

A Controlled Trial of “Family Approach to Diabetes Management” in Poorly Controlled Adolescents with Type 1 Diabetes



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Background

Management of adolescents with Type 1 Diabetes Mellitus (T1DM) is notoriously difficult. The burden of a relentless chronic condition that requires multiple points of care per day does not fit well with an adolescent's need to feel increasingly independent yet not different to peers. The addition of a complex mix of hormonal changes, rapid growth, self-image awakening, limit testing and exposure to drugs and alcohol fosters a potent cocktail that makes good glycaemic control difficult.

The impact of T1DM on the adolescent and family, especially the shared trauma of diagnosis that cannot be cured or “fixed”, and the parallel and interconnectedness between family functioning, adolescent behaviour and glycaemic control makes diabetes a family disease. With increasing evidence of a permanent metabolic memory of poor control, the wayward adolescent risks long term complications which in turn increases their parents' distress and sense of disempowerment.

Diabetes teams strive to assist adolescents and families achieve a balance where neither glycaemic control nor quality of life are compromised but do not necessarily have the tools to deal with the poorly controlled adolescent with T1DM. Unfortunately few intervention models are both cost-effective and successful in addressing adolescent problems with diabetes management. (1)

The Family Approach to Diabetes Management (FADM) is a model of intervention that stresses family self-management by identifying and exploring patterns of family communication that hinder or support positive clinical outcomes. It has been successfully implemented in small clinics in the USA, with reported improved glycaemic control, reduced depression, anger, non-compliance and mismanagement. (1) Parents and siblings have less anxiety and health care professionals report less burnout and improved sense of professional competence.

Psychological care of families with T1DM tends to be separated from the clinical aspects of diabetes in Australia with many medical and nursing staff having insufficient training or support in psychological techniques. Hence if issues of non-compliance, anger, distress or deliberate mismanagement occur, a referral to psychology or social work services is often initiated. The acquisition of such skills by medical and nursing staff empowers a team with tools that can be applied immediately, consistently and as “normal” management of T1DM.

FADM techniques have been taught to members of Australian diabetes teams through workshops over the past few years. Our regional diabetes team has embraced the FADM techniques and sought to evaluate its effect on Australian families.

Objectives

To evaluate the impact of the Family Approach to Diabetes Management on glycaemic control of poorly controlled adolescents with T1DM.

Methods

Our independent diabetes team manages 103 children, adolescents and young adults with T1DM over a broad section of regional Victoria and metropolitan Melbourne. The model has evolved over the past 10 years to its current self-sufficient, co-located multidisciplinary team. Before 2007 management was attempted through individual practitioner consultations with tertiary outreach. The “RADICAL” (Rural Australian Diabetes Inspiring Control Activity and Lifestyle) model (2) created in 2007 incorporated psychology skills as part of all consultations as well as post consultation multidisciplinary case meetings. We embraced modern technology including insulin pumps (currently approximately 80% of patients) and Continuous Glucose Monitoring.

The current model of care comprises the core team of general paediatrician specialising in diabetes and diabetes nurse educator co-consulting with families, reserving psychology services for genuine depression rather than diabetes distress symptoms. The successful development of such a model has required both core members to be upskilled in psychological techniques involving a family based approach.

In 2013, an Australian training workshop in the Family Approach to Diabetes Management was facilitated by FADM creator and coach Joe Solowiejczyk and attracted over 25 diabetes nurse educators and included our team.

Immediately before the workshop, our team selected seven adolescents (mean age 14.9 years) with poorly controlled diabetes to be subject to the FADM approach. Eligibility criteria included a reasonably stable two parent family with symptoms of diabetes distress whose adolescent with T1DM had poor glycaemic control (HbA1c >8.3% or 67 mmol/mol) over the previous year and had demonstrated symptoms of defiance, anger and indifference to requested management.

The initial FADM consultation comprised the FADM coach and the core diabetes team (paediatrician and diabetes nurse educator) and was conducted by a one hour videoconference to the family.

Follow up comprised face to face consultations, and some videoconference consultations, phone calls and SMS messages done entirely by our local diabetes team who had been by then up-skilled in FADM.

We compared the intervention group with seven aged matched adolescents (mean age 14.1 years) with the same eligibility criteria who continued standard diabetes management and support with the same diabetes team. In both groups, 6 of 7 were managed with Insulin Pump Therapy.

Methods (ctd)

The study was terminated after 9 months because the effect of the FADM intervention was obvious and the team planned to implement the intervention to adolescents in the control group.

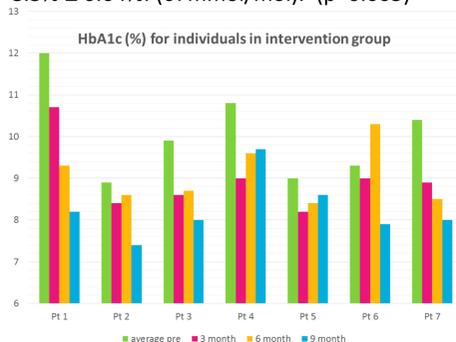
The average HbA1c for the twelve months prior to therapy was compared with the HbA1c at three six and nine months after the intervention and to corresponding HbA1c of the control group.

Statistical analysis between groups was made using Student t-test.

Results

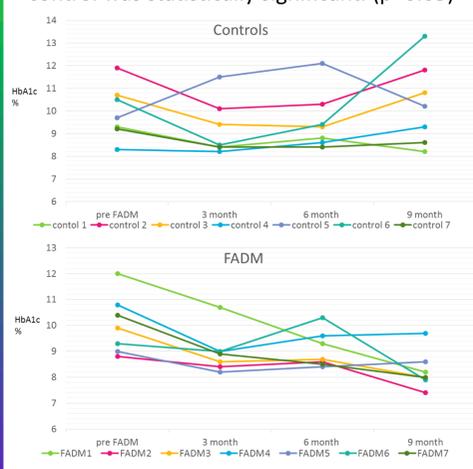
Glycaemic control over previous year in the intervention group measured mean HbA1c of 10.0% ± 1.12 (86mmol/mol) with age matched control glycaemic control HbA1c over the previous year of 10.1% ± 1.02 (87mmol/mol).

By 9 months post intervention the intervention group had improved HbA1c from 10.0% (86mmol/mol) (median 9.8%) to 8.3% ± 0.64%. (67mmol/mol). (p=0.005)



The control group had no significant change in HbA1c, moving from 10.1% (86mmol/l) (median 10.0%) to 10.3% (89mmol/mol) ± 1.81 (NS) over the same period.

Compared with controls at 9 months post intervention, the improvement in glycaemic control was statistically significant. (p=0.05)



All parents expressed enormous gratitude and felt more empowered by the initial intervention. One adolescent expressed initial anger - “isn't having diabetes punishment enough?” and displayed ongoing defiance but after a further 6 months of FADM therapy demonstrated improved adherence.

Discussion

Often the focus of the adolescent's poor diabetes is directed solely against the adolescent with punishment or “more education.” Often clinicians and teams are bereft of management ideas and skills and rely upon psychology referral of the adolescent alone which rarely works.

Life with diabetes is an intensive struggle and health professionals must understand the overwhelming and exhaustive nature of the disease. Failure to keep their child in good diabetes control when they are doing their best often makes parents feel judged as “bad parents”, which further disempowers them.

FADM recognises diabetes as a family disease and facilitates resolution of issues through a whole family approach focussing on family patterns of rule making and communication. (3) FADM gives parents permission to be parents and to re-institute intergenerational boundaries. Parents report a greater empowerment to approach the mismanagement in their child's diabetes no differently to misbehaviour in other aspects of life.

The FADM approach addresses the psychic control of diabetes management recognising and acknowledging powerlessness, allowing the family to accept reality and deal with anger. FADM gives families scope to express fear (which often is expressed as anger) and validates their frustration and anxieties and creates harmony within families. When the conflict about performing diabetes tasks is removed, the adolescent awakens to love, support and structure within the family.

FADM assists with the classic situations of overburdened mother with “absent” father, unhealthy interfamily alliances, diagnosis trauma, fear of sudden death, marriage disharmony or undisclosed confronting issues. Time invested in re-empowering families though FADM results in less time spent in trying to rescue acute and medically serious (and expensive) complications of diabetes misbehaviour such as DKA.

Some families are so dysfunctional that FADM will not assist apart from providing some sense of connectedness and support.

FADM is a tool that can be learned and refined by medical and nursing personal in the front line diabetes care and should be incorporated into the standard management of diabetes from diagnosis. It is a philosophy that creates order out of chaos in a family with diabetes.

Conclusion

➤ FADM is an effective intervention in improving glycaemic control in poorly controlled adolescents with T1DM with stable families. (p=0.005)

➤ Compared with controls, the patients experiencing the FADM approach significantly improved glycaemic control at 9 months post intervention. (p=0.05)

➤ FADM techniques can be learned and effectively utilized by up-skilled diabetes teams after commencement of intervention in combination with a FADM coach.

“Joe's techniques (FADM) have really changed our lives – I used to feel guilty. Now we are all happy” – mother (DNE) of adolescent with T1DM, 2015



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