A systematic review of parent/peer-based group interventions for adolescents with type 1 diabetes: interventions based on theoretical/therapeutic frameworks

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Abstract

Objective: Although interventions which provide psychosocial support can have a positive impact on diabetes self-care, the impact of family/peer- and theory-based interventions has not yet been clearly identified. This systematic review investigates the randomised controlled trials (RCTs) employing family/peer-based interventions (based on theoretical/therapeutic frameworks) which aim to improve adolescents’ glycaemic control, psychosocial and/or behavioural functioning.

Methods: The Cochrane Library, database of systematic reviews, database of abstracts of reviews of effectiveness and Health Technology Assessment database were searched (from start date until February 2016) for any previously conducted systematic reviews. Seventeen RCTs/interventions were included. The literature was also identified by contacting the leading researchers. Glycaemic control was measured by HbA1c and psychosocial functioning by measures of self-care, knowledge and communication, collaboration/ teamwork, quality of life, problem solving, social functioning and family functioning. Only those interventions which reported the use of theories/therapies to manage type 1 diabetes and other psychosocial issues among adolescents (aged 12–17) were included in the present review. Data summarising the key features of the interventions was extracted from each article. Where possible, the effect sizes were calculated.

Results: The effect sizes could be computed for HbA1c in six of the 17 interventions. The overall outcomes indicated that interventions including parents have a small to large effect size on a variety of diabetes management and psychosocial outcomes. This review identified interventions, mostly including parents and rarely including peers.

Conclusion: The results of this systematic review demonstrate that multicomponent interventions may be more successful for adolescents than ones that just focus on one aspect. Effectiveness is also greater if they demonstrate inter-relatedness with the various aspects of diabetes management. Short-term behavioural approach-based interventions promote improvements in parent/adolescent relationships. Outreach home-based interventions could be a more accessible alternative for intervening with families than office/hospital-based interventions. This approach may also be more acceptable to adolescents and their families. There is a need to develop evaluated interventions for adolescents involving parents. Development should involve stakeholders (ie, adolescents, their families and healthcare professionals) to co-design potentially cost-effective and feasible interventions in the context of NHS diabetes services.

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Key words: family/peer-based interventions, psychosocial and behavioural theories/therapies, diabetes and psychosocial functioning, type 1 diabetes, adolescents

Introduction

Type 1 diabetes requires managing an intensive and challenging regimen. This includes integration of daily medical tasks (insulin injections, frequent blood glucose tests) and lifestyle modifications (close monitoring of food intake and regular exercise) in everyday life. 1,2 Although near-normal blood glucose control may decrease the risk of several long-term diabetes complications in individuals with type 1 diabetes, 3,4 adolescents often have difficulty juggling all aspects of such a demanding treatment regimen. Parents and other family members are especially important for adolescents with type 1 diabetes to encourage and provide support for treatment-related behaviours. 2 Anderson and colleagues 6 showed that a low-intensity office-based family intervention for youths with type 1 diabetes increased parental involvement, while decreasing diabetes-related family conflict. 6,7

Research has highlighted that, during adolescence, young adults strive for autonomy and parents’ attempts to monitor/control
their children’s treatment may be viewed as intrusive or nagging. Such attempts may result in adolescents becoming resistant, defiant and non-compliant. Research supports the need for adolescents and parents to work cooperatively, with open communication and flexible problem-solving skills, in order to negotiate shared responsibility for treatment management. On the other hand, research has shown that age needs to be considered and that support needs to occur at both home and school. Consequently, both family members and peers can facilitate optimal diabetes management. Support from peers has been rated as important by adolescents with type 1 diabetes; peers are more likely than family members to provide companionship and emotional support in relation to diabetes care. In one structured group intervention, adolescents and their friends demonstrated higher levels of knowledge about diabetes and support, as well as a higher ratio of peers to family support. In addition, parents reported a decrease in diabetes-related conflict. Nonetheless, the shift from parental to peer support is not absolute, as adolescents continue to seek guidance and advice from their parents. Numerous theoretical and therapeutic frameworks have been devised to explain and adapt the relationship between patients’ perceptions and their behaviour (see Box 1 for a brief overview). 

**Box 1 Theoretical frameworks included in the review**

**Self-regulation model**
The Self-Regulation Model of Illness (SRMI) provides a framework for understanding how individual symptoms and emotions experienced during a health threat or diagnosis influence perception of illness and guide subsequent coping behaviour. The SRMI may be further understood using Bandura’s cognitive-behavioural theory that emphasised learning through direct experience, Bandura posited that virtually all learning phenomena can occur by observing other people’s behaviour and its consequence. Positive psychology suggests understanding the role of positive traits, experiences and environmental factors that contribute to wellness. Given the wide variability in how patients with chronic illness are able to manage their daily behaviours needed to maintain physical and mental well-being, positive psychology has provided a particularly useful framework to identify the factors that promote successful disease management.

**Empowerment approach**
The goal of patient empowerment is to build up the capacity of patients to help them to become active partners in their own care, to enable them to share in clinical decision making, and to contribute to a wider perspective in the healthcare system. Empowerment is a positive concept that refers to the patient’s facilities, abilities and surrounding environment. Power is an inner feeling of self-awareness and self-education. Empowerment is achieved through interaction between people and causes interpersonal and intrapersonal communications. It is a practical strategy in improving health conditions, which includes skills (eg, solving problems, boosting self-confidence and creating strategies to create mutual trust). The empowerment process begins with providing the patient with information and education and ends when he/she can actively participate in making ‘smart’ decisions about his/her disease. With this approach, health professionals facilitate patients to make informed decisions regarding their particular conditions. Patients are encouraged to fully participate in their treatment process by sharing their knowledge and experiences and making decisions through mutual assistance. Empowerment discovers and expands one’s inner capacity to accept responsibility towards their health. It is an intervention or a strategy to help people change their behaviour in order to adhere to the treatment plan.

**Self-efficacy theory**
Self-efficacy (SE) was first proposed by Albert Bandura, who suggested that self-efficacy is a belief of individuals in their abilities to carry out a successful practice and is a theory in itself, as well as a structure of the social cognitive theory. The self-efficacy theory argues that people will take action when they believe they are able to do it and will avoid actions when they believe they may fail. Self-efficacy is the prerequisite of a behaviour and should be considered as an independent part of basic skills. In total, Bandura believes that self-efficacy (or ‘mastery’) is the main structure in predicting individuals’ behaviour change and usually the ones that show a high level of behavioural changes have higher efficacy. Self-efficacy has a prominent role in diabetes self-management and predicts its outcome.
No systematic review exists relating to the currently explored area. Therefore, the purpose of this systematic review is to investigate the effects of family/peer-based interventions (involving theoretical frameworks) on type 1 diabetes management and psychosocial functioning among adolescents.

Methods
Eligibility criteria
Studies were included if they were RCTs, used any theoretical/therapeutic frameworks and included adolescents with type 1 diabetes (age <18 years), their peers or friends and parents or families. Two domains of outcome measures were extracted: diabetes functioning/medically performing/HbA1c and psychosocial functioning. Studies were excluded if they involved improving education alone, had no explicit theoretical background, were not a RCT, included children only or adults and did not involve parents or peers.

Search strategy and data extraction
A systematic computerised search was performed in CINAHL, E-journals, Econlit library, Information Science and Technology abstracts, Psycharticles, Socindex, Medline, PsychInfo, Embase, Psychological and Behavioural Sciences Collection, Socindex and Cochrane Central Register of Controlled Trials (from their start date to February 2016). The National Research Register database was searched for unpublished literature and information on unpublished or in-progress research was requested via contacting leading authors. The reference lists of the retrieved studies and other key reviews (eg, Hampson et al) were checked in order to capture other relevant publications (see Appendix A for search terms at www.bjd-abcd.com).

The first researcher independently reviewed all titles and abstracts in two phases. First, the retrieved titles and abstracts were reviewed to identify relevant studies. The full texts of retrieved studies were then read to determine eligibility. A second researcher reviewed all the articles in order to determine the inter-rater reliability in inclusion/exclusion of studies. Any discrepancies or differences in opinion were resolved by consensus. Information from the included articles was extracted using a standardised form. The extraction process identified the following areas from each article: study and country, study population, theoretical framework, time to follow-up, outcome measures and results.

Quality assessment
A tool to assess the methodological quality of quantitative studies was used, which was developed and tested by the Effective Public Health Practice Project. Each study was appraised according to the six criteria and rated as ‘strong’, ‘moderate’ or ‘weak’. The reviewers independently scored all relevant articles for methodological quality. Any discrepancies were resolved through discussion. Ten studies were strong and seven were moderate with none being weak in terms of their quality (see Table 1).

Results
Search results
The search of the databases retrieved 3,074 records. Following broad and narrow screening, 17 papers were considered suitable for inclusion in the review. A study flow diagram of included and excluded studies is provided in Figure 1.

Included studies also differed with regard to the theories, durations and outcome measures (see Table 2). Due to this heterogeneity, it was not possible to perform a meta-analysis. Instead, findings are presented in a narrative format.

Study characteristics
The selected studies varied considerably with regard to their study

| Study reference | Selection bias | Study design | Confounders | Blinding | Data collection methods | Withdrawals/dropouts | Global rating |
|-----------------|----------------|--------------|-------------|----------|-------------------------|----------------------|--------------|
| 56              | Strong         | Strong       | Moderate    | Strong   | Strong                  | Moderate            | Strong       |
| 57              | Moderate       | Strong       | Moderate    | Moderate | Strong                  | Strong              | Strong       |
| 58              | Strong         | Strong       | Moderate    | Weak     | Strong                  | Strong              | Moderate     |
| 59              | Moderate       | Strong       | Weak        | Moderate | Strong                  | Strong              | Moderate     |
| 60              | Strong         | Strong       | Strong      | Strong   | Strong                  | Strong              | Strong       |
| 61              | Moderate       | Strong       | Strong      | Strong   | Strong                  | Strong              | Strong       |
| 62              | Strong         | Strong       | Moderate    | Strong   | Strong                  | Strong              | Strong       |
| 63              | Moderate       | Strong       | Moderate    | Strong   | Strong                  | Strong              | Moderate     |
| 64              | Strong         | Strong       | Weak        | Moderate | Strong                  | Moderate            | Moderate     |
| 65              | Strong         | Strong       | Strong      | Strong   | Weak                    | Moderate            | Moderate     |
| 66              | Strong         | Strong       | Moderate    | Strong   | Strong                  | Strong              | Strong       |
| 67              | Strong         | Moderate     | Moderate    | Strong   | Strong                  | Strong              | Strong       |
| 68              | Strong         | Moderate     | Moderate    | Strong   | Strong                  | Strong              | Strong       |
| 69              | Strong         | Moderate     | Moderate    | Strong   | Strong                  | Strong              | Strong       |
| 70              | Strong         | Strong       | Weak        | Moderate | Strong                  | Strong              | Moderate     |
| 71              | Strong         | Strong       | Weak        | Moderate | Strong                  | Strong              | Moderate     |
| 72              | Moderate       | Strong       | Moderate    | Strong   | Moderate                | Strong              | Strong       |
characteristics (see Appendix B at www.bjd-abcd.com). Studies were conducted between 1985 and 2014, but the majority were published after 2000.

**Efficacy of theory-based interventions on diabetes and psychosocial functioning**

The majority of the reviewed studies involved parents/families except two involving peers. The reviewed studies were group-based except the one by Newton and Ashley, which was a web-based intervention. This section will draw attention towards the efficacy of the interventions based on various theories/therapies mentioned in Box 1. These theories/therapies were used to understand the behaviours influencing the diabetes and psychosocial functioning of the trial participants.

**Social learning and self-efficacy theory** (involving peers and adolescents)

Two studies used and evaluated the value of both theories. The study by Kaplan et al was based on social learning and self-efficacy theory to improve social learning skills and resist peer pressure. Training based on theoretical frameworks produced better glycaemic control at 4 months compared with the control group. There were positive (but non-significant) correlations between social support satisfaction and HbA1C, as well as knowledge and HbA1C. Similarly, there was a positive and significant correlation between the Mean Ends Problem Solving test (MEPS) and HbA1C (p<0.01). These correlations suggest that those who were most satisfied with their networks of social support actually had the poorest glycaemic control. The results of this study also highlight the importance of behaviour in the management of type 1 diabetes rather than just focusing upon knowledge.

Similarly, Newton and Ashley conducted a web-based intervention using self-efficacy theory to improve compliance with treatment protocols and psychosocial functioning. This website seemed to provide problem-solving activities, knowledge about diabetes and a source of social support as well. Self-efficacy was significantly correlated with positive outcome expectations, diabetes self-management and quality of life for youths. In an exit survey, 90% of participants indicated that they were more willing to comply with their treatment protocol after participating in the intervention.

**Empowerment approach** (involving parents and adolescents)

The study by Viklund and colleagues aimed to determine the effects of an empowerment programme on glycaemic control and empowerment and to study the role of parental involvement. Overall, this empowerment programme showed no beneficial glycaemic or empowerment effects 6 and 12 months after the intervention.

**Social cognitive theory, self-regulation model** (families and adolescents)

Nansel and colleagues designed a multicentre group study grounded in social cognitive and self-regulation theories to help families improve diabetes management by facilitating problem-solving skills, communication skills and appropriate responsibility sharing. A significant improvement in glycaemic control was seen in the 12–14-year age group from baseline at the 24-month interval, but not in adherence.

**Positive psychology** (involving parents and adolescents)

Jaser and colleagues focused on testing the feasibility and acceptability of a positive psychology intervention to improve adherence. No main effects for treatment were observed at the 6-month follow-up. However, there was a significant association between adolescents’ levels of positive effect and measures of adherence, including self-report and meter downloads of glucose monitoring. Overall, the high levels of participation and retention indicate that adolescents and their parents were receptive to a positive psychology approach, which places an emphasis on positive emotions and strengths rather than problems.

**Behavioural systems theory (of family functioning)**

**underlying Behavioural Family Systems Therapy** (families and adolescents)

This theory is a combination of behavioural and family systems models (see Box 1) and its efficacy is demonstrated through Behavioural Family Systems Therapy (BFST). Seven studies compared the social validity of the BFST and evaluations of the application of BFST for families of adolescents with diabetes. BFST is based on psychosocial principles of targeting family communication and problem-solving factors. Harris and colleagues examined whether home-based BFST produced clinically significant changes in family conflict in a sample of adolescents with poorly controlled diabetes and their families. The findings of this study suggested improvements in mothers’ and adolescents’ reported diabetes-specific conflict, as well as parent-reported general parent/adolescent conflict.

Wysocki et al compared the social validity of the BFST and Education Support (ES) group interventions as treatments for communication, problem-solving and conflict-resolution skills.
Table 2  Data extraction

| Study/ country | Study population | Theoretical framework | Time to follow-up | Outcome measures | Effect sizes | Results |
|----------------|------------------|-----------------------|-------------------|-----------------|-------------|---------|
| 64/USA         | N=119 2 groups: ES BFST | BFST                  | 3 months          | Treatment evaluation questionnaire | X           | BFST was rated significantly more positively by parents and/or adolescents. Adolescents rated ES less positively than did parents |
|                |                  |                       | 6 and 12 months (results not reported) |                 |             |         |
| 65/USA         | N =119 3 groups: BFST ES CT | BFST                  | 3 months          | PARQ: Overt conflict/skill deficits, Extreme beliefs, Family structure, Number of items endorsed, Total frequency of conflict, Total intensity of conflict | \(-0.13\) | \(-0.19\) | Compared with CT and ES, BFST yielded more improvement in parent/adolescent relations and reduced diabetes-specific conflict. Effects on psychological adjustment to diabetes and diabetes control were less robust. There were no effects on treatment adherence |
|                |                  |                       | 6 and 12 months (results not reported) |                 |             |         |
| 66/USA         | N=119 3 groups: BFST ES CT | BFST                  | 3 months          | PARQ: Overt conflict/skill deficits, Extreme beliefs, Family structure, Number of items endorsed, Total frequency of conflict, Total intensity of conflict, Recall interview conflict scores: Frequency, Intensity, Duration, DRC, TADS, Recall interview adherence factors: Insulin, Testing/eating frequency, Diet composition, Diet amount, Exercise, SCI, HbA1c | X           |                   | Compared with CT and ES, BFST yielded lasting improvements in parent/adolescent relationships and diabetes-specific conflict. Delayed effects on treatment adherence emerged at 6- and 12-month follow-ups. There were no immediate or delayed effects on adolescents’ adjustment to diabetes or diabetic control |
|                |                  |                       | 6 months          |                 |             |         |
|                |                  |                       | 12 months         |                 |             |         | Continued on following page... |
### Table 2  Data extraction continued

| Study/ country | Study population | Theoretical framework | Time to follow-up | Outcome measures | Effect sizes | Results |
|----------------|------------------|-----------------------|-------------------|-----------------|-------------|---------|
| 67/USA         | N=104            | Group BFST-D          | 6 months (post-treatment) | PARQ: Overt conflict/skill deficit | 0.01 0.06 | BFST-D significantly improved family conflict and adherence compared with SC and ES, especially among those with baseline HbA₁C ≥9.0%. BFST-D and ES significantly improved HbA₁C compared with SC among those with baseline HbA₁C ≥9.0% |
|                |                  |                       |                   | Extreme beliefs | 0.0 -0.01 |         |
|                |                  |                       |                   | Family structure| 0.49 0.50 |         |
|                |                  |                       |                   | DRC             | X           |         |
|                |                  |                       |                   | DSMP            | X           |         |
|                |                  |                       |                   | HbA₁C           | X           |         |
| 68/USA         | N=104            | Group BFST-D          | 3 months          | DSMP (total scores) | X         | BFST-D was significantly superior to both SC and ES in effects on HbA₁C while effects on treatment adherence and family conflict were equivocal. A significantly higher percentage of BFST-D youth achieved moderate or greater improvement (0.5 SD) in treatment adherence compared with the SC group at each follow-up and the ES group at 6 and 18 months. Change in treatment adherence correlated significantly with change in HbA₁C at each follow-up |
|                |                  |                       |                   | DRC (family composite score) | X |         |
|                |                  |                       |                   | HbA₁C (%)       | -0.18 0.06 |         |
|                |                  |                       | 6 months          | DSMP (total scores) | 0.60 0.26 |         |
|                |                  |                       |                   | DRC (family composite score) | -0.30 -0.53 |         |
|                |                  |                       |                   | HbA₁C (%)       | -0.18 -0.07 |         |
|                |                  |                       | 9 months          | DSMP (total scores) | X |         |
|                |                  |                       |                   | DRC (family composite score) | X |         |
|                |                  |                       |                   | HbA₁C (%)       | -0.52 -0.61 |         |
|                |                  |                       | 12 months         | DSMP (total scores) | 0.65 0.24 |         |
|                |                  |                       |                   | DRC (family composite score) | 0.06 -0.19 |         |
|                |                  |                       |                   | HbA₁C (%)       | -0.46 -0.28 |         |
|                |                  |                       | 15 months         | DSMP (total scores) | X |         |
|                |                  |                       |                   | DRC (family composite score) | X |         |
|                |                  |                       |                   | HbA₁C (%)       | -0.68 -0.74 |         |
|                |                  |                       | 18 months         | DSMP (total scores) | 0.37 0.18 |         |
|                |                  |                       |                   | DRC (family composite score) | 0.17 -0.33 |         |
|                |                  |                       |                   | HbA₁C (%)       | -0.49 -0.46 |         |

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| Study/ country | Study population | Theoretical framework | Time to follow-up | Outcome measures | Effect sizes | Results |
|---------------|------------------|-----------------------|------------------|-----------------|-------------|---------|
| 69/USA        | N=104            | Group BFST-D          | 6 months         | IBC for negative communication Adolescents | −0.88 | BFST-D improved individual communication of adolescents and mothers, but not fathers. BFST-D significantly improved quality of family interaction compared with SC and ES. Changes in family communication were differentially associated with changes in glycaemic control, adherence and family conflict |
|               |                  |                       |                  | Mothers          | −0.47 | |
|               |                  |                       |                  | Fathers           | 0.13 | |
|               |                  |                       | 12 months        | IBC for negative communication Adolescents | −0.83 | |
|               |                  |                       |                  | Mothers           | −0.46 | |
|               |                  |                       |                  | Fathers           | −0.23 | |
|               |                  |                       | 18 months        | IBC for negative communication Adolescents | −0.71 | |
|               |                  |                       |                  | Mothers           | −0.58 | |
|               |                  |                       |                  | Fathers           | −0.06 | 0.0 |
|               |                  |                       | 6 months         | IBC for positive communication Adolescents | 0.49 | |
|               |                  |                       |                  | Mothers           | 0.69 | 0.51 |
|               |                  |                       |                  | Fathers           | 0.28 | 0.39 |
|               |                  |                       | 12 months        | IBC for positive communication Adolescents | 0.29 | |
|               |                  |                       |                  | Mothers           | 0.55 | 0.58 |
|               |                  |                       |                  | Fathers           | 0.66 | 0.58 |
|               |                  |                       | 18 months        | IBC for positive communication Adolescents | 0.49 | |
|               |                  |                       |                  | Mothers           | 0.63 | 0.23 |
|               |                  |                       |                  | Fathers           | 0.44 | 0.46 |
|               |                  |                       |                  | HbA1c             | X | |
|               |                  |                       |                  | DRC               | X | |
|               |                  |                       |                  | DSMP              | X | |

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### Table 2  Data extraction continued

| Study/ country | Study population | Theoretical framework | Time to follow-up | Outcome measures | Effect sizes | Results |
|----------------|------------------|-----------------------|-------------------|------------------|-------------|---------|
| 63/Sweden      | N=55 2 groups: Intervention Control | Empowerment theory | 6 months 12 months 2 months | HbA1c | X | HbA1c and empowerment were similar in the intervention group and the control group 6 months after intervention. In pre/post analysis, HbA1c was significantly higher 6 and 12 months after intervention in teenagers >14 years (from 8.4% to 9.3%; P<0.05 to 9.6%; P<0.01), but returned to baseline 18 months after the programme. In teenagers ≤14 years of age, HbA1c did not change during the study. The teenagers felt more ready for changes after the programme than before (3.9 (SD 0.5) to 4.1 (SD 0.5); P< 0.05). In the teenagers’ group that involved their parents there was a significant decrease in HbA1c 12 and 24 months after intervention (from 8.9% (SD 1.1) to 7.6% (SD 1.3); P<0.05, CI 0.37 to 2.26) |
| 70/USA         | N=50 2 groups: Intervention Control | Self-efficacy theory | 7 weeks | Diabetes quality of life | 0.16 | There was a marginally significant difference between the two groups on the combined measures (P=0.052), with the control group scoring significantly higher on positive outcome expectations (P=0.03) both pre- and post-treatment. Self-efficacy was significantly correlated with positive outcome expectations (r=0.30, P=0.037) and Diabetes Self-Management and Diabetes Quality of Life for Youths (r=0.43, P=0.002). In an exit survey, 90% of participants indicated that they were more willing to comply with their treatment protocol after participating in the web-based intervention |
| 72/USA         | N=30 2 groups: Intervention Control | Peer group and family-based | 6 months | Primary care giver: Brief symptom inventory | 0.03 | At 4 months post treatment, parents and youths reported increased parent responsibility, and parents reported improved youth diabetes-specific quality of life. Although there were no statistically significant changes in HbA1c values and healthcare utilisation frequency from 6 months prior to and 6 months post treatment, other psychosocial changes (e.g., increases in parent responsibility and diabetes-specific quality of life) were documented. Therefore, this treatment was found to be a promising intervention for use in an outpatient clinical setting to aid in improving the psychosocial functioning of youth with type 1 diabetes mellitus |
|                |                  |                       |                   | Behavioural assessment scale for children | 0.00 | |
|                |                  |                       |                   | Diabetes family relationship questionnaire | 0.47 | |
|                |                  |                       |                   | Paediatric quality of life inventory generic | 0.06 | |
|                |                  |                       |                   | Paediatric quality of life family impact module | 0.05 | |
|                |                  |                       |                   | Readiness to change the balance of responsibility scale | 0.23 | |
|                |                  |                       |                   | SCI | 0.11 | |
|                |                  |                       |                   | Diabetes family responsibility questionnaire | 0.47 | |
|                |                  |                       |                   | Paediatric quality of life inventory diabetes | 0.43 | |
|                |                  |                       |                   | Youth: Brief symptom inventory | 0.00 | |
|                |                  |                       |                   | Diabetes family relationship questionnaire | 0.28 | |
|                |                  |                       |                   | Readiness to change the balance of responsibility scale | 0.09 | |

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### Table 2 Data extraction continued

| Study/ country | Study population | Theoretical framework | Time to follow-up | Outcome measures | Effect sizes | Results |
|----------------|------------------|-----------------------|-------------------|------------------|-------------|---------|
|                |                  |                       |                   | Paediatric quality of life inventory generic | 0.11        |         |
|                |                  |                       |                   | Paediatric quality of life inventory diabetes | 0.00        |         |
|                |                  |                       |                   | SCI              | 0.14        |         |
|                |                  |                       |                   | HbA1c            | X           |         |
| 56/USA         | N=25             | MST= cognitive-behavioural therapy, parent training and behavioural family systems therapy | 6 months          | GHb              | -0.69       |         |
|                |                  |                       |                   | DMS-A            | -0.17       |         |
|                |                  |                       |                   | DMS-P            | -0.06       |         |
|                |                  |                       |                   | Meter (frequency of blood glucose testing from meter) | 0.29 |         |
|                |                  |                       |                   | INSADH (24-hour recall insulin adherence) | 0.59 |         |
|                |                  |                       |                   | EATADH (24-hour recall dietary adherence) | -0.61 |         |
|                |                  |                       |                   | BGTS (24-hour recall blood glucose testing adherence) | 0.17 |         |
|                |                  |                       |                   | Emergency room visits | 0 |         |
|                |                  |                       |                   | Inpatient hospital admissions | -0.68 |         |
|                |                  |                       |                   | Satisfaction with treatment | X |         |
|                |                  |                       |                   | Adolescents who received MST had significantly improved adherence to blood glucose testing and metabolic control from study entry to the 6-month post-test, whereas controls did not. Adolescents receiving MST also had a decreased number of inpatient admissions at the 6-month post-test. Improvements in metabolic control were related to improvements in parent report of adolescent adherence. Results suggest that MST holds promise as an intervention for improving adherence behaviour and health outcomes among adolescents in poor metabolic control. |
| 57/USA         | N=127            | MST= cognitive-behavioural therapy, parent training and behavioural family systems therapy | 7 months          | HbA1c            | NS          |         |
|                |                  |                       |                   | Meter            | 1.09        |         |
|                |                  |                       |                   | Insulin adherence | NS          |         |
|                |                  |                       |                   | Dietary adherence | NS          |         |
|                |                  |                       |                   | Blood glucose testing adherence | 0.83 |         |
|                |                  |                       |                   | Emergency department visits | NS |         |
|                |                  |                       |                   | Admissions       | 0.63        |         |
|                |                  |                       |                   | Not reported     |             |         |
|                |                  |                       |                   | Intent to treat (ES given) | In intention-to-treat analyses, participation in MST was associated with significant improvements in the frequency of blood glucose testing as assessed by blood glucose meter readings (F[1,125]=16.75, P=0.001) and 24-hour recall interviews (F[1,125]=6.70, P=0.011). Participants in MST also had a decreasing number of inpatient admissions, whereas the number of inpatient admissions increased for control subjects (F[1,125]=6.25, P=0.014). |
| 58/USA         | N=127            | MST                      | Post-treatment 7 months | DFBC primary caregiver | 0.14 |         |
|                |                  | Therapists               |                   | DFBC secondary caregiver | 0.73 |         |
|                |                  | Therapists               |                   | FRI               | 0.02        |         |
|                |                  | Therapists               |                   | MST increased support for diabetes care from both primary and secondary caregivers in two-parent but not in single-parent families. However, MST had the strongest effects on BGT and metabolic control in single-parent families. MST had a direct effect on BGT for all participants. BGT mediated improvements in metabolic control among single-parent families. Overall, MST improved family | Continued on following page... |
Table 2  Data extraction continued

| Study/country | Study population | Theoretical framework | Time to follow-up | Outcome measures | Effect sizes | Results |
|---------------|------------------|-----------------------|-------------------|-----------------|-------------|---------|
|               |                  |                       |                   | HbA1C           | −0.46       |         |
|               |                  |                       |                   | BGT frequency   | 0.73        |         |
|               | 12 months        |                       |                   |                 |             |         |
|               | 18 months        |                       |                   |                 |             |         |
|               | 24 months        |                       |                   |                 |             |         |
|               | (not reported)   |                       |                   |                 |             |         |
| 61/USA        | N=70             | Social cognitive theory, self-regulation models and systems theory | 6 months | HbA1C | X | A significant overall intervention effect on change in glycemic control from baseline was observed at the 24-month interval (P=0.03). Among participants aged 12–14, a significant effect on glycemic control was observed (P=0.009 for change from baseline to 24-month interval; P=0.035 for mixed-effect model across study duration). There was no intervention effect on child or parent report of adherence; however, associations of change in adherence with change in glycemic control were weak. This clinic-integrated behavioral intervention was effective in preventing the deterioration in glycemic control evident during adolescence, offering a potential model for integrating medical and behavioral sciences in clinical care. |
|               | 2 groups:        |                       |                   |                 |             |         |
|               | Intervention     |                       |                   |                 |             |         |
|               | Control          |                       |                   |                 |             |         |
|               | N=32             |                       | 12 months         | HbA1C | X |         |
|               | 3 groups:        |                       | 18 months         | HbA1C | X |         |
|               | MF + S           |                       | 24 months         | HbA1C | X |         |
|               | Control          |                       |                   | Adherence in parents and older youth 11+ (DSMP) | X |         |
|               | N=21             | Social learning theory | 6 weeks post- intervention | HbA1C | X | Adolescents in the MF+S group displayed significant decrements in HbA1C and adolescents in both intervention groups reported more positive perceptions of a ‘teenager with diabetes’ post-treatment relative to controls. Adolescents participating in smaller family groups demonstrated clinically significant improvements in HbA1C that were maintained at 6-month follow-up. Parent reports suggested that adolescents in the intervention groups improved their diabetes care. Findings support the use of multifamily groups plus parent simulation of diabetes as an intervention strategy for adolescents with type 1 diabetes. |
|               | 2 groups:        | Psychological social worker and a nurse practitioner | 6 weeks | HbA1C | −0.63 |         |
|               | Intervention     |                       |                   |                 | 0.24        |         |
|               | Control          |                       | 3 months (planned comparison) | HbA1C | −0.67 |         |
|               |                 |                       |                   |                 | 0.27        |         |
|               | N=58             | BFST-D model          | Post-treatment (6–10 weeks) | HbA1C | −0.97 | Four months after the intervention, HbA1C was significantly lower in the social skills intervention group. A variety of variables were significantly correlated with good metabolic control. These included self-reported compliance with a diabetes regimen and attitudes toward self-care. Unexpectedly, variables correlated with poor diabetes control included social problem-solving ability and satisfaction with social support. |
|               | 2 groups:        |                       |                   | Diabetes knowledge | −1.27 |         |
|               | BFST Control     |                       |                   | Attitude | −1.01 |         |
|               |                 |                       |                   | Behaviour, Sarason social support questionnaire | X |         |
|               |                 |                       |                   | MEPS test | X |         |
|               |                 |                       |                   |                 |             |         |
|               |                 |                       |                   |               |             |         |

Continued on following page...
The results indicated that adolescents and their mothers who had experienced BFST rated it as significantly more acceptable, applicable and effective in terms of improving family communication, problem-solving and conflict-resolution skills than did those who experienced the ES intervention. Furthermore, Wysocki and his associates demonstrated that 10 sessions of BFST improved family communication and problem-solving based on parent and adolescent reports and direct observation of family interactions. These benefits persisted for 12 months. Wysocki and co-workers conducted another randomised controlled trial implementing a modified version of BFST-D. The results demonstrated significant improvements in glycaemic control, treatment adherence and diabetes-related family conflict immediately post-treatment. These effects were maintained over a 12-month follow-up period.

**Theory of social ecology underlying Multi-Systemic Therapy (families and adolescents)**

This theory has been used as a conceptual framework of Multi-Systemic Therapy (MST; see Box 1). MST is an intensive home-based treatment model, designed to target adherence-related problems within the family system, schools, peer network, healthcare system and broader community systems. Ellis and colleagues demonstrated that adolescents who received MST had significantly improved adherence to blood glucose testing and metabolic control (compared with standard care) at 6 months post-test. In general, parents in the treatment condition reported high levels of satisfaction with MST. Adolescents who received MST had a significantly decreased number of hospital admissions during the 6-month study period.

Following the findings of this study, Ellis and colleagues conducted a study in 2005, which demonstrated that participation in MST was associated with significant improvements in the frequency of blood glucose testing and 24-hour recall interviews. The MST group also had a decreased number of inpatient admissions whereas the number of inpatient admissions increased among control group participants. Furthermore, the findings of their study in 2007 demonstrated that MST increased support for diabetes care from both primary and secondary caregivers in two-parent but not in single-parent families. However, MST had the strongest effects on blood glucose testing and metabolic control in single-parent families.

Following the review of the MST and BFST, Kichler et al developed the ‘Kicking in Diabetes Support’ project, which aimed to provide both peer group and family-based interventions to adolescents with type 1 diabetes and their parents. Although there were no statistically significant changes in HbA1C and healthcare utilisation...
frequency at 6 months post-treatment, other psychosocial changes were documented, such as increases in parent responsibility and parents reported improved youth diabetes-specific quality of life. Therefore, this intervention appears to be a treatment modality that is feasible, acceptable and adaptable in a clinical setting by licensed psychologists and trainees (to improve the psychosocial functioning of youths with type 1 diabetes). 1

**Family systems theory underlying multi-family group intervention plus parent simulation** (parents and adolescents).

Family systems approach is applied within a group therapy format (mentioned above). One study evaluated the impact of a 6-week multi-family (MF) intervention and parent simulation (S) on adolescents’ metabolic control and psychosocial and family functioning. The results demonstrated significant improvements/decrements in metabolic control in the MF and S groups in comparison with the control group in the first, second and third cycle of the study. In terms of perception/attitude, improvement was noted in adolescents’ attitudes towards a teenager with diabetes for those in the MF and MF+S groups relative to the controls. Overall, it is important for parents and their child to gain a better insight into each other’s views. Asking parents to simulate diabetes management for 1 week was a novel way of trying to achieve this. 74

Please see the supplementary material in Appendix C (see www.bjd-abcd.com) for a brief description about effect sizes.

**Discussion**

Seventeen studies were included in this review, but few studies included the same comparisons and outcomes and therefore a meta-analysis was not conducted. The initial studies by Wysocki and colleagues reported that BFST compared with current therapy and ES yielded more improvements in parent/adolescent relationships. However, in 2006 they reported non-significant findings related to the same measure (all subscales of the Parent-Adolescent Relationship Questionnaire= N5). In 2000, it was indicated that their intervention had no effect on treatment adherence at post-treatment. This was contrary to the results reported by them in 2001, in which the BFST group showed significantly improved treatment adherence at 6 and 12 months follow-up. In their 2000 study Wysocki et al included 3-month follow-up but, unlike other studies, they did not measure outcomes at 6 and 12 months. It may be that short-term behavioural approach-based interventions promote improvements in parent/adolescent relationships. However, treatment adherence can be improved and maintained by a prolonged change in family interaction patterns.

Although tried to tailor their intervention to support adolescents through the empowerment programme, no positive glycaemic or empowerment effects were found for teenagers with diabetes. One interpretation was that perhaps the teenagers (<14 years) were too young to incorporate the described components of empowerment. Additionally, among teenagers who invited their parents to participate in the intervention, HbA1C did not increase, which was in accordance with the literature, suggesting the importance of family support to facilitate coping with everyday management and demands of diabetes. 5,76,77

In this review, a variety of interventions which resulted in significant reductions in HbA1C involved parents and had beneficial effects on diabetes management. The parental simulation approach used by Satin and colleagues also resulted in a large beneficial effect on HbA1C. Research has suggested that the frequency of blood glucose monitoring is increased with parental involvement which, in turn, is associated with better metabolic control. Furthermore, a high level of support from family members leads adolescents to better adhere to their diabetes regimen.

A variety of other interventions indicate that family-based behavioural approaches such as goal-setting, self-monitoring, positive reinforcement, behavioural contracts, supportive parental communications and appropriately shared responsibility for diabetes management have improved regimen adherence, parent/adolescent relationships and glycaemic control. However, low levels of family support and increased family conflict have been consistently associated with poor diabetes self-management, metabolic control, psychosocial adaptation and quality of life in adolescents with type 1 diabetes. 2,11,81

On the other hand, peer group interventions indicate that peer group support and problem solving can improve short-term glycaemic control. Group coping skill training improved glycaemic control and quality of life for adolescents involved in intensive insulin regimens. Stress management, problem solving and coping skill training, delivered in small groups, has reduced diabetes-related stress, improved social interaction, increased glucose monitoring and improved glycaemic control.

In the current review, the importance of integrating medical, behavioural and psychosocial components into the interventions were underscored by at least six of the RCTs. The results suggest that multi-component interventions may be more successful for adolescents than those that just focus on one aspect – for example, psychological in the study by Newton and Ashley.

Home-based interventions, although more time consuming for healthcare professionals (HCPs), appear to be a viable and accessible alternative for intervening with many of the families. Such interventions provide an ecologically valid family-centered means of engaging adolescents and their parents in treatments. In addition, they may also allow the HCPs to better understand the ‘real-world’ barriers to regimen adherence. It is also important to note that the home-based intervention by Ellis et al demonstrated high rates of recruitment (70%) as well as high retention rates (75%) in a treatment that lasted >5 months on average. This suggests that, when such interventions are provided in a way that increases access, they have a high likelihood of being accepted by such adolescents and their families. Cost-effectiveness studies are needed to assess whether the greater uptake and effects offset the costs of staff travel.

**Strengths of the study**

This review was not limited to one geographical area or one country. Furthermore, to the best of our knowledge, no systematic review has evaluated family/peer- and theory-based interventions involving adolescents and families/peers. Studies included in the review were RCTs, which reduced evaluation of...
interventions with recruitment and other study design bias eliminated by randomisation.

Limitations of the study
It is acknowledged that this review includes a relatively small number of studies with rather small sample sizes, which makes it difficult to draw conclusions from the results. Interventions developed in the USA require modification and re-evaluation for application in the UK. This review exposed interventions, mostly including parents and rarely including peers, which were evaluated by assessing widely differing outcomes. Due to the heterogeneity of the studies, it was not possible to perform a meta-analysis.

The heterogeneity of young people with diabetes was generally not reflected in the RCTs undertaken to date, although some did select those with poor glucose control. A patient group at high risk are those with repeated hospitalisations, who are particularly likely to have a high prevalence of psychosocial issues and among whom a combined outreach diabetes specialist–mental health team approach might be able to reduce admissions and length of stay and improve glycaemic control.

Conclusion
Overall, interventions including parents have small- to large-sized beneficial effects on a variety of diabetes management outcomes. Studies identified here addressing the issue of parental involvement support the evidence that developmentally appropriate and negotiated responsibility has beneficial outcomes. Narrative analysis suggests that interventions are more likely to be effective if they demonstrate the inter-relatedness of the various aspects of diabetes management. The evaluation of interventions needs to be by well-designed theory-based RCTs, of sufficient size, over a long-term period, which report results in such a way that effect sizes can be calculated. Home-based interventions could be more viable and accessible alternatives for intervening with many of the families than office- or hospital-based interventions. Future studies should estimate the costs associated with delivering such interventions involving families and also clarify the theoretically guided design of the intervention and the selection of the outcomes. The development process should involve stakeholders (i.e., adolescents, their families and HCPs) to co-design a potentially cost-effective and feasible intervention in the context of NHS diabetes services. Such interventions need to be understood and accepted by the HCPs and managers as key and integral parts of diabetes care.

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None.

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Key messages
• Interventions involving parents had beneficial effects on diabetes management and significant reduction in HbA1c
• Family-based behavioural approaches such as goal-setting, self-monitoring, positive reinforcement, behavioural contracts, supportive parental communications, and appropriately shared responsibility for diabetes management showed improved regimen adherence, parent-adolescent relationship and glycaemic control
• Multi-component interventions may be more successful than those just focusing upon one aspect
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Appendix A

The following search terms were used to find studies:

(1) Adolescence OR adolescent OR youth OR young people OR young person, OR teen OR juvenile OR puberty
(2) Diabetes
(3) Program OR intervention OR randomised controlled trial OR RCT
(4) Peer OR family OR parent OR friend and
(5) Outcome OR efficacy OR control OR communicat OR social OR knowledge OR diet OR skill OR exercise.
Appendix B

Study characteristics

Country of origin
The majority of studies (n=16) were conducted in the USA (94.2%) and only one study was conducted in Sweden (5.8%). These countries are classified as individualist and so can be considered broadly homogenous.

Study design
Although all studies within this review were RCTs, only 14 reported the method of randomisation and the remaining three did not specify it clearly. Studies including RCTs in the review typically had one intervention group with a control group (58.8%). A small number had one intervention group with two control/comparison groups (41.2%).

Data collection
Ten of the 17 studies collected data at two time points (baseline and post-treatment); one study collected data at three time points (baseline, 3 and 6 months follow-up); three studies collected data at four different time points (baseline, 3, 6 and 12 months; baseline, 2, 6 and 12 months; and pre-treatment, 6 weeks, 3 and 6 months); one study collected data at five time points (baseline, 6, 12, 18 and 24 months); and two studies collected data at seven time points (baseline, 3, 6, 9, 12, 15 and 18 months).

Baseline reported results
Nine studies reported baseline differences between groups but no significant differences were noted. Of the remaining studies, one reported significant and non-significant differences at baseline, two reported significant differences between groups at baseline and five did not specifically report baseline differences between groups.

Intervention characteristics

Intervention length
The duration of the peer/parent-based interventions ranged from 1 hour to 3 weeks; 6 weeks; 8 weeks; 3 months; 6 months; 6 months; 8 weeks; 6 months; 3 months; 6 weeks; 3 months; 6 months; 24 months.

Setting
Reports were frequently explicit about where the interventions had been conducted. Hospital outpatient clinics (n=13, 76.5%) were the most likely setting for interventions, followed by home and community-based settings (17.6%) and a school based-setting (5.9%). The most typical setting was the diabetes outpatient clinic.

Delivery of interventions
Most interventions were delivered by a range of highly qualified professionals (eg, psychologist, therapist, health advisor or social worker). However, in some studies it was difficult to identify who delivered which part of the intervention.

Skills training
The majority of the interventions used some form of social, psychological, cognitive and behavioural skills training (82.4%), followed by group therapy, independent problem solving (11.7%) and lecture/discussion-based sessions (5.9%).

Intervention measures
All studies (except the study by Newton and Ashley) provided a full description of the intervention and used HbA1c as the primary outcome measure, which was measured at baseline and at each follow-up. Validated measures were used to assess secondary outcomes, which varied between studies (see Table 1).

Participant characteristics

Demographics
Most studies reported the ethnicity of the participants with the exception of two studies. The sample size varied greatly from 11 to 127 (in each group). Details of sample size justification were only provided for five studies based on power analysis calculations. Across the 17 studies, the total number of adolescents was 1,623. More than half of the studies involved fewer than 130 participants. Given that most of the studies involved an intervention group and a control group, subject numbers per condition tended to be sufficient. The mean age of adolescents across all the studies was 14.29 years and the mean duration of diabetes was 5.6 years. Only 13 studies reported attrition rates (4–37%).
**Appendix C**

**Effect sizes**

Effect sizes could be computed using Cohen’s $d$ for HbA1c in five of the 17 interventions and for psychosocial functioning and other outcome measures in 10. The remaining interventions had insufficient data (eg, no means or SDs) to calculate the effect sizes.

**HbA1c**

Negative effect sizes regarding HbA1c were indicated in Wysocki et al. at 6-month follow-up periods. However, it is noted that HbA1c for the Behavioural Family Systems Therapy (BFST-D) group was significantly lower than that of the standard care (SC) group at months 6, 9, 12, 15 and 18, and significantly lower than that of the Education and Support (ES) group at months 9, 15 and 18. Additionally, two more studies demonstrated negative effect sizes regarding HbA1c. However, in the study by Ellis et al., adolescents receiving Multi-Systemic Therapy (MST) had significant improvements in metabolic control from study entry to 6 months post-test. Similarly, Ellis et al. reported a significant change (ie, HbA1c decreased 0.92%) in youth in single-parent families assigned to MST.

At 3-month follow-up, a multi-family (MF) group intervention plus parent simulation (S)-based study (three groups) was found to have a large effect size on metabolic control measured by the HbA1c. Further follow-up effect size was also quite large in this study when MF+S was compared with control at 6 months. The findings of the second and third cycles of this study also demonstrated a large effect size at 3 and 6 months.

Findings of a 3-month study demonstrated a small effect size on HbA1c (0.28 when BFST was compared with ES rather than current therapy (CT), 0.18). At 7 months the MST-based intervention was compared with SC using two approaches: intent to treat analysis and per-protocol analysis, where a medium effect size on HbA1c (0.64) was found only in the per-protocol analysis.

**Psychosocial, diabetes management and adherence measures**

Negative effect sizes regarding psychosocial measures were indicated in the study by Wysocki et al. at the 3-month period. However, the BFST group improved significantly more on the overt conflict and deficit scale and on the extreme belief scale than the CT group. A significant main effect for groups on change in the DRC family composite scores was found, favouring the BFST group, but no significant main effects for the SCI and TADS. At 6 months the BFST-based intervention was found to have a moderate effect size on one of the subscales called family structure (0.48).

In a later study, Wysocki et al. at 6-month follow-up reported a medium effect size on the diabetes self-management profile (0.56). These results are indicated to be sustained at 1 year (0.6) and at 18 months (0.36). This study had negative effect sizes related to the DRC scale at 6, 12 and 18 months. Furthermore, negative effect sizes were indicated in a further study by Wysocki et al. related to IBC for negative communication for all participants at 6, 12 and 18 months. However, it is noted that adolescents and mothers in the BFST-D group had significantly lower scores than the SC group (at all follow-ups) and ES at the 6-month follow-up only. For positive communication, high medium effect sizes were indicated in this study for:

1. Adolescents (at 6 months, 0.6; 12 months, 0.30; and 18 months, 0.54)
2. Mothers (at 6 months, 0.60; 12 months, 0.53; and 18 months, 0.61)
3. Fathers (at 6 months, 0.37; 12 months, 0.66; and 18 months, 0.44).

A 5–8-week long home-based BFST indicated negative effect sizes on DRC and CBQ outcome measures for all participants. However, post treatment the BFST group (including all participants) scored much lower on the DRC and CBQ measures than the control group. At 7 months the MST-based intervention was found to have very small and large effect sizes on family functioning as measured by the FRI (0.02), DFBC (primary caregivers, 0.13) and DFBC (secondary caregivers, 0.94).

A web-based 7-week long intervention demonstrated small effect sizes for diabetes quality of life (0.19) and self-efficacy of diabetes management (0.21). However, Kichler and colleagues’ ‘Kicking in Diabetes Support’ intervention demonstrated small to medium effect sizes at 6 months post test on readiness to change the balance of responsibility scale (0.23), diabetes family relationship questionnaire (0.28), paediatric quality of life inventory diabetes (0.43) and diabetes family relationship questionnaire (0.47).
In terms of diabetes management and adherence-related factors, negative effect sizes were indicated in the study by Wysocki and colleagues on all IC, intensity, duration and diet amount scores at 3 months. This study also indicated small effect sizes on frequency (0.06), insulin (0.20) and exercise (0.17), a moderate effect size on diet composition (0.5) and a large effect size on testing/eating frequency (0.71). Moreover, another study indicated negative effect sizes at 6-month follow-up related to DMS-A, DMS-P, EATADH (24-hour recall dietary adherence) and hospital admissions. However, there was a significant difference in hospital admission between the intervention and control groups at 6 months. This study also indicated a small effect size on BGTS (24-hour recall blood glucose testing adherence) (0.15) and moderate effect sizes on meter (0.36) and 24-hour recall insulin adherence (INSADH) (0.48). Furthermore, at 7 months an MST-based intervention was found to have moderate effect sizes on admissions (0.63 and 0.65) and large effect sizes on meter (1.09 and 1.01) and BGTS (0.83 and 1.05). A moderate effect size was indicated by Ellis et al on BGT frequency (0.67) at 7 months post-test.

Overall, a variety of studies used diverse outcome measures. Some studies provided insufficient data to estimate accurate effect sizes. However, three outcome measures were consistently used across studies: (1) HbA1c (6 studies); (2) PARQ (2 studies); and (3) DRC (3 studies). These studies had inconsistencies in the follow-up periods and had small sample sizes (see Table 1). It should be noted by looking at the individual effect sizes of the studies that two interventions were much longer in duration (e.g., 18 months) than the remaining seven interventions. However, much larger effect sizes (at 3 months, 2.08; 6 months, 1.25) were found in the study by Satin et al related to HbA1c compared with all the remaining studies.