# UNIT 3 Special care groups The challenges of managing diabetes in hard-to-reach groups

# Alia Gilani

We are in the midst of a global diabetes epidemic that is multifaceted in its impact. This includes effects on population health, the economy and healthcare services. The management of diabetes is becoming increasingly challenging. The number of people to treat is rising and there are many pressures in primary care to achieve targets, not least because annual reviews are expected to be delivered in the same format for all. Population trends indicate that diversity is increasing, and this may mean that there will be widening gaps in the health needs of different groups, leading to further challenges for healthcare providers. Meeting the challenges of managing diabetes in hard-to-reach groups is a significant part of this, and this article explores a range of groups, highlighting the difficulties in engagement and the different needs that exist in each.

ard-to-reach groups can be defined as people who are underserved, serviceresistant or "slipping through the net" (Doherty et al, 2004). Marginalised groups tend to experience more significant inequalities than the general population, and it is thus of great importance for the NHS and Government to have strategies to tackle this. Often, such groups receive the least healthcare. This was eloquently described by Julian Tudor Hart as the inverse care law: "The availability of good medical care tends to vary inversely with the need for the population served." Targeting inequalities may require the adoption of novel ways of working and thinking "outside the box".

Engagement with hard-to-reach groups is essential, as one of the determinants of population health is access to healthcare (Bambra et al, 2010). Hard-to-reach groups include minority ethnic groups (South Asians are presented as an example in this article), people with mental illness, travelling communities, people in prisons and young-offender institutions, and the homeless. It is difficult to get an accurate estimation of the number of individuals who are in hard-to-reach groups, not least because of poor engagement with services.

# South Asians in the UK

The driving force behind migration is multifactorial, with elements including conflicts, political changes and the desire to seek a better life. The post-World War II economic boom led to a significant influx of migrants into the UK, and into other European countries, with people from former colonies recruited for labour. One of the most important groups for the UK were people from South Asia – Bangladesh, India, Pakistan and Sri Lanka – many of whom arrived between the early 1960s and late 1970s (Nazroo and Williams, 2006). Many family members followed. In addition, there have been at least two generations of South Asians born



# **Online learning**

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# Learning objectives

After reading this article, the participant should be able to:

- Give examples of a range of hard-to-reach groups in which diabetes care may be suboptimal.
- 2. Describe barriers to healthcare faced by different hard-to-reach groups.
- 3. Explain potential links between the inequalities faced and diabetes outcomes.

### **Key words**

- Hard-to-reach groups
- Health inequalities
- Quality of care

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# **Page points**

- Within South Asian subgroups, the risk of developing type 2 diabetes varies. Bangladeshis are at greater risk than Indian people, who in turn are at higher risk than the Pakistani population.
- 2. South Asian people present with type 2 diabetes earlier, and at a lower BMI, than people of European descent. The importance of physical exercise and lifestyle measures needs to be particularly emphasised in these populations.
- There is evidence suggesting that the current healthcare service is providing inadequate ease of access to services for minority ethnic groups.
- There is a strong relationship between diabetes and mental illness, with causality in both directions, and the link between the two can manifest in many ways.



# Read more online

#### Article

Delivering grassroots diabetes education in the South Asian community

Samina Ali and colleagues discuss the delivery of culturally tailored education at the grassroots level to help tackle health inequalities in South Asian people.

Diabetes & Primary Care **19**: 121–5

Available at: https://is.gd/SAHFeducation in the UK in the last 50 years. With regard to diabetes, there are known to be ethnic inequalities in individuals from South Asia, a relationship that was established back in the 1980s. The Southall study highlighted the higher prevalence of diabetes among people of South Asian origin in an area of west London, compared to those with a European background (Mather and Keen, 1985). This pattern has continued. South Asian people living in high-income countries have a two to four times higher rate of diabetes compared with white Europeans (Sattar and Gill, 2015).

Within South Asian subgroups, the risk of developing type 2 diabetes varies. Bangladeshis constitute a higher-risk group than Indian people, who in turn are at higher risk than the Pakistani population (Hippisley-Cox et al, 2008). In addition to higher rates compared with the white British population, there is a higher prevalence of type 2 diabetes among South Asian migrants compared with levels in their countries of origin (Garduno-Diaz and Khokhar, 2012). A propensity to adopt a Western diet and urbanisation are likely to account for this. These are similar to the causative factors that are leading to the diabetes epidemic among the global population.

Presentation of diabetes is seen around 5–10 years earlier, and at a lower BMI, among South Asians compared with other groups (Sattar and Gill, 2015). Lower muscle mass and higher adiposity levels could contribute to this. There is also a lower level of cardiorespiratory fitness. Furthermore, because South Asians tend to develop type 2 diabetes at an earlier age, they have a resultant greater risk of complications. However, despite the increased risk of diabetes complications over time, cardiovascular risk has lowered. This may be attributed to more effective use of statins and antihypertensives.

### The role of culture

Hanif and Karamat (2009) describe culture as "a complex interaction of multitudes of factors that give people an ethnic belonging" that "has an impact on their lifestyle and predisposition to chronic disease." They describe factors that are influenced by culture and, in turn, impact on the management of diabetes. Culture can have a significant influence on chronic disease management, including through perception of disease, reduced access to services,

lifestyle choices, concordance with medication, and language barriers and thus communication with healthcare professionals.

There is conflicting evidence as to whether the current healthcare service is providing adequate ease of access to services for minority ethnic groups. Some evidence suggests that people whose first language is not English find it harder to access care and that services are not necessarily as suitable for ethnic minorities as they are for the majority population (Naish, 1994). In one study, no ethnic inequalities were identified for use of GP services by South Asians (Nazroo et al, 2009). However, this study showed that, among the Pakistani population, there were worse outcomes of care for diabetes and reduced hospital access.

South Asians are, of course, a heterogeneous group, and there is variation in religious practice, culture, diet, lifestyle choices and beliefs, even among those coming from a single country. This should be considered when engaging with this population. Consideration should be given to South Asians' increased risks, and the importance of physical exercise and lifestyle measures needs to be emphasised. This should also be the case for primary type 2 diabetes prevention, as South Asians have a more rapid progression from prediabetes to diabetes (Sattar and Gill, 2015).

# **Mental health**

Even historically, people have drawn connections between diabetes and depression. In the  $17^{th}$ century, the physician Thomas Willis proposed that diabetes was caused by "long sorrow and other depression" (Balhara, 2011). There remains some truth to this hypothesis in modern healthcare. In a review of the evidence, the odds of depression across 20 controlled studies in people with diabetes was found to be double that of the comparison group without the condition (Anderson et al, 2001). Around 10–20% of people with diabetes (both type 1 and type 2) are affected by depression (Roy and Lloyd, 2012). Prevalence rates are higher when depression is self-reported compared with clinical diagnosis (Snoek et al, 2015).

The strong relationship between diabetes and mental illness is in fact a bidirectional one, and the link between the two can manifest in many ways, as follows (Balhara, 2011):

- The two conditions can develop independently of one another.
- During the course of diabetes, the condition can have a role in the pathogenesis of psychiatric disorders.
- Conversely, psychiatric disorders are independent risk factors for diabetes, and medications used to treat mental illness can have side effects resulting in diabetes or impaired glucose tolerance. This is particularly true with antipsychotic polypharmacy (Gallego et al, 2012).
- It is also important to note that there may be an overlap between the clinical presentation of hypoglycaemia and psychiatric disorders (e.g. panic attacks).

# **Depression and diabetes distress**

The causes of depression in diabetes remain unknown and further research is required, but the link is thought to be partly due to the psychological burden of living with diabetes (Snoek et al, 2015).

Engagement with individuals who have a mental condition and diabetes can be challenging, and this may be made more difficult if the mental condition is undiagnosed. Indeed, there may be up to 45% of people with diabetes in whom such a condition remains undiagnosed (Li et al, 2010). Other potential implications for healthcare beyond engagement in a clinical setting are poor treatment adherence (Gonzalez et al, 2007), poor glycaemic control (Lustman et al, 2000) and an increased risk of hospitalisation (Das-Munshi et al, 2007). Overall, there is strong evidence of poor self-care behaviour in people with diabetes and a mental condition (Gonzalez et al, 2007).

In terms of accessing healthcare, there is evidence of increased healthcare use and associated costs in people with diabetes who have depression compared with those who do not (Egede et al, 2002). But this does not necessarily lead to better outcomes; rather, the evidence shows worse outcomes, in part because of the difficulties in communicating with clinicians (Piette et al, 2004). Models of care may have to be adapted to improve engagement and enhance diabetes outcomes (Kahn et al, 2009).

Diabetes distress describes the emotional response to the implications of having diabetes. This can include the impact on quality of life, hypoglycaemia concerns and the impact of diabetes on physical exercise and food intake. Depression and diabetes distress are linked to poor adherence and glycaemic control, so healthcare professionals should play a role in addressing this. The links between depression, diabetes distress and poor glycaemic control are not fully understood; however, depression is thought to indirectly affect diabetes due to poor self-care behaviours, whereas diabetes distress may directly affect glycaemic control via stress hormones that lead to hyperglycaemia (Snoek at al, 2015).

As research has found depression to be common in people with diabetes, it should be routinely screened for by healthcare professionals, especially as it is often undetected (Petrak et al, 2015). Further research into effective treatment strategies is required as there are conflicting data on the effectiveness of treatment with antidepressants and psychological approaches.

# **Psychotic disorders**

The estimated prevalence of diabetes in people with psychotic disorders ranges from 1.26% to 50% (median, 13%), and people with psychosis have additional risk factors for diabetes, including the use of antipsychotic medication and adverse socioeconomic circumstances (Ward and Druss, 2015). Despite this high prevalence and risk, diabetes in psychotic disorders is often not diagnosed, leading to increased morbidity and mortality. Healthcare professionals need to be more proactive in ensuring that people with psychotic disorders are screened effectively.

# Homelessness

The legal definition of homelessness is when people lack a secure place in which they are entitled to live or are not reasonably able to stay in their current accommodation (Crisis, 2014). The homeless broadly fall into two categories: those who are sleeping rough, known as "street homeless"; and those who have a roof over their heads but are not in stable or secure housing, known as "hidden homeless". Some may transition between these two categories (Reeve, 2011). In 2012–13, 81 000 "households" approaching Local Authorities in England were found to be homeless or threatened with homelessness (Shelter, 2014). Even though Local Authorities have a duty under

# **Page points**

- There is evidence of increased healthcare use and associated costs in people with diabetes who have depression compared with those who do not, but this does not necessarily lead to better outcomes.
- 2. Diabetes distress a negative emotional response to the implications of having diabetes – and depression are common and can negatively affect glycaemic control.
- Although common, depression is frequently undiagnosed in people with diabetes. Healthcare professionals should routinely screen for this condition.
- 4. Proactive screening for diabetes is required in people with psychotic disorders.



# Read more online

# Article

A solution-focused approach to diabetes-related distress

Emma Shuttlewood and Jen Nash describe a helpful technique for managing diabetes distress.

Journal of Diabetes Nursing **20**: 102–7

Available at: https://is.gd/SFTdiabetesdistress

### **Page points**

- As homeless individuals may not have stability in their lives and their lifestyle behaviours may be sporadic, it can be very challenging for healthcare professionals to engage with this population.
- Existing services may need to be modified to meet the needs of the homeless population, but there is evidence that this is possible and can be effective.
- The lifestyle in prisons and young-offender institutions may be vastly different from that of the general population. Guidelines are available on diabetes treatment in this setting.



# Read more online

#### Article

Practicalities of working with homeless people with diabetes in an inner-London borough

Martin Jones and David Gable describe an engagement programme in Westminster for homeless people with diabetes.

Journal of Diabetes Nursing 18: 414–9

Available at: https://is.gd/homelessdiabetes the 1996 Housing Act to provide for some of those who are homeless, the number of such individuals has increased over the last few years, probably owing to benefits cuts and shortages in housing (*The Guardian*, 2013). It should be noted that it is difficult to get an accurate figure for total numbers of homeless individuals, as different areas record data differently and some cases do not appear in official statistics.

# Implications for healthcare

The average life expectancy of someone who is homeless is between 40.5 and 47 years (Royal College of GPs, 2013). There is a higher prevalence of mental illness in the homeless population; they are twice as likely to present with a mental health problem and 4–15 times more likely to experience psychosis (Rees, 2009). The homeless population not only is more prone to chronic medical conditions but also experiences barriers to accessing healthcare (Hwang and Bugeja, 2000).

Of particular relevance is the evidence of poor glycaemic control and difficulties in managing diabetes (Hwang and Bugeja, 2000). Glucose levels may be higher owing to poor medication adherence and dietary behaviours that may exacerbate diabetes control, such as alcohol use and a highercarbohydrate diet (McCary and O'Connell, 2005). In addition to this, there is evidence of poor nutritional status and mental health problems in the homeless population (Langnäse and Müller, 2001). The prevalence of diabetes was also found to be higher in some studies (Arnaud et al, 2010).

The increased risks associated with diabetes that are experienced by the homeless population include hypoglycaemia, foot problems, medication storage issues, non-adherence and insulin misuse. These may seem like obvious risks, and similar to those in non-homeless people, but a lack of easy access to healthcare services is liable to augment each of them. In this population, drug and alcohol use are also common in amongst the complex social issues.

While average healthcare costs can be higher in the homeless population, it is important to observe that, often, the care these individuals receive is in emergency departments (Padgett et al, 1990; Salit et al, 1998). Indeed, a homeless individual is up to five times more likely to be admitted to hospital than someone in the general population (Martell et al, 1992). Effective management of a long-term condition may not be at the top of the individual's, or the healthcare provider's, list of priorities. Rather, it may be that an acute condition takes priority. Finally, as homeless individuals may not have stability in their lives and their lifestyle behaviours may be sporadic, it can be very challenging for healthcare professionals to engage with this population.

One example of an effective way to engage with the homeless population is a multidisciplinary engagement programme for those with diabetes in Westminster (Jones and Gable, 2014). On referral, patients are assigned a case manager and are then triaged and referred to various health and social care organisations. Individualised support is provided to aid patients and allows navigation of services. If required, psychological support is also provided. This successful programme shows that the provision of effective healthcare services may require tailoring of existing services and lateral thinking to meet the needs of the homeless population. Other examples of good practice are in NHS Westminster, who are committed to tackle inequalities in the homeless by producing a report on the health needs and healthcare costs, which should support commissioners in tailoring and adapting services for this group (Williams et al, 2010).

# **Prisons and young-offender institutions**

There are currently 85414 people in prisons and young-offender institutions in England (Ministry of Justice et al, 2014). Bayle et al (2011) report that the prevalence rate of diabetes here is around 6.7%, which is higher than in the general population. However, some studies report a lower prevalence compared with the general population, attributing this to the younger age of people in correctional facilities (American Diabetes Association, 2008). The lifestyle in prisons and young-offender institutions may be vastly different from that of the general population; however, the care of people with diabetes should be on a par, and in line with national guidelines. There are guidelines available for diabetes management in correctional institutions (American Diabetes Association, 2012; Diabetes UK, 2017). Things to consider for those providing diabetes care in such settings are:

- Difficulties accessing individuals in highsecurity settings.
- Barriers to promoting an active lifestyle.
- Limited access to food choices.
- Use of drugs and alcohol.
- Mental health problems.
- Limited follow-up for those who are transferred or released.

An audit by the Royal College of Nursing found that many aspects of care for people with diabetes in correctional institutions were fragmented; however, a number of strategies to improve care were identified (Booles, 2011). Diabetes management is challenging in many respects (see *Box 1*), and it is typically unstructured from the perspective of both the healthcare professional and the person receiving care. Nevertheless, there is evidence that, if the appropriate care is given, it can lead to favourable diabetes outcomes (Mills, 2014).

# **Travelling communities**

Gypsies and travellers can be defined as people with a cultural tradition of nomadism or of living in a caravan, and all other people of a nomadic habit of life, whatever their race or origin (Office of the Deputy Prime Minister, 2006). Roma, Gypsies and travellers of Irish heritage have different origins and cultural practices but have commonalities in the way they live their lives (Ryder, 2011).

It is estimated that there are between 200000 and 300000 members of travelling communities within the UK (Commission for Racial Equality, 2006). Obtaining accurate data on the population can be difficult as they are not only a transient population but also among the most socially excluded minority groups (Cemlyn et al, 2009).

One study found only a slightly higher prevalence of diabetes in travelling communities compared with the general population (Parry et al, 2004). Whether or not these figures are accurate, it is known that, within this group, those who have diabetes will face barriers to good diabetes care resulting from inequalities.

Overall, current data suggest the health of travelling communities is worse than in the general population (Equality and Human Rights Commission, 2016), and compared with other minority communities (Parry et al, 2004). There

# Box 1. Case example of diabetes management in prison (from Bellary, 2011).

#### Narrative

SJ, a 52-year-old man with type 2 diabetes, was recently moved to a high-security prison. Prior to his move, he initiated insulin with support from a hospital specialist team. Following the move, SJ had lost contact with his specialist diabetes team and encountered difficulties in managing his diabetes. The prison meal times did not coincide with his insulin regimen and his glycaemic control worsened as he took his insulin several hours after his evening meal and started to experience frequent hypoglycaemic episodes. His request for the prison staff to allow him to have a snack late in the evening was turned down. After repeated requests he was referred to the hospital diabetes team and was seen by a consultant physician and a dietitian. His diabetes treatment was reviewed and his insulin regimen changed. Prison staff were involved in his diabetes care plan and an agreement was made to allow him to have a bedtime snack. His diabetes control improved and he continued to receive regular input from the hospital diabetes team.

## Discussion

Failure of continuity of care is a significant problem among offenders with diabetes and can have a major effect on their diabetes control. Prison staff may not be aware of the specific needs of people with diabetes. Adherence to the prison timetable and usual restrictions on diet may not be suitable for people with diabetes, especially if they are on complex insulin regimens. Occasionally, issues such as manipulation of their diabetes by the prisoners to gain attention (such as missing insulin doses to precipitate hyperglycaemic crises) may lead to further loss of trust between the prison staff and prisoners. Some of these problems could be avoided by educating the prison staff and ensuring access to specialist diabetes teams on a regular basis.

is a higher prevalence of some chronic conditions, higher mortality rates, more poverty, lower literacy levels and poorer access to healthcare services. Furthermore, as in the general population, there is an ongoing shift towards unhealthy behaviours, such as an increasingly sedentary lifestyle and reliance on convenience foods (Matthews, 2008). There is also a general reticence towards accessing healthcare services (the factors contributing to this are multifactorial), and many remain unregistered with GPs (Royal College of GPs, 2013). They have poor health expectations, and poor health is associated with premature mortality (Matthews, 2008). The statistics on this are stark: in this group, the life expectancy of women and men, respectively, is 10 and 12 years lower than in other populations (Crawley, 2004). Self-reported health is worse in Gypsy travellers compared with the indigenous white population (Office for National Statistics, 2013), with 42% of English Gypsies affected by a long-term condition compared with

"Overall, there is no one solution to improving diabetes care in groups where there are inequalities. Recognising the inequalities is the first step, which then allows us to confront the challenge of taking effective action." 18% of the general population (Parry et al, 2007).

Diabetes UK has been spearheading work to improve diabetes care in this population (Diabetes UK, 2009). Approaches to this will require adapting services to meet the distinct needs, and this may require alternatives to traditional healthcare provision. Cultural awareness training for frontline staff, outreach work and peer education have been proposed as a way of engaging and improving health outcomes in this group (Royal College of GPs, 2013).

# Conclusion

It can be easy for us as healthcare professionals to get so caught up in the management of diabetes in the general population (which often is the majority of the population we serve) that we become tempted to apply a standard template of healthcare provision for all. Minority groups often are hard to reach and have greater inequalities compared with the general population, and can often be neglected. Successful approaches in diabetes management for hard-to-reach populations should be championed and learnings disseminated widely to promote replication in other areas with other groups. Although this module has focused on certain groups, it has applicability to other hardto-reach groups, including people with learning disabilities and children and young people with diabetes. Overall, there is no one solution to improving diabetes care in groups where there are inequalities. Recognising the inequalities is the first step, which then allows us to confront the challenge of taking effective action.

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# Online CPD activity

# Visit www.diabetesonthenet.com/cpd to record your answers and gain a certificate of participation

Participants should read the preceding article before answering the multiple choice questions below. There is ONE correct answer to each question. After submitting your answers online, you will be immediately notified of your score. A pass mark of 70% is required to obtain a certificate of successful participation; however, it is possible to take the test a maximum of three times. A short explanation of the correct answer is provided. Before accessing your certificate, you will be given the opportunity to evaluate the activity and reflect on the module, stating how you will use what you have learnt in practice. The CPD centre keeps a record of your CPD activities and provides the option to add items to an action plan, which will help you to collate evidence for your annual appraisal.

- Which ONE of the following groups are NOT traditionally recognised as being "hard-to-reach" in terms of access to diabetes services? Select ONE option only.
  - A. Ethnic minority groups
  - B. People with mental ill health
  - C. Prison inmates
  - D. Rural dwellers
  - E. Travelling communities
- 2. According to Sattar et al (2013), what is the **ESTIMATED** prevalence of diabetes in South Asian ethnic minority groups living in high-income countries compared with white Europeans? Select **ONE** option only.
  - A. Half
  - B. The same
  - C. Two to four times higher
  - D. Eight to ten times higher
  - E. Sixteen times higher
- 3. According to Hippisley-Cox et al (2008), which ethnic minority group living in the UK has the **HIGHEST** prevalence of diabetes? Select **ONE** option only.
  - A. Bangladeshi
  - B. Chinese
  - C. Indian
  - D. Pakistani
  - E. Vietnamese
- Compared to other ethnic groups, what is the ESTIMATED age at presentation of diabetes in South Asian ethnic minorities? Select ONE option only.
  - A. 11-20 years earlier
  - B. 5–10 years earlier
  - C. Similar age at presentation
  - D. 5-10 years later
  - E. 11–20 years later

- According to Roy et al (2012), what APPROXIMATE percentage of people with diabetes are affected by depression? Select ONE option only.
  - A. 5
  - B. 15
  - C. 30
  - D. 45
  - E. 60
- A 47-year-old man has severe, chronic mental ill health. Which ONE of his long-term medications is MOST LIKELY to be associated with the development of hyperglycaemia? Select ONE option only.
  - A. Haloperidol
  - B. Lithium
  - C. Procyclidine
  - D. Risperidone
  - E. Venlafaxine
- According to RCGP (2013) figures, what is the approximate AVERAGE life expectancy (in years) of homeless people in the UK? Select ONE option only.
  - A. 35
  - B. 45
  - C. 55
  - D. 65
  - E. 75
- According to Crisis (2014), which ONE of the following definitions MOST accurately describes the "hidden homeless"? Select ONE option only.
  - A. Illegal immigrants living rough on the streets
  - B. People living on the streets who are not recorded in official statistics

- C. Street homeless who decline to have their personal details recorded
- D. People whose applications for rehousing have been turned down
- E. People with a roof over their heads, but not in stable or secure housing
- 9. Approximately 20% of the general population are affected by long-term conditions. What is the **ESTIMATED** percentage of English Gypsy travellers affected by long-term conditions? Select **ONE** option only.
  - A. 10
  - B. 20
  - C. 40
  - D. 60
  - E. 80
- 10.A primary care health organisation is looking to improve access to diabetes services for the homeless. Which is the **MOST** effective solution, if any? Select **ONE** option only.
  - A. Assign individual case workers
  - B. Community-based "walk-in" diabetes education programmes
  - C. Individual psychological support
  - D. Social housing projects
  - E. No single solution to improve diabetes care