Partners' experiences of living with someone with type 1 diabetes

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Article points

1. The impact of living with someone with diabetes is significant.
2. Partners of people with diabetes feel excluded and isolated.
3. Diabetes places restrictions on lifestyle and future planning.
4. Healthcare professionals do not address the needs of partners.
5. Knowledge and support for partners can improve diabetes management.

Key words

- Partners
- Relationships
- Emotional impact

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It is well established that living with diabetes requires the maintenance of a demanding and time-consuming self-management regimen (Hampson et al, 2000; Senecal et al, 2000; Stenstrom et al, 2003). It is also clear that people with diabetes do not live in isolation and the impact of managing this condition affects those who live with and provide support for them (Rajaram, 1997; Trief et al, 2003; Morris et al, 2005). This article describes a qualitative study of the experiences of partners living with someone with type 1 diabetes.

In research carried out by the authors and several colleagues, people with type 1 diabetes commented frequently on and expressed concern regarding the impact this condition has on their partners (Morris et al, 2004). This is echoed in recent Department of Health (DoH) and Diabetes UK publications whose guidance has suggested that the provision of education for the partners of people with diabetes would be beneficial to all concerned (DoH, 2005; Diabetes UK, 2005).

For the purposes of this article the term 'partner' refers to any person living, or significantly involved, with a person with type 1 diabetes, as defined by the person with type 1 diabetes.

Current literature consistently suggests that living, or being closely associated, with someone who has diabetes can be psychologically detrimental (Wearden et al, 2000). Gwyther (1998) and Kuyper and Wester (1998) indicated that couples believed providing information about the person with diabetes' condition can greatly enhance the partner's ability to cope. Furthermore, involvement of the partner in the person with diabetes' treatment and management can improve adherence to self-management regimens and improve the psychological health of both of them (Matire et al, 2004; Ohman and Soderberg, 2004).

Equally, a partner who has condition-specific knowledge and is able and confident to participate in its management will improve the psychological wellbeing of the whole family and adherence to treatment (Garay-Sevilla et al, 1995; Rajaram, 1997; Trief et al, 2003).

Where family interventions to support diabetes management and other long-term conditions have been advocated and researched, the focus has been on childhood and adolescent diabetes (Azar and Solomon, 2001; Gillibrand, 2003), and not adults. Most research into family interventions to date has employed quantitative methodology focussing on explaining the factors associated with effective diabetes management: marital quality, relationship satisfaction, emotional expression, and attitudes towards diabetes of the partner. Work by Trief et al (2003) suggests that more qualitative research would offer a greater understanding of the daily experiences of living with a partner with diabetes.

The aim of this study was to explore the experience of living with an adult with type 1 diabetes and the impact that this has on the

partner, using a qualitative approach in the form of semi-structured interviews.

Methods

Participants were selected with the aid of an invitation letter presented to people with type 1 diabetes during their clinic visits at Southmead Hospital. Fifteen semi-structured interviews were conducted (with seven male and eight female partners), tape recorded, transcribed verbatim and analysed using interpretative phenomenological analysis (IPA; Smith, 1995).

The participants were all partners of people with type 1 diabetes (duration, 7–41 years), were aged between 37 and 71 years, and were all married (duration, 4–50 years). Partners were initially asked 'What is it like living with someone with diabetes from a personal and familial perspective?', which was explored more fully by reflective questioning. They were then asked 'What do you need to help you manage the impact more effectively?'.

IPA allows the exploration of the 'lived experience' of being a partner of someone with type 1 diabetes. It recognises the dynamic nature of the interview process and the involvement of the researcher's own perceptions, which are necessary to make sense of the partner's world through a process of interpretative activity. This role of interpretation encourages reflexivity by the researcher, acknowledging how the analysis was shaped both by the researcher and through social interaction with the respondent.

Data analysis was completed by three researchers, who compared and discussed their own independent coding of themes and subsequent interpretations of the data, to ensure the analysis was credible and trustworthy (Smith and Osborn, 2003).

Results

A consolidated list of master themes derived from the transcripts included: 'emotional issues', 'lifestyle changes', 'control', 'thoughts about the future' and 'knowledge'. They provide an insight into the impact diabetes has on partners, as an individual and in their relationship with the person with diabetes.

Themes are interlinked and describe the concerns of partners for the future, emphasising the emotional impact, a perceived lack of control that they experience, and their need for diabetes-specific knowledge and support.

There was a strong sense of the partners being left out – excluded from a 'diabetes club'. This is a 'club' providing membership to a fraternity with shared experiences, an opportunity to gain knowledge and support from healthcare professionals and peers, and a common identity. For several partners this created frustration and conflict. For instance, as one partner explained:

> *'Well I should imagine quite a few marriages have broken up because of difficulties [associated with management of diabetes].'*

However, some partners acknowledged how important the support from people in a similar position could be for the person with diabetes in order to show that their experiences were not unique:

> *'[It is good to know that the person with diabetes] is among kindred spirits who can perhaps add dimensions that you possibly can't.'*

The results of this qualitative study illustrate the experiences of partners of people with type 1 diabetes. Quotes from the transcripts are presented below for three of the themes: 'emotional issues', 'control' and 'knowledge'.

Emotional issues

Partners expressed a range of emotional responses to living with a person with diabetes. For example, frustration was expressed at not being involved. In addition, the loss of spontaneity within the life of a partner, because of the constant need to plan around diabetes, was noted:

> *'It's a bit restrictive with meal times […] You can't do things spontaneously […] You know if we are out […] and we haven't finished […] you can't just grab a sandwich.'*

The practicalities of self-management, particularly the lifestyle changes required in managing diabetes, often raised feelings of guilt and frustration:

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Page points

1. Partners explained that negative feelings concerning control are due to a lack of involvement in the management regimen, which was associated with increased feelings of helplessness and frustration when things go wrong and they cannot help.
2. Partners, like people with type 1 diabetes, require a greater understanding of the condition to enable them to integrate diabetes into their lives and achieve a sense of control in its management.

'But it does seem awkward sometimes […] I don't feel right sitting and eating food in front of her that I know she can't eat […] That's the main thing.'

'[I ask] "Why are you doing this? Why are you doing that?" And sometimes it gets a bit "uhhh!", having to always think about [diabetes].'

This emotional impact can be experienced by both the partner and the person with diabetes:

'You know it causes distress on both sides!'

The impact perhaps results from a knowledge deficit and a need for a greater understanding of diabetes and its management by them both. An example is provided by one participant talking about the impact of changing from porcine insulin to an early human insulin preparation. This was an avoidable experience had the partner or the person with diabetes known more about the physiological effects of the human insulin:

'It was about 5 years which […] I try to forget. Because […] we just had some awful experiences […] I mean you do get worried but […] since the few years with the […] early] human insulin, nothing's been as bad.'

The couple's awareness of difficulties with this insulin arose by chance as they watched a television programme where GPs with diabetes discussed the problems they had encountered.

Control

Partners' negative perceptions of control relate to a lack of control over the person with diabetes' management of the condition. Specifically, they explained that these negative feelings are due to a lack of involvement in the management regimen, which was associated with increased feelings of helplessness and frustration when things go wrong and the partner cannot help:

'And if she gets a bit slack about something that's quite hard for me.'

However, several partners described a positive experience of a partnership in adapting to and managing their partners' diabetes:

'And then actually we manage to do it. But she is very good at doing it herself […] She basically runs the show herself […] I know how to do it. I know what injections she uses.'

'I have got her recently to do more frequent blood tests. That's another way of managing it so you know what your situation is.'

Isolation was a key sub-theme, which often reflected a relationship conflict due to a difference in perceived needs:

'Improvement for me is not necessarily improvement for her.'

'Whether I like it or not […] she's very […] strong willed.'

Isolation was reinforced by partners' perceived lack of support opportunities from healthcare professionals:

'I must say there was no involvement of myself at all in the hospital […] I wasn't told anything […] He was given a diet sheet; he was given instructions in how to inject. They never involved me in one thing at all and they didn't warn me of anything.'

Knowledge

Partners, like people with type 1 diabetes, require a greater understanding of the condition to enable them to integrate diabetes into their lives and achieve a sense of control in its management. However, knowledge acquisition is limited and often obtained second-hand through chance conversations. Yet healthcare professionals assume that partners have the knowledge:

'Nobody has ever in my life shown me how to give an injection. I have never been instructed […] And that is something I ought to know […] You only really need showing once don't you? But instead you get a prescription for something that you don't know how to use […] If I ever need the doctor again, I shall say to him I don't care if I've got a prescription because why should I have to do it without having been told.'

This theme linked strongly with lifestyle restrictions and future concerns regarding the onset of complications and reduced life expectancy. A misconception of what complications meant led one partner to consider them as cancer-like 'secondaries' and therefore diabetes as a 'malignancy':

'She's got slight problems with diabetes – the secondaries.'

These restrictions and concerns increased levels of emotional distress and self-blame for

partners, which is exemplified by the following extract:

> *'I might have realised about impotence, but I didn't and things went a bit haywire. "J" was in his late 50s early 60s and of course he was frustrated […] but [he was] blaming it on me […] And I was the one thinking "Why is it? […] You're obviously not interested in me." [… The healthcare professionals] may well have been saying […] "you are showing signs of impotence," and he of course would have said "no". I would have realised that it wasn't my fault, [but] really something to do with the illness […] I never made that connection until very much later.'*

Here the partner was kept in ignorance, which led to feelings of guilt that the couple's sexual difficulties were her fault; however, realising later that impotence was a complication of diabetes created tension and anger in their relationship.

The ability to recognise the signs and symptoms of actual or pending low blood glucose and having knowledge regarding diet are commonplace, but knowledge regarding the management of hypoglycaemic events is limited.

Equally, the emotional impact of poor glycaemic control for partners was found to be significant. Partners were worried about the person with diabetes' safety when driving and having to take control of the diabetes management without permission of the person with diabetes to avoid a hypoglycaemic event developing. The emotional impact also included embarrassment for the person with diabetes experiencing a hypoglycaemic event in public:

> *'I do get worried when she's driving […] especially when she is stuck on the motorways.'*

> *'I do sometimes say to him "do you think you should eat something?" Of course he gets very cross then and denies [going hypoglycaemic].'*

> *'[The hypoglycaemic episodes] are the lows […] because she acts as though she is drunk.'*

Reflecting on the question 'What do you need to help you manage the impact more effectively?', partners commented on their willingness to be involved in the process of managing diabetes and to provide support when required:

> *'I was very pleased to be invited to that initial meeting […] I thought […] it is a good thing that they are inviting partners.'*

> *'Agreeing to this interview was part of the fact that I want to get involved [… and] maybe learn a bit.'*

However, their need for knowledge and support was evident, as one partner enquired whether there would be a 'society' for this:

> *'One thing maybe is whether there is a form of communications that [provides support]. [Is there] maybe a society I could look for?'*

Discussion

Although the small number of people interviewed means that the results from this study are not generalisable, the data do agree with previous research suggesting that diabetes, like other long-term conditions, has a profound impact on the dynamics and inter-relationships that exist within couples and families (Kuyper and Wester, 1998; Matire et al, 2004).

Equally, the emotional costs associated with living with a person with type 1 diabetes are significant. These range from anxiety in dealing with the unpredictable nature of diabetes control, to feelings of isolation, guilt and frustration, as well as anger towards the person with type 1 diabetes and at the restrictions that this condition places on the couple's relationship and life. This is reinforced by healthcare professionals failing to acknowledge the educational and support needs of partners and the impact that diabetes has on the relationship dynamics.

People with a long-term condition do not live in social isolation and have to interact and negotiate relationships with their partners (Rossi Ferrario et al, 2004). Partners who experience isolation, a lack of knowledge and emotional distress will have a direct effect on how the person with diabetes manages and adapts to his or her condition (Heijmans et al, 1999).

Findings from a parallel project

In research carried out by the authors and several colleagues, people with type 1 diabetes reported the demands placed upon their partners and their partners' needs for education and support (Morris et al, 2004). With this in mind, specific scheduled sessions were designed and run for partners

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1. Partners were invited to attend one of four evening sessions facilitated by a diabetes specialist nurse and a clinical psychologist.
2. The 3-hour sessions were run on an informal, non-didactic basis.
3. The sessions were informally evaluated and were received positively by those attending.

in conjunction with the existing structured intervention programme for people with type 1 diabetes attending clinics at Southmead Hospital (Johnson et al, 2005). Partners were invited to attend one of four evening sessions facilitated by a diabetes specialist nurse and a clinical psychologist. The 3-hour sessions were run on an informal, non-didactic basis. During the sessions, partners requested information about managing hypoglycaemic events and illness, the physiology of diabetes and going on holiday, as well as emotional support. The sessions were informally evaluated and were received positively by those attending. Partners highlighted aspects that they liked:

'Understanding that you are not the only person who has to deal with it.'

'Being able for the first time to talk to other people who are going through the same problems as me.'

One attendee summed the session up as follows:

'An excellent meeting which was very reassuring for me as my husband has been recently diagnosed.'

Conclusions

The views of the partners interviewed in this study suggest that an intervention providing education and support is necessary to reduce the negative impact that diabetes has on them. Recent publications highlight the potential benefits of involving partners and families in the management of chronic conditions, to help improve the outcomes (DoH, 2005; Diabetes UK, 2005). Therefore, the next stage of the research will be to respond to these guidelines and the needs of partners – taking into account the findings from the parallel project – by developing, implementing and evaluating a programme of education and support for them. ■

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