

Coping with diabetes in adolescence: a critical literature review

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Introduction

Adolescence can be a difficult period of life. The need to become more independent, to create an identity and to adopt a new lifestyle can influence the way that adolescents with diabetes cope with their disease. The following survey of studies reveals other factors that also come into play. These include both internal (e.g. self-esteem) and external (e.g. peer group and parents) influences. The complexity of the problem indicates that further research is needed to find out the best way of helping adolescents to cope with their diabetes.

Adolescence is a time of transition from childhood to maturity which happens at a different time and pace for each individual (Erikson, 1963; Coleman and Hendry, 1990; Musen et al, 1990; Adams et al, 1996; Skinner, 1997). It is a time of great change, inconsistency and emotional turmoil and often creates tension and anxiety for the adolescent and parents.

This critical literature review examines the psychosocial factors which influence the way in which adolescents cope with their diabetes.

For the purposes of this review, coping is seen as a psychosocial activity concerned with support and social influences, as opposed to the practical management of injections and blood tests.

A rigorous methodological approach was taken to ensure the trustworthiness of the review.

Methods

For the search process, both electronic databases and manual methods were used to identify relevant studies. Inclusion criteria were as follows:

- Research studies from 1990 onwards
- Published work
- Written in English.

Exclusion criteria were:

- Studies with a medical bias
- Journals not available through the three library centres available; Bath, Bristol and the RCN.

Publication bias may be a factor in this review (using published studies alone sometimes overemphasises positive results).

The searches used the words 'diabetes', 'adolescent/adolescence' and 'research' and yielded an enormous number of studies. The papers were narrowed down by identifying key words and themes, which themselves were chosen to best reflect the known psychosocial factors affecting how adolescents cope with diabetes. The key words and themes were:

- Family influences on coping
- Peer group influences on coping
- Feelings and attitudes about how they cope
- Quality of life and how this affected coping
- Fear for the future and how this affected coping.

There were ten studies, from seven journals, that were eligible for review.

Results

The sample

The sample groups ranged in age from 8 to 18 years, with the majority aged 13 to 17 years old. Sample size was adequate for all the studies except that of Lawler et al (1990) who acknowledged that the small sample size was a threat to the reliability and validity of their study.

The age range in all the studies was very wide and only one, Olsen and Sutton (1998), acknowledged the potential for adolescent psychosocial development to change over time.

ARTICLE POINTS

1 Adolescence is a time of great change, inconsistency and emotional turmoil.

2 There is potential for adolescents' psychosocial development to change over time.

3 Adolescents who had a high self-esteem had an increased ability to cope with a self-care regime.

4 A personal feeling of self-worth and self-efficacy is fundamental to how adolescents cope with diabetes self-care.

KEY WORDS

- Adolescence
- Psychosocial factors
- Self-care regime

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PAGE POINTS

1 Convenience sampling was the most common method of selecting the sample.

2 Bias may be present in convenience sampling.

3 In qualitative research, the interviewer is the data collection tool.

4 In one study, parents were categorised as motivating, accepting or having disciplined control.

5 Parental actions were described in detail by the adolescents in the same study.

Convenience sampling was the most common method of selecting the sample with clinic attendance being the main method of recruitment. Bias may be present because subjects in convenience sampling may be atypical of the population as a whole and this may affect the generalisability of the studies. Gardiner (1997) and Bond et al (1992) were the only authors to identify the potential bias from this method of sampling and suggest it is often the non-attendees at clinic who may be having a difficult time managing their diabetes.

Data collection

Two studies, Kyngas and Hentinen (1995) and Kyngas and Barlow (1995), used unstructured interviews to describe and discover the meaning of self-care in adolescents. In qualitative research the interviewer is the data collection tool and researcher credibility is important to establishing confidence in the data collected. None of the studies in this review that used an interviewer identified what skills they had as interviewers and this presents a threat to the credibility of these studies.

A descriptive study (Kyngas et al, 1998), used a structured questionnaire and open ended interviews to measure adolescents' perceptions of the role of health professionals, peers and parents in compliance with diabetes care. The results were cross tabulated to identify relationships between compliance and how adolescents viewed significant others. Though the questionnaire had been used in previous studies and found to be reliable and valid the results of the interviews were not subjected to a member check or peer debrief to assess credibility.

Challen et al (1993) used a semi-structured interview and psychometric rating scales to investigate adolescents' attitude to diabetes and the degree of emotional difficulty they may have in coping with diabetes. The authors had tested the interview schedule previously in a pilot study to ensure reliability and validity. Several of the participants in this study refused to be interviewed but did fill out the questionnaire. The potential for bias in the results is acknowledged by the authors.

Bond et al (1992) in a quantitative study used five structured questionnaires, a semi-structured interview and a blood test to assess their health belief model. Since all the questionnaires had been used in previous studies, it can be presumed that they were reliable and valid. The results were presented in five sections with complex statistical analyses and tables which are difficult to relate to the data collected.

Both of the quantitative studies by Grey et al (1991, 1997) used a descriptive approach with structured questionnaires to identify coping behaviours in young people. The instruments were tested for content validity by comparing the results with previous studies and through the use of experts to examine the instrument.

Gardiner (1997) used a quantitative approach with an analytical survey design to investigate adolescents' attitudes through a previously piloted postal questionnaire. This study had a high response rate of 67.8% (40/59) which improves the generalisability of the results.

Family and peer influences on coping

The study by Kyngas et al (1998) on adolescents' perception of the actions of health professionals, families and friends was compared with their self-reported compliance with a diabetes regime.

In a questionnaire, adolescents identified themselves as having good or poor compliance. In the interview, parents were categorised into one of three groups in accordance with their actions:

- Motivating
- Accepting
- Having disciplined control.

The relationship between the two was measured by cross tabulating the results.

Parental actions were described in detail by the participants. For example, the following quote refers to 'disciplined control' parents:

'It's terrible that my parents always take part in my self-care or perhaps it's better to say they try to take part in it. I don't like it and I try to hinder it.'

The adolescents in this group described themselves as having poor compliance.

On the other hand motivating parents

were seen as giving positive feedback and working with the adolescent on self-care. These adolescents saw themselves as having good compliance with self-care. Parents whose actions were described as accepting were seen as supportive but they allowed the young person freedom to make choices and accepted them as they were.

Friends were described as dominating, giving silent support or having no meaning. Silent support sometimes reminded the adolescent about self-care. Alternatively, it was manifested by the friends trying to change their own behaviour to 'fit in'. A quote by one diabetes patient illustrates such behaviour modification:

'Because my friends don't eat sweets when they are with me, it helps me and encourages me to care for myself. I believe that they think of me and want to help me.'

On the other hand, the diabetes patient whose life was dominated by friends coped by adopting their friends' lifestyle which did not include adherence with a health regime:

'I can't care for myself because self-care activities don't fit my friends' lifestyle.'

The data from this study support the findings of two earlier studies (Kyngas and Hentinen, 1995; Grey et al, 1991).

Kyngas and Barlow (1995) found that conflicts with parents were more common among adolescents with poor compliance who viewed their parents as disciplinarians. Some of the young people in this study believed their peers without diabetes received less control from, and were less dependent on, their parents. Parental control was seen in a more positive light by others, who described it as helping them to lead a healthy life.

Lying to parents and healthcare staff in order to avoid arguments was a common occurrence. Although this often led to feelings of guilt, adolescents would soon become accustomed to this method of coping:

'I have learned to lie. It is better to lie to my parents, nurses and doctors than to be nagged.'

The majority of adolescents who felt

they coped better with self-care had parents and friends who accepted them as they were and provided support and motivation. Young people who saw parents as too restrictive coped by lying or ignoring their self-care. Further, they were particularly influenced by their friends' lifestyle and wanted to live as they did.

Personal meaning

In a study looking at the contribution of coping behaviours to psychosocial adjustment, Grey et al (1997) found that adolescents who coped by using negative behaviours had poor metabolic control, as measured by glycosylated haemoglobin, and poor self-image.

A study by Gardiner (1997) to investigate the attitudes of young people towards their diabetes found a statistically significant association ($P=0.001$) between a good self-image and a positive way of coping with diabetes.

Kyngas and Barlow (1995) found that the way adolescents viewed their diabetes determined how they coped with it. Those who described diabetes as a 'habit' or 'little devil' had a more positive attitude towards the disease and coped by incorporating self-care into their everyday life. Those who saw it as 'a nightmare, stress, hell etc.' held more negative views about diabetes and were more likely to express feelings of stress and anxiety. Contrasting views are given below:

'It is a little devil. All the time it causes certain actions in my daily life. I have to eat regularly and so on. My friends do not have such a regular timetable and do not have their own little devil living with them. On the other hand, this little devil reminds me to take care of myself. It is not so bad.'

'I am like a little boy in prison. I do not know anything about freedom. My life is a prison, separated from other peoples lives.'

Some of the studies looked at how knowledge of complications affects the way adolescents cope with diabetes.

Bond et al (1992) discussed how increasing age was associated with an increase in perceived threat, defined as the perceived level of severity of, and susceptibility to, the disease. Their results

PAGE POINTS

1 Motivating parents gave positive feedback and worked with adolescents on self-care.

2 Some adolescents neglected their self-care regime because it did not fit into their friends' lifestyles.

3 A statistically significant association was found between good self-management and a positive way of coping with self-care.

4 Some studies looked at how knowledge of complications affects the way adolescents cope with diabetes.

PAGE POINTS

1 Overly anxious parents may interfere with the young persons lifestyle.

2 The psychosocial background of friends is important.

3 Adolescents with high self-esteem coped better with a self-care regime.

4 Diabetes was generally seen in negative terms by study participants.

suggest that people who see themselves as high-risk cope by controlling the fear to alleviate uncomfortable emotional feelings.

In a study by Challen et al (1993), young people's views about glycaemic control were investigated and a statistically significant ($P < 0.01$) association was found between knowledge of complications and a negative attitude to diabetes (as measured on a previously tested 'attitude to diabetes scale'). These young people did not cope so well with a diabetes regime.

On the other hand, Gardiner (1997) found that fewer adolescents worried about complications than about future career prospects (14 versus 22 out of a total of 59). However, he did not indicate how this affected coping with a self-care regime.

Kyngas and Hentinen (1995) found that fear of complications was a powerful incentive for those adolescents who felt they coped well. For those who coped less well, complication risk was associated with guilt, fear or ignored as a factor in self-care.

Discussion

Adolescence is a time of increasing independence from parents as young people take on responsibility for themselves in preparation for adulthood. The freedom to make one's own choices about lifestyle is seen as important in this age group. Taking increasing responsibility for diabetes self-care is part of the process. However, it is not difficult to see why parents may be over-restrictive and anxious about self-care in view of the potential for serious long-term adverse effects from poorly managed diabetes. Overly anxious parents may interfere with young people's lifestyle causing conflict and argument. This could lead to poor compliance with a healthcare regime, and further parental anxiety. Such a cycle of events can be difficult to break.

Throughout the adolescent period, there is an increasing need to create a self-identity outside the family. Hence, peers also have a big influence on how young people cope with diabetes. The way this influence manifests itself is complex. It may be positive, e.g. with understanding friends who provide support.

A negative influence could arise when the adolescent's desire to be accepted within the group is stronger than the desire to adhere to a self-care regime.

Other important factors are the psychosocial background of friends and their views and experiences about health and illness. Also important is the degree to which friends can influence the adolescent with diabetes. It could be that the degree of peer group influence and the ability of the adolescent to exert his/her own will on the situation is dependent on personal characteristics such as self-esteem.

In the review, young people who had a high self-esteem had an increased ability to cope with a self-care regime. But this may be part of a positive feedback cycle: increased self-care leading to decreased parental anxiety leading to an increased sense of self-worth and self-efficacy and so on.

The personal meaning of diabetes was richly described by study participants who generally saw it in negative terms. However, some of them seemed to have the ability to turn the negative into the positive such as the girl who felt her diabetes was a 'little devil' who helped her to cope. Others did not seem to have the same coping mechanism and expressed feelings of hopelessness about the disease. The ability to turn the negative into the positive could also be related to personal characteristics such as a high self-esteem which empowers the young person to find ways of coping.

It is apparent that no single factor (parents, peers or personal meaning) could be seen in isolation from the others since they all appear to be interdependent. However, it could be a firm conclusion that a personal feeling of self-worth and self-efficacy are fundamental to how young people cope with diabetes self-care.

The complex nature of the problem and the bias in the results of the studies (attributable to convenience sampling) mean that it is difficult to draw too many firm conclusions from this review. However, some suggestions for practice can be made. For example, the healthcare professional could consider how to improve adolescents' feelings of self-worth, e.g. by

teaching them assertiveness skills. Extra support through increased telephone contact could be given to adolescents with low self-esteem to help them through difficult periods.

Limitations

There are some limitations to this review that need to be acknowledged. None of the studies collected data from clinic non-attendees hence there is a potential bias to all the results. In my experience, non-attendees have an increased rate of admission to hospital with poorly-managed diabetes. These are often the same group of young people who have a poor self-esteem, are in conflict with their parents and are heavily influenced by their peers. Ways of finding out their views need to be established in order to identify how we can support them.

Conclusion

The subject under review was more complex than first envisaged. Interesting data were revealed, which were analysed both for methodological quality and content. No firm conclusions were drawn from the study findings. However, based on the results and personal experience from working with this group of people, it was possible to make some suggestions for changing practice.

There is a need for further comparative studies to identify how coping with self-care changes over the long period of adolescence. Also, none of the studies investigated the influence of environmental factors on young people, e.g. possible

differences in socialisation between adolescents living in an inner city area and those living in small towns or villages. This would be a subject worth exploring as it is expected that city teenagers may mature faster than their country counterparts. ■

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PAGE POINTS

1 Adolescents with low self-esteem could be given extra support.

2 Non-attendees' opinions need to be sought in future research.

3 There is a need for comparative studies on how coping changes over time.