Resilience, stress and perceptions of school-based support for young people managing diabetes in school

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Article points

1. Type 1 diabetes management and stress reactions are reciprocal in children and young people.
2. Resilience can mediate reactions.
3. Perceptions of school support play an important role in resilience.

Key words

- Perceptions of support
- Resilience
- Stress
- Type 1 diabetes

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Personal resilience was studied in relation to perceived support and perceived stress in students aged between 11 and 16 managing school demands and type 1 diabetes. Fifty-four participants completed measures of personal resilience, perceived school-based support and perceived stress. Six students were interviewed in the qualitative phase. Correlational analysis identified significant relationships between personal resilience and perceived support, and personal resilience and perceived stress. Thematic analysis of interview data identified six themes linked to personal resilience, school-based support and overcoming stress in managing type 1 diabetes in a school setting. Perceptions of support were related to resilience in children and young people with type 1 diabetes. Young people's perceptions of the support they receive in school should be considered in management plans.

Stress affects large numbers of children and young people (CYP) with type 1 diabetes (T1D; Diabetes Control and Complications Trial Research Group, 1994; Diabetes UK, 2015). The ability to cope with stress and the level of glycaemic control in T1D are known to be reciprocal. Effective coping is associated with, and promotes, better glycaemic control (Delamater et al, 2014).

CYP with T1D have to manage the daily life stressors experienced by all children as well as a number of additional stressors associated with having a chronic health condition (Nabors et al, 2003; Bade-White and Obrzut, 2009; Kucera and Sullivan, 2011; Delamater et al, 2014). The effects of stress on blood glucose levels are mediated by how the stressor is appraised and the extent to which the individual responds to the source of stress (Ellis et al, 2005).

The experience of stress associated with T1D and its reciprocal interactions with glycaemic control make those who show resilience and positive outcomes of great interest. Research has explored protective factors associated with parenting and family life (Monaghan et al, 2015). Yi-Fraizer et al (2015) explored the association between resilience, stress and coping in a study of 50 adolescents in the United States. Mirroring the results with adults (Yi et al, 2008), they demonstrated that low resilience was associated with higher distress, poor quality of life and poor glycaemic control in adolescents.

Diabetes support in schools

A child or young person with T1D is likely to have three principal sources of support. Support from family is often seen as the most important source (Delameter et al, 2014). The health team overseeing his or her care is also a key source of support. School, where CYP spend most of their time when not with their family, is the third. It follows that perceptions of school support are likely to play a key role in the resilience of CYP with T1D. It could also be hypothesised that school and health team support should be the main elements of a support

plan where family support is not reliable or cannot be influenced.

Lehmkuhl and Nabors (2008) carried out a pilot study to assess children's perceptions of satisfaction with school-based support for their diabetes. The authors found that children were satisfied with support; however they felt they would like increased support during after-school activities. They also found that children who reported greater satisfaction with school support had lower HbA_{1c}. Their research suggests a need for further investigation into what creates a supportive environment at school and how this contributes to disease management. They also highlight the need for further development of the revised How is School Going Survey (HISGS), which was used in their study.

There is a growing picture that links resilience to positive outcomes in CYP who have T1D. Despite the significance of schools as a potential source of perceived support and their legal obligation to provide support for CYP with disability (most recently in the UK under the Children and Families Act 2014), very little research considers the personal resilience or strengths that pupils with T1D utilise daily to manage their condition and participate in school life. A summary of the psychological care that might support CYP with T1D makes no mention of school-based support (Dalameter et al, 2014). Support that is perceived as relevant by young people may result in increased resilience and create protective factors that mitigate the impact of the stress associated with having T1D. Therefore this study aimed to assess the impact that school-based support has on CYP by answering two questions:

- Is there a relationship between personal resilience and: a) perceived support; and b) perceived stress in students with T1D?
- What kinds of support are perceived as valuable or relevant to managing diabetes in school?

Method

A mixed method design employing a sequential explanatory strategy was used in this study (Creswell et al, 2002; Robson, 2011). Quantitative data were collected and partially analysed in the first phase to define sampling parameters for phase two. In the second phase, qualitative data were collected and analysed.

Participants

A total of 54 students (35 female and 19 male) with T1D from across 31 secondary schools from south-east England participated in the study. Participants were aged between 11 and 16 years with a mean age of 13.7 years. The modal age of participants was 15 years. Most participants described themselves as white British (*n*=17, 31.5%), followed by Asian (*n*=12, 22.2%) and black (*n*=12, 22.2%). Five (9.3%) identified themselves as being of mixed heritage, three (5.6%) as white Latin, South or Central American, three (5.6%) as white other, one (1.9%) as white Irish and one (1.9%) as Chinese. Forty-one participants had no additional needs. Reported additional needs of the remaining participants included medical needs, learning difficulties (i.e. dyslexia), and diagnosed disorders (i.e. Tourette's syndrome and autism). One student was in care. Students were diagnosed with diabetes between the ages of 2 and 15; most were diagnosed between the ages of 9 and 12. Eighty-nine per cent of participants took insulin injections to manage their diabetes, while 11% used insulin pumps.

Phase one

In phase one, participants completed three quantitative measures individually or in small group sessions led by the second author. These measures were:

- Resiliency Scales for Children and Adolescents (RSCA; Prince-Embury, 2006)
- The revised HISGS (Lehmkuhl and Nabors, 2008)
- The Perceived Stress Scale – 10-item version (PSS-10; Cohen et al, 1983)

The RSCA comprises three scales: "sense of mastery" (MAS), covering optimism, self-efficacy and adaptability; "sense of relatedness" (REL), covering relationships with others and sense of relatedness; and "emotional reactivity" (REA), covering vulnerability to stress or impact of adversity.

Indexes for resilience (RES) and vulnerability (VUL) can be calculated and ranked as high, above average, average, below average or low perceived personal resources or vulnerability based on the three measures. The RES score is a standard (T) score with a mean of 50. Across age ranges in the standardisation sample, validity and test–retest

Page points

1. Children who reported greater satisfaction with school support had lower HbA_{1c}.
2. A growing picture links resilience to positive outcomes in children and young people with type 1 diabetes.
3. Support that is perceived as relevant by young people may result in increased resilience and mitigate the impact of stress associated with having type 1 diabetes.

Table 1. Average results from three measures (*n*=54).

Study	Age (years)	Age at diagnosis (years)	Resilience index (mean=50)	Perceived stress scale (max=40)	Revised how school is going survey (max=5)
Mean	13.70	8.40	49.50	14.40	4.10
Standard deviation	1.57	3.54	10.15	6.61	0.81

reliability were >0.76 for the three scales. The coefficient alphas for both the RES and VUL indexes ranged from 0.93 to 0.97.

The HISGS explores perceptions of support being provided in school. It has been adapted and anglicised to reflect terminology and words used in the UK. Higher scores reflect a better perception of support.

The PSS-10 has been widely used and has shown validity through higher scores in respondents who have diabetes and are failing to control their blood glucose (Pateraki et al, 2015). PSS-10 scores of 0 (never) to 4 (very often) are given for each question. To obtain the PSS-10 score, the scores given for the four positive items (questions 4, 5, 7 and 8) are reversed (e.g. 0=4, 1=3, etc) and then the scores for all 10 questions are added together. Scores of around 13 are considered average, and scores ≥20 are considered high stress. Cohen (1988) reported an internal reliability alpha coefficient of 0.78, and this score can be at least as good a stress measure as the 14-item PSS.

Phase two

RSCA data from phase one were used to select participants for phase two of the study. Based on initial analysis, pupils were selected based on their RSCA resource index ratings, and had T scores ranging between low and high. One participant was selected to represent each index profile from high to below average and two from the low profile, based on geographic convenience and availability for interview.

A semi-structured interview schedule was developed to elicit pupils' views. A sequence was devised with an introduction, warm-up questions, the main body of the interview, cooling off and closure (Robson, 2011). Thematic analysis (Braun and Clarke, 2006, 2012, 2013; Guest et al, 2011) was used to analyse data from semi-structured interviews in phase two. Braun and Clarke (2006) define thematic analysis as "a method for identifying, analysing and reporting patterns (themes) within data. It minimally organizes and describes your data set in (rich) detail". Themes were determined flexibly but consistently across all data. An inter-coder agreement of 96% was found.

Results

Table 1 gives average results from the three measures completed by the 54 participants in phase one of the study. *Table 2* provides details given by the six participants who were interviewed during phase two.

Personal resilience in relation to perceived support and perceived stress

Tests of normality (skew, kurtosis and Shapiro–Wilk) indicated that the scores for RES and PSS were normally distributed for the question: "Is there a relationship between the personal resiliency and: a) perceived support; and b) perceived stress of students with T1D?". The Shapiro–Wilk test was significant for the mean HISGS support score (P=0.001), therefore the assumptions of normality needed for correlation were not met (Pallant, 2011). It was thus deemed appropriate to carry out a non-parametric test of correlation to look for relationships in the first part of the question. A bivariate correlational analysis, Spearman's Rho test, was carried out in SPSS. For the second part of the question, a bivariate correlational analysis (Pearson's correlation test) was carried out.

A significant positive correlation was found between RES scores, which were calculated from self-ratings on RSCA, and perceived support that was rated by students on HISGS (r_s[df=52]=0.474 [where r_s=1 is a perfect positive and r_s=−1 a perfect negative correlation]; P<0.001). This represents a medium effect. High levels of self-rated personal resilience were associated with higher ratings of satisfaction with perceived support. A significant negative correlation was found between RES scores and perceived stress (r_s[df=52]=−0.621; P<0.001), which was rated on PSS by students. This represents a large effect. High levels of perceived stress were associated with lower levels of perceived resilience.

According to Cohen (1988), a medium positive correlation was found between personal resilience and perceived support. When correlation coefficients

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were used to calculate a "percentage of variance" (Pallant, 2011), personal resilience helped to explain 22% of the variance in perceived support scores rated by students with T1D. A large negative correlation was found between personal resilience and perceived stress. A calculation of shared variance suggests that the personal resilience of students with T1D helped to explain 38% of the variance in perceived stress.

Qualitative analysis

Six over-arching themes were identified in relation to the research questions. The themes are presented in a thematic map in *Figure 1*.

Discussion

Quantitative data highlighted the strength of relationships between personal resilience, perceived support and perceived stress. The perceived support and stress measure is not diabetes-specific but is known to be closely related to diabetes care experiences. Although correlation does not provide a causal link, these findings strengthen the evidence for the relationship between perceptions of support in school and resilience in CYP with T1D.

Overall, personal resilience was significantly related to both perceived school-based support and perceived stress. The findings from both correlations mirror diabetes and resilience research in adults, where higher resilience was found to be associated with lower diabetes-related distress (Yi et al, 2008) and help to establish this association in CYP (Yi-Frazier et al, 2015). Participants who rated themselves as having high personal resilience tended to have lower ratings of perceived stress. This research also supports previous literature highlighting the importance of perceived support as part of resilience (Werner and Smith, 1982; Prince-Embury and Courville, 2008).

The qualitative data built on the findings of the quantitative data and pupils' views highlighted important themes related to resilience and managing T1D in a UK school setting. The over-arching themes identified in this research highlight the interaction between students, living with a medical condition, the understanding individuals have about T1D, the role of others in T1D management, and balancing T1D, life and school.

Overall, clear support that could be relied upon was perceived by CYP in this study as being the most valuable. Students felt they benefitted from having a named person and a designated place, i.e. a medical room, to facilitate their diabetes management. Even where students did not use support, only used it when unwell or in emergencies, the belief that support was available was important and may have contributed to resilience. This finding supports the distinction between actual and perceived support that exists in resilience research.

Support that was perceived as not helpful seemed to be associated with a lack of understanding from others and, in some cases, misconceptions students held about their own condition. A number of stereotypes and assumptions were associated with diabetes in relation to diagnosis and the feeling students were in some cases using T1D as an "excuse". Pupils highlighted that teachers and peers forgetting about their diabetes was an issue, especially when their T1D management was good and students would appear just like their peers without T1D. In some cases key adults and peers were unaware that students had T1D.

Perceptions of support should be considered alongside existing guidance for the psychological care of CYP with T1D (Delamater et al, 2014). This research suggests that taking a person-centred approach that considers individual perceptions

Table 2. Details given during phase two interviews with participants.

Child	Year group	Current age	Age at diagnosis	Ethnicity	Treatment	School	RSCA score and range descriptor
1	7	12	9	Black (African)	Injection 3–5 times a day	1	34, low
2	8	12	3	Black*	Injection 4 times a day	2	23, low
3	7	12	7	White (British)	Injection 4 times a day	3	43, below average
4	7	12	12	Black*	Injection 4 times a day	1	54, average
5	10	15	10	White (British)	Insulin pump	2	63, high
6	7	12	4	Asian†	Insulin pump	1	58, above average

RSCA=Resiliency Scales for Children and Adolescents; *Somalian; †Bangladeshi

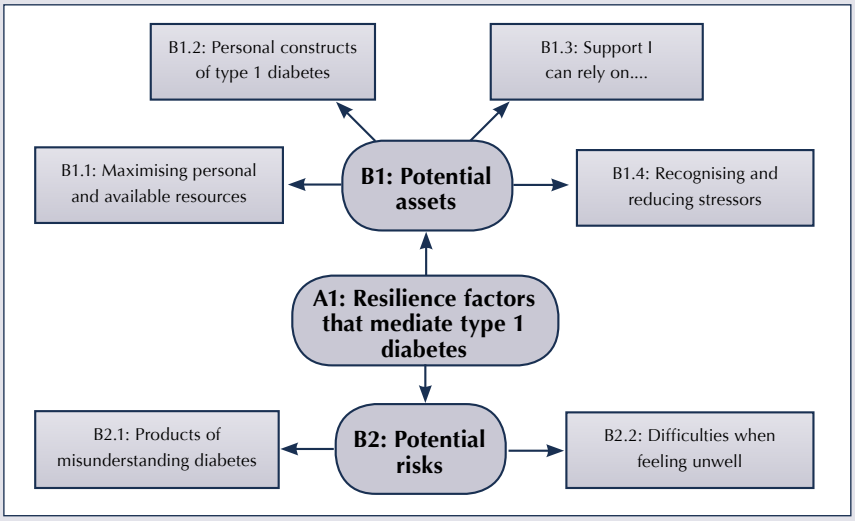

Figure 1. Thematic map of resilience factors that have an impact on type 1 diabetes in children and young people.

about care and support will be important in achieving positive outcomes.

Diabetes care teams should consider how to foster resilience in CYP with T1D and investigate perceptions of school support with CYP routinely as part of this process. Helping CYP will ordinarily involve direct work with schools to establish what support is in place. It should also involve asking CYP what they feel is supportive, what could be done to improve a sense of perceived support if lacking, and possibly also helping them think in new ways about support already available or to take a different perspective so perceptions of support can be enhanced.

The perceptions of support elicited from participants in this research will not necessarily be the same as those of other CYP. The process of discussing what the individual child or young person feels is supportive is likely to be fundamental to identifying what might be contributing to resilience and what might be harming it. The HISGS could be helpful in guiding the individualised school care plans that are in place for CYP in schools (Lehmkuhl and Nabors, 2008). Screening for overall stress would also be valuable.

Future research should explore CYP's HbA_{1c} levels alongside measures of resilience, taking a longitudinal approach. A limitation of this research, which future research could address, is the development of the HISGS. This study found that results did not meet assumptions of normality needed for correlation. An improvement would have been to trial this beforehand and to include triangulation measures. It was also not possible to return to the participants after the qualitative phase to check their views about the themes that were elicited from the data.

Conclusion

This study found that both perceived support and perceived stress had an effect on personal resilience. The findings of this study strengthen the evidence supporting a relationship between perceptions of support in school and resilience in CYP with T1D. ■

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