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Short title/*Authors running head*: Systematic review of interventions involving young adults with Type 1 diabetes •
M.C. O'Hara et al.

A systematic review of interventions to improve outcomes for young adults with Type 1 diabetes

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What's new?

- To our knowledge, this systematic review using a narrative synthesis methodology is the first to synthesize evidence relating to interventions aimed at improving clinical,

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behavioural and psychosocial outcomes among young adults (aged 15–30 years) with Type 1 diabetes.

- Evidence on the effectiveness of interventions to improve outcomes among young adults with Type 1 diabetes is inconclusive, with the findings of this review highlighting the lack of high-quality, well-designed studies in this area.
- This review highlights the importance of continuity of care, support, education and tailoring of interventions, and provides a basis for the development of future interventions.

Abstract

Background Many young adults with Type 1 diabetes experience poor outcomes. The aim of this systematic review was to synthesize the evidence regarding the effectiveness of interventions aimed at improving clinical, behavioural or psychosocial outcomes for young adults with Type 1 diabetes.

Methods Electronic databases were searched. Any intervention studies related to education, support, behaviour change or health service organizational change for young adults aged between 15-30 years with Type 1 diabetes were included. A narrative synthesis of all studies was undertaken due to the large degree of heterogeneity between studies.

Results Eighteen studies (of a possible 1700) were selected and categorized: Health Services Delivery ($n = 4$), Group Education and Peer Support ($n = 6$), Digital Platforms ($n = 4$) and Diabetes Devices ($n = 4$). Study designs included one randomized controlled trial, three retrospective studies, seven feasibility/acceptability studies and eight studies with a pre/post design. Continuity, support, education and tailoring of interventions to young adults were the most common themes across studies. HbA_{1c} was the most frequently measured outcome, but only 5 of 12 studies that measured it showed a significant improvement.

Conclusion Based on the heterogeneity among the studies, the effectiveness of interventions on clinical, behavioural and psychosocial outcomes among young adults is inconclusive. This review has highlighted a lack of high-quality, well-designed interventions, aimed at improving health outcomes for young adults with Type 1 diabetes.

Introduction

Many young adults with Type 1 diabetes struggle with their glycaemic control, resulting in poor outcomes [1,2]. The National Diabetes Mortality Audit in England reported that males and females aged 15–34 years with Type 1 diabetes had a mortality rate 3.8 and 6.6 times greater than the background age- and sex-matched population, respectively [3]. A recent international comparison of glycaemic control among people with Type 1 diabetes highlighted that 15–24 year olds were most likely to have HbA_{1c} values > 58 mmol/mol (> 7.5%) [4].

Type 1 diabetes requires intensive self-management (including monitoring blood glucose, administering insulin, regulating diet and exercise) to maintain optimal glycaemic control.

This daily self-care regimen is challenging for most, but is especially difficult for young adults because they face additional challenges in their lives (leaving home, starting work and/or college) [5]. Physiological factors in this age group such as insulin resistance and young adult lifestyles, risk-taking behaviour, peer influence and family conflict also impact negatively on diabetes self-care [6–8].

As young adults transition from paediatric to adult services, they often struggle to adjust to different styles of Health Service Delivery and the new levels of personal responsibility expected of them [9,10]. A systematic review found that transition experiences, relationships with service providers and the perceived value of attending clinic appointments influenced clinic attendance among young adults (15–30 years) [5]. Clinic attendance in young adults

may be improved by increasing opportunities for relationship development between young adults and service providers [11]. A recent systematic review concluded that technology may increase communication between healthcare providers and young adults with Type 1 diabetes [12].

Preliminary searches of the literature suggest that there are few studies evaluating interventions in this population [5]. The Medical Research Council's guidance for developing and evaluating complex interventions, defined as interventions that contain several interacting components, recommends conducting a systematic review to inform the development of a new intervention to establish what has already been tried and tested and to establish the degree to which an intervention has been effective or not [13].

Aim

The aim of this study was to conduct a systematic review of both the quantitative and qualitative literature to identify and describe any interventions aimed at improving clinical, behavioural and psychosocial outcomes for young adults with Type 1 diabetes. The key objectives were to identify components of interventions and to measure the effectiveness of these interventions on young adult outcomes.

Participants and methods

Five electronic databases (Embase, MEDLINE, PsycINFO, CINAHL and the Cochrane Library) were searched from their inception date to September 2014. Endnote was used to organize the results from each search engine and to remove duplicates. Expert groups were also contacted to identify relevant unpublished literature such as reports or theses (Appendix S1).

Inclusion/exclusion criteria

All quantitative studies published in English for young adults aged 15–30 years with Type 1 diabetes who had transitioned to adult diabetes clinic services and addressed interventions relating to young adult education, support, behaviour or lifestyle change, or health service organizational change were included in the review. A key inclusion criterion was that the study took place in an adult clinic setting. Because varying definitions of emerging adults exist in the literature [5] and the age of transition can also vary, the authors chose the age range 15–30 years to ensure that we captured all interventions targeting emerging adults that had already transitioned to adult services.

Qualitative studies were also included if they reported on young adults' or healthcare professionals' views or experiences of an intervention. Interventions by pharmacological or physiological means alone were excluded because this review aimed to inform future self-management or diabetes service delivery interventions.

Search strategy

The search strategy aimed to identify all references to young adults, Type 1 diabetes and any educational, psychosocial, behavioural and health service organizational interventions to improve outcomes for young adults with Type 1 diabetes. The search was undertaken between June and September 2014. The searches were intentionally broad and used hierarchically structured, vocabulary controlled search terms where possible and where appropriate, for example, Emtree was used in the Embase database. Search terms and the search strategy were agreed after consulting with a librarian in health sciences and other diabetes researchers and clinicians involved in the area of young adult diabetes. Population, intervention, comparator and outcomes were used to guide the search strategy as described in Appendix S2 [14].

PRISMA guidance was followed [15]. Figure 1 describes in detail how many papers were included and how many were excluded and why.

The review team included diabetes clinicians (SD, SH), health psychologists (MB, LH) and health service researchers (MCOH, MOD, NN). Following agreement among the review team on the inclusion/exclusion criteria, four researchers (MCOH, MOD, LH and NN) screened the abstracts. Each abstract was independently reviewed twice. Any discrepancies were resolved by consensus among the four reviewers. Where it was unclear if a publication met the inclusion criteria from the title and abstract alone, a full text appraisal was carried out. In studies in which the age group was broader than our inclusion age group (15–30 years), the authors were contacted to determine whether data for the age range of interest could be extracted. Corresponding authors were contacted up to three times.

Comprehensive data extraction was undertaken for all studies that met the inclusion criteria using a pre-defined template (Appendix S3).

During the data extraction phase, it was apparent that there was considerable heterogeneity in terms of study design and methodological and statistical approaches, meaning the tight analytical framework associated with a meta-analysis was not possible. A narrative synthesis using the Guidance on the Conduct of Narrative Synthesis in Systematic Reviews was therefore applied [16]. This approach uses qualitative methodology to arrange studies into more homogenous groups or subgroups and synthesizes the evidence of different designs and outcomes more coherently.

The reviewers repeatedly read the studies to identify themes and concepts. This approach codes using an iterative process until final themes and concepts emerge from the data, the methodology is not a linear process. Relationships in the data were explored; for example, papers that were categorized together were further analysed for similarities and differences,

especially where there were components of interventions that emerged as common across papers.

Outcomes measured

Outcomes included in the studies were categorized into clinical outcomes (e.g. glycaemic control, blood glucose measurements), behavioural outcomes (e.g. blood glucose monitoring and recording, changes to lifestyle) and psychosocial outcomes (e.g. diabetes-related distress, treatment satisfaction, diabetes knowledge and attitudes).

Quality assessment

A quality assessment of studies was undertaken. This assessment was informed by the Cochrane Risk of Bias tool [17] and the guidance from the Critical Appraisal Skills Programme [18]. Because the quality of studies varied considerably, our quality assessment focused on the main methodological weaknesses of studies commenting primarily on the presence and appropriateness of control groups and study attrition rates.

Data synthesis

Guidance on the conduct of narrative synthesis in systematic reviews [16] informed the synthesis to enable the findings of a diverse range of interventions to be assessed. Themes that reflected the findings of each study were identified and similarities and differences across the interventions were examined to produce an in-depth understanding of the intervention strategies.

Results

Of 1700 abstracts screened, 18 studies published between 1991 and 2013 met the inclusion criteria, as illustrated in Fig. 1 [19–36]. Most were published by research groups in North America and Canada ($n = 10$), five were from northwest Europe, two from Israel and one from Australia. A further 36 studies included age groups broader than our inclusion age group (15–30 years). Of the 36 authors contacted, 29 were unable to extract data on the age range of interest and 7 did not respond.

Study design characteristics

Study design, duration, intervention description, main findings and methodological issues are summarized in Table 1. Study designs were varied and included one randomized controlled trial (RCT), three retrospective studies, seven feasibility/acceptability studies and eight studies with a pre/post design.

The 18 papers included in this review were categorized according to the main purpose of the intervention described: Health Service Delivery, Group Education and Peer Support, Digital Platforms to Influence Self-care Behaviours, and Diabetes Devices. In some cases, a study could have been placed in more than one category, for example, one of the studies [23] was categorized under the Group Education and Peer Support category because this was the main focus of the intervention, but this study could also have been included in the health services delivery category.

A brief summary of the types of interventions and methodological characteristics of studies is described below. Common themes and the main findings across all types of intervention are described below and are summarized in Table 2. We describe and summarize data on engagement with the intervention where this information is available.

Summary of intervention type and their methodological characteristics

Health services delivery (n = 4)

All four studies targeted Health Service Delivery by either implementing a structured transition programme to support young adults moving from paediatric to adult diabetes services [19–21], or by setting up a specialized young adult clinic [22]. All four studies were retrospective using non-randomized pre-/post-intervention designs. Sample sizes ranged from 62 to 249 and all included a control or comparison group.

Group education and peer support (n = 6)

Six studies were included in the Group Education and Peer Support category [23–28]. All incorporated group education as part of their intervention, but two studies focused primarily on peer support [23,24]. The remaining four interventions focused primarily on education.

Only two were designed specifically for young adult populations, focusing on college students [24,28]. Five studies had small sample sizes (≤ 32 participants) although only two described themselves as pilot studies [23,24] and four were prospective with no control groups [23–26].

Digital Platforms to Influence Self-care Behaviours (n = 4)

Four studies delivered digital interventions targeting young adults with Type 1 diabetes using real-time telemedicine [29], self-care recording and reminder systems using e-mail or mobile technology [30,31], and online peer support and education [32]. One study was an RCT [29], a second was an exploratory RCT [30] and two were pilot studies [31,32]. All four focused on improving participants' self-care behaviours including blood glucose self-monitoring [29,31], insulin administration [30] and interaction with the adult diabetes team [32]. In all four studies, digital technology was chosen as the mode of delivery of the interventions to

appeal to young adults. The sample size in this category ranged from 18 to 93. Control groups were included in all but one study [32].

Diabetes devices (n = 4)

Diabetes devices were tested in four studies [33–36]. Two focused on insulin pumps [33,34], one on an insulin pen [35], and one on a blood glucose monitor [36]. They included a two-arm randomized crossover study [34], a retrospective study [33] and two cohort studies [35,36]. Sample sizes ranged from 29 to 129, and a control or comparison was included in three of the four [33–35]. In two studies, participants acted as their own controls [33,34], and in one matched controls were used [35].

Common themes across interventions

Continuity, which refers to aspects of interventions that facilitate contact between young adults and the diabetes service, was the most prominent theme across studies, occurring in 13 of the 18 studies reviewed [19–29,33,34]. Continuity within diabetes services or in the context of a study was implemented by ensuring that participants met, or were in contact with, the same diabetes team members at each clinic [22] or by a research visit [34], or by assigning one care coordinator [20]. Hernandez *et al.* placed a particular emphasis on the development of a collaborative relationship between the diabetes educator and participants in their blood glucose awareness training intervention [26]. Digital Technology and Diabetes Device interventions were less likely to include components to support continuity than the Health Service Delivery and Group Education and Peer Support interventions.

The theme of support, referring to intervention strategies for addressing the psychosocial and diabetes-specific needs of young adults, was also a prominent intervention theme occurring in 12 of the 18 reviewed studies [20–24,26,28,29,31–34]. Support was provided by peers with diabetes, diabetes service providers or the diabetes service itself to provide opportunities for sharing experiences [23], to facilitate a successful transition from a paediatric setting [21], or to advise regarding daily self-management [29].

Education, defined as intervention strategies to teach young adults diabetes self-management skills, was also a core intervention theme in this review [21,22,24–28,32–34]. Self-management interventions that featured an education or information component focused on intensive treatment including carbohydrate counting [27] and insulin pumps [33]. Information provision was a strong theme in one of the studies, to remove barriers and encourage engagement with adult diabetes services [21].

Tailoring interventions to a young adult population was also a common theme, although not as prominent as support, continuity and education [19–24,28,31,32]. Interventions that were tailored to young adults with Type 1 diabetes included strategies for delivering appropriate and acceptable interventions and were either designed in consultation with young adults [32] or could be adapted by participants according to their own preferences [31].

Other less-prominent themes included the use of psychological theory to inform the design of interventions [26,28,30] and the use of incentives to achieve goal and completing intervention activities [28].

Effectiveness of interventions

Clinical outcomes

Twelve of the 18 studies assessed the effectiveness of the intervention on HbA_{1c}. These included three of the Health Service Delivery studies, three of the Group Education and Peer Support studies, two of the Digital Intervention studies and all four Diabetes Device studies, as detailed in Table 1 [19,20,22–24,27,29,31,33–36]. Of the 12 studies, 8 used a pre/post design [19,22–24,27,33,35,36], 2 used comparison groups [20,31], 1 used a RCT design [29] and 1 used a randomized crossover design [34]. Five of the 12 studies reported a significant improvement in HbA_{1c} [19,20,24,27,33]. The two involving structured transition reported a significant improvement in HbA_{1c} in those transitioning using a structured process with the greatest improvement being reported in those with higher baseline HbA_{1c} (Table 1) [20]. The young adult clinic study reported no significant difference in HbA_{1c} between the intervention and control groups, but a subgroup analysis of participants with HbA_{1c} > 80.3 mmol/mol (9.5%) found a significantly lower HbA_{1c} in the intervention group at 3 years [22]. Two of the three Group Education and Peer Support interventions that measured HbA_{1c} reported a significant reduction in HbA_{1c} (Table 1) [24,27]. The Digital Intervention studies including telemedicine support that measured HbA_{1c} reported no significant improvement [29,31] and only one of the four Diabetes Device interventions that compared continuous subcutaneous insulin infusion with multiple daily injections reported a significant improvement in HbA_{1c} after participants switched to continuous subcutaneous insulin infusion [33].

Blood glucose levels

Two studies reported on daily blood glucose levels [29,34]. One using real-time blood glucose result transmission with nurse support reported a significantly lower mean blood glucose level in the intervention group who received nurse feedback compared with the

control group [29]. Another comparing insulin pump treatment with conventional subcutaneous insulin infusion (CSII) therapy reported no differences in the euglycaemic, hypoglycaemic or hyperglycaemic ranges in both groups [34].

Diabetic ketoacidosis and severe hypoglycaemia

Five studies provided data on severe hypoglycaemia and/or ketoacidosis. These included two of the Health Service Delivery studies [20–22], one of the Group Education and Peer Support interventions [27] and two of the four Diabetes Device studies [33,35]. Of the two structured transition studies, one reported a significant decrease in ketoacidosis-related hospital admissions and a decrease in length of stay for ketoacidosis-related re-admissions following commencement of the transition programme [20], whereas the other reported no significant differences in ketoacidosis or severe hypoglycaemia [21]. One educational intervention reported a significant decrease in severe hypoglycaemia and ketoacidosis after the educational intervention [27]. Another reported a significant decrease in severe hypoglycaemia 1 year after introduction of insulin pump treatment but no change in ketoacidosis [33]. One reported no significant change in severe hypoglycaemia or ketoacidosis between the intervention and control groups following introduction of an insulin pen [35].

BMI and weight

Two of the Diabetes Devices studies measured BMI and/or weight [33,35]. One reported a significant decrease in BMI after participants switched to CSII [33] and another reported a significant weight gain in the intervention group after a minimum of 1 year using an insulin pen [35].

Behavioural outcomes

Self-care behaviours

Eight of the 18 studies measured diabetes self-care behaviours, but only one study used a validated measure [23]. Three of the Group Education and Peer Support studies measured self-care behaviours [23,24,28]. One study using the validated Self-care Inventory measure [37] to assess self-care behaviours relating to diet, exercise, blood glucose monitoring and medication administration, reported no significant changes in self-care behaviours before and after the peer group support sessions [23]. Another using a 5-point non-validated scale reported significant improvements in testing blood glucose levels and adherence to the prescribed insulin regimen in the intervention group compared with the control group [28]. Qualitative feedback from participants in one study also reported improvements in self-care behaviours with 85% of respondents reporting improved adherence to a designated diet and 45% reporting beginning a routine exercise regimen [24]. Three of the Digital Platform studies measured diabetes self-care behaviours [29–31]. One assessing real-time blood glucose transmission with nurse feedback reported a significant improvement in frequency of blood glucose reporting in the intervention group compared with the control group [29]. Another reported that participants who received text message reminders to monitor blood glucose responded with blood glucose results significantly more often than those who received e-mail reminders [31]. One using an exploratory RCT to assess text message reminders to promote insulin administration reported no significant difference in insulin administration between the intervention and control group [30].

Two of the four Diabetes Devices studies that measured self-care behaviours also reported improvements [35,36]. One reported that accurate self-monitoring of blood glucose, as reflected by entries in participants' logbooks, increased to 100% after the introduction of a

blood glucose meter that could retrieve results [36]. Another reported no significant change in mean total insulin dose in intervention and control groups following the introduction of an insulin pen, but participants did indicate in a self-report questionnaire that they were compliant with the multiple-shot regimen on weekdays, although not on weekends and holidays [35].

Clinic attendance

Two of the four Health Service Delivery studies [19,21] and one of the Group Educational and Peer Support studies [23] reported on clinic attendance with only the two transition Health Service Delivery studies reporting a significant improvement. One study measured length of transition time, time from the last paediatric to the first adult diabetes clinic appointment and reported a significantly shorter length of time taken to transition in the intervention group than in the control group [19].

Psychosocial outcomes

Knowledge

Four of the 18 studies measured diabetes knowledge using non-validated measures. All four reported improvements [24–26,28]. Two studies reported significant differences following the intervention. One reported a significant increase in mean knowledge scores in the intervention group before and after the intervention using a 12-item questionnaire evaluating the topics covered in the programme [28]. It also reported a significant difference in participants' knowledge of their own HbA_{1c} at 3-month follow-up. Another study reported that education sessions on cues enhanced blood glucose awareness, they reported a significant improvement in the intervention group estimating their blood glucose levels compared with the control group [25]. One delivered a 1-h education session on blood

glucose cue self-awareness, and reported an increase in awareness of cues for hypoglycaemia, hyperglycaemic and normal blood glucose 12 months post intervention [26]. Qualitative feedback from participants in a peer support group intervention found that 90% of participants reported being more knowledgeable about diabetes following completion of the intervention [24].

Satisfaction with the intervention

Five studies reported on patient satisfaction with the intervention with only one study using a validated measure [34]. Only one of the four Health Service Delivery intervention studies provided feedback from participants on the intervention [19], with all of those in the structured transition group reporting a good experience of structured transition, whereas 70% of the control group reported a poor/bad experience of the unstructured transition process.

Two of the Digital Platform studies provided feedback from participants on the intervention [31,32]. Half of the participants indicated a preference for using text messaging rather than e-mail to encourage blood glucose monitoring in the Hanauer *et al.* study [31]. In the study with the internet-based transition support programme [32], all 12 participants who provided feedback found the online modules useful, with half of them finding modules easy to complete. However, two thirds reported trouble completing module activities on time due to work, school and family commitments.

Two of the Diabetes Device studies reported on participant satisfaction with the intervention [34,35]. One reported no significant differences in scores on the Diabetes Treatment Satisfaction Questionnaire [38] when comparing the OmniPod System with conventional CSII therapy [34]. However, two-thirds of participants indicated a preference for the OmniPod cannula insertion system and over half said OmniPod fitted better into their

lifestyle than conventional CSII. Another study reported that most participants were satisfied with the insulin pen and found it more convenient, but they did not find it less discrete nor did it improve attitudes towards taking injections [35].

Psychological distress

Only one study involving peer support, where the group met monthly over a 5-month period measured diabetes psychological distress using the validated Problem Areas in Diabetes (PAID) measure [23]. It showed a significant decrease in diabetes distress between the first and last group sessions [23].

Health belief attitudes

Only one study measured health belief attitudes/beliefs using an non-validated measure [28]. It resulted in a significant difference in attitudes towards social support, with the intervention group more likely to feel support on the college campus for their diabetes following completion of the intervention compared to the control group.

Engagement with the intervention and technical issues

Two of the Digital Platform studies provided information on engagement with the intervention [31,32]. One involving an internet programme study reported that the diabetes educator found it necessary to phone participants frequently (14–38 calls per participant) to remind them to log into the internet programme over the 6 months [32]. Although the discussion board was the most used service of the programme, it was primarily used by 4 of the 19 participants. Most people accessed the service in the evening between 9 and 11 p.m., with greatest usage of website occurring during the first 2 months of the study. Another study involving a computerized automated blood glucose monitoring reminder system also reported

declining usage with the average number of blood glucose values submitted decreasing in both groups over time with only one of the 18 users in the e-mail group and 5 of the 22 users in the cell phone group continuing to submit blood glucose measurements by the third month of the study [31]. This study also reported that females were more likely to use the system than males and over a quarter of participants did not use the system at all.

Discussion

To our knowledge, this study is the first to review the evidence related to interventions aimed at improving clinical, behavioural and psychosocial outcomes among young adults (aged 15–30 years) with Type 1 diabetes, using a systematic narrative synthesis methodology. Previous studies have included a broader age range of people with Type 1 diabetes [39] or children and adolescents with Type 1 diabetes [40], focused on narrower intervention types, such as psychosocial or educational interventions [41], or summarized the impact and experiences of transition from paediatric to adult diabetes services [42]. This work evaluates the impact of a broader range of intervention types, on a range of outcomes, assessed following transition to an adult clinic.

We found that the evidence for the effectiveness of existing interventions for improving clinical, behavioural and psychosocial outcomes among young adults is inconclusive, with few high-quality, well-designed intervention studies having been conducted. Only 18 studies met the inclusion criteria, emphasizing the low level of intervention research focusing on young adults with Type 1 diabetes. Two of the educational intervention studies [24,25] and two of the digital device studies [35,36] were conducted over 20 years ago, with one insulin pen intervention now considered standard treatment [35].

Glycaemic control was the most common clinical outcome measured, with 5 of the 12 studies that measured it reporting a significant improvement following intervention. Behavioural and psychosocial outcomes including self-care behaviours, diabetes knowledge and satisfaction with the intervention were measured to a lesser degree, highlighting the emphasis on clinical outcomes. We found little evidence demonstrating effective interventions on outcomes among young adults with Type 1 diabetes. Studies report a range of outcome measures, making it difficult to synthesize results. There is an international effort to standardize sets of outcomes. Identification of a core outcome set for future studies targeting young adults with Type 1 diabetes is needed to progress research in this area [43].

The themes of continuity, support, education and tailoring of interventions, were the broad strategies employed across the interventions reviewed, indicating strong agreement among researchers and service providers in terms of the needs of young adults with Type 1 diabetes. However, only three studies underpinned their intervention development by psychological theory [26,28,30], as recommended by current guidelines [13,44].

Continuity of care was the most prominent intervention theme across studies although it is rarely the target of interventions. Previous cross-sectional studies illustrate the importance of continuity of care to improve the value of diabetes clinic appointments from the perspectives of young adults [45] and service providers [46], and the potential role of collaborative relationships for establishing and maintaining regular clinic attendance [5,11]. Approaches to supporting successful transition often involve implementing continuity in the pathway to adult diabetes clinics. Sheehan *et al.* concluded that there was some evidence for the role of structured transition programmes in supporting transition among young adults [42].

Interventions regularly aimed to address the psychosocial needs of young adults, by providing diabetes education and support. It could be argued that without skills, people with Type 1 diabetes are going to struggle to self-manage successfully. Previous reviews among children, adolescents and adults with Type 1 and Type 2 diabetes also confirm the importance of psychosocial interventions providing education and support for improving outcomes [41,42,47]. Hampson *et al.* reported small to medium effects of educational and psychosocial interventions for young people aged 9–21 years with Type 1 diabetes [41].

Only two studies commented on the involvement of young adults in the design of interventions [28,32] and low levels of engagement with some of the digital technology interventions were also reported [31,32]. Involving young adults in the development of interventions has been recently highlighted in the literature [48] to avoid implementing interventions with low rates of engagement and participation.

Although this review identified common themes across interventions, methodological issues prevented links being made between intervention components and outcomes. Existing reviews in this area report similar methodological issues [5,41,42]. To address these issues, it is recommended to draw on frameworks for designing, underpinning intervention development in psychological theory and describing interventions aiming to change behaviour and health systems, such as the Medical Research Council framework for developing and evaluating complex interventions [13], the Behaviour Change Wheel [44] and the Template for Intervention Description and Replication (TIDieR) checklist [49]. Researchers have started to use these frameworks in designing complex interventions for young adults with Type 1 diabetes [50].

The use of such systematic approaches will encourage researchers to engage in a comprehensive intervention development process, to engage stakeholders such as service providers and young adults with Type 1 diabetes, to make use of theory to understand the problems experienced by young adults and the mechanisms by which behaviour can be effectively changed, and to address issues surrounding the quality of measurement tools and timing of data collection [13]. Such an approach will inform what components are important to include in an intervention and what outcomes should be assessed.

Limitations

There were significant methodological issues in the study design of many studies included in the review, and sample size, study duration, age range of participants and outcomes assessed varied greatly. The majority of the studies adopted cross-sectional or retrospective designs which were limited in terms of the variables that could be assessed and the availability of suitable control groups. Only one RCT was identified and over half the studies had small sample sizes of 40 participants or fewer. Behavioural and psychosocial outcomes were often assessed using non-validated rather than validated self-report measures. In addition, important factors including socio-economic status, insurance coverage and geographical location were not assessed in any of the studies. Because of the heterogeneity of studies, the data were not suitable for a meta-analysis and the recommendations which can be made are limited. Despite these limitations, this review provides useful information to inform the development of future interventions for young adults with Type 1 diabetes.

Conclusion

This review highlights the potential importance of continuity of care, support, education and tailoring or individualizing support across different types of interventions targeting young adults with Type 1 diabetes. However, the evidence base for interventions that improve outcomes among young adults with Type 1 diabetes is limited and is not adequate to guide changes to practice that might support better self-care and outcomes in this population. Future research should adopt recommended tools such as the Medical Research Council framework when developing complex interventions aimed at improving outcomes among young adults with Type 1 diabetes.

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Competing interests

None declared.

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FIGURE 1 Author to supply caption.

Supporting Information

Additional Supporting Information may be found in the online version of this article:

Appendix S1. Experts group who were contacted to identify relevant grey literature.

Appendix S2. Search strategy.

Appendix S3. Data extraction form.

Appendix S4. Members of Irish Type 1 Diabetes Young Adult Study Steering Group.

Table 1 Characteristics of studies included in the systematic review

First author, year, country	Study design/follow up	Intervention	Sample size/age range	Summary of main findings	Methodological issues
Health Service Delivery					
Cadario, 2009, Italy	Retrospective study with a pre/post design, 3-year follow-up.	Structured transition (IG) with transition coordinator versus unstructured transition (CG) from paediatric diabetes services to adult diabetes services care.	IG = 30; CG = 32 Age range: 19 ± 2.8 years.	<i>HbA_{1c}</i> At 1 year: ↓HbA _{1c} in IG than in CG ($P < 0.01$). At 3 years: no significant difference in HbA _{1c} between the two groups. <i>Clinic attendance</i> At 3 years: ↑ clinic attendance in IG compared with CG ($P < 0.05$). ↓waiting time before first ADS appointment in IG compared with CG ($P < 0.001$). Patient satisfaction with transition (non-validated questionnaire). All of IG reported a favourable experience for structured transition. 70% of CG reported a poor/bad experience of unstructured transition.	A past cohort of patients served as the CG.
Van Wallegem, 2008, Canada	Retrospective comparison study with a pre/post design, 1-year follow-up.	Structured transition with transition coordinator (IG) versus unstructured transition (CG) from paediatric diabetes services to adult diabetes services.	IG = 84; CG = 64 Age range: 19–25 years (mean age: 18 years).	<i>Diabetic ketoacidosis or severe hypoglycaemia</i> No significant difference between IG and CG. <i>Clinic attendance</i> At 1 year: ↑ clinic attendance in IG compared with CG (89% vs. 60%, no P -value stated).	Non-matched control group.
Holmes-Walker, 2007, Australia	Retrospective study, median follow-up of five visits (~ 2 years).	A structured transition support programme in a young adult diabetes clinic setting with transition coordinator (IG) compared with a reference group (CG).	IG = 164; CG = 27 Age range: 15–25 years (mean age: 18.9 years).	<i>HbA_{1c}</i> ↓ HbA _{1c} between first adult clinic attendance and after a median of five visits ($P < 0.001$). Greatest improvement in those with starting HbA _{1c} > 96.7 mmol/mol or 11 ($P < 0.001$) after a median follow-up of 24 months. <i>Diabetic ketoacidosis admissions/re-admissions</i> ↓ Diabetic ketoacidosis admissions ($P < 0.05$) and ↓ diabetic ketoacidosis re-admission length of stay ($P = 0.02$) after structured transition. Diabetic ketoacidosis re-admissions and total mean diabetic ketoacidosis admission length of stay: no significant difference.	Patients in a pre-existing young adult clinic acted as the reference group/ CG.

Lane, 2007, USA	Retrospective comparison study with a pre/post design, 3-year follow-up.	Specialized young adult clinic (YAC/IG) compared with general endocrine clinic (GEC/CG).	IG = 96, mean age: 19 ± 2 years CG = 153, mean age: 21 ± 3 years.	<i>HbA_{1c}</i> At 6 months, 1, 2 and 3 years between IG and CG: no significant difference. At 3 years: ↓ <i>HbA_{1c}</i> in IG compared with CG in subgroup of patients with <i>HbA_{1c}</i> > 80.3 mmol/mol (9.5%), (<i>P</i> < 0.05).	Significant differences in age at baseline with GEC patients 2 years older than YAC.
Education Markowitz, 2012, USA	Prospective pilot with a pre/post design, 5-month follow-up.	Psychologist-led support group met monthly over 5 months to facilitate peer-to-peer interactions to enhance the transition process among college students. Participants identified topics for discussion and were emailed topics ahead of time to reflect on them.	<i>N</i> = 15 Age range: 18–30 years.	<i>HbA_{1c}</i> At 1 year before and 1 year after group sessions: no significant difference. <i>Self-care behaviours (Self Care Inventory-R – validated measure)</i> At 5 months: no significant difference in diabetes related self-care behaviours. <i>Clinic attendance</i> At 1 year prior to and 1 year after group session: no significant difference. Diabetes distress (Problem Areas in Diabetes – validated measure). At 5 months: ↓ diabetes distress between first and last group session (<i>P</i> = 0.02).	No control group. Pilot study so small sample size.
Sämman, 2008, Germany	Retrospective evaluation with a pre/post design, 12-month follow-up.	Five-day in-patient structured group education programme of 20 h specially targeted at intensive insulin management (carbohydrate counting, insulin dose adjustment).	<i>N</i> = 1422 Age range: 15–24 years.	<i>HbA_{1c}</i> At 12 months: ↓ <i>HbA_{1c}</i> (<i>P</i> < 0.01). <i>Severe hypoglycaemia</i> At 12 months: ↓ severe hypoglycaemia (<i>P</i> < 0.05 to 0.01). <i>Diabetic ketoacidosis</i> At 12 months: ↓ diabetic ketoacidosis (<i>P</i> < 0.05 to 0.01).	No control group.
Hernandez, 2004, Canada	Described as intervention study with a pre/post design but sample size would suggest pilot study. 12 month follow-up.	One-hour education session on BG cue self-awareness which included a video on BG self-awareness followed by a facilitator-led group discussion on cues of low, high and normal blood glucose and circumstances associated with these. Participants received instruction on how to use a ‘what’s your blood sugar’ exercise and encouraged to use this exercise to improve BG accuracy.	<i>N</i> = 29 Age range: 18–26 years (mean age: 22 years).	<i>Diabetes knowledge (non-validated questionnaire)</i> At 12 months: ↑ awareness of cues for hypoglycaemia and hyperglycaemia and normal blood glucose (no <i>P</i> -value stated).	No control group. Small sample size. High attrition at 12 months, only 12/29 returned 1-year questionnaire.

Wdowik, 2000, USA	Quantitative and qualitative prospective evaluation with a pre/post design, 3-month follow-up.	Participants attended three group education sessions of 2 h each over three consecutive weeks. Topics from a diabetes management guide tailored to the needs and perspectives of college students were presented. There was also 1 one-to-one session with the group facilitator (dietician/diabetes educator) to discuss issues of personal interest. Participants in IG received prizes and incentives for goals met. Another set of college students with diabetes acted as the CG.	IG = 21; CG = 11 Age range: 18–27 years (mean age: 22 years).	<p><i>Diabetes self-care behaviours (non-validated questionnaire)</i></p> <p>At 3 months: ↑ BG level testing in the IG ($P < 0.5$) with no change reported in CG.</p> <p>At 3 months: ↑ adherence to the prescribed insulin regimen in the IG ($P < 0.5$)</p> <p>↓ adherence to the prescribed insulin regimen in CG ($P < 0.5$).</p> <p><i>Diabetes knowledge (non-validated questionnaire)</i></p> <p>At 3 months: ↑ diabetes knowledge in IG ($P < 0.001$), no change in CG</p> <p>At 3 months: ↑ in knowledge of HbA_{1c} in IG compared with CG ($P = 0.003$).</p> <p><i>Attitudes (non-validated measure)</i></p> <p>At 3 months: ↑ in feeling support on campus for their diabetes in IG compared with CG: ($P < 0.05$).</p> <p><i>HbA_{1c}</i></p> <p>At 10 weeks: ↓ HbA_{1c} pre- to post intervention ($P < 0.001$).</p> <p><i>Self-care behaviours</i></p> <p>Qualitative feedback to essay question ‘How did the group experience affect you?’ 85% reporting improved adherence to a designated diet and 45% reporting beginning a routine exercise regimen.</p> <p><i>Diabetes knowledge</i></p> <p>Qualitative feedback to essay question: 90% of participants reported being more knowledgeable about diabetes.</p> <p><i>BG estimate accuracy</i></p> <p>↑BG estimate accuracy for the IG group compared to CG ($p < 0.005$).</p>	Did not use validated questionnaires. Small sample size.
Shalom, 1991, USA	Prospective pilot with a pre/post design, 10-week-follow-up.	Three peer support groups of college students met for 10 consecutive weeks for 1.5 h each. It consisted of a 30 minute formal presentation by an educator followed by an open group discussion.	$N = 20$ Age range: 17–30 years.	<p><i>HbA_{1c}</i></p> <p>At 10 weeks: ↓ HbA_{1c} pre- to post intervention ($P < 0.001$).</p> <p><i>Self-care behaviours</i></p> <p>Qualitative feedback to essay question ‘How did the group experience affect you?’ 85% reporting improved adherence to a designated diet and 45% reporting beginning a routine exercise regimen.</p> <p><i>Diabetes knowledge</i></p> <p>Qualitative feedback to essay question: 90% of participants reported being more knowledgeable about diabetes.</p> <p><i>BG estimate accuracy</i></p> <p>↑BG estimate accuracy for the IG group compared to CG ($p < 0.005$).</p>	No control group. Pilot study so small sample size.
Nurick, 1991, USA	Described as intervention study with pre-/ post-design but sample size would suggest pilot study, 3-day follow-up.	Three 45–60-minute education sessions administered individually or in small groups over three consecutive days. Sessions focused on the internal (e.g. personal symptoms) and external (e.g. timing and amount of insulin, food and exercise) cues that could be used to enhance BG awareness. IG also received instruction in the use of the Insulin, Symptoms, Eating, Exercise (ISEE) questionnaire to estimate blood glucose. The CG did not.	IG: eight young adult outpatients (mean age: 22 years) and six adolescent inpatients (mean age: 14.5 years). CG: nine adolescent	<p><i>BG estimate accuracy</i></p> <p>↑BG estimate accuracy for the IG group compared to CG ($p < 0.005$).</p>	Non-matched control group. Small sample size.

inpatients
(mean age:
13.9 years).
Eight
excluded
because they
were outside
the age range
of interest.

Digital Platforms to Influence Self-Care Behaviours

Louch, 2013, UK	Exploratory RCT assessing intervention effectiveness, 2-week follow-up.	An SMS intervention to promote insulin administration. IG received one daily text message (correct insulin administration targets). CG participants received one general health message a week. All messages were sent at 10 a.m.	IG = 8; CG = 11 Age range: 18–30 years	<i>Insulin injections</i> At 2 weeks: morning/afternoon/evening insulin administration injections – no significant difference between IG and CG.	Exploratory study so small sample size.
Hanauer, 2009, USA	Pilot/feasibility study. Participants were randomized to text group or e-mail group, 3-month follow-up.	Computerized Automated Reminder Diabetes System (CARDS): using mobile phone text or email reminders to encourage BG monitoring. Participants received a 15-minute introduction to CARDS. The number and frequency of reminders were set by participants by logging into website and usage of the system was encouraged at 1 and 4 weeks. CARDS sent a BG test reminder and if a response was not entered within 15 minutes, it sent a repeat reminder. Positive feedback was automatically sent by CARDS following submission of BG result. If BG result was out of target, CARDS sent a warning to take corrective action.	E-mail group = 18 (Mean age: 18.2 ± 2.3 years). Text group = 22 (Mean age 17.7 ± 3 years).	<i>HbA_{1c}</i> At 3 months: no significant difference between text and e-mail groups. <i>BG values reminders requested and submitted</i> ↑BG measures submitted following reminders by text group compared with e-mail group ($P < 0.02$). Text group compared with e-mail group requested more reminders, submitted more BG values and responded to a higher percentage of reminders within 30 minutes (P -values not reported). <i>Patient preferences</i> 50% of all participants would prefer using mobile phones to access CARDS, 7% prefer email, 10% both and 23% chose neither option.	Pilot study so small sample size. High attrition (4/22 text group and 7/18 e-mail group never used the system).
Gerber, 2007, USA	Pilot study assessing development of an intervention, 6-month follow-up.	An internet-based transition support programme called STYLE tailored for college students to assist transition to ADS. Modules (one module/week over 6 months) with a navigation system. Informed by qualitative interviews with young adults. The programme included goal-setting, individualized feedback, role-playing, group discussions, empowerment activities and communication skills training to improve interactions with HCPs.	$N = 19$ Age range: 19–26 years (mean age 22.3 years). 18 (email reminders); 22 (mobile phone text	<i>Patient satisfaction with intervention</i> At 6 months: 12/19 participants who attended feedback sessions indicated that modules were helpful. 6/12 felt that the modules were ‘very easy’ or ‘easy’ to complete, with the remainder describing them as ‘somewhat hard’. 8/12 participants reported trouble completing module activities on time due to work, school and family commitments.	No control group. Pilot study so small sample size. High attrition with only 12/19 participants providing

Farmer, 2005, UK	Prospective RCT. Nine-month follow-up.	<p>It also included a discussion board, three ask the expert segments (which allowed consultation with psychologist, social worker, patient advocacy expert and/ or other diabetes healthcare worker). Diabetes educator encouraged usage during study period.</p> <p>Blood glucose self-monitoring results were transmitted in real time to CG with limited graphical feedback of the results for the previous 24 h, the data were not available to the DSN.</p> <p>Blood glucose self-monitoring with real time intensive graphical feedback for IG for the previous 24 h, DSN-initiated phone support using the web-based graphs of glucose self-monitoring results for the previous 2 weeks.</p>	<p>messages).</p> <p>IG = 47; CG = 46 Age range: 18–30 years.</p>	<p><i>HbA_{1c}</i> At 9 months: no significant difference between the two groups but ↓ HbA_{1c} in both the IG ($P < 0.001$) and CG ($P < 0.04$) between baseline and 9-month follow up.</p> <p><i>BG results</i> ↓ Mean BG level for IG compared with CG ($P < 0.0001$).</p> <p><i>BG transmissions</i> Transmission of BG results: IG transmitted 29 765 BG results over the 9 months and CG transmitted 21 400 BG results. The number of weeks at least seven BG/week were transmitted was higher in IG compared with CG ($P < 0.001$). ↑ BG tests in the hypoglycaemic range transmitted by IG compared with CG ($P < 0.0001$).</p>	feedback at the end of the study.
Lebenthal, 2012, Israel	Prospective, randomized two-arm crossover study. 12 week follow-up.	<p style="text-align: center;">Diabetes Devices</p> <p>OmniPod System is a combined wireless pump and personal diabetes manager. It was compared with conventional CSII therapy. Participants received a 2–3-h training session, they were given a demo kit for 3 days prior to the treatment period. They had three clinic visits at baseline and at 12 and 24 weeks. They received four telephone calls at 4, 8, 16 and 20 weeks (for reporting adverse events as well as pump-related technical problems). They completed a 7-point glucose profile for 3 days and a 4-point glucose profile for 4 days prior to each visit, FreeStyle Navigator is a CGMS and was used to profile BG for 5 days prior to completion.</p>	<p><i>N</i> = 29 Mean age: 24 ± 5.1 years</p>	<p><i>HbA_{1c}</i> 12 weeks: no significant difference between two groups.</p> <p><i>BG levels</i> At 12 weeks: euglycaemic, hypoglycaemic and hyperglycaemic ranges – no significant differences between the two groups.</p> <p><i>Diabetes Treatment Satisfaction Questionnaire (DTSQ – validated measure)</i> At 12 weeks: no significant difference between the two groups.</p> <p><i>Patient satisfaction with intervention (non-validated measure)</i> 67% of participants preferred the OmniPod cannula insertion system and 56% said OmniPod fit better into their lifestyle than conventional CSII. 42% would</p>	Small sample size.

Nimri, 2006, Israel	Retrospective paired study with a pre/post design. 12-month follow-up.	To compare glycaemic control using MDI (3-4 injections/day and 2-8 SMBG/day) vs. CSII (3 pump training sessions facilitated by a fixed diabetes team covering pump techniques, carbohydrate counting, insertion site care, SMBG, insulin bolus dosing, 24-h support via calls and faxes) in Type 1 diabetes.	N = 129 Age range: 17–40 years, (medium age 22.8 years).	switch to OmniPod, 36% were undecided and 21% would not switch pumps. <i>HbA_{1c}</i> At 12 months: ↓HbA _{1c} following CSII initiation ($P < 0.01$). <i>Severe hypoglycaemia/diabetic ketoacidosis</i> At 12 months: ↓ severe hypoglycaemia ($P < 0.05$). Diabetic ketoacidosis: no significant change <i>BMI</i> ↓ BMI after switching to CSII ($p = 0.016$).	Non-matched control group.
Dorchy, 1997, Belgium	Retrospective cohort study with a pre/post design.	The Sensorlink system allows healthcare professionals to retrieve the last 125 BG measurements stored in a patient's BG monitoring device. It was used to assess compliance with patient self-reporting of BG levels in patient logbooks after patients were informed of this ability to retrieve data.	N = 60. 33 had a HbA _{1c} < 7% (good control; GC). 27 had a HbA _{1c} ≥ 7% (insufficient control; IC). Mean age: 21.3 ± 6.3 years.	<i>HbA_{1c}</i> After three visits (~ 6 months): no significant difference before or after Sensorlink in GC or IC groups. After three visits (~ 6 months): ↓ HbA _{1c} in IC subgroup with poor initial control ($P < 0.05$). <i>Reporting of BG</i> Patient accurate reporting of BG readings in logbooks increased to 100% after introduction of Sensorlink.	No group control.

Chase, 1991, USA	Retrospective cohort study with a pre/post design. 12-month follow-up.	To compare whether two injections/day vs. Novolin Pen with four injections/day approach in college students can impact on glycaemic control. Participants were started on fixed doses and adjustments to these doses were made after 1 week of SMBG. Participants were asked to follow a restricted diet.	IG = 16; CG = 16 Mean age: 19.2 years at Novolin Pen initiation.	<p><i>HbA_{1c}</i> At 12 months: no significant difference between groups.</p> <p><i>Total insulin dose</i> No change in mean total insulin dose in either group over the 12-month period</p> <p><i>Severe hypoglycaemia/diabetic ketoacidosis</i> No episodes of severe hypoglycaemia or diabetic ketoacidosis in either group over the 12-month period</p> <p><i>Weight</i> ↑weight in Novolin Pen compared with controls ($P < 0.05$).</p> <p><i>Insulin adherence</i> Most participants were compliant with their MDI on week days but admitted non-compliance during weekend days and/ or holidays.</p> <p><i>Patient satisfaction</i> Most were satisfied with Novolin Pen and found it more convenient but did not find it less discrete nor did it improve attitudes towards taking injection.</p>
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IG, intervention group; CG, control group; HCP, healthcare professionals; SMGB, self-monitoring of blood glucose; BG, blood glucose; MDI, multiple daily injection; CSII, continuous subcutaneous insulin infusion; RCT, randomized controlled trial; SMS, short messaging system; STYLE, Self-management Training in Youth for Lifelong Effectiveness; CGMS, continuous glucose monitoring system; DSN, diabetes specialist nurse.

Table 2 Representation of overarching themes related to intervention design and delivery

	Continuity: Strategies that facilitate contact between young adults and diabetes services	Support: Strategies for addressing the psychosocial and diabetes-specific needs of young adults	Education: Strategies for informing young adults regarding diabetes management	Tailored to young adults: Strategies for delivering appropriate and acceptable interventions
		Health Service Delivery		
Van Walleghem <i>et al.</i> , 2008	✓	✓	✓	✓
Holmes-Walker <i>et al.</i> , 2007	✓	✓		✓
Cadario <i>et al.</i> , 2009	✓			✓
Lane <i>et al.</i> , 2007	✓	✓	✓	✓
		Group Education and Peer Support		
Shalom, 1991	✓	✓	✓	✓
Wdowik <i>et al.</i> , 2000	✓	✓	✓	✓
Nurick <i>et al.</i> , 1991	✓		✓	
Sämann <i>et al.</i> , 2008	✓		✓	
Hernandez <i>et al.</i> , 2004	✓	✓	✓	
Markowitz <i>et al.</i> , 2012	✓	✓		✓
		Digital Platform to Influence Self Care Behaviours		
Farmer <i>et al.</i> , 2005	✓	✓		
Louch <i>et al.</i> , 2013				
Hanauer <i>et al.</i> , 2009		✓		✓
Gerber <i>et al.</i> , 2007		✓	✓	✓
		Diabetes Devices		
Nimri <i>et al.</i> , 2006	✓	✓	✓	
Lebenthal <i>et al.</i> , 2012	✓	✓	✓	
Chase <i>et al.</i> , 1991				
Dorchy <i>et al.</i> , 1997				

