

Review Article

Technology-based approaches to patient education for young people living with diabetes: a systematic literature review

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The aims of this paper were to report on a systematic review of technology-based approaches to diabetes education for young people (defined as children and young people up to the age of 21 yr) and to determine effectiveness and gaps in current research. We report on the search for relevant studies, the critical appraisal process resulting in the selection of five studies and the clinical and research recommendations arising from the narrative synthesis of these studies.

Background

Four out of five young people with diabetes in the UK have inadequate blood glucose control, and research continues to describe poor long-term clinical and psychological prognosis (1). To improve outcomes,

evidence points to the need for educational and psychological support based on clearly identified needs (2). This is particularly relevant to young people who show a precipitous decline in treatment adherence as they move through adolescence towards adulthood (3). However, significant gaps in educational provision have been found for this age group (4), and as a result, a number of educational models have been funded in the UK for research. Alongside this, Information and Communication Technology (ICT) has been identified as an area for further investigation (5, 6). The question to be explored here is what role ICT can play in the education process, particularly for young people for whom diabetes self-management evolves alongside adaptation to developmental changes in association with individual contextual factors and disease course.

From this perspective, the educational process is dynamic. It runs along a timeline that has a history as well as a current and a future perspective. In this light, education is a phenomenon characterized by change and transformation (7).

Various reviews have already looked at the use of ICT in patient education. Some have focused on young people and all types of educational interventions with no subgroup analyses for ICT (8–12), others have included all ages with no subgroup analyses for young people (13–15) and some have focused on a single type/form of ICT intervention (16–18). The majority have reported positive effects in relation to knowledge and social support with possible improvements in behavioural and clinical outcomes, highlighting the potential of educational technology to provide a link between education and treatment concordance. Recommendations include the need to look at effects for different groups of people with chronic illness. In line with this, our review sought to synthesize the best available evidence on ICT-based interventions for young people (up to the age of 21 yr) living with diabetes. It aimed to review effectiveness and to identify gaps in current research. Its purpose was to inform a new research study that is developing an Adolescent Diabetes Needs Assessment Tool (ADNAT study).

The review

For this review, ICT interventions were defined as those aiming to enable learning about diabetes self-management using technology-based environments, which allow for diversity of information and/or information flow and/or connectivity between different information paths. Examples include social networking tools, such as mobile phones and chat rooms, Internet sites and specialist CD-ROMs.

The review also focused on learning about diabetes self-management as an evolving process with learners' needs in a constant state of change and adaptation. This view recognizes education as a complex intervention that must account for the facts that knowledge is necessary but not sufficient; that developmental factors, stress and coping mechanisms play an important role and that interaction between medical, social and psychological factors are key to self-care (19). From this perspective, the aim of any form of education is to develop not only self-care competence, that is, relevant knowledge, skills and attitudes, but also coping skills to help young people deal with uncertainty and new problems as they arise and to be able to creatively adapt to change. This perspective sees learning as an open system within a series of other interrelated systems (e.g., formal learning at school or in the hospital, informal learning from significant others, e.g., parents and peers, and situational learning through personal experience) that feed back on themselves with

individual learning needs assessment, an ongoing part of the process (20). From this perspective, the role of educators is to help young people make connections between all these different forms of learning. Such learning is therefore an emergent process, and ICT may have a role to play in supporting this process, given the high profile of technology in young people's lives.

Aim

The aims of this study were to provide a systematic review of the clinical effectiveness of ICT-based educational interventions for young people living with diabetes, to provide guidelines for practice and to identify research gaps.

Design

The review followed the Centre for Reviews and Dissemination (CRD) (March 2001) report number 4 (21). Clinical effectiveness was based on those defined by the UK Health Technology Assessment (HTA) report (13).

Search methods

Electronic databases covering the medical and social science literatures were searched including: Medline, Scopus, Psycinfo, CINHALL, Web of science, British Nursing Index, UK National Research Register, Conference Papers Index, Research Finding Electronic Register, Cochrane Library, CRD (covering DARE, HTA and NHS EED databases), FADE (the North West Grey Literature Search) and the National Library for Health (full search strategy available from authors). The search strategy had high recall and low precision because of the diversity of terms used to represent the topic (14 447 titles inspected, including duplicates). For papers to be included, they therefore had to meet specific criteria shown in Table 1.

All potential titles and abstracts were provisionally included for consideration on the basis of full text articles ($n = 196$). Any papers that fitted the inclusion criteria were given a reference number and exported into bibliographic databases set-up in Endnote Reference Manager ($n = 86$). The reproducibility of this process was tested in the early stages of the review and found to be good. Final inclusion/exclusion decisions were made by consensus of two researchers after subjecting the papers to detailed analysis using a screening tool adapted from the HTA report (13). Reference lists were searched for additional papers, and contact made with authors/institutions where further information was required. Where decisions were unclear, papers were reviewed by a third independent researcher for discussion.

Table 1. Inclusion criteria

Participants	Up to 21 yr of age with any form of diabetes
Intervention	Information and Communication Technology-based educational interventions
Setting	Primary (general practice), secondary (hospital based) and community
Outcomes (14)	
Clinical end-points	Glycated haemoglobin
Quality of life	Psychosocial effects
Cognitive changes	Knowledge and specific skill development, for example, blood glucose monitoring skills
Diabetes-related complications	Hypoglycaemia and hyperglycaemia (acute)
Follow-up	Immediate, intermediate (up to 6 months.) and long term (>6 months)
Study design	Randomised controlled trial Cohort or case-controlled studies Qualitative studies Existing systematic reviews Exclude: Pre/post studies Posttest studies only Descriptive studies
Reporting	Must report sufficient detail of intervention being tested
Dates	1990–2007
Language	English

Quality appraisal

All quantitative studies were systematically evaluated by two researchers using quality checklists in accordance with criteria recommended by the CRD (21). For qualitative studies, the checklist developed by Attree and Milton (22) was used. Main reasons for exclusions included age of participants (for mixed age groups, paper excluded if no subgroup analysis for young people), health professional education, description of intervention only, initial feasibility/pilot studies with no follow-up, biotechnology or telemedicine, diabetes not the main focus and non-English language texts. For those that remained, many focused primarily on technological development with little if any information on outcome effects, while others reported limited evaluations. While these studies were excluded [(18, 23–37), papers that met the inclusion criteria but failed the quality assessment process], some provided useful detailed information on intervention development and implementation. Good examples include interactive educational games (24–26), a personal interactive tool kit (23), an instructional problem solving and goal setting system (31) and computer simulations (32, 33, 35). Following systematic evaluation, five research studies were selected, of which two had been described in more than one article. Thus, the five studies are represented by a total of 11 papers (38–48). The dearth

of available studies for inclusion and the pilot and feasibility nature of many of the published investigations illustrate the fact that the use of educational technology to enhance diabetes education for this age group is very early in its evolution.

Data extraction and synthesis of the evidence

Data were extracted and synthesized onto computer-based forms developed for the review. Meta-analysis was not undertaken because of heterogeneity of the studies: mixed methods were used in two of the studies; two used quantitative and one qualitative methods only. They varied in relation to numbers of participants, reporting of participant characteristics, duration and type of interventions, length of follow-up, theoretical foundations, and settings (only one was UK based and remaining four USA based). Table 2 provides a detailed summary of each of the studies.

Description of the interventions

ICT interventions included 'self-instructional' ($n = 2$), 'information feedback', 'online forums' and an 'interactive game'. Those with linked papers [Franklin et al. (38–42) and Charron-Prochownik et al. (43–45)] paid particular attention to reporting the process of intervention (technology) development, including the involvement of users. In the case of Franklin et al., a participatory design methodology was reported demonstrating how practitioners, software developers and users worked together. In the case of Charron-Prochownik et al., six phases of CD-ROM programme development are described, including user involvement, pilot testing and evaluation. Three of the studies mentioned training: Franklin et al. – members of the diabetes team received training in goal setting; Kumar et al. (48) – participants and their families received intervention training and Charron-Prochownik et al. – intervention groups received one training session pre-trial. Duration of follow-up was primarily short term (1–3 months) with only one study (Franklin et al.) reporting outcomes at 12 months. Numbers of participants varied from 7 to 92, and ages of participants ranged from 8 to 21 yr.

One of the studies (Charron-Prochownik et al.) focused specifically on one topic (preconceptual counselling). The remaining four focused on multiple components (and therefore outcomes) despite the fact that this raised confounding issues that had to be taken into account in the interpretation of the results. Those studies that used mixed methods [Franklin et al. and Ravert et al. (47)] allowed different dimensions to be captured, expanding their scope through triangulation. This, however, demands strong theoretical underpinnings to allow sense to be made of the combined data, particularly where

Table 2. Description of studies included

Study, year, setting	Research design, QA, FU	Sample population	Intervention/theory	Results
Franklin et al. (38–42), 2003–2007, UK	Mixed methods (RCT + interviews). Three groups: 1. CIT only (controls, n = 28) 2. CIT + Intervention (I) (n = 33) 3. IIT + I (n = 31) QA: Adequate in all areas FU: 12 months	n = 92 Mean age: 13.1 yr Range: 8–18 yr M : F = 53:47% Disease duration: 1.7–8.6 yr Socio-economic: carstairs deprivation score: –3.73 to 0.73 Ethnicity: 3 non-white	Self-instructional: Sweet Talk Goal setting in clinic and scheduled patient-specific text messages Website: biofeedback of BG results and graphs Questions and answers using text messages Text 'newsletter' Staff training: motivational goal setting Theory: STAR, Health Belief Model	ghb: IIT only ($p < 0.001$) Groups 2 and 1: Self-efficacy: $p = 0.003$ Adherence scale (self-report): $p = 0.042$ Perceptions of quality and frequency of support for: BG testing: <0.001 Healthy eating: <0.001 Exercise: <0.001 Groups 3 and 2: Perceptions of quality and frequency of support for: Healthy eating: 0.02 Secondary outcome measures: No. of clinic visits: $p = 0.016$ Emergency hotline contacts: $p = 0.011$ 82% felt intervention had improved self-management Liked: messages relating to diabetes; shared experiences; practical aspects Most annoying: receiving repeats of same message Book and CD: Rated as helpful and easy to understand Significant increases in knowledge, sustained at 3 months Significant group-by-time effects for beliefs (benefits and barriers) Perceptions of benefits improved, sustained at 3 months Perceptions of barriers: CD significant decrease, book significant increase No significant group-by-time or group effects for susceptibility/severity/self-efficacy Social support significant increase, sustained at 3 months Intention to seek PC/family planning: significant time effect, but book showed significant decrease at 3 months, CD sustained increase Actual behaviours: no significant group-by-time effect
Charron-Prochownik (43–45), 1998–2006, USA	Randomised controlled repeated measures study. Three groups: 1. SC (controls, n = 20) 2. SC + CD-ROM (n = 17) 3. SC + Book (n = 16) QA: Adequate: 1 flaw – treatment allocation concealment not reported FU: immediate and 3 months	n = 53 Mean age: 17.4 yr Range: 16–19.9 yr All females Mean disease duration: 9.9 yr Socio-economic: 64% >middle income Ethnicity: 4.4% Afro-American	Self-instructional: CD-ROM – preconceptual counselling Theory: STAR, Expanded Health Belief Model Training: intervention groups – 1 comprehensive session of programme	

Table 2. Continued

Study, year, setting	Research design, QA, FU	Sample population	Intervention/theory	Results
Smith et al. (46), 2006, USA	Qualitative ethnographic study QA: Overall adequate: 1 flaw – sampling strategy not reported FU: 4 weeks	n = 7 Mean age: not reported Range: 19–21 yr M : F – 57:43% Mean disease duration: >1 yr Socio economic: all university students Ethnicity: all Caucasian	Information feedback: BG monitors and digital cameras to collect BG results and photos of routines participants believed had impact on their health Data transferred to visualization software that hyperlinked data Reviewed with staff using guided questions Theories: Predictive theories of learning	Those with problems took more pictures (cognitive changes) Emphasized psychosocial concerns impacting upon diabetes including harmful behaviours (quality of life) Explained BG levels in terms of photos, useful to understand relationship between diet and BG levels (cognitive changes) Photos used as memory aid to reconstruct events that led to a particular BG profile (cognitive changes) Data showed desire to pursue unique identity more important than potential health risks (quality of life) Photos of food symbolised annoyance with restrictions (quality of life) Photos emphasised the need for education of peers (quality of life) Those already conscious of their health behaviours gained little (cognitive changes) Total no. of messages = 340; of these: 74% (100%) to Q/A forum; 43% to peer D/F Topics D/F : Q/A (%): Life tasks relating to adolescence = 21:14 Social support = 50:1 Medical/health care = 1:7 Factual information on diabetes = 45:11 Problems in self-managing diabetes = 28:9 Intrapsychic concerns, for example, eating disorders = 8:6 Statistical analysis (chi-squared): Social support and life tasks more common in D/F (p < 0.001) Females posted more messages at D/Fs and males more on Q/A forums (p = 0.041) No significant gender differences for requests/replies/topics 14–16 yr, posted most messages, then 17–19, then 11–13. No significant differences between age/forum type/ topics Age at diagnosis: 10 yr+ posted most messages, followed by 6–10 yr, then <5 yr No significant differences between duration of illness and type of forum
Ravert et al. (47), 2004, USA	Mixed methods QA: Overall adequate: 1 flaw – ethical issues not reported FU: Not applicable	Websites (n = 8) Age range: 11–19 yr Gender for 48.5% of messages: M : F – 21:79% Disease duration for 63% of messages: <1 yr, 14%; 1–5 yr, 24% Socio-economic: unknown Ethnicity: unknown	Online forum: Question/answer forums (Q/A, n = 155, 46%) – messages posted and publicly answered by professionals Discussion forums (D/F, n = 185, 55%) – theme centred Internet support groups and message boards in which peers query and reply to one another's messages No theory reported	

Table 2. Continued

Study, year, setting	Research design, QA, FU	Sample population	Intervention/theory	Results
Kumar et al. (48), 2004	Prospective RCT. Assigned to PDAs using age strata: 8–12 and 13–18 yr. With Game (n = 19) Without game (controls, n = 21) QA: Overall adequate but treatment allocation concealment & intention to treat analysis not reported FU: 4 weeks and 3 months	N = 40 Mean age: 13.6 yr Range: 8–18 yr M : F = 50:50% Disease duration: 6.4 yr T1D, n = 39/T2, n = 1 Socio-economic factors/ethnicity not reported	Interactive game: DiabetNet software PDAs/wireless enabled diabetes data management software + BG monitor + motivational game Integrates BG levels + insulin doses + CHOs eaten Aim: to predict BG levels based on graphical display of personal data Points given for playing game and accuracy of predictions Training: parents and adolescents – use of intervention No theory reported	Overall participation: no significant differences. At 3.5–4 months: ghb: No significant differences Game group 3.4 times more likely to achieve/maintain ghb levels of <8% (p = 0.06) At 4 weeks: BGM/No. transmitted: Game group p < 0.001 (significantly more) Mean daily CHO intake: no differences but those checking BG levels 4+ times/day: p < 0.05 Frequency of hyperglycaemia: game group p < 0.001 (significantly less) Diabetes knowledge: game group p < 0.005 (significantly increase) Satisfaction: neither age nor gender predicted success

CIT, conventional insulin therapy; FU, follow-up; IIT, intensive insulin therapy; QA, quality assess; SC, standard care; STAR, stop-think-act-reflect. BG, blood glucose; RCT, randomised controlled trial; PC, pre-conceptual counselling; D/F, discussion forums; PDA, personal digital assistant; CHO, carbohydrate

inconsistencies exist (49, 50). Three of the studies reported using theory: Franklin et al. and Charron-Prochownik et al. used the STAR (Stop-Think-Act-Reflect) decision-making theoretical framework and the Health Belief Model. Smith et al. (46) used a pedagogical approach based on the emergence of interventions driven by the ways in which users interact with them, rather than focusing strictly on a set of learning outcomes as an endpoint for evaluation. This approach appreciated education as an interrelated open system, as discussed in the Introduction. The remaining two failed to mention theory.

Results

Glycaemic control

The two studies reporting ghb data (glycated hemoglobin) (Franklin et al. and Kumar et al.) found no proven significant differences between intervention and control groups in the short term (3.5–5 months) or longer term (12 months). However, Kumar et al. (n = 40 participants) found that the intervention group was 3.4 times more likely to achieve or maintain ghb levels of <8% (p = 0.06) with the frequency of hyperglycaemia significantly less in the game group (p < 0.001). Franklin et al.'s study (n = 92 participants) had three arms: conventional insulin therapy (CIT) only (control group), CIT + intervention and intensive insulin therapy (IIT) + intervention. They reported no significant differences between the CIT group with and without 'Sweet Talk' intervention, and while the IIT group showed significant differences (p < 0.001) in ghb, they also found significant differences in the number of clinic visits (p = 0.016) and emergency hotline contacts (p = 0.011). They concluded that differences in glycaemic control may be because of increased contact with the diabetes team. This finding recognizes the complex interplay of factors that influence clinical outcomes. Of particular note here is that no study reported outcome data on changes in insulin treatment.

Knowledge

Not all studies reported knowledge outcomes. This may reflect research that has shown knowledge to be only weakly associated with other outcomes (51, 52), given that there is a threshold of knowledge beyond which other factors (e.g., socio-economic status and levels of social support) are more important to achieve diabetes-related treatment goals. For those that did report knowledge outcomes – Charron-Prochownik et al. (n = 53 participants) and Kumar et al. (n = 40 participants) – significant changes were noted. Ravert et al. (n = 340 messages on eight websites) also found that the majority of requests (74%) in discussion and question and answer forums were for information. For young people, knowledge increments are an essential cognitive

component for developing diabetes self-care. However, it is the concept of meaningful learning/engagement that is important here. The aim should be to move learners from an understanding of general concepts to an understanding of specifics that have individual relevance. Franklin et al. (n = 92), for example, found that messages containing personal information relating to their diabetes and shared experiences of living with diabetes, alongside practical aspects such as clinic reminders were particularly valued. Smith et al. found that personal visualizations helped young people make connections between their blood glucose measures and their behavioural routines. Such approaches, however, demand that participants are able to manipulate ideas, highlighting the need for interventions to be developmentally appropriate (in this study, participants were 19–21 yr old). This is particularly important given the need to interact with young people when they are ready to take over some of their self-care behaviours. For this, they must have developed reasoning powers, be able to see the relationships that link things together and be aware of what active measures are needed to control diabetes (53). While specific length of time since diagnosis was reported in four of the studies, none reported developmental stages of participants in relation to reasoning abilities and cognition.

Diabetes self-management

In relation to translation of what participants had learnt into self-care behaviours, Franklin et al. (n = 92) reported significant (positive) differences in self-efficacy, adherence and perceptions of quality and frequency of self-care support at 12 months. Kumar et al. (n = 40) found significant short-term differences in the numbers of transmitted blood glucose tests [alongside frequency of hyperglycaemia (significantly less) and a positive trend towards achievement/maintenance of ghb levels of <8% (p = 0.06)]. Franklin et al. reported that 82% of participants felt that the intervention had improved their self-management, correlating with a significant change in self-reported adherence. However, Charron-Prochownik et al. (n = 53) found that while intentions to use preconceptual counselling/family planning increased in all groups, there was no significant group-by-time effect on actual behaviours at 3 months. However, short-term follow-up for two of these studies limits the significance of these findings, given recommendations for longitudinal measures of behaviour change (54).

Psychosocial effects

A key issue with participants is facilitating discussion in a way that enables them to talk about personal and often sensitive information. Findings from three of the studies provide insights into how ITC could support

this process. Ravert et al. (n = 340 messages) found that social support was the most common form of communication in online discussions. Franklin et al. reported that their intervention provided a forum for disclosure of personal or embarrassing questions that the young people may have felt unable to ask in clinic. Smith et al. (n = 7) reported that their intervention enabled discussion of psychosocial concerns and personal issues, including harmful behaviours. They found that a desire to pursue a unique identity was more important than the potential health risks associated with certain behaviours. This is not new information. It is, however, central to our understanding of the need to meet patients on their own terms and to place them within their everyday social context emphasizing connectedness, relationships and modes of belonging (23). ICT, in this case in the form of an information feedback system, appeared to provide a tool for allowing this to happen but only for those not conscious of their health behaviours. This reinforces the need for such tools to be appropriately targeted, as highlighted by Ravert et al. They found that 14- to 16-yr-old patients and those diagnosed longer posted the highest number of messages on interactive forums, that there were no significant gender differences for requests/replies/topics, but females posted significantly more messages at discussion forums and males more on the question and answer forums. Franklin found that females sent significantly more discussion-based messages unrelated to diabetes than did boys, and Kumar et al. found that gender differences were not a predictor of success in their intervention. Information on other characteristics, in particular ethnicity and socioeconomic status, was limited, and no correlations were reported. Franklin, for example, found no correlation between total messaging frequency and clinical and sociodemographic characteristics. What was reported in all the studies, however, related primarily to Caucasian populations creating a limitation to transferring the results of this review and highlighting the need for more targeted research.

Discussion

This paper has systematically reviewed five quality-assessed studies of ICT interventions for young people (ages 8–21 yr) living with diabetes. Findings suggest that ICT has beneficial effects on knowledge and psychosocial well-being, with probable improvements in self-care behaviours. Confounding variables (e.g., changes in treatment, significant increases in health care professional contact and the absence in Franklin et al.'s study of an ITT arm only) make it impossible to prove ghb benefits, although positive trends were reported. These findings are limited, however, by a number of factors, including the small number of viable studies, the heterogeneity of interventions,

short-term follow-up and diverse focal points (vs. interventions focused solely on a single outcome). What is important though is that these findings correspond with those from other less targeted reviews of ICT-based patient education reinforcing the potential of ICT to provide an impact on and a link between education and treatment concordance in the paediatric and young adult populations. Noteworthy and different was that ICT made available peer-based psychological support applicable to both genders. This is an important area to emerge, given the need for young people to define self while conforming to a peer group within a different (diabetes) experience and demands further research. Also apparent is the need for more rigorous evidence and in line with this, the following research gaps have been identified:

- (i) To date, there is a lack of rigorous ICT diabetes research in the developing nations, highlighting the fact that the use of technology to enhance diabetes education is very early in its evolution. Four of five of the included studies had been conducted in the USA; Japan and Sweden were also prominent in the excluded studies, perhaps reflecting nations where ICT plays a bigger part in their health care systems.
- (ii) The review has highlighted the need to address the complexities of this type of research using a phased approach to link intervention development, training and implementation with research design. In line with this, our review has reinforced the importance of theory for discerning mechanisms of action so that data can be properly utilized for better clinical outcomes. These conclusions reinforce those reported in other diabetes educational reviews (13). Smith et al.'s study provides an example of how this can work. Their study appreciated education as an interrelated open system characterized by emergence of personal learning outcomes/needs. Here, the intervention enabled participants to make meaningful connections between their feelings (psychosocial concerns) and their treatment regimen as well as providing a channel for the flow of personal information (memory aid). While findings are limited by short follow-up and the number and range of participants, it does provide an example of a creative intervention that could be tested further using a well-designed quantitative trial.
- (iii) The review found a lack of long-term outcomes, and there was no cost-effectiveness data reported. Without this, it is unlikely that educational technology will be implemented into clinical practice because questions about how long effects can be maintained have not yet been answered.

- (iv) To address the uniqueness of each young person, research is needed to develop learning needs assessment tools in alignment with their developmental stages, i.e., age-related reasoning and cognitive abilities, alongside age of and time since diagnosis.
- (v) Research needs to be targeted to look at different ethnic and socio-economic communities to answer questions regarding cultural disparities and health inequalities.
- (vi) There is evidence to suggest that ICT has the potential to act as a social networking vehicle offering psychosocial support. The latter is an important area for further investigation given the importance of socializing (conversations) to this age group and to education as a whole.

Conclusions

This review has explored the effectiveness of ICT interventions for young people living with diabetes. While large numbers of studies were located, the vast majority were limited by their primary focus on design and implementation without rigorous testing. For the five studies included, benefit was found in relation to knowledge and psychosocial well being with probable improvements in self-care behaviours. While positive trends were reported for glycaemic control, there were no proven effects. The review has therefore supported findings from other less targeted reviews and has highlighted the need to improve the quantity and quality of ICT research in line with evaluating other complex interventions. In addition, the fact that young people's learning is an emergent process means that longitudinal studies are required to explore impact over time in alignment with the developmental stages of participants. Such research is urgently needed if we are to realize the full potential of technology for a disease that has rising prevalence and increasing educational need, which is currently not being met effectively.

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