Perceived support needs for intensive diabetes self-management

Valerie Wilson

Article points

1. Government policy in the UK highlights the need for addressing the psychosocial needs of people with diabetes.
2. This study investigated the support needs of 147 people who intensively manage their type 1 diabetes.
3. The results show that participants would like more help from their diabetes team in addressing the psychosocial issues surrounding diabetes.

Key words

- Intensive diabetes self-management
- Insulin pump therapy
- Multiple daily injections
- Psychosocial barriers
- Psychosocial support

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Intensive management of type 1 diabetes using either multiple daily injections or insulin pump therapy allows improved glycaemic control and a better quality of life to be achieved by the person with diabetes (The Diabetes Control and Complications Trial Research Group, 1993). Technological advances in pump therapy and multiple daily injections provide tools to help achieve optimum diabetes self-management. However, general and psychosocial support from trained health professionals is also necessary to enable any perceived barriers to self-management to be overcome. This article reports the support needs of 147 people using intensive methods to self-manage their diabetes and discusses practical implications highlighted by the results arising from this research.

Evidence suggests that psychosocial issues exert a major influence on diabetes self-care behaviours that affect metabolic control (Russell et al, 2001; Weinger et al, 2001; Herpertz et al, 2000). Intensive diabetes self-management can be frustrating for both the person with diabetes and their practitioner; treatment-related difficulties and emotional distress may initially act as motivators to improve glycaemic control, but can later become barriers to that goal (Weinger and Jacobson, 2001). Information is therefore needed about the individual's support needs in order for these needs to be met.

The Government's White paper *Saving Lives: Our Healthier Nation* (Department of Health [DoH], 1999) called for the establishment of programmes to help people with chronic conditions such as diabetes to maintain their health, highlighting the need for people to be supported in diabetes self-management.

In addition, Standard 3 of the National Service Framework (NSF) for diabetes (DoH, 2005) aims to ensure that:

> *'... people with diabetes are empowered to enhance their personal control over the day-to-day management of their diabetes in a way that enables them to experience the best possible quality of life.'*

The NSF for diabetes also recognises the need for research exploring the psychological needs of people with diabetes. In addition, patient-centred care is key for everyone with diabetes (Wilson, 2004; Avery, 2001). Care should be tailored

around the needs of the individual wherever it is delivered and people with diabetes should be able to work in partnership with healthcare professionals to draw up a care plan (World Health Organization, 2002). This teamwork is pivotal to local and national diabetes services, and has been outlined in the document *Improving Diabetes Services – The NSF Two Years On* (DoH, 2005). The role of diabetes-specific support for self-management has also been recognised in the NSF for diabetes document (DoH, 2001) which states that:

> ***'The provision of information, education and psychological support that facilitates self management is therefore the cornerstone of diabetes care.'***

In order to overcome any psychosocial barriers to successful self-management there is a need to better understand the support required by people who intensively manage their type 1 diabetes. Intensive self-management of diabetes can be a complex issue, and it is vital that people who do so have the skills to manage the condition effectively. Therefore, this study was carried out in order to examine the support needs of people with type 1 diabetes who use intensive treatment methods to enable effective management of their condition. The objectives were to identify their support needs, the support they would like and any perceived barriers to effective diabetes self-care if these needs were not being met.

Methods

The research sample contained 100 males and 100 females who were randomly selected from the national diabetes voluntary organisation INsulin PUmp Therapy (INPUT) group database, which provides support and information to people with a need to intensively self-manage their diabetes, for either clinical or personal reasons. The inclusion criteria were:

- age 18–80 years
- diagnosis of type 1 diabetes for a minimum of five years
- UK resident
- user of either multiple daily injections or insulin pump therapy to control their diabetes.

Diagnosis of type 1 diabetes relied on self-reporting by respondents treating their diabetes with insulin and the respondent being told they had type 1 diabetes by their hospital diabetes team. The Multi Regional Ethics Committee was consulted prior to undertaking the research regarding ethical approval. This was not required as the voluntary organisation from which participants were drawn is a non-NHS organisation that has no access to patients' records nor involvement in their treatment regimens.

The original research questionnaire was designed to measure respondents' information, education and support needs. Only the support needs component is reported in this article. The support-related statements in the research questionnaire were validated by a pilot study (unpublished), and consultation with an expert group in the field of diabetes. The expert group used in the study comprised:

- Four diabetes clinical nurse tutors
- the Chair of INPUT organisation
- the Care Manager of Social Services
- the NHS Sorporate Fincance Manager
- the Director of Research, Diabetes UK
- the Commissioner for Diabetes (Kent)
- the Head of Service, Metabolic Medicine.

The statements were informed by themes identified from the available literature (DoH, 2003; Hall et al, 2003; Anderson et al, 2000; Helz and Templeton, 1990). The support themes considered most salient were:

- psychosocial and quality of life correlates
- diabetes-related stress
- psychosocial barriers to diabetes self-management
- locus of control, social support and concordance with the diabetes treatement regimen
- empowerment as a measure of psychosocial self-efficacy
- rates of depression in diabetes
- overcoming obstacles to behavioural change in diabetes self-management.

The self-completion questionnaire used semi-structured statements scored on a four point Likert response scale: agree, tend to agree, tend to disagree and disagree. A 'don't know' category was also added. The pilot study and consultation

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1. Understanding the needs of people who intensively manage their type 1 diabetes will allow their psychosocial needs to be better adressed.
2. This study aimed to identify their support needs, the support desired and any perceived barriers to effective diabetes self-care.
3. One hundred men and 100 women were sent a research questionnaire that contained multiple-choice and open-ended questions.

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1. The questionnaire was repeated one year later to allow test/re-test reliability and stability of answers and consistent responses between surveys.
2. One hundred and forty-seven people completed both questionnaires.
3. The four themes identified by the study focused on how healthcare professionals were perceived as deficient in providing emotional or psychological support and understanding, too concerned with metabolic control, and likely to make the individual feel like a burden.

with the expert group enabled the assessment of the relevance, clarity, and external validity of the statements. In addition, respondents were given the opportunity to provide comments about their general and psychosocial support needs, relating to intensive diabetes self-management.

The survey was repeated one year later with the same sample and same questionnaire. This allowed an assessment of test/re-test reliability and stability of responses over time.

The quantitative research data was coded as 1='agree' (combining 'tend to agree' and 'agree' responses); 2='disagree' (combining 'tend to disagree' and 'disagree' responses); and 3='don't know', which were entered onto SPSS software, (SPSS Inc, Chicago, IL, USA), for frequency analysis. Factor analysis and the construction of scales was performed for the whole questionnaire measuring information, education and support needs to assess construct reliability. Chi-square tests were performed to assess relationships between variables. Qualitative comments were entered into winMAX software (Udo Kuckartz, Humboldt University, Berlin, Germany) to help identify common themes and to reduce any element of selection bias concerning these themes.

Results

One hundred and fifty-five people (77.5%) responded to the first survey, and 147 (73.5%) to the repeat a year later, giving an overall crossover sample of 147 who responded to both surveys. The following data relate to these 147 repsondents. Seventy-one (48.3%) were using multiple daily injections and 76 (51.7%) were using insulin pump therapy to help manage their diabetes.

Item loadings on the factors emerging from the questionnaire measuring information, education and support needs showed that the support component contained ten items:

- I can contact my diabetes team for advice and support.
- I find it hard to stick to my diabetes regimen.
- I strictly follow what I am told by my diabetes team.
- I don't feel I receive any support in coping with my diabetes.
- My diabetes team have solutions if I have a problem.
- My diabetes team provides support for living with diabetes.
- My diabetes team provides advice on social aspects of diabetes.
- I find my needs are often overlooked or misunderstood.
- I've been advised of coping strategies regarding my diabetes.
- There's a trained psychologist or counsellor available through my diabetes team.

Factor analysis of the second survey showed similar findings to those of the first survey (see *Table 1*). Construction of item scales to measure internal consistency in both surveys showed a Cronbach alpha coefficient of 0.8 for the support component. This suggests that the questionnaire measured the support component with a high degree of reliability and stability.

Table 1 provides a summary of response rates for each of the quantitative support statements across both surveys. Analysis of each statement suggested a strong relationship between support needs and communication with the individual's diabetes team, the data showing a high level of stability over time.

Correlations between the scores of both surveys showed a high level of consistency and test/re-test reliability in the answers the respondents had provided.

Qualitative comments were analysed using winMAX software to identify common themes in the text. *Table 2* shows that several main themes emerged from the qualitative data:

- a perceived lack of emotional or psychological support from diabetes teams
- a perceived lack of understanding by health professionals of living with and intensively self-managing diabetes
- too much emphasis on poor metabolic control and not exploring the reasons behind this
- and the individual feeling they were treated like a burden.

Discussion

These results show that the respondents in this study required support from their diabetes

Table 1. Statements about psychosocial support needs for intensive diabetes self-management, N=147. (n = number.)

Statement	n agree (%) Survey 1	n agree (%) Survey 2	n disagree (%) Survey 1	n disagree (%) Survey 2	n do not know (%)	n same response (%)	*P*-value
I can contact my diabetes team for advice and support.	98 (66.7)	97 (66.0)	49 (33.3)	50 (34.0)	0	143 (97.3)	<0.001
I find it hard to stick to the diabetes regimen.	96 (65.3)	77 (52.4)	51 (34.7)	70 (47.6)	0	127 (86.4)	<0.001
I strictly follow what I am told by my diabetes team.	81 (55.8)	81 (55.8)	66 (44.9)	66 (44.9)	0	143 (97.3)	<0.001
I don't feel I receive any support in coping with my diabetes.	53 (36.1)	51 (34.7)	94 (63.9)	96 (65.3)	0	143 (97.3)	<0.001
My diabetes team has solutions if I have a problem.	49 (33.3)	50 (34.0)	98 (66.7)	97 (60.0)	0	143 (97.3)	<0.001
My diabetes team provides support for living with diabetes.	45 (30.6)	45 (30.6)	102 (69.4)	102 (69.4)	0	147 (100)	<0.001
My diabetes team offers advice on social aspects of diabetes.	34 (23.1)	34 (23.1)	113 (76.9)	113 (76.9)	0	147 (100)	<0.001
I find my needs are often overlooked or misunderstood.	34 (23.1)	53 (36.1)	113 (76.9)	94 (63.9)	0	126 (85.7)	<0.001
I've been advised of coping strategies with regard to my diabetes.	20 (13.6)	18 (12.2)	127 (86.4)	129 (87.8)	0	139 (94.6)	<0.001
There is a trained psychologist or counsellor available.	11 (7.5)	11 (7.5)	130 (88.4)	130 (88.4)	6 (4.1)	147 (100)	<0.001

team to overcome any psychosocial barriers to intensive self-management of the condition. This perception is similar to documented studies that have examined psychosocial issues in the general population who treat their type 1 diabetes non-intensively (Russell et al, 2001; Herpertz et al, 2000; Tillotson and Smith, 1996; Polonsky et al, 1995; Helz and Templeton, 1990). It is clear that many issues affect the individual's perception of their diabetes care in the general population. The results presented above demonstrate that the 1–2% of individuals who intensively manage their diabetes in the UK with insulin pump therapy (NICE, 2003) and a number of people taking multiple daily injections, may feel their support needs are overlooked. This could be the case if the health professional's focus is on achieving glycaemic control, without the provision of the tools and coping strategies to assist them to do so. This is demonstrated by the percentage of people who agree with the statement, 'I don't feel I receive any support in coping with my diabetes': 36.1% in survey one, and 34.7% in survey two. In addition, 40 people (27.2%) raised this issue in their qualitative comments (see *Table 2*).

The results also show that respondents felt that there was a distinction between 'general support' and 'psychosocial support'. In this respect, general support refers to support and understanding of the issues concerning living with diabetes and sticking to an intensive diabetes regimen, with a 66.7% and 66.0% agreement for the receipt of general support respectively for surveys one and two.

Psychosocial support was identified as specialised support to overcome barriers of, for example, non-concordance, ability to carry out self-care activities and lack of motivation for self-care activities. The qualitative results showed that 40 people (27.2%) felt their psychosocial needs were overlooked, and only 7.5% of respondents in both surveys agreed they had a trained psychologist or counsellor attached to their diabetes team to provide psychosocial support. However, a minority of respondents (6 people, 4.1%) did not know whether a trained psychologist or counsellor was available to discuss psychosocial issues concerning intensive diabetes management. This raises the issue that these health professionals may not be needed by the

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1. Many issues affect the individual's perception of his or her diabetes care.
2. The qualitative results showed that 40 people (27.2%) felt their psychosocial needs were being overlooked by their diabetes team.
3. Of those surveyed, 88.4% responded that there was no psychologist or counsellor attached to their care team.

Table 2. Main themes that emerged from analysis of the qualitative data. N=147

Theme	Number (%)	Comments
General support from diabetes clinic	65 (44.2%)	'I get all the support I need from my clinic.' 'I feel I need social support to help me manage my diabetes.'
No lifestyle support or understanding from clinic (too much emphasis on poor metabolic control rather than looking at the reasons for this)	41 (27.9%)	'They are well meaning but fail to understand details of my life and diabetes management problems.' 'I would like support to attain a better quality of life whilst I try to intensively manage my diabetes.'
No emotional or psychological support (lack of provision of coping strategies)	40 (27.2%)	'A counsellor/psychologist should be part of the diabetes team to provide support when necessary.' 'No one has ever assessed why my diabetes control is so erratic and my levels of stress.'
Person feeling they are treated as a burden (emphasis on metabolic control)	38 (25.9%)	'I feel my diabetes team have little patience in dealing with diabetes management issues after a few attempts'. 'I feel depression stops me from managing my diabetes effectively, and I am treated as a burden because of this.'
Obstacles to improved diabetes control and behavioural change	38 (25.9%)	'I phoned the out of hours service and was told off for bothering them.' 'I really wanted to improve my diabetes control with intensive management, but my diabetes team didn't support me in this.'
Lack of psychological services	37 (25.2%)	'I am appalled by the lack of everything.' 'Because no one is willing to listen to why I have problems managing my diabetes on eight injections a day, I feel I am left to manage it alone.'
Empowerment/locus of control	35 (23.8%)	'I am very proactive in my diabetes self-management, but have to tell the diabetes team what I need, rather than it being automatically offered.' 'I feel that I cannot fight against the system to get improved diabetes control with intensive management. I just have to accept that certain services aren't available to me.'

majority of people who intensively manage their diabetes, or that the individual may be referred to a clinical psychologist or counsellor by the GP if required, and not via their diabetes team. The perception of support for this group was therefore classed as general (in terms of provision of information and facilitation), or specific (in terms of specialised psychiatric intervention).

A lack of perceived support from diabetes teams regarding understanding of social aspects of diabetes, and living with diabetes, was highlighted by respondents in both surveys. For the statement, 'my diabetes team offers advice on social aspects of diabetes' (such as eating out, going on holiday), agreement was only 23.1% in both surveys. Support for living with diabetes achieved a 30.6% agreement in both surveys, and 41 people (27.9%) provided qualitative comments about a perceived lack of support for managing diabetes in social situations, and for living with an intensive diabetes management regimen.

In terms of recognition of psychosocial issues which affect diabetes self-management for the individual, the data has shown that over half the respondents in both surveys found it hard to stick to an intensive diabetes regimen (65.3% in survey one; 52.4% in survey two). Over half the respondents agreed they strictly followed what their diabetes team told them concerning intensive management strategies (55.8% in surveys one and two), although it could be inferred that the remainder perceived they were not concordant with medical advice.

Almost two-thirds of respondents also felt their diabetes team did not have solutions if they had a problem with their intensive diabetes self-management, with only 33.3% agreeing in survey one, and 34.0% in survey two. The qualitative comments provide further insight to this perceived lack of recognition by health

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1. While support for living with diabetes was perceived by 30.6% of participants, only 23.1% reported support for dealing with the social aspects of diabetes.
2. Over half the respondents admitted to strictly following the instructions from their diabetes team.
3. Two-thirds reported that they felt their diabetes teams did not solve their problems relating to intensive diabetes self-management.

Box 1. Practice implications.

Practice implications

- Availability of psychosocial support from trained health professionals who are part of the diabetes team, or accessible via GP referral when necessary.
- Improved understanding of the experience of living with/self-managing diabetes to strengthen the relationship between the patient and their health professional.
- Recognition and action regarding psychosocial issues affecting diabetes self-management.
- Further research regarding effective models of diabetes patient psychosocial support.

professionals of psychosocial issues, with 40 people (27.2%) commenting on a lack of emotional or psychological support, and 37 people (25.2%) commenting on a lack of psychological services.

While these results might raise the question of whether people with diabetes want the responsibility of self-managing their diabetes effectively with intensive insulin treatments; they provide a benchmark against which diabetes support services may be measured in the future.

Conclusions

This research provides a picture of the support needs of a group of people with type 1 diabetes in order to assist with intensive diabetes self-management and the extent to which these needs were met by the diabetes care provided to them. This research also highlights the need for a trained psychologist or counsellor to be attached to diabetes teams, or be available through GP referral, to address psychosocial needs of this population. This finding has previously been under-reported from the service users' perspective, both for those who intensively manage their diabetes and for those using insulin pens or injections once or twice daily.

It can be said that this group of people with type 1 diabetes are not representative of the wider population because they had contacted a self-help organisation and used intensive methods to improve their diabetes control. This point highlights the issue that, if these individuals are proactive and empowered for intensive diabetes self-management and yet have un-met support needs to be able to achieve this, how can we be sure that the support needs of every individual with diabetes are being met? These findings also reflect the differing levels at which patient support needs are met in the wider population with diabetes according to resources, as documented in other studies (Clark, 2003; Herpertz et al, 2000; Tillotson and Smith, 1996). The practice implications shown in *Box 1* could therefore be generalised to the whole population with type 1 diabetes. ■

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1. The support needs of the person with diabetes are met differently, depending on resources.
2. The practice implications from this study focus on improving the services to address the psychosocial needs of people who are intensively managing their type 1 diabetes (e.g. increasing access to counselling services) and the needs for further research into ways to provide effective psychosocial support.