

Dancing with diabetes: brief therapy conversations with children, young people and families living with diabetes

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Introduction

In the UK, only 1:7 to 1:5 children with diabetes (depending on age group) meet the recommended values (<7.5%). The National Paediatric Diabetes Audit concluded, 'UK diabetes care currently does not meet nationally agreed standards and this will continue to cause health problems for children with diabetes now and in the future.'1 Caring for children and young people with diabetes is fundamentally different to providing services for adults. It is a complex process that must be firmly focused on the child or young person and their family and/or other carers, supported by the skills and experiences of a multidisciplinary team. Consideration must be given to the physical and emotional

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Received: 12 July 2007 Accepted in revised form: 05 October 2007

Summary

This paper describes a combination of brief therapy approaches that have been used in a paediatric diabetes service to enhance engagement and communication with children, young people and their families. These psychological approaches are integrated into the team's practice. Brief therapy approaches are respectful of a family's expertise in their situation and take a non-judgmental and motivational stance in relation to promoting self management. Diabetes team members maintain a position of curiosity and interest in how children, young people and families find ways to deal with the day-to-day challenges of living with diabetes and keep their lives on track.

Eur Diabetes Nursing 2008; 5(1): 28-32.

Key Words

Solution-focused therapy; narrative therapy; problem-free talk; setting a focus; externalising the problem; focussing on the future; scaling; looking for exceptions; coping; positive feedback

needs of the developing and growing individual, along with the social constraints of family, friends, early years and school. A key component of effective chronic-care management - involving young people and their families (or carers) - is establishing and maintaining the motivation that will enable them to manage the complex juggling act required, to achieve effective management of their condition.²

Family therapy, incorporating developmentally appropriate negotiated responsibility, has been reported to be effective in improving metabolic control.3-5 Solutionfocused therapy (SFT) is another approach that has the potential for improving HbA_{1c} values in young people with diabetes who are reluctant to engage with standard approaches.^{2,6} psychological Solution-focused therapy assumes that the client is the expert and invites them to describe how they want things to be, to focus on what is already working and to notice how small changes are possible.⁷ The change looked for is in how the client sees the world, or how to do things differently in it. There is no attempt to find the cause of the problem or attempt to take the problem away.

The psychology service at University College London Hospital (UCH) is an integrated part of the multidisciplinary diabetes team. We offer solutionfocused therapy with a twist: we include approaches from narrative therapy⁸ and invite families to talk about things that they are already doing to challenge the negative effects diabetes. These of approaches can be used with children and families of all ages. We think of our approach as 'dancing with diabetes'. Using it helps us be sure that we are all listening to the same music and invites families to take the lead in the dance.



Problem-free questions:

Can I get to know you a bit first?

What do you enjoy at school?

What is your favourite lesson/subject?

What do you like doing when you are not at school?

What else are you good at?

What do you and your friends enjoy doing?

What do you like doing out of school?

Box 1. Problem-free questions can identify skills from non-problem areas

Remember, it is much harder to follow, as you need to know how to dance backwards!

This paper describes some of the dance steps we use in order to help children, young people and families think about needle protest (our version of needle phobia), finger pricks, managing eating difficulties, how diabetes gets in the way of being a family and the effect of sadness or anger associated with living with diabetes.

Problem-free talk

Problem-free talk allows us to get to know the person outside the problem and invites the family to focus on resources rather than deficits. It highlights areas that can be drawn on later in the conversation and sets the scene for positive change.7 Conversations begin by asking for examples of strengths, abilities and resources, in order to identify skills from non-problem areas that can then be transferred to the problem area (Box 1). Examples of doing well at school suggest intelligence and an ability to learn; having friends suggests social skills, loyalty, an ability to listen and help others; hobbies and other activities indicate a commitment to enjoying life. Parents are asked to describe strengths and abilities that they are proud of in their son or daughter. The following illustrates how skills can be transferred to a problem area:

John (age 7) was having prob-

lems looking after his diabetes pump at school. During the problem-free talk we heard how he loved watching Power Ranger cartoons. At the end of the session, we asked him if he would like to become a 'pump ranger', which was a special group, dedicated to protecting diabetes pumps. He was awarded a special certificate and badge when he came to the next session to tell us how well he had been looking after the pump.

Setting a Focus

Parents, children and the referrer may have different ideas about what would make the meeting helpful, therefore we want to hear what everybody's best hopes are. This invites people to see themselves as experts in their own situation; they know what they need to talk about:

'As you have come all the way here to meet us today I want to be as helpful as I can be. If this was going to be a helpful meeting what would be different by the end of our conversation?'

'How do you want to use our time together for it to be helpful?'

Responding to 'don't know'

However, children and young people rarely want to see a psychologist and often don't want to talk about diabetes. They may not know why they have been brought to the meeting, therefore we ask 'whose idea was it that you come along to meet with us today?' If it was their parents' or doctor's idea, we ask what they think they might want to talk about:

'What would be your best guess as to why the doctor/mum/dad wanted us to meet?'

'Are they worried about things you are not particularly worried about?'

'What is worrying making them

Young people are usually good at identifying what other people think the problem is and describing the effect that this has on the family. Parents want children to sort out their 'attitude', be aware of potential late effects, or take responsibility for their own care. The medical team want them to cope better with their diabetes regimen, do more injections or finger pricks, try to not miss injections, or stop eating the 'wrong' food. We then ask what they think needs to be different in order to not have to come and see us again:

'What would your mum/the doctor notice you doing for them not to want you to be coming here?'

Externalising the problem

Rather than seeing a problem as a fixed attribute, externalising is a way to separate the person from the problem and invite them to talk about how they might live their life without being pushed around by their difficulties.^{8,9} Finding a shared language allows us to think how to challenge a problem together. The 'diabetic girl' becomes the girl who is 'living with the challenges of diabetes'.

Families are used to being asked 'What seems to be the problem?' and are expecting to tell you all they can about it. They may begin to tell us about the problem without being asked, wanting us to hear about what they have been



When, even for an instant, were you in charge of the problem?

What did you do?

What did others notice?

Who wouldn't be surprised you were able to do this?

Box 2. Exception guestions invite families to describe times when they have been close to the miracle - even if only very briefly

struggling with. But it is important to listen to the problem without fanning the flames - and without asking for too much clarification. As we listen, we begin to ask questions to externalise the problem. When the problem is that a young person hates being diabetic we ask them to introduce us to the diabetes:

'I know this may sound like a funny question but could you introduce me to diabetes?'

'When did it turn up at your house?

'Where does it live?'

'If diabetes was sitting on that chair next to you, how would I recognise it?'

'Is it big or small?'

'Does it remind you of anything?'

Some responses that we have heard: Mark (age 8): 'It's a big purple monster with syringes for teeth and needles for a tail.

Susan (age 14): 'It's a badtempered imp – called Charlie.' Jane (age 15): 'It's like a big black cloud that follows me around all the time.

This lets us think together about how the children find ways to tame the monster, stop 'Charlie' spoiling things for them or find ways to shrink the cloud.

Externalising can also be used with other difficulties. Rather than talking with young people about being depressed or aggressive, we express an interest in understanding how to characterise 'the sadness' or 'the anger'

associated with managing the diabetes. We ask what kind of things 'the problem' gets them to do. It is not unusual to be told that anger makes them skip injections or eat chocolate. We check if they want things to be different and then ask how they find ways to put anger in its place.

Stepping into the Future

The next step is to invite the family to step into the future, at a time when the problem would be solved, by describing a 'preferred future' that depicts how they would like things to look. de Shazer developed the miracle question as a way to help people step into the future without being tripped up by the present.¹⁰ An example of how you might ask this type of question is given below:

'I have a strange, perhaps unusual, question – a question that takes some imagination... suppose... after we finish here, you leave, watch TV, have dinner etc go to bed/sleep... and while you are sleeping a miracle happens... and the problems that brought you here - to see me - are solved, just like that!... But you were sleeping and don't know the miracle has happened. So when you wake up in the morning ... how will you go about discovering that this miracle has happened to you? What will you be doing, or saying, or thinking differently that will give you clues that the miracle has happened?'

Now the difficult bit! You have to be patient and wait for the answer. Stick to your guns and

keep silent. If they say it's a difficult question, just agree. With slightly younger children, you can repeat the last part of the ques-

It is important to get as rich a description as possible, with details and concrete examples of what they will be doing in the future without having to think about how they got there. If they say they would be 'feeling happy', ask how they would notice they were happier. What would their parents/ friends/teachers be noticing? We also invite parents to tell us what they think they would notice, and ask them what they would notice themselves doing or saying differently. Here is a typical scene:

Jane: I wouldn't have diabetes.

Therapist: So what else would you notice?

Jane: I wouldn't be arguing with mum about my BMs...

Therapist: What would you be doing that would help you notice that you weren't arguing?

Jane: We'd be having breakfast... maybe (laughing).

Therapist: What else?

Jane: I'd be going out with my friends... for a sleepover...going out shopping.

Therapist: What else would you notice?

Jane: Mum wouldn't be phoning me all the time.

Therapist: What else?

Jane: I'd feel more confident.

Details of where they would be going, or what they would be doing with friends or with parents (if they were arguing less), and what they would be noticing themselves doing and saying (if they had more confidence) all contribute to this rich description.

For a younger child we might say that something 'magical' happened during the night (as if a fairy waved a magic wand). Selekman invites families to gaze



into a crystal ball and describe what they can see happening in the future. 11 We also invite young people to step into a 'time machine' that we keep in the corner of the room and travel into the future, then get out and look around while the young person describes what is happening.¹¹

Scaling

Having got a clear and detailed picture of the preferred future, the next step invites young people to identify where they are in relation to this:7

'Let's imagine that if things were how you have just described them were a 10... and 0 is the furthest away that you could be from this ...how close to 10 are you today?'

With younger child we might draw a line on a piece of paper, point to the two ends and ask them to show us where they are on the line.

Young people rarely say they are at 0. If at 3, we ask how come they are already a third of the way towards where they want to be. If at 5, we are curious about how they are already half way towards how they want things to be. Scaling creates an opportunity for us to ask how come they have managed to take these steps to the future on their own and hear about what has enabled this to happen. We ask, 'Where would you like to be?' and 'What would be good enough?' For each answer, we ask for descriptions of what they would be doing, noticing or saying. People are asked to say what they are doing at the next step, not what they need to do to get there. This breaks goals down into small, concrete, manageable and observable steps, e.g. 'What would things look like if you were one step closer to 10?

Scaling can also be used to ask

What have you done to prevent things being worse?

How did you do that?

In which ways was that helpful?

What do you think you would want to continue doing to get that to happen

How come you haven't given up?

What has stopped you going below a 0?

How come you managed to do what you did today?

Box 3. Responses to coping questions like those listed here enable the health care professional to learn why a child hasn't given up

how confident young people feel about making changes, how much they actually want things to change, how safe someone feels or how much they like themselves.

Exceptions

solution-focused approach assumes that small change is always possible. Exception questions invite families to talk about times when they have been close to the miracle - even if only for a brief moment (Box 2). de Shazer called this 'looking for little pieces of the miracle'.¹⁰ These 'sparkling moments' are exceptions to the problem story and identify abilities that can be harnessed to bring about subsequent steps towards the preferred future

Coping

If someone scales themselves at a 0 (or even a negative number), we can ask coping questions in order to hear why they have not yet given up and are still prepared to meet with us, or learn about what has prevented things from getting worse (Box 3).

Taking a break and giving feedback

After talking with young people for about 50 minutes, break for 5-10 minutes before summarising the conversation.

We are very careful not to give people advice. This can sometimes be tricky as it is not unusual for a parent to say that they want us to tell them how to sort out a problem or give advice on how to manage a specific situation. A young person may ask us to say how he/she can learn not to be scared of needles. We will often hear stories of previous teams who have given lots of advice where 'nothing worked'. If we ignore these warning signs and fall into the 'must do something to help' trap and are compelled to give advice, invariably the family will say 'yes but... we already did that.' My only advice at this point is to remember not to give any.

In the feedback, we begin by validating and acknowledging the difficulties. We use the family's words to show we have been listening carefully. We summarise resources, strengths, skills and abilities, pointing out steps that they have already taken towards their preferred future. We may invite young people to look out for times when they take a step closer to the miracle, when they notice the diabetes being less of a bully (or less scary or less heavy) and ask if they would be willing to come back and tell us what has made this possible. The feedback must be sincere, genuine and based on what we have heard in answer to our questions.¹²

Finally, young people and their parents are invited to tell us how



helpful the session has been and are asked when, or if, they would like to meet with us again. Half of the families we have met found just one session to be helpful, with the remaining families asking for further individual or family work.

Family responses

These conversations can provide a very different experience for families who have told us they felt blamed or criticised for difficulties they had in managing diabetes. Mothers have often been told they are anxious or 'enmeshed', young people have been described as non-compliant or manipulative.

We are always moved by the reaction of families as we offer them compliments on their commitment to their son/daughter, and their determination in ensuring they get the best care. Parents may become tearful when told that we are impressed by what a good job they have done bringing up a smart, articulate and engaging young person (who in previous interactions had been moody and silent). Young people previously described as non-compliant or manipulative grow visibly taller in their chair when congratulated on their talents and abilities. We thank them for having been so helpful to us in our understanding of what makes diabetes difficult to live with, as well as letting us benefit from their expertise in finding ways to put diabetes in its place.

In a recent audit of 32 parents who had been in contact with the service, 94% said they had found the contact helpful.

Conclusions

Living with diabetes can be challenging and demanding for families and young people who are striving to achieve regular developmental goals. The relentless daily demands of a diabetes regimen

can easily hijack progress, knocking young people and their families off track.

In our experience, a solutionfocussed approach with a twist is a powerful facilitator of change. The approach fits with models of empowerment that are seen as increasingly relevant in the management of long-term chronic ill-

If you have enjoyed reading this paper, it would be in keeping with the model to try a few of the questions in your next conversation with a family and - if they work - to carry on doing them. Our psychology team has provided in-house training as well as joint consultations, to help develop these skills. We have also provided a range of training workshops for other teams that are interested in introducing aspects of this work into their practice. All members of the diabetes team have begun to incorporate some of these questions into clinic consultations. We have found that the questions are helpful in engaging and motivating young people and families to join us in a dance with diabetes.

Acknowledgements

I would like to acknowledge the supervision and support of Glenda Fredman and the training workshops and writings of Steve de Shazer, Bill O'Hanlon, Matthew Selekman, Michael White and the Brief Therapy Practice. Their passion and commitment to these ways of talking with young people and their families have been the inspiration and driving force behind all of the ideas described in this paper.

I would also like to thank all the families that have helped me learn how to dance with diabetes.

Conflict of interest statement:

None

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