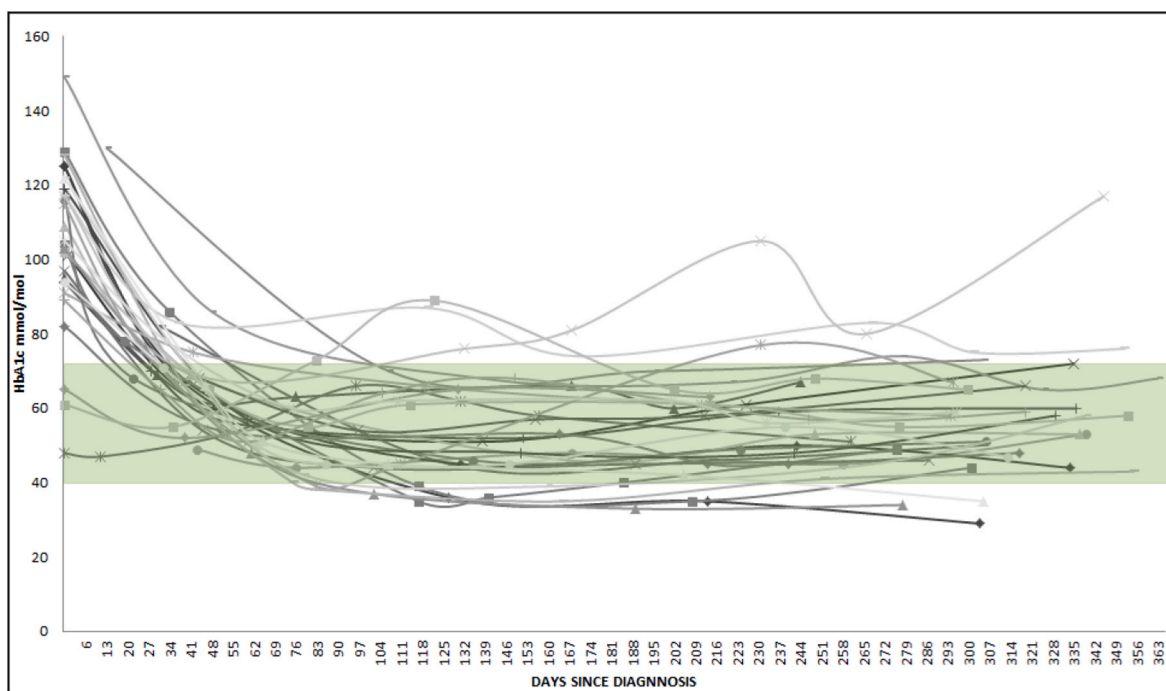


Fig. 2. HbA1c levels at diagnosis and subsequent clinic visits during the first year of care.

Table 1
Mean source of influence (SOI) scores.

Sources of Influence	All (N=37)	HCPs (n=18)	Families (n=19)
Personal Level	17.70 (±1.19)	17.89 (±1.02)	17.53 (±1.35)
Personal Motivation	9.89 (±0.39)	10.00 (±0.00)	9.79 (±0.53)
Personal Ability	7.81 (±1.15)	7.89 (±1.02)	7.74 (±1.28)
Social Level	16.68 (±2.29)*	17.61 (±1.85)	15.79 (±0.59)
Social Motivation	8.54 (±1.43)*	9.17 (±1.09)	7.95 (±1.47)
Social Ability	8.14 (±1.08)	8.44 (±0.98)	7.84 (±1.12)
System Level	15.78 (±2.44)	16.22 (±1.70)	15.37 (±2.97)
System Motivation	7.59 (±1.52)	7.83 (±1.15)	7.37 (±1.80)
System Ability	8.19 (±1.08)	8.39 (±0.77)	8.00 (±1.29)
SOI TOTAL	50.16 (±4.20)*	51.72 (±3.41)	48.68 (±4.42)

Note: * = Statistically significant difference between HCPs and CYPF ($p < 0.05$).

3.2.1. Interviews with CYPF

3.2.1.1. Initial hospital admission. CYPF really valued the time spent in hospital following diagnosis and the support they received from the HCPs, which included both the ward staff and members of the diabetes team. They appreciated being able to remain in hospital for as long as they needed and were reassured by the HCPs knowledge and proficient approach,

“They were absolutely amazing, I was blown away, they were just phenomenal ... it’s like they scaffolded around us.” (A24)

However, CYPF said there needed to be more of a structure to the hospital stay, so they knew what would be done in the time they were there, who would be visiting and when,

“I think a structured week when you’re in hospital would be better ... ‘This is what’s going to happen over the course of the week’ would be quite useful ... whereas you didn’t quite know who was going to rock up which day and when they were coming.” (A26)

CYPF were reluctant to say anything negative about the time around diagnosis and were keen to point out that any criticisms were only minor ones. One criticism related to CYPF experiences of weekend hospital admissions and the absence of diabetes specialists on a weekend. For those children and young people who were diagnosed on a weekend, CYPF emphasised the importance of seeing a diabetes specialist at the time rather than having to wait until the Monday,

“Going to hospital on a weekend, there are no specialists ... so the first time we met someone from the diabetes team was on the Monday, yet she was diagnosed on the Friday. It would have made a massive difference actually seeing someone from the diabetes team on that first weekend ... When the care kicked in, it was great, but it was just a shame it didn’t kick in a couple of days earlier.” (A26)

3.2.1.2. Information. When asked about the information they were given following diagnosis all CYPF were keen to emphasise that they were able to contact HCPs whenever they needed information and in particular, CYPF liked the inclusive approach adopted by the HCPs. Children, young people and parents/carers were involved in the information sharing process,

“X went over what was happening really slowly, to make sure we all actually got it and not just one of us, so rather than just making sure I’d understood it and then moving on, she made sure my parents understood it as well, in case I’d forgotten something by the next day.” (A1)

3.2.1.3. Continuing care. CYPF appreciated that they were able to see different HCP specialists (consultants, nurses, etc.) in a single clinic appointment. However, they stated there were often too many people in the room at the same time, which could be overwhelming,

“You know, it feels ... I don’t want to say over the top, but you know when you walk in and there’s a full team. I wonder if that’s a bit of what puts X off.” (A19)

CYPF wondered whether children and young people would engage more in clinics if they were structured around them and organised

differently, perhaps in an environment that was less clinical and more attractive to children and young people,

“An idea I had was actually if every other clinic or something was maybe a bit of group work with other children ... rather than focused all on the HbA1c ... I was wondering, would X engage more if clinics were delivered in a potentially different way?” (A19)

In terms of their scheduled clinic appointments, CYPF valued having an appointment within the first month of diagnosis,

“We had it (clinic) monthly to start with, that was really helpful ... the set-up does feel reassuring, it feels we are in a cared community.” (A28)

3.2.1.4. Technology. Many CYPF felt extremely fortunate to be under the care of the Children’s and Young People’s Diabetes Service at St James’s University Hospital, mainly because they thought the team were technology-focussed and HCPs actively promoted technology as a means of managing diabetes. This made CYPF feel that they were in receipt of the best care possible,

“The fact that you know in Leeds there is more advancement in the technology and in the options you’ve got ... that instils confidence in X’s treatment, because you know that they’re at the forefront of what’s going on.” (A19)

CYPF reported the benefits of technology in terms of T1DM self-management. Many stated they felt more in control and better able to manage the condition. In many cases, a pump and/or a continuous glucose monitor represented a game-changer in terms of improved T1DM self-management and wellbeing.

Support. CYPF highlighted the importance of support for mental and emotional health and access to a psychologist. Some CYPF were aware of the psychologists within the team and stated that it was good to know the psychologists were there should they need them. Other CYPF thought that little, if any, mention was made of the psychologists and the type of care they could provide. To raise awareness of the psychological expertise within the team, CYPF thought that introducing the psychologist at diagnosis might be something that the team could consider,

“More psychological help in the hospital ... I’m glad that I saw on the back of the book that we were given that there was a psychologist in the team. But they didn’t come to us in the first week. She said ‘Oh, we don’t, because it’s a lot of information to take in in that first week and it can overload.’ Maybe they could take that on a case by case.” (A31)

Children and young people spoke about the type of support they needed. They stated that it would help if HCPs were able to put them in touch with other children and young people with T1DM within the first few months following diagnosis,

“I really think it would help if maybe they could get an ex-patient or someone to come in, just someone who is diabetic, who doesn’t mind talking about it ... Because it’s one thing talking to doctors, they’ll help you but they’re not going through it. And when you’re talking to someone who is, it’s a bit easier.” (A4)

3.2.2. Interviews with HCPs

3.2.2.1. Glycaemic control. The key message to emerge from all the HCPs was to enable CYPF to feel confident enough to self-manage their T1DM and make appropriate changes to achieve better glycaemic control. The ‘First Year of Care’ intervention was regarded as crucial for this, with all the diabetes team focusing their efforts on achieving the recommended HbA1c target for all children and young people,

“The target being 48 mmol/mol now ... I guess we want more of our young people to achieve that target at 12 months ... We know we can influence these children and young people at the point of diagnosis ... set these children and young people off on the right foot and if we can help them achieve excellent control in that time, that should stand them in good stead moving forward.” (P12)

3.2.2.2. Hospital admission. Strategies for optimising glycaemic control in the first year, together with processes to guide HCPs in operationalising the ‘First Year of Care’ intervention, were in place. These included an extended time in hospital at diagnosis. This was typically four or five days, but could be longer if a child or young person were admitted at a weekend or if they were unwell. During the hospital admission, the HCPs were able to provide tailored support from the different professional disciplines, i.e. nursing, dietetics, etc., and give CYPF the time they needed to adjust to their T1DM diagnosis and be well enough to start T1DM education,

“I do think if a child is very unwell and they go high dependency, then actually sometimes that takes precedent. And the discussion about the diabetes can wait, because the child needs to be on the mend a little bit before families are open to hearing about what diabetes is, what happens, etc. So, it’s more about the experience of feeling safe, that the child is in good hands, that the people, whoever it is looking after them, are competent and know what they’re doing and that they know what will happen next.” (P10)

If a child or young person was admitted at the end of a week, for example, a Friday, HCPs relied on ward staff to provide the support and begin delivering the diabetes education. Whilst ward staff were appropriately trained, HCPs acknowledged that CYPF might have specific questions for a diabetes nurse specialist and yet, they probably would not see someone until after the weekend,

“Not seeing them Saturday and Sunday after we started their education ... I sometimes just feel that those two days are opportunities missed, where maybe if they’d had the education, that they could do that practice over the weekend and come back, and I’d see them on Monday ‘How did that go?’ So I think it can delay discharge.” (P6)

3.2.2.3. Structured education programme. A ‘First Year of Care’ intervention timeline had been developed by the diabetes team to guide them in their delivery of care throughout the first year. This included a structured education programme detailing the different topics to be covered with the CYPF at diagnosis, 1–2 weeks after diagnosis, 1 month after diagnosis, etc. The main change initiated by the ‘First Year of Care’ intervention was an increase in the frequency of outpatient clinics (once a month for the first three months), providing more opportunities for CYPF to meet with the multidisciplinary team (MDT) and for the HCPs to monitor more closely CYPF T1DM management. The written plan provided a structure for the HCPs indicating what HCPs needed to say and do, and when, ensuring consistency across the team. HCPs felt this was important for both them as a team and for CYPF,

“I think for new families, it’s really important to hear from us similar messages across the team, and a team that works well together gives people confidence that they’re being held by a safe space.” (P16)

3.2.2.4. Individualised, holistic care. HCPs recognised that the information they delivered as part of the structured education programme and lesson plans was different depending on the individual child, young person and family,

“It’s finding that balance, isn’t it? They’ve got to know enough to manage at home for them to go home, but you don’t want to make them feel snowed under and they can’t remember anything. And

that's tricky, I don't think you can say 'this is the right way to do it' because it's going to vary, depending on each family, really." (P9)

In addition, HCPs recognised the importance of holistic care and the many contributory factors affecting an individual's ability to manage their T1DM and to achieving good glycaemic control. All the team were clearly patient-centred and focused on treating CYPF holistically,

"I think we try and consider all the different angles and aspects of their lives and see how it's going to fit in, and try and adapt it and individualise it, rather than just saying 'right, this is what we're telling everybody' and doing it the same for everybody." (P1)

One factor that all the HCPs thought contributed towards a holistic way of working was the Diabetes Centre environment. Everyone, including consultants, nurses, dietitians, psychologists, youth worker, secretaries and clerks were physically located in the same place. This facilitated communication and enabled HCPs to have informal conversations with one another and respond more quickly to CYPF questions,

"I think it's really helpful, actually, to be in one place, in the same environment, so that team working ethos is promoted just by being in proximity with each other, because we can communicate much more easily, we can talk about patients ... I think it's easier to individualise the care because of that as well." (P12)

The individualised approach to care was further enhanced by the secretaries and clerks, who were regarded as indispensable members of the team,

"That consistency with the admin people is as important as the clinical people ... It's not like they're coming to the hospital once and they're never coming again. They're coming for years. And so that consistency with everybody goes a long way to making it run smoothly and giving people a better experience." (P3)

3.2.2.5. Continuing care. Regular outpatient clinics, home visits and various means of communication between HCPs and CYPF, for example texts, emails, etc., formed the basis of the 'First Year of Care' intervention once children and young people were discharged from hospital. HCPs referred to the balance of care and the type of relationship established between the diabetes team and CYPF. HCPs made a huge effort to get to know their CYPF, making themselves available and working with them to manage a child's or young person's T1DM. Equally, HCPs stressed the importance of individual responsibility and CYPF being proactive in their continued care. In providing the tools and knowledge to be able to manage T1DM, HCPs emphasised their expectation was that CYPF would eventually feel confident to self-manage and make the necessary changes to their care,

"We have to be being quite careful that we don't hold all the responsibility for diabetes management and that we support families for them to hold it and that we will always be there for that support and advice, but to help them build the skills, that they are the ones managing their condition confidently." (P16)

3.2.2.6. Technology/resources. Everyone in the diabetes team commented on the forward-thinking ethos of the team and their willingness to try more intense treatments quickly, for example, different pumps and glucose monitoring systems,

"Everyone is really keen on updating themselves in new technologies and new ways to manage and then feeding that back to families. We're also quite good if we have got a family who comes in with something new to ask them for feedback on it. We don't shy away from it." (P2)

HCPs used a variety of paper and online resources with CYPF, for example, Ready Steady Go [21] and DigiBete, as well as structured

education programmes such as WICKED [22]. In addition, HCPs provided regular training for ward staff and in-house workshops for school staff. Having access to a portfolio of different resources as part of the 'First Year of Care' intervention was helpful, in particular if a resource contained lots of visual information. HCPs said that this was helpful for CYPF, especially for those who did not speak English as their first language,

"The DigiBete website of late has been of great benefit to do visuals. Because even if you turn the sound off and get families to just watch the actions, it actually is really helpful to demonstrate, watch it, and then we do it." (P13)

HCPs referred to their frustrations regarding technology, in particular their inability to show CYPF online information on the ward at diagnosis because of the hospital firewall. Even when they could access information, typically online videos, these took a long time to download because of the slow broadband speed. In addition, HCPs reported they would like more laptops or tablets to be available in the Diabetes Centre for HCPs to use. Not having routine access to technology was a hindrance for many HCPs.

3.2.2.7. Psychology. Increasingly, psychology was becoming an integrated component of care in the first year following diagnosis, with psychologists having allocated time to work as part of the diabetes team. Generally, they met CYPF for the first time in their initial clinic appointments, rather than as an in-patient at diagnosis. There was no set way of working for the 'First Year of Care' intervention and the psychologists tried to be as flexible as possible to meet the individual needs of CYPF. They saw people on a one-to-one basis and offered informal group sessions to break down any barriers CYPF had relating to the stigma associated with psychology and mental health,

"I think where we're at now is we've got the right psychology level of input, that resource, here, in terms of qualified psychology time, and I think we can offer a really accessible and flexible service. And that's really rare in the psychology world, to be able to do it, because there are massive ... months and months' waiting lists are the norm." (P5)

4. Discussion

This study evaluated a paediatric T1DM intervention designed to maximise the care that newly diagnosed children and young people received. Key findings demonstrate that HCPs focused on the 'First Year of Care' intervention as a priority, ensuring that continual improvements were made to the care that newly diagnosed CYPF received. CYPF and HCP identified what worked well (MDT located in a central physical location, holistic needs-led approach and structured education programme). However, recognising that there are always further improvements to be made, the CYPF, as well as HCPs and members of the diabetes team, highlighted certain aspects of the 'First Year of Care' intervention that needed to be addressed. For example, the CYPF social networks were less developed, and IT infrastructure, processes and systems to support patient care and CYPF access to out-of-hours services, all needed refining. Public health guidance recommends an evaluation of diabetes services in order to support service improvement and better outcomes for patients [23]. These outcomes illustrate the basis for service refinement and our evaluation methodology provides insight as to how these outcomes can be implemented in real world settings.

Key results from the SOI questionnaire pointed towards potential areas for improvement. Importantly, HCPs scores at all levels of the influencer model, across motivation and ability, were significantly higher compared to CYPF. This suggests that care needs to be exercised so as not to assume that motivation and ability is the same for both groups, especially at the social level. At present, some CYPF appear to lack positive networks and relationships that enable them to function

effectively and thrive, i.e. social capital. Therefore, the persuasive power of those who make up the social networks of CYPF and HCPs at Leeds Children's and Young Peoples Diabetes Service should not be ignored. It is likely that encouragement and assistance from CYPF social networks, including wider family and schools, could be improved. Thinking about the implications for practice emerging from this study, training is needed for HCPs that helps to increase their awareness of this variation in social capital, as well as the powerful influence that HCP can have on CYPF. Further, with social networks in mind, training for HCP could offer suggestions for how social capital can be developed through CYPF networks as well as sign posting to peer mentoring programmes and supportive technology that facilitate social interaction and connectivity around T1DM. Research investigating the implementation of the DigiBete app, a mobile and web-based software application for CYPF with T1DM, identified the role of the app in developing supportive social networks [24].

Unsurprisingly, CYPF reported challenges with the initial admission relating to (i) the lack of communication and accessibility to specialist doctors at weekends and (ii) a lack of structure and information regarding what they could expect once on the ward. However, research indicates that access to diabetes HCPs out-of-hours could support patients by providing timely assistance and determining the requirement for, and potentially preventing unnecessary, hospital presentations [25]. Government guidance has highlighted the supportive role that technology can play in supporting CYP with T1DM [26], and recommends that CYPF or carers have 24-h access to advice from their diabetes team [27]. With those thoughts in mind, technology which provides timely advice and guidance to CYPF, including what to do in an emergency and at weekends and evenings when access to services is more limited is vital. Furthermore, app based interventions have been reported as being helpful in supporting CYPF during the COVID-19 pandemic, resulting in changes to the way CYPF accessed health services [24].

As far as continuing care was concerned, CYPF commented on their good fortune to be cared for within a service that adopted a cohesive and collaborative approach, embracing the latest health technology and resources in a way that was tailored to individual CYPF. We encountered CYPF who, as a result of technology and access to online resources, for example, DigiBete [10,24], felt more in control and better able to manage their/their children's condition, which resulted in improved T1DM self-management and wellbeing.

This is confirmed in existing research where the use of technology, for example, continuous glucose monitoring, is associated with a significant reduction in HbA1c in children and young people [28]. HCPs reported being proactive when embracing technology and online resources in diabetes management [24,29], helped by a well-established programme of staff training to support HCPs in their delivery. However, many HCPs reported the need for better IT availability and system capability in order to use resources without being impacted by infrastructure issues, including security restrictions and broadband speeds. Findings show the importance of regular and ongoing investment in IT hardware, processes and infrastructure in order to help HCP secure good outcomes for CYPF [30]. Further ongoing training and education to help HCP is an important practice implication as far as making use of the supportive technology.

A structured education programme was an integral component of CYPF continuing diabetes care. HCPs reported that the information they delivered as part of the structured education programme and lesson plans was different depending on the individual child, young person and family. Indeed, a number of CYPF stated that this patient-centred education had helped them engage in preventative and health enhancing practices. The NICE guidance recommends that children and young people with diabetes are offered an ongoing integrated package of care, provided by a multidisciplinary paediatric diabetes team. Confirmation of this is provided in the literature where working practices that are patient-centred, inclusive and multidisciplinary in style are recommended for improving health outcomes [31]. Furthermore, HCPs

provided resources to CYPF where English was not their first language. This resonates with existing guidance, which again recommends that HCPs consider the individual needs of CYPF when delivering diabetes management services [4].

In addition to a patient-centred approach, the importance of the whole or MDT, as an integral aspect for managing chronic diseases, has been endorsed in policy guidance provided by the Department of Health [32]. The service that we evaluated adopted such an approach with a range of experts supporting the delivery. This was facilitated by the physical proximity of different MDT members and most importantly, all members being located in one place, which helped to cement the MDT approach. A scenario where consultants, nurses, dietitians, psychologists, youth worker, secretaries, clerks and other members of the diabetes team all work in one place is surprising; this is very much the exception rather than the norm. Indeed, research indicates that administrators are frequently disregarded as core members of the MDT. However, in this evaluation, findings demonstrated that administrators were frequently the first and repeated point of contact with CYPF. They were regarded as an essential element of the diabetes team, both by the CYPF and other members of the MDT. Likewise, HCPs reported that psychology was becoming an integrated component of care in the first year following diagnosis and again psychologists were supported to work as part of the MDT. This is important as CYP with T1DM face unique challenges, which at times can affect their mental health [33,34]. Therefore, it was encouraging to find that both HCPs and CYPF reported the valuable role of psychologists in breaking down the barriers and stigma associated with mental wellbeing and T1DM. Sharing this outcome with International and National Diabetes Networks and professional groups is important in order that it might inform future delivery of local CYPF diabetes services.

Furthermore and perhaps unsurprisingly, HCPs expressed frustrations with the use of remote systems, in terms of accessibility and portability. Indeed, inconsistencies in record keeping were an important finding in terms of the influence on T1DM management. This is not uncommon in healthcare settings and is reinforced in the literature [35, 36]. Findings highlight the need for staff training to facilitate and standardise record completions. This is advocated in other research which suggests that the use of standardised reporting forms in the follow-up of patients who have diabetes, could contribute to lower mortality and morbidity [37].

4.1. Limitations and strengths

Limitations include a self-selected sample of CYPF who felt fortunate to be cared for within the service and, therefore, were perhaps less inclined to offer substantial criticism of the intervention that was evaluated. Limitations are balanced by the strengths of this study. These included the use of a mixed-methods evaluation design and the adoption of the Influencer Framework which provides a valuable framework for capturing outcomes for capability and motivation at different levels, along with explanations from CYPF and HCPs, both key stakeholders in this evaluation process [5]. In addition, the evaluation identifies what works less well and why in an intervention of this type and provides suggestions for intervention iteration and remedial action. Furthermore, reporting on what works less well is important [5,38]. Our evaluation provides evaluators with some suggestions for how evaluations can be undertaken in order to secure programme improvements that provide better outcomes for CYPF.

5. Conclusions

CYP with T1DM are a high-risk group [22]. This paper identifies contemporary issues in practice and provides the agenda for refinement in a paediatric diabetes intervention. These results confirm the potential of layered approaches to behaviour change across multiple domains of influence [12] and further support the case for behaviour change

strategies in any intervention that is aimed at managing T1DM [18]. Our evaluation strongly suggests that enhancing social motivation among CYPF can support successful long-term engagement in a paediatric diabetes intervention. Furthermore, the findings demonstrate opportunities for change, in terms of improving patient care and experience, as well as patient outcomes.

Declarations

Ethics approval and consent to participate.

Ethical approval was provided by the Faculty Research Ethics Committee

at Leeds Beckett University. Research and Development approval was obtained from Leeds Teaching Hospitals NHS Trust. Informed consent to participate was obtained in writing from all the participants involved.

Availability of data and material

The data generated and analysed during the current study are not publicly available due to the risk of individual privacy being compromised, but are available from the corresponding author on reasonable request.

Competing interests

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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Authors' contributions

All authors made substantial contributions to the conception, design, analysis and interpretation of the data. All authors were involved in writing the manuscript and have read and approved the final version of the manuscript. All authors have agreed both to be personally accountable for the author's own contributions and to ensure that questions related to the accuracy or integrity of any part of the work, even ones in which the author was not personally involved, are appropriately investigated, resolved, and the resolution documented in the literature.

Declaration of interests

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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List of abbreviations

AGP Ambulatory Glucose Profile

CYP	Children and Young People
CYPF	Children and Young People with diabetes and their Families
DCCT	Diabetes Control and Complications Trial
DMS	Data Management System
DUK	Diabetes UK
EDIC	Epidemiology of Diabetes Interventions and Complications
HbA1c	Glycated haemoglobin
HCPs	Healthcare Professionals
JDRF	Juvenile Diabetes Research Foundation
MDI	Multiple Daily Injections
MDT	Multidisciplinary Team
NICE	National Institute for Health and Care Excellence
SOI	Sources of Influence
T1DM	Type 1 Diabetes Mellitus
WICKED	Wolverhampton Interface Care Knowledge Empowered Diabetes Project

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