Anxiety and illness beliefs among parents and children with type 1 diabetes and the implications for diabetes management

Jade Smith, Dorothy Frizelle, Emily Bell

Article points

1. Parental illness beliefs have an impact on a child's illness beliefs. For example, parents who did not perceive having personal control over diabetes tended to have children who perceived the illness as emotionally distressing.

2. Parents' and children's increased anxiety was associated with a perception of diabetes as having more severe consequences, and being emotionally distressing.

3. Families with children with type 1 diabetes may need support to make the transition from parental-management to self-management of the disease.

Key words

- Anxiety
- Child
- Illness beliefs
- Management
- Parent
- Responsibility
- Type 1 diabetes

Authors

Author details an be found at the end of the article.

This study examines parent and child trait anxiety and illness beliefs in children with type 1 diabetes and investigates these as predictors of diabetes management and metabolic control. Children aged 6–11 years and their parents (*n*=52) completed measures of trait anxiety, illness beliefs and diabetes responsibility along with HbA$_{1c}$ levels. Pearson's correlations highlighted significant relationships between parent and child's illness beliefs and trait anxiety. Parent and child regimen responsibility was best predicted by age, trait anxiety, coherence and time cycle when controlling for age and time since diagnosis using multiple regression. The interplay between parent and child trait anxiety and illness beliefs within the dyad created a shared emotional and cognitive representation and influenced a shared responsibility for diabetes.

Type 1 diabetes is one of the most common childhood chronic illnesses, characterised by the body producing little or no insulin (NICE, 2004). Parents typically take on most responsibility for management of the condition when children are young or newly diagnosed (Anderson and Brackett, 2005). As the child gets older, too much or too little age-appropriate responsibility for the condition is associated with family disagreement, child anxiety and poor metabolic control (Wysocki, 2002). The transition from parents being in control of management to the child taking control as they develop is an important part of the path to self-management and would ideally occur gradually over the years (Beveridge et al, 2006). Further understanding and management is crucial at an early stage especially because of the rising costs of managing diabetes.

A recent review stated that "psychosocial factors are the most important influences affecting the care and management of diabetes" (International Society for Pediatric and Adolescent Diabetes, 2009). Anxiety, family and psychosocial factors are known to play a role but the interaction between them is less clear. Trait anxiety is defined as "a relatively stable, individual difference in anxiety proneness" (Spielberger, 1973). During illness, anxiety can increase vigilance to threat perception (Sanders and Willis, 2002) observed as vigilance to symptoms and illness threat and linked to changes in behaviour relating to illness management.

Mothers who have a high trait anxiety level perceived more symptoms of type 1 diabetes and threat from type 1 diabetes and have been shown to take increased responsibility for their child's diabetes management (Cameron et al, 2007), while adolescents reported perceiving anxious mothers as intrusive (Weinger et al, 2001; Leonard et al, 2005; Cameron et al, 2007). Parental trait anxiety may be inferred by young people as meaning that type 1 diabetes is unmanageable or threatening and it may be associated with increased anxiety or low self-efficacy (a person's perception of their ability or capability to manage). Some findings show higher parent trait anxiety to be related to better metabolic control through increased parental input

(Stallwood, 2005; Streisand et al, 2005).

Perceptions of illness can be understood using the Common Sense Model (CSM; Leventhal et al, 1984) in which illness beliefs are induced by triggers (symptoms) associated with the illness, leading to changes in management behaviour. Within the CSM, illness beliefs are represented by:

- Identity (symptoms associated with type 1 diabetes).
- Timeline (perceived duration of type 1 diabetes).
- Consequences (perceived consequences of type 1 diabetes on life).
- Cause (perception of original cause of illness).
- Personal control.
- Treatment control.
- Coherence (perception of the illness as understandable and making sense).
- Time cycle (perception that type 1 diabetes will come and go).
- Emotional distress.

Illness beliefs are thought to evolve with time and experience. Within a systemically managed illness (i.e. one that is managed by a team of people or within a family system), the interplay between the parent and child's illness beliefs and management can be evaluated within this model with anxiety playing an influencing role (Kaptein and Weinman, 2004).

Literature examining illness beliefs is developing and has had mixed findings. Parental and child trait anxiety have been found to positively correlate with perceiving more symptoms and severe consequences and having less sense of personal control (Edgar and Skinner, 2003; Wheatcroft and Creswell, 2007). Illness beliefs about identity, treatment efficacy and consequence have been associated with adherence to management regimens (Griva et al, 2000; Skinner and Hampson, 2001) while other studies have found no association (Patino et al, 2005). Law (2002) used the CSM to find that beliefs did not predict diabetes management in adolescents but did predict well-being.

The rationale for the present study is to extend findings from existing research and examine both parent and child trait anxiety and illness beliefs in type 1 diabetes within the parent–child dyad and in relation to responsibility for illness management. It sets out to answer the following questions:

- Can there be relationships between parent and child illness beliefs for type 1 diabetes?
- Are there relationships between parent and child trait anxiety and illness beliefs?
- Do parent and child trait anxiety and illness beliefs predict responsibility for the management of diabetes?
- Do parent and child trait anxiety and illness beliefs influence HbA_{1c} levels?

Method
Participants

Participants were recruited at routine clinic visits from paediatric diabetes outpatient clinics across three sites over an 11-month period. The average age of the recruits was 9.1 years (range=6–11.9 years; standard deviation [SD]=1.6). Mean length of time since diagnosis was 3.9 years (range=1–10 years; SD=2.5). Potential participants were identified by the diabetes team 2 weeks before their routine appointment. All children who were between the ages of 6–11 years and who were able to give informed consent and complete the measures were included. Non-English speaking families were excluded, as were children with comorbidities. Both parent and child needed to give consent. Fifty-two dyads took part.

Measures

The Trait Anxiety Inventory (Spielberger, 1973; Spielberger et al, 1974) was used to measure trait anxiety. The child was given a 20-item version using a three-point scale to measure the frequency of experience of statements (1=hardly ever; 2=sometimes, 3=often) with a maximum score of 60. The 20-item parent version used a four-point scale to measure frequency of experience of statements (1=hardly ever, 2=sometimes, 3=often, 4=almost always) with a maximum score of 80.

The Illness Perceptions Questionnaire – Revised (IPQ–R; Moss-Morris et al, 2002) was also used. This 72-item measure assesses illness beliefs across seven domains on nine subscales that correlate to Leventhal et al's CSM (1984) as listed earlier. Statements are rated by participants on a five-point scale by how much they agree with them (1=disagree a lot, to 5=agree a lot). The internal consistency (or correlation between different questionnaire items measuring the same general construct) in the Parent IPQ was as follows (timeline α=0.041, consequence α=0.7, personal control α=0.54, treatment control α=0.57, coherence α=0.87, time cycle α=0.64, emotional distress α=0.82) for this sample.

Parent	Identity	Consequence	Time cycle	Personal control	Treatment control	Coherence	Emotional Distress
Child							
Identity	0.131	0.090	−0.007	−0.243	−0.102	0.019	0.068
Consequence	−0.031	0.204	−0.132	−0.310*	0.084	0.017	−0.004
Time cycle	0.306*	−0.124	0.375**	0.035	−0.082	−0.074	0.345*
Personal control	−0.057	−0.144	−0.332*	0.114	0.339*	0.324*	−0.273
Treatment control	0.104	0.036	0.088	0.183	0.312*	0.156	−0.198
Emotional distress	0.108	0.138	0.219	−0.479**	−0.162	−0.173	0.525**

Table 1. Correlations between parent and child illness beliefs using Pearson's correlations.

*$P<0.05$, **$P<0.01$

The IPQ–R was reworded for children with diabetes by the researcher to use language suitable for the participants' age range and then tested on a small sample (n=5). Indices of reading level give the IPQ–R a Flesch Reading Ease of 80 (where 100 is very easy and 0 is very confusing) and a Flesch Kincaid Reading Grade level of 4.7 (where Grades 4 and 5 include children aged 7 to 11 years), which indicate that the questionnaire was suitable for the study group. The Child IPQ–R has moderate to good internal consistency (timeline α=0.8, consequence α=0.6, personal control α=0.37, treatment control α=0.28, coherence α=0.87, time cycle α=0.63, emotional distress α=0.85) for this sample.

The Diabetes Family Responsibility Questionnaire (DFRQ; Anderson et al, 1990) measures diabetes responsibility as shared between child and parent on three subscales:
● Regimen (giving injections)
● Social tasks (such as telling school)
● General health (noticing ill health).

Lower totals or scale items show more child responsibility. The Child's DFRQ had moderate to good internal consistency (general health α=0.6, diabetes regimen α=0.69, social aspects α=0.44) for this sample. The Parent's DFRQ also showed moderate to good internal consistency (general health α=0.69, diabetes regimen α=0.69, social aspects α=0.41) for this sample. The children's metabolic control was measured by HbA_{1c} levels.

Results

Parent and child illness beliefs

Children perceived more personal control when their parents perceived that the medical treatment offered control and when the parents perceived the diabetes as "making sense" (coherence) (*Table 1*). Similarly, when parents perceived that they had more personal control, their children reported diabetes as more coherent. Parents who perceived diabetes as distressing had children who thought that it made less sense (coherence).

Parent and child perceptions of the variable nature of diabetes were positively correlated. Parents perceiving that diabetes had many symptoms and caused distress was associated with children perceiving the illness as more variable. A moderate positive correlation was found between emotional distress from both parent and child.

Children perceived diabetes as having more severe consequences when parents perceived less personal control. Children who perceived the illness as making less sense tended to have parents who perceived the illness as being more variable. Parents who did not perceive having personal control over the diabetes tended to have children who perceived the illness as emotionally distressing.

Parent and child anxiety and illness beliefs

Both parents' and children's increased anxiety was associated with a perception of diabetes as having

more symptoms (identity) and severe consequences, being more cyclical and emotionally distressing and making less sense (coherence). No other correlations were significant (*Tables 2 and 3*).

Pearson's correlations were performed to examine the relationships between child anxiety and parent beliefs and parental anxiety and the child's beliefs. Children were more anxious when parents perceived less personal control over type 1 diabetes, $r=-0.329$, $P=0.017$ and parents perceived more emotional distress, $r=0.340$, $P=0.014$. Children perceived the illness as more variable when parents reported higher levels of anxiety $r=0.367$, $P=0.007$.

Parent and child anxiety, illness beliefs and management

Hierarchical multiple regression analyses were conducted. Time since diagnosis was controlled for by being entered into Block 1 and child's age was controlled for in Block 2 (a block being a grouping of variables put together to examine the variance that they have at each step of the analysis on the measured variable). Illness duration was controlled for because of between-group differences, and age was controlled for due to its apparent significance in relation to regimen responsibility. In Block 3, parental trait anxiety, coherence, personal control and time cycle were entered as predictors of responsibility. The next analyses were conducted the same way including child factors (child trait anxiety, coherence, personal control and time cycle).

Table 4 shows that there were a number of factors that predicted the variation in parent and child regimen responsibility when controlling for how long the child had had type 1 diabetes and the child's age. The left-hand column shows the amount (%) of variation in responsibility predicted by the factors in the right-hand column. The variables were chosen based on their significance in previous analyses and were limited due to the small sample size. The child's age was a significant predictor for both parent and child regimen responsibility. Variation in regimen responsibility was also predicted by parental anxiety, parent/child perception of the cyclical nature of the illness and parental coherence. Time since diagnosis may predict child regimen responsibility, as older children are likely to have been diagnosed for longer.

HbA₁c

No relationships were found between HbA_{1c} levels and other variables using Pearson's correlation.

Discussion

It is not possible to establish cause and effect from the correlations, but the results can be interpreted based on theory and clinical relevance. The findings relating to illness beliefs show a complicated interplay in the dynamics between parents and children. Illness beliefs intertwine to create the individual's representation of the illness as well as within the parent–child dyad. When diabetes seemed controllable and it "made sense" there was

Table 2. Correlations between parent anxiety and beliefs.

Parent	Identity	Consequences	Time cycle	Coherence	Emotional distress
Parent trait anxiety	0.376**	0.410**	0.326*	−0.383**	0.506**

*P<0.05, **P<0.01

Table 3. Correlations between child anxiety and beliefs.

Child	Identity	Consequences	Time cycle	Coherence	Emotional distress
Child trait anxiety	0.430**	0.301*	0.348*	−0.431**	0.695**

*P<0.05, **P<0.01

Table 4. Variables predicting parent/child regimen responsibility.

Parent/ Child regimen responsibility	Contributing factors to regimen responsibility
57% of parent regimen responsibility	Child age (β=−0.501, *t*=−4.73, *P*<0.001)
	Parent anxiety (β=0.352, *t*=3.15, *P*=0.003)
	Parent time cycle (β=0.259, *t*=2.4, *P*=0.021)
52% child regimen responsibility	Child age (β=−0.441, *t*=−3.92, *P*<0.000)
	Illness duration (β=0.339, *t*=2.93, *P*=0.005)
	Parent coherence (β=−0.317, *t*=−2.4, *P*=0.019)
31% of child regimen responsibility	Child age (β=−0.510, *t*=−3.75, *P*=0.001)
44% parent regimen responsibility	Child age (β=−0.513, *t*=−4.2, *P*<0.001)
	Child time cycle (β=0.394, *t*=3.15, *P*=0.003)

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also a perception of less severe consequences, fewer symptoms and it felt less distressing.

This supports existing research (Edgar and Skinner, 2003; Wheatcroft and Cresswell, 2007) that anxiety and illness beliefs are linked with higher anxiety being associated with more severe beliefs about diabetes. In line with existing literature (Cameron et al, 2007), it may be hypothesised that anxiety and increased vigilance lead to the perception that the illness is more severe, which in turn increases anxiety.

It appears that when parents believe that the illness is variable, their own anxiety levels lead them to take responsibility for its management as well as accounting for the age of the child, while children's management responsibility was rated as mostly dependent on getting older. It is hypothesised that the psychological factors make it necessary for parents to assume responsibility as a means of coping and managing a variable and life-threatening illness, regardless of perceived personal control. For children, it seems that responsibility increases with age, regardless of other factors.

Clinics must support families and children with the transition to self-management, and there should be strategies to judge a family's readiness to put in place a gradual transfer of responsibility. This is particularly important as inappropriate and untimely responsibility may have negative outcomes (Wysocki, 2002; Anderson and Brackett, 2005). A sense of emotional containment (reduced distress or tolerance and attunement of emotions) appears to stem from the parent–child dyad having a shared understanding of the illness. This may be as important in improving self-management as focusing on medical symptoms and consequences, and it provides further evidence for the need to be aware of psychosocial factors when caring for people with type 1 diabetes (International Society for Pediatric and Adolescent Diabetes, 2009).

Limitations of the study

It is important to note that a study of this kind carries a high risk of finding falsely positive results because of the large number of variables being considered. Further hypothesis testing of one variable against another should be carried out to properly evaluate this study's findings.

Conclusion

More research is needed into interventions for diabetes using systemic and cognitive behavioural approaches to manage beliefs and anxiety and adjust behaviour. It is important that healthcare professionals consider how responsibility for management of the illness is transferred from parent to child as they grow older. Regular type 1 diabetes education may also be useful in assessing and developing helpful and protective beliefs about the illness. ■

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Authors

Jade Smith is Clinical Psychologist, Lambeth Neurodevelopmental Team, Mary Sheridan Centre; Dorothy Frizelle is Consultant Clinical Heath Psychologist, Bradford Hospital; and Emily Bell is Clinical Psychologist, Lincolnshire Paediatrics.