Introduction

It is widely accepted that to maintain the knowledge, skills and confidence required to successfully self-manage and limit the risk of future complications, people with type 1 diabetes (T1D) need regular contact with health services. The did not attend (DNA) rate (whereby people give no indication that they will not be attending their appointments) at specialist secondary care diabetes clinics in the UK is about 10–20%.\(^1\)\(^,\)\(^2\) While we do know that in Scotland overall and in Grampian specifically the vast majority (86% and 92%, respectively) of adults with T1D engage sufficiently with health care services (in secondary and/or primary care) to have a recorded HbA\(_1c\) value in a 15-month period,\(^3\) we know little about those who have disengaged entirely from NHS services. The aim of this study was to establish the characteristics of adults with T1D who had become disconnected from diabetes care provision.

Methods

In Scotland, a database called SCI-Diabetes is used to record a variety of important clinical information obtained at all medical review appointments in primary and secondary care where diabetes management is discussed. Primary care databases and SCI-Diabetes communicate to allow this to occur. People who were disengaged from NHS diabetes services were defined as those who had not had an HbA\(_1c\) value recorded in the preceding 15 months, because this allows direct comparison to the annual publication of national statistics.\(^3\) SCI-Diabetes was used to identify and explore those with TID who were disengaged (including the last recorded HbA\(_1c\) value), and to generate the comparative data on those who managed to attend at least one appointment where HbA\(_1c\) was recorded in the previous 15 months (these people were classified as engaged). The Diabetes Centre in Aberdeen screens all adults with T1D annually using the Hospital Anxiety and Depression Scale (HADS).\(^4\) The 2012 data (n=1012) were used to compare the last recorded HADS anxiety and depression scores of those who were classified as disengaged.

Abstract

The aim of this study was to establish the characteristics of adults with type 1 diabetes who disengaged entirely from diabetes care provision.

Those who were classified as disengaged had no recorded HbA\(_1c\) value in either primary or secondary care during the preceding 15 months. A clinical database was used to identify patients with type 1 diabetes who were disengaged and to generate comparative data on those patients who had at least one HbA\(_1c\) value recorded in the previous 15 months (classified as engaged).

Of 2772 adults with type 1 diabetes in Grampian, there was no recorded HbA\(_1c\) value for 229 (8.3%) in the previous 15 months. Those who were disengaged were significantly younger (p<0.001), more commonly experienced clinical levels of anxiety (Fisher’s exact test, p=0.0442) and depression (Fisher’s exact test, p=0.0474), and at their most recent diabetes appointment had higher recorded HbA\(_1c\) values (p=0.007). Significantly more males than females were disengaged (9.2% versus 7.0%; Fisher’s exact test, p=0.037), and those disengaged more frequently came from the two most deprived categories of the Scottish Index of Multiple Deprivation (24.8% versus 18.1%; Fisher’s exact test, p=0.005).

A proportion of those disengaged from diabetes care are markedly struggling to self-manage their condition, and it is difficult to see how they will get the support they need. Innovative methods and systems are required to keep vulnerable adults with type 1 diabetes engaged in services and re-engage them if they drop out. Copyright © 2014 John Wiley & Sons.

Practical Diabetes 2014; 31(3): 117–118

Keywords

type 1 diabetes; adults; disengagement; non-attendance; HbA\(_1c\)
Disengagement from health services in type 1 diabetes

<table>
<thead>
<tr>
<th></th>
<th>Disengaged: mean (SD)</th>
<th>Engaged: mean (SD)</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>37.2 (13.2)</td>
<td>44.8 (15.8)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>HbA1c</td>
<td>81.8 (21.5)</td>
<td>76.5 (21.5)</td>
<td>0.007</td>
</tr>
<tr>
<td>HADS anxiety</td>
<td>6.9 (4.91)</td>
<td>5.5 (4.18)</td>
<td>0.043</td>
</tr>
<tr>
<td>HADS depression</td>
<td>4.2 (4.97)</td>
<td>3.5 (3.78)</td>
<td>0.262</td>
</tr>
</tbody>
</table>

Table 1. Comparison of age, diabetes control, and emotional wellbeing among those engaged and disengaged with NHS diabetes care (HADS = Hospital Anxiety and Depression Scale)

(n=39) and those who were engaged with specialist diabetes services. The Scottish Index of Multiple Deprivation (SIMD) quintiles was used to categorise levels of relative deprivation (1 = most deprived and 5 = least deprived).

Independent t-tests were used to compare the two groups’ HbA1c values, age, HADS anxiety, and HADS depression scores. The Fisher’s exact test was used to compare the two groups regarding sex, SIMD, HADS anxiety and depression clinical status, and subgroups of HbA1c values.

Results

Of 2772 adults with T1D in Grampian, 229 (8.3%) had not had an HbA1c value recorded in the previous 15 months. Significantly more males (9.2%) than females (7.0%) were disengaged (Fisher’s exact test, p=0.037). Although there was no significant difference between the overall distribution of deprivation among those engaged and disengaged (Fisher’s exact test, p=0.067), the latter group contained significantly more (Fisher’s exact test, p=0.005) adults in the two most deprived categories compared to the former (24.8% vs 18.1%). Compared to those engaged, those who were disengaged were significantly younger, more anxious, and at their most recent diabetes appointment had higher recorded HbA1c values (see Table 1). For the disengaged group, the mean time to the last recorded HbA1c was 31 months and to last HADS was 24 months.

Furthermore, compared to those who were engaged, it was significantly more common (Fisher’s exact test, p=0.001) that those disengaged were under the age of 50 (22.2% vs 37%). While there was no significant difference among the percentage of those engaged and disengaged (15.8% vs 13.1%; Fisher’s exact test, p=0.3604) obtaining what is commonly regarded as ‘good’ control (HbA1c ≤58mmol/mol), differences did become evident when we explored the proportion of adults with T1D struggling the most to self-manage. Compared to those engaged with diabetes services, those disengaged were significantly more likely (Fisher’s exact test, p=0.001) to have a most recent HbA1c above 80mmol/mol (35.7% vs 50.3%) and similarly significantly more commonly (Fisher’s exact test, p=0.0014) had a most recently recorded HbA1c value above 108mmol/mol (6.0% vs 13.1%). Significantly more of those disengaged than engaged scored in the clinical range for anxiety (23.1% and 11.6%; Fisher’s exact test, p=0.0442) and depression (15.4% and 6.6%; Fisher’s exact test, p=0.0474).

Discussion

There appears to be a cohort of especially vulnerable people with T1D who are not able, willing or sufficiently interested to attend diabetes appointments. Adults who are disengaged from NHS diabetes care provision tend to be younger, are more often from the most deprived areas of our community, and are more poorly controlled. Also, clinical levels of anxiety and depression are about twice as common (we need to be cautious here because of the low percentage of HADS scores available from the disengaged group).

While it is clear that a proportion of those who are disengaged appear to be self-managing their condition effectively (about one in seven), many are not (about one in every two had a most recently recorded HbA1c value >80mmol/mol). It is difficult to imagine how those who are especially struggling to self-manage will obtain the help they need if they are attending no diabetes appointments either in primary or secondary care.

In view of the fact that many of the factors identified herein are in keeping with the literature on DNA patterns in diabetes services, it may be that total disengagement is a more serious example of a relatively common problem. If so, then there are fairly straightforward methods that diabetes services can use to increase attendance. For example, recent systematic reviews have indicated that telephone calls and SMS text message reminders reduce DNA rates by about 39% and between 29–50%, respectively. Further research is required to establish if these approaches can be utilised to re-engage people with diabetes services. It is understandably frustrating to clinicians and managers that some continually DNA their appointments, and in some health services this can result in discharge from care. On the other hand, perhaps we need innovative and smarter systems to try to ensure that those most needing care stay engaged to some extent with diabetes services, wherever they are delivered.

Acknowledgement

Thanks to Mr Robert O’Donnell, the local administrator of SCI-Diabetes, for his help and support.

Declaration of interests

There are no conflicts of interest declared.

References

References are available online at www.practicaldiabetes.com.
References