



Lessons to be learned from partnerships with families: a case study

S Davidson*, K Spowart

Introduction

Working within paediatric diabetes there are always multiple levels of context (e.g. biological, physical, behavioural, familial and cultural) to consider and the multiple narratives of family members and professionals.^{1,2}

In order to join with and support families and facilitate change we find it most helpful to consider a variety of systemic family therapies, which value the core concepts of: circular causality, reflexive questioning, and the importance of context and language (see Minuchin³ and Selvini Palassoli *et al.*⁴ for more information). In finding a focus for our work we aim to be thoughtful and respectful of the young people and other family members about their experiences of 'living with diabetes' and the difficulties they

Abstract

The following case study describes a therapeutic intervention with a seven-year-old child with diabetes and her family, at the centre of which was the partnership between two professionals, and between the family and the team. The work was informed by systemic models of family therapy and elements of cognitive behavioural therapy as well as best practice in working with families and young people with type 1 diabetes. The collaborative nature of multidisciplinary teams within paediatric diabetes, facilitates best outcomes for families of young children with type 1 diabetes and promotes continuity of care. The case study pays particular regard to the way in which practice is informed and evaluated by theory. Thus, relevant literature is signposted throughout the article, reflecting our use of documented strategies and issues that have been discussed further (and in greater depth) elsewhere. Copyright © 2005 FEND.

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Key words

collaboration; partnerships; multidisciplinary teams; family therapy; systemic therapy; clinical psychology

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encounter, in order to promote a seamless service.^{5,6} We aim to facilitate joining with the family by suspending judgement and being curious⁷ to create and be sensitive to a multiplicity of views (such as those between different family members). We also consider what the family's 'relationship to help' might be⁸ in terms of what the family feel would be most useful, what their previous experiences of helping professions are and what their expectations are about coming to see us. Informed consent is thus gained through thorough discussions about what is wanted and how to provide this. We are also mindful of evidenced-based practice in this area.^{9,10}

Case history

The family of a seven-year-old girl was referred by a local team when relationships between themselves and the family had deteriorated. Poor diabetes control and 'behaviour problems' were the focus of the referral.

The referral was discussed at the team's weekly meeting to establish best possible approaches involving the most relevant members of the team. The Paediatric Diabetes Team consisted of a paediatric endocrinologist, specialist nurse, clinical psychologist and dietitian. It was decided that a routine clinic appointment would provide the opportunity for an overall assessment including the specialist nurse and clinical psychologist.

Mrs Falerick and Maria (all names and identifying features have been changed to protect anonymity) attended the appointment. The main problems presented by Mrs Falerick were fluctuating blood glucose levels despite changes to insulin therapy, 'bad behaviour' and occasional periods of 'fussy eating'.

Maria was diagnosed with type 1 diabetes in March 2001 at four-and-a-half years of age. This was two years after her brother (aged seven) was diagnosed with Asperger



Syndrome and epilepsy. At the time of referral Maria was on twice daily insulin injections of Mixtard 30 before breakfast and her evening meal. Mrs Falerick administered all the injections and performed numerous capillary blood tests (up to eight a day). The HbA_{1c} result was 10.1% (DCA 2000). The glycaemic control was erratic with variable high (>17mmol/L) and low (<4mmol/L) readings compounded by the 'fussy eating'.

Mrs Falerick was concerned about future diabetes related complications from the high readings but was also worried about hypoglycaemia if Maria didn't eat enough. She became tearful, describing how worried she felt about Maria and how overwhelming she found Maria's behaviour at home.

Initially it was felt unnecessary to interfere with the current insulin regimen, since this may have prematurely reinforced the 'problem' as being the diabetes and detracted from the context and family issues. Instead, we focused on the family to obtain a wider perspective of family dynamics, extended family support and the professional systems with which they had come into contact. On an out-patient basis both parents and Maria were invited to, and attended, sessions.

Three clear themes emerged from these initial sessions:

- The significant upheaval the family had experienced in the previous two years associated with the children's health problems.
- Mrs Falerick's dominant role in the caring and responsibility for the children and liaising with services.
- The evident lack of resources in the form of supportive family/friends nearby.

The key request at this stage from the parents was for us to address Maria's diabetes control and her behaviour. The emerging theme

from early conversations involved the degree to which Mrs Falerick felt unsupported and undermined by Mr Falerick. This seemed linked to an escalating pattern of 'bad behaviour' from Maria, which was in turn met with increasing forms of punishment used. This caused us concern for Maria's safety. The family's local Social Services department had limited resources available and so no additional support could be offered. Our team therefore made the decision to admit Maria to the ward for further assessment and as a way of intervening in the spiral of escalating violence.

The Child Protection concerns altered the focus of our work. The demands of our professional context required in depth liaison with other services. At ward level we created a structure to Maria's day with routines such as attending the hospital school and having friends and family visit on the ward. Collaboration around the diabetes management, control and education involved the team, parents and Maria in decision making relating to numbers of capillary blood tests performed per day and responsibility for administering injections.

Star charts were very successfully employed in both these areas, as a means of monitoring and rewarding certain behaviours such as blood testing. The 'fussy eating' mentioned by Mrs Falerick did not appear to be a major issue on the ward and Maria was encouraged by the ward nurses and play specialists to socialise with other children on the ward at mealtimes.

In discussions outside sessions, the authors wondered about the state of the marriage and whether the children's problems provided a more 'comfortable' focus rather than the more 'uncomfortable' area of the parenting relationship.¹¹

In attending to the concerns raised, the authors changed their

style slightly and adopted a more structural approach, as advocated by structural family therapists.³ Thus, we set out to explore the boundary between the parent and child sub-systems, hypothesising that this had become weak and confused. To punctuate this, we held sessions with the parents in the Psychology Department where we could talk more openly without the children being present. Using circular questioning we invited each parent to consider different perspectives (e.g. 'How would you, Mr Falerick, know when Mrs Falerick needed more support?'). We were interested in their perceived ability to make decisions without being undermined and how they exercised power as parents. We wanted to be as transparent as possible, letting them know that we considered some of their responses to be unhelpful and too extreme. We strongly emphasised our need to act in Maria's best interests and to involve Social Services as the lead child protection agency. Through this level of openness we hoped to maintain a facilitative relationship whereby we could continue working with Mr and Mrs Falerick in order to identify different ways of understanding what had happened and encourage them to consider different methods of responding.

Following further meetings with the parents and Maria our levels of concern lessened. Our focus shifted to considering how Mr and Mrs Falerick managed their parental relationship and decision making around the children's routines and discipline. They were both encouraged to think about their 'scripts' from their own experiences of childhood and how these influenced their current parenting skills.¹² Their different experiences and expectations of childhood, children and behaviour were considered in the light of their cultural



heritage: Mr Falerick from his Polish parentage where difficulties and conflict had been avoided, and Mrs Falerick's strict, Protestant, middle class family which valued respect and obedience. Both were able to discuss their frustrations at the lack of support they received from their families of origin and the difficulties they experienced attaining the level of discipline they aimed for in their own children.

The methods and timings of their communication were also discussed, in terms of how much they allowed the children to influence them. By prescribing certain interventions designed to enhance Mr and Mrs Falerick's autonomy and effectiveness in dealing with conflict, we invited them to try different methods of parenting.¹³ For example, alternative methods of managing the children's behaviour were considered, such as focusing more on positives, agreeing a more collaborative approach to parenting and being clearer about intergenerational boundaries. Planned home leave was set up as *'in vivo'* experiments, where Mr and Mrs Falerick could try out their new skills, but with the back up of the hospital ward if all did not go to plan.

A key element of the intervention was the partnership between the specialist nurse and the clinical psychologist. Our paediatric diabetes team is fortunate to have dedicated sessions provided by a dietitian and clinical psychologist, enabling all members of the team to meet weekly to review families' progress and share concerns. Team meetings and joint work facilitate communication and the sharing of responsibility – for example, around child protection issues. As autonomous health professionals with direct contact with the family, the specialist nurse and clinical psychologist were responsible for ensuring that child protection

concerns were monitored and addressed. However, the specialist nurse benefited from closer relationships with the ward staff, the hospital school and the local school, and therefore became the key contact for these teams, while the clinical psychologist led on liaison with the local mental health and social services teams. The specialist nurse also had greater skills and familiarity around treatment issues (such as diet, glucose monitoring and control) so led on these areas, whereas the clinical psychologist was better placed to chair the meetings, review progress and consider family dynamics. Imperative to good communication and engagement was the need to be explicit about our areas of specialist knowledge and about whom and what we were liaising with others. Thus, family meetings always started with the setting of an agenda, where both professionals and family members could feed back on areas of progress since the last meeting and highlight areas they wished to discuss. This is a model the team has used for many years to facilitate clarity of roles and responsibility in working in partnerships together and with families.

Therapeutic outcome

Maria continued to have a bed on the ward for the next eight weeks during which planned home leave grew progressively longer and reportedly calmer until her discharge which was agreed by all.

Ongoing contact and feedback indicate a generally positive trend particularly with regard to diabetes control, behaviour and diet. A more collaborative approach to giving insulin and blood testing exists between Maria and her parents. Maria decided to bring a 'questions notebook' with her to clinic appointments, which was encouraged by her parents. Maria makes notes of questions she wishes to ask

different team members. A particular issue for Maria in the early stage following discharge was the desire for more flexibility around her diabetes care, and a multiple injection regimen was explained to her including any advantages (flexibility) and disadvantages (more injections). She was encouraged to think about this and have discussions with her parents before coming to the next clinic appointment two months later when she decided she wanted to try it. Her insulin regimen was changed to glargine insulin before bed and NovoRapid before meals. Within the next month her HbA_{1c} was 8.9% (DCA 2000). Meal times are reportedly more peaceful and Maria described feeling happier. Her parents have said how well behaved she and her brother are.

Discussion

On reflection we felt pleased with the way this piece of work had gone, both in terms of the process and outcome. It was useful to think about the different priorities that needed attending to and how to integrate different professional roles and responsibilities. We are, however, left with some thoughts concerning gender, our positions and the notion of change.

Our approach is one that facilitates change through a co-construction of what is difficult and what might be helpful and using collaboration to achieve this. However, when there are many people in the system there are often a number of potentially incongruent priorities. It is important to acknowledge the multiplicity of ideas and experiences brought by professionals, referrers and families that influence the work.⁸ These often take time to map out and, when they are mapped out, much of the work is dependent on the goodness of fit or match between professional(s) and family.¹



Both of us are white British women who have not been mothers. We were familiar with the hospital environment and in working with young children with diabetes and their families. We are also familiar with liaising with colleagues, including those in Social Services. Although the Falericks had some previous contact with health services, they were commuting to a hospital, some distance from them, where they had had no previous contact. Upon disclosing the degree of escalating punishment they were using, the little control they had (i.e. relating to confidentiality and of who would be involved) was further diminished, as this information had to be shared in following child protection procedures. The fit or match between the family and the team at this point seemed almost the most remote possible and therefore risked the viability of further work. We had to work hard to maintain our alliance with the family, particularly with Mr Falerick (the only man in the sessions) and did this through being clear about what we were doing, our aims and acknowledging the gender imbalance in the room.

As no therapy is value free and no therapist neutral, therapists must be aware of their own attitudes and their effect on the family they are seeing.¹⁴ In intending to embrace a more neutral position we were aiming to draw a clearer boundary between ourselves and the family as professionals who had specific responsibilities beyond their expectations. Outside of the meetings with the family, we found it important to reflect on our own concerns and connections to previous experiences (such as those relating to our families of origin and previous involvement in child protection procedures) as well as the hopes and fears we had for each session. This allowed us to be more available to

reflect on what was said in sessions and be more transparent with the Falericks about our roles, actions and reflections. It was also useful to work collaboratively; as members of two distinct disciplines we brought different professional (and personal) perspectives and were able to join with different members of the system at different times.

One concern we had was with regard to Maria's lengthy admission, which deprived her of contact with family, friends, home and school. We worried that Maria had become subject to a different form of punishment and that, within our intervention, she was becoming pathologised. Mindful of this, we aimed to increase her contact with as many of these systems as possible. During our individual meetings with her, we were sensitive to her wishes and thoughtful as to how we could bridge the gaps. We worked in partnership with her local diabetes team and staff at her school, and invited them to write to Maria and keep in contact with her. She attended the hospital school and, as soon as possible, she returned to her school. Overall, we feel that while it may have been possible to discharge her home sooner, it was important for Maria and for her parents to have sufficient time to learn and try out new skills, whilst having the fall back of the hospital ward. In total, Maria only spent 20 nights over an eight-week period on the ward.

Although clear that as adults we (in partnership with her parents) held the responsibility ultimately for her care, we were keen to empower Maria as much as possible, whilst being mindful of her developmental stage. Thus, we encouraged Maria to be part of our prioritising process – for example, determining where and when she had her fingers pricked (for glucose monitoring), about which areas the

star chart recorded progress, and about the frequency and duration of our individual meetings with her.

In adopting a 'reflexive re-position'¹⁵ therapists are challenged to respond creatively, thoughtfully and in a timely fashion to the changing demands of the family, the wider system and professional responsibilities. Different priorities dominate, making feedback critical to learning and re-positioning essential. Working collaboratively, and in partnership, challenges us to be mindful of ever changing priorities and be thoughtful of multiple perspectives and experiences.

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Symposium

PROUD – Professionals United by Diabetes 'DOUBLE TAKE'

An official Satellite Symposium at the Diabetes UK Annual Professional Conference by and for health professionals who live with diabetes themselves, with a display and presentation of 'Diabetes Narratives' by members of PROUD

**Ness Room, Seminar Suite, Scottish Exhibition & Conference Centre, Glasgow, UK
Wednesday, 20 April 2005 (7.00–8.30pm)**

PROGRAMME

7.00pm	Welcome and introduction to PROUD	Eileen Emptage and Jeannette Josse (PROUD Steering Group)
7.10pm	Presentation of 1st Diabetes Narrative: <i>Failures in empowering our children</i>	Jo Butler, Diabetes Nurse Consultant
7.25pm	Presentation of 2nd Diabetes Narrative: <i>The sadness of diabetes</i>	Norma Grundy, Diabetes Specialist Nurse
7.40pm	Break for refreshments and to view a display of posters of Diabetes Narratives by members of PROUD	
8.05pm	Presentation of 3rd Diabetes Narrative: <i>Diabetes, the NHS and me</i>	Stuart Bootle, General Practitioner
8.20pm	Discussion of future PROUD ideas, led by	Mary MacKinnon (PROUD Steering Group)
8.30pm	Close of Symposium	

For further details please e-mail James Wroe, Hon Administrator, PROUD, at jameswroe@eclipse.co.uk

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