Diabetes and Mental Health

ALL PARTY PARLIAMENTARY GROUP FOR DIABETES

Contact Us:
Email: diabetes-appg@outlook.com
Website: https://diabetesappg.wordpress.com
Twitter: @APPG_Diabetes

The All-Party Parliamentary Group for Diabetes (APPG Diabetes) is a nonpartisan cross-party interest group of UK parliamentarians who have a shared interest in raising the profile of diabetes, its prevention and improving the quality of treatment and care for people living with diabetes.

The secretariat to the All-Party Parliamentary Group for Diabetes is provided by:

DiABETES UK
KNOW DIABETES. FIGHT DIABETES.

Chair's Introduction

About four in ten people with diabetes will experience diabetes-specific emotional distress. This impacts on their ability to manage their diabetes[1] and has important implications for their long-term health and the NHS.

Evidence suggests about 42 per cent people with Type 1 diabetes[2] and 36 per cent of people with Type 2 diabetes[3] will experience elevated diabetes distress. As effective diabetes management heavily depends on how people care for themselves, the impact of this distress can be profound. Economic analysis show that poor mental health increases the average cost of NHS service use by each person with a long-term condition from approximately £3,910 to £5,670 per year[4].

NHS England's Five Year Forward View for Mental Health has been remarkable in recognising how emotional and psychological issues can impact the health of people with diabetes and other long-term conditions, having as a priority 'an integrated mental and physical health approach'[5].

However, the APPG has received evidence showing people with diabetes are still facing significant barriers to getting the support they need, with services varying in quality and availability.

The APPG heard patients and their families often feel ignored and that they were offered no support, encouragement or signposting. There is a lack of awareness of the challenges of living with diabetes, which can make accessing psychological support a lengthy, confusing and distressing process.

Despite these challenges, there are fantastic examples of good practice. The APPG heard from healthcare professionals who are embedding clinical psychology in Type 1 diabetes pathways, piloting GP practice psychology services for people with Type 2, delivering psychological skills training for Diabetes Specialist Nurses, and linking psychological support with diabetes structured education.

These examples show change is possible and can bring significant long-term benefits for people with diabetes and the NHS.

It is time for a fundamental shift in the way diabetes care is planned and delivered. This reports details the picture painted by patients, families and healthcare professionals on their experience of care and the measures that are urgently needed to guarantee the health and wellbeing of people with diabetes.

Rt Hon Keith Vaz MP

Chair of the APPG for Diabetes


Rt Hon Keith Vaz MP
Chair


Jim Shannon MP
Vice-Chair


John Howell MP
Vice-Chair


Liz McInnes MP
Co-Secretary


John McNally MP
Co-Secretary


Baroness Ludford
Treasurer

[1] Nicolucci A, Kovacs Burns K, Holt RI et al (2013) Diabetes Attitudes, Wishes and Needs second study (DAWN2): cross-national benchmarking of diabetes-related psychosocial outcomes for people with diabetes. Diabetic Medicine 30(7):767-777.

[2] Fisher L, Hessler D, Polonsky W et al (2016) Diabetes distress in adults with type 1 diabetes: Prevalence, incidence and change over time. Journal of Diabetes Complications 30(6):1123-8.

[3] Perrin NE, Davies MJ, Robertson N et al (2017) The prevalence of diabetes-specific emotional distress in people with Type 2 diabetes: a systematic review and meta-analyses. Diabetic Medicine.

[4] Naylor C, Galea A, Parsonage M et al (2012) Long-term conditions and mental health: The cost of co-morbidities. The King's Fund.

[5] Mental Health Taskforce (2016) The Five Year Forward View for Mental Health. https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf

The Evidence Session

The APPG for Diabetes held an evidence session at the House of Commons on Thursday 22 March 2018 into Emotional and Psychological Support for People with Diabetes, chaired by the Rt Hon Keith Vaz MP.

Evidence was heard from patient Jess Croll-Knight; Dr Chris Gillespie, Consultant Psychologist at Royal Derby Hospital; Dr Kirsty MacLennan, Clinical Psychologist at MacLeod Centre for Diabetes; Dr Buchi Reddy, Program Manager and Clinical Lead; Ruth Miller, Diabetes Nurse Consultant; Dr Amrit Sachar, Mental Health Work Lead at NHS North West London CCG; Anne Moore, Group Nurse Director at Northumberland Tyne and Wear NHS Foundation Trust.

Summary

For this inquiry, the APPG heard from over 30 people living with diabetes, parents, healthcare professionals and researchers about the complex relationship between diabetes, wellbeing and mental health.

The evidence gathered by the APPG indicates that the current provision of psychological support for people with diabetes is inadequate and highly variable, though there are pockets of excellent practice.

1) Due to the heavy burden of self-management, particularly for people who use insulin to treat their diabetes, there is a compelling case for making psychological support a routine part of diabetes care.

2) Many people report that they are given no opportunity to talk about emotional or psychological issues with their diabetes team because consultations centre heavily on clinical outcomes, rather than what matters most to them.

3) For people with levels of need which require specialist psychological support, the APPG heard that IAPT (Improving Access to Psychological Therapies) practitioners and general psychologists do not necessarily have sufficient knowledge of diabetes to provide this support, and that these general mental health services are not effectively joined up with diabetes services.

4) Where specialist services do exist, they face the challenge of trying to meet growing demand in the context of increasing financial pressures. Evidence received by the APPG suggests that adults with diabetes are waiting up to a year for treatment from a psychologist following assessment.

5) It appears very difficult for diabetes teams to secure sustained funding for psychological input into the multi-disciplinary team, despite this having clear direct benefits for patient care and indirect benefits, e.g. delivery of staff training.

6) The situation for people with diabetes who have an eating disorder is particularly worrying. Despite the high level of morbidity and mortality in this patient group, there is a lack of awareness and very few specialist services across the UK.

7) The introduction of the Paediatric Best Practice Tariff in England means that many diabetes services for children and young people in England now have access to a Child Psychologist. However, there are still problems of variation, demand exceeding supply and a lack of available space to provide psychological support.

By developing clear plans for supporting the psychological needs of people with diabetes and their families across all localities, there are significant gains to be made both in terms of health and wellbeing, but also for NHS costs.

The complex relationship between diabetes, wellbeing and mental health

Diabetes is a complex and demanding condition with potentially debilitating complications. The vast majority of diabetes management is the responsibility of the person with diabetes (or a parent or carer), which requires constant personal motivation and changes in behaviour and routine. Not surprisingly, the impact of diabetes on emotional and psychological wellbeing can be profound. Yet the effects that the physical challenges of living with diabetes can have on mental health are often overlooked or misunderstood.

No diabetes health without mental health

The relationship between physical and mental health for people with diabetes can be complicated. Variable blood glucose levels can cause feelings of anxiety and anger. Similarly, an individual's mood may affect how they engage with their diabetes.

People who treat their diabetes with insulin (everyone with Type 1 diabetes and some people with Type 2 diabetes) and their carers said that the continual trade-offs involved in managing the condition and balancing their treatment regime against eating, exercising, driving, preparing for bed and other activities with no opportunity for a break can be overwhelming.

"Diabetes is completely draining both physically and mentally. The day to day care requirements completely exhausts me and makes me unwilling to take part in the vital care routines. This then means I don't check my sugar levels. This of course leads to high levels which then makes my mood low. In short, diabetes and mental health is one vicious cycle of self-destruction at times."

Person with Type 1 diabetes

"As a parent of a child with Type 1 diabetes I feel that I am constantly alert. Every phone call from school sends my heart racing, every beep at night has the same effect."

Helen Bailey, Parent

A number of inquiry respondents described how this has led them into damaging cycles of unstable blood glucose levels, poor emotional wellbeing, and disengagement from diabetes management. This is important because effective self-management is critical for long-term health and avoiding diabetes complications. On average, people with diabetes spend three hours a year with a healthcare professional. For the remaining 8,757 hours they manage their diabetes themselves.

"I also live with a variety of long-term medical conditions, and managing these takes a toll on you emotionally and can be exhausting. Your diabetes can affect your mental wellbeing, which can affect how you manage your diabetes and those other conditions. You have to keep a close eye on it so it doesn't spiral out of control."

Person with Type 2 diabetes

The stigma faced by people with both Type 1 and Type 2 diabetes, worries about complications and the need for some to balance multiple long-term conditions can amplify these negative thoughts and feelings.

Distress and depression

Research has previously found that people with diabetes are twice as likely to

experience depression[6]. However, the contribution of a broader diabetes-specific kind of emotional distress – 'diabetes distress' – may have been under-appreciated[7]. The prevalence of elevated diabetes distress, which has a significant impact on ability to self-manage, may be as high as 42 per cent in people with Type 1 diabetes[8] and 36 per cent for people with Type 2 diabetes[9].

"There is a lot of scope, with more funding, to support people with diabetes who have 'invisible' psychological problems (diabetes distress) that are sub-clinical but, if improved, would have a dramatic individual and population shift in outcomes like HbA1c, providing cost-savings for the NHS."

Dr Debbie Cooke, Chartered Health Psychologist

Diabetes distress is not classified as a mental health condition. Rather, it is a response to the pressures of living with a demanding long-term condition. Distinguishing between depression and diabetes distress is important because they require different treatments.

Whereas depression may require a referral to mental health services, diabetes distress can typically be identified and managed by members of the diabetes team. Emotional distress experienced by people with diabetes and their carers may or may not be related to or caused by diabetes, and it may take many different forms, not limited to diabetes distress, depression and anxiety. Diabetes clinicians need to be aware of these distinctions and have the knowledge and confidence to identify and address them.

Standard interventions for depression have been shown to work with people with diabetes[10]. However, further research is needed into interventions that are effective in improving both depressive symptoms and glycaemic control.

Power of conversation

Too often diabetes consultations are not person-centred or collaborative. They focus solely on clinical treatment targets and do not allow for conversations about wellbeing and coping.

"I have in the past mentioned to my diabetes specialist nurse that my mental health is deteriorating. I was ignored and offered no support, encouragement or signposting. Instead I was given the remark, 'Don't worry, lots of people feel like you. You'll get over it."

Person with Type 1 diabetes

Personalised care planning has been shown to lead to improvements in psychological and physical health for people with long-term conditions[11]. For adults who have diabetes and depression, there is some evidence that a collaborative care model can significantly improve depression[12].

6 Anderson RJ, Freedland KE, Clouse RE, Lustman PJ (2001) The prevalence of cormorbid depression in adults with diabetes: a meta-analysis. Diabetes Care 24 (6) 1069-87.
[7] Fisher L, Gonzalez JS, Polonsky WH (2014) The confusing tale of depression and distress in patients with diabetes: a call for greater clarity and precision. Diabetic Medicine 31 (7): 764-772. doi:10.1111/dme.12428.
[8] Fisher L, Hessler D, Polonsky W et al (2016) Diabetes distress in adults with type 1 diabetes: Prevalence, incidence and change over time. Journal of Diabetes Complications 30(6):1123-8. https://www.ncbi.nlm.nih.gov/pubmed/27118163
[9] Perrin NE, Davies MJ, Robertson N et al (2017) The prevalence of diabetes-specific emotional distress in people with Type 2 diabetes: a systematic review and meta-analyses. Diabetic Medicine. https://onlinelibrary.wiley.com/doi/pdf/10.1111/dme.13448
[10] Baumeister H, Hutter N, Bengel J (2012) Psychological and pharmacological interventions for depression in patients with diabetes mellitus. Cochrane Database of Systematic Reviews, Issue 12. DOI: 10.1002/14651858.CD008381.pub2
11 Coulter A, Entwistle VA, Eccles A et al (2015) Personalised care planning for adults with chronic or long-term health conditions. Cochrane Database of Systematic Reviews.
12 Huang U, Wei X, Wu T et al. Collaborative care for patients with depression and diabetes mellitus: a systematic review and meta-analysis. BMC Psychiatry 13:260.

Economic analysis has found that the presence of poor mental health increases the average cost of NHS service use by each person with a long-term condition from approximately £3,910 to £5,670 per year[13]. Currently 3.7 million people in the UK are diagnosed with diabetes. The cost-savings associated with giving people with diabetes the opportunities to talk about emotional distress so it can be identified and addressed are, therefore, potentially huge.

Specialist psychological support is difficult to access

Accessing psychological support can be a lengthy, confusing and distressing process. When people with diabetes do finally see a mental health professional, often they do not understand diabetes and its effects.

"When I asked the hospital clinic to see a psychologist, I was told to see my GP, but my GP said that a diabetes-specialist is not something they have the ability to refer to. Everywhere I went, it was always someone else who should offer this service."

Person with Type 1 diabetes

People with diabetes can spend years trying to get an appropriate referral, taking a considerable toll on their health and happiness. Those who can afford it may choose to pay privately.

"I am certain that had I not been able to afford counselling at the time I needed it, my condition would have got a lot worse."

Person with Type 1 diabetes

Difficulties with food, body image and eating disorders

The APPG heard from female and male respondents with Type 1 diabetes who had struggled with food and body image, and some had omitted insulin in order to lose weight (often referred to as 'diabulimia'), particularly in their teenage years.

"Since early teenage-hood I had periods of reducing or stopping insulin and losing weight, very secretively. I developed problems around binging, purging, fasting. Long periods of high sugars – losing then putting on lots of weight. All linked in with drinking. Getting very depressed."

Person with Type 1 diabetes

Research suggests that eating disorders are common and persistent in girls and women with Type 1, with rates of over 30 per cent for women in their twenties[14]. Men with Type 1 have also been found to have a 'higher drive for thinness'[15]. Disordered eating and diabulimia are associated with poor biomedical outcomes and greater mortality, yet most interventions currently available offer little or no improvement[16].

Levels of need

Not everyone with diabetes will experience a mental health problem, and an individual's level of need for support might fluctuate throughout their life. The pyramid model of psychological needs for people with diabetes[17] illustrates the broadly inverse relationship between prevalence

[13] Naylor C, Galea A, Parsonage M et al (2012) Long-term conditions and mental health: The cost of co-morbidities. The King's Fund. https://www.kingsfund.org.uk/publications/long-term-conditions-and-mental-health

[14] Colton PA, Olmsted MP, Daneman D et al (2015) Eating disorders in girls and women with Type 1 diabetes: A longitudinal study of prevalence, onset, remission and recurrence. Diabetes care 38 (7); 1212-7. doi: 10.2337/dc14-2646.

[15] Diabetes UK (2017) Position statement: Diabulimia. https://www.diabetes.org.uk/resources-s3/2017-10/Diabulimia%20Position%20statement%20Mar%202017.pdf

[16] Clery P, Stahl D, Ismail K et al (2017) Systematic review and meta-analysis of the efficacy of interventions for people with Type 1 diabetes mellitus and disordered eating. Diabetic Medicine. https://doi.org/10.1111/dme.13509.

[17] Diabetes UK and NHS Diabetes (2010) Emotional and Psychological Support and Care in Diabetes: Report from the emotional and psychological support working group.

and severity of need. Times when a person with diabetes may need additional assessment and support include at diagnosis, at the onset of a complication or another health condition, during a change in their treatment regime, through transition from paediatric to adult services, and at university, or during pregnancy.

"I remember being very angry when I was first diagnosed. [I thought] 'Why me there are other people who are much more overweight than I am'. It took me quite a while to accept… all the time I was angry, I was not listening to any advice on caring for myself."

Person with Type 2 diabetes

There is a compelling case for increasing the opportunities for psychological support available to everyone affected by diabetes, parents of children with diabetes and other carers.

Respondents gave several suggestions and good practice examples for addressing lower level need, such as transforming diabetes consultations, broadening diabetes education, increasing the peer support offer and digital interventions.

Severe mental illness

The APPG also heard evidence about diabetes care for people with severe and enduring mental illness (SMI). People with SMI, such as schizophrenia, psychosis, bipolar depression and anxiety, are at double the risk of developing obesity and Type 2 diabetes. One submission raised a major concern that the risk of premature death from preventable conditions for patients with SMI has been seriously overlooked as a system issue. However, as the vast majority of the evidence received by the APPG related to the emotional and psychological support available to people with diabetes, this is the focus of this report. The case of people with SMI and diabetes could be an important area to explore in future.

Barriers to receiving adequate psychological support

Adults

A 2008 analysis of the provision of psychological support and care for people with diabetes in the UK found that 85 per cent of people with diabetes have either no defined access to psychological support and care, or at best access only in the form of local generic services[18]. The APPG's evidence suggests that there has been little improvement in the past ten years. Where integrated services have developed they make a significant positive difference, but financial pressures, rising demand and national policy initiatives can undermine progress.

Funding, demand and waiting times

There are significant funding challenges to securing psychological input to the diabetes team. Obtaining funding can take many years, often it does not cover a whole time equivalent (WTE) post, and there is not enough funding for long-term posts as opposed to time-specific projects. At the same time, as psychological services become more widely known about and integrated within the diabetes MDT, demand increases and leads to longer waiting lists.

"It is very difficult for diabetes teams to obtain funding to access psychological input to their multi-disciplinary teams e.g. UCLH (London) have just obtained funding for a small amount of input from a clinical psychologist. This has taken 14 years to obtain."

Dr Debbie Cooke, Chartered Health Psychologist

"With no specialist funding available for a dedicated psychologist, this has meant that following assessment, patients are now waiting up to a year for treatment. This is not acceptable. It also means that there is limited capacity for urgent referrals."

Dr Emily Robinson, Department of Medical Psychology, Leicester Partnerships Trust

Inadequate funding for dedicated psychological support means that people with diabetes who experience psychological problems often do not receive the right care at the right time. However, the implications are much wider, as psychological professionals also support multi-disciplinary teams (MDTs) in case reviews, develop interventions and materials, and provide psychological skills training to colleagues.

"Without specialist funding it is not possible to do any other service development work such as integrating psychology into diabetes clinics, implementing screening measures for anxiety, depression and diabetes distress, and developing other interventions such as written psycho-educational material, group programs, teaching and consultation work."

Dr Emily Robinson, Department of Medical Psychology, Leicester Partnerships Trust

Models of care for different needs

The national roll-out of IAPT-LTC services in England seeks to embed therapy within existing primary or secondary pathways for long-term conditions such as diabetes and to co-locate physical and mental health care provision.

[18] Diabetes UK (2008) Minding the Gap: The provision of psychological support and care for people with diabetes in the UK https://www.diabetes.org.uk/resources-s3/2017-11/minding_the_gap_psychological_report.pdf

There was general consensus among respondents that IAPT-LTC services can effectively meet the needs of people with well-controlled Type 2 diabetes who experience mild to moderate anxiety and depression, particularly where this is supported by clear referral pathways and close working with the diabetes team.

"In our experience generic mental health staff can have some knowledge of (but would by no means be safe to work with) people with diabetes on a self-management issue without supervision from a Diabetes Specialist Nurse or Psychologist. They certainly should be discouraged from working with people with Type 1 diabetes as this has proved clinically dangerous."

Dr Sonya Frearson, Barts Health NHS Trust

However, there was concern that in some services, IAPT-LTC practitioners are not given the skills, training or wider support to meet the needs of people with Type 1 diabetes, or those whose diabetes is not well-controlled. As these are typically the patients who are most in need of psychological support, this suggests the national policy direction and available funding is not fully catering for the different levels of psychological need within the diabetes population.

"Interventions are sometimes being delivered with very little consultation from existing services delivering psychological care in diabetes. It is concerning that investment is currently being made only in services that do not target patients most at need of psychological support in diabetes. From our focus group data patients who identified most need were those newly diagnosed with Type 1 diabetes, those not accessing services or those whom are struggling to adjust with the demands of their self-care regime."

Samina Hassan, Hackney Diabetes Centre

"[My GP] ended up referring me to the local IAPT service. After meeting various people and being passed around in a confusing way I was referred to the psychologist in the diabetes clinic in a hospital in Hackney […]. And really that has been the most important intervention yet."

Person with Type 1 diabetes

Respondents to the inquiry suggested other therapies, particularly those that support people to consider childhood experiences such as Cognitive Analytic Therapy (CAT), can also show encouraging results.

Poorly integrated psychology and diabetes services

For people with diabetes who experience high levels of psychological need, including people with Type 1 diabetes who require specialist eating disorders services, there is evidence of serious communication and liaison failures between different parts of the health system. The APPG heard of dangerous and fatal cases of 'diagnostic overshadowing', where treatment focused predominantly on mental health does not recognise the risk or presence of diabetes emergencies, such as severe hypoglycaemic episodes or diabetic ketoacidosis (DKA). This is very serious as both can be fatal if left untreated.

"During her outpatient treatment via the eating disorder unit there was no liaison with any diabetic clinic or specialist. In fact her diabetes was dismissed as 'secondary'. She was admitted to hospital with DKA several times while an outpatient. There does not appear to have been

any communication between the eating disorder unit and the GP."

Lesley Davison, parent of a child with Type 1 diabetes

CCGs in North West London are now piloting a mental health worker version of Ruth Miller's award winning Diabetes 10 Point Training Plan to start to address the issue[19].

The culture of care

Despite a raft of evidence in favour of integrating psychological support[20] and use of systematic care and support planning[21], the prevailing culture is one where consultations focus on biomedical outcomes such as HbA1c (average blood sugar levels), cholesterol and blood pressure.

"I would like all HCPs [healthcare professionals] to be more aware of the person living with diabetes. We are much more than just our diabetes. I would like HCPs to not initially be focused on the numbers, but on me. I would like HCPs to see me more as a valuable team member - my care is a partnership."

Person with Type 1 diabetes

Key performance indicators (KPIs) used by commissioners can reinforce this practice by emphasising physical targets over psychological targets. There is also frustration that there is no comparable 'route to market' for psychological therapies as there is for medicines through NICE, even when evidence shows them to be cheaper and more empowering.

"KPI's set by commissioners may mean that more emphasis is placed on physical targets as opposed to psychological targets. This can place unnecessary demands on consultation times and patient caseloads of the wider staff team, indirectly affecting opportunities to enquire about patients' psychological health."

Samina Hassan, Hackney Diabetes Centre

This narrow clinical focus and time restrictions can preclude diabetes teams from having conversations with their patients about their psychological health. It also creates a climate where people with diabetes feel like they cannot raise issues because they will not be heard or understood. The APPG's evidence suggests there is a significant need to increase the skills, knowledge and capacity of diabetes teams to recognise that their patients may be struggling and then help them to find support. This includes greater awareness that living with diabetes brings about its own emotional and psychological challenges, and joined-up local referral pathways to ensure people can get the care they need.

This lack of awareness is a serious failure which can have devastating consequences.

[19] Diabetes 10 Point Training https://www.diabetes.org.uk/professionals/resources/resources-to-improve-your-clinical-practice/diabetes-10-point-training

[20] Diabetes UK and NHS Diabetes (2010) Emotional and Psychological Support and Care in Diabetes: Report from the emotional and psychological support working group.

[21] Graffy J, Easton S, Sturt J, Chadwick P (2009) Personalised care planning for diabetes: policy lessons from systematic reviews of consultation and self-management interventions. Primary Health Care Research & Development 10(3); 210-222

Children and Young People

The UK has the highest number of children and young people with diagnosed Type 1 diabetes in Europe[22]. The Paediatric Best Practice Tariff emphasises that psychological support should be an integral part of diabetes care for this group[23]. Since the Tariff's introduction in 2011/12, many paediatric diabetes units now have access to a Child Psychologist. However, many of the problems with adult services are also affecting paediatric services.

"In the first year that the Clinical Psychologist joined our team for 18.75 hours a week, she received 95 referrals for children and young people needing psychological support, which is approximately 60 per cent of the total number of children we support."

West Hertfordshire Children and Young People's Diabetes Team

Availability of psychological support is variable and cannot meet demand

The APPG heard that major gaps remain in the accessibility and provision of integrated (rather than generalist) psychological care for children and young people with diabetes. This is despite substantial evidence of the effectiveness of psychological interventions[24], as reflected in NICE Quality statement 7: 'Children and young people with Type 1 or Type 2 diabetes are offered access to mental health professionals with an understanding of diabetes'[25].

"The psychological need has consistently outweighed the amount of time the Clinical Psychologist has available, and as a team we have asked for more hours to be given to this."

West Hertfordshire Children and Young People's Diabetes Team

The lack of funding for sufficient WTE specialist Clinical Psychologist positions has implications beyond the amount of direct care that can be provided. Psychologists can provide training to other professionals, such as staff in schools or on hospital wards, about the psychological aspects of managing a long-term condition as a child. These training needs go unmet when psychological expertise are not available.

Diabetes clinics are not set up to facilitate psychological support

Even in areas where a Clinical Psychologist is available, the environment of the diabetes clinic can act as a barrier to delivering psychological support (e.g. there may be a lack of space for one-to-one support). A concern was also raised to the APPG that in certain Trusts there are no clear management lines for Clinical Psychologists, meaning they work in professional isolation and lack supervision.

Parents are not getting the support they need

In a recent survey by Diabetes UK, parents of children with Type 1 diabetes were the most likely to report that they often felt

[22] Iacobucci G (2013) UK has fifth highest rate of type 1 diabetes in children, new figures show. BMJ Jan 3;346:f22. doi: 10.1136/bmj.f22.

[23] The Best Practice Tariff for 2017 includes the criterion that "Each patient must be annually assessed by their MDT for whether they need care from a clinical psychologist and access to psychological support, which the MDT itself should be able to provide"

[24] Winkley K, Ismail K, Landau S, Eisler I (2006) Psychological interventions to improve glycaemic control in patients with type 1 diabetes: systematic review and meta-analysis of randomised controlled trials. BMJ 8;333(7558):65. DOI: 10.1136/bmj.38874.652569.55

[25] NICE (2016) Diabetes in children and young people. Quality standard [QS125] https://www.nice.org.uk/guidance/qs125/chapter/Quality-statement-6-Access-to-mental-health-professionals-with-an-understanding-of-type-1-or-type-2-diabetes

down because of the demands of diabetes and to want more support[26]. The APPG heard from a number of parents who reported they had struggled to get the help or encouragement they needed to look after their own wellbeing to support them in caring for their child.

"There should be a chance at clinic for us to talk about how we are feeling too, sometimes all we need is for someone to tell us we are doing a good job and if we are struggling to be on our side and not make us feel like a failure."

Helen Bailey, Parent

"In my opinion people who care for others (especially children) with diabetes, should be encouraged to see a psychologist to help with the mental and emotional strain. There should be local peer support groups but there should also be a specialist dealing specifically with the psychological impact of diabetes. It is so hard."

Erika Payne, Parent

[26] Diabetes UK (2017) The future of diabetes. https://www.diabetes.org.uk/resources-s3/2017-11/1111B%20The%20future%20of%20diabetes%20report_FINAL_.pdf

Overcoming the barriers

Overcoming these barriers requires a fundamental shift in the way much of diabetes care is planned and delivered. The examples of excellent practice that the APPG received show this is not an insurmountable task, and that change can bring significant long-term benefits for the health and happiness of people with diabetes, as well as cost-savings for the NHS.

Making psychological support the norm rather than the exception

The APPG received numerous examples of services which have successfully integrated or are integrating psychological expertise into the diabetes multi-disciplinary team, demonstrating that there is scope for sharing good practice across the UK. Integrating services helps to embed wellbeing and psychology as core components of good diabetes care. This helps to challenge stigma and reflects that many people with diabetes who need additional psychological support do not need to be referred to mental health services.

"Sometimes patients who may benefit from psychology are reluctant to access the service due to the stigma they associate with accessing psychology. If Diabetes Psychology or Wellbeing services became more mainstream this would protect against some of this."

Samina Hassan, Hackney Diabetes Centre

"The majority of people with diabetes do not meet 'mental health service' criteria but instead require specialist psychological input to help them accept their diagnosis, self-manage their condition and adapt across their life course. We do not send people with cancer to mental health services for support and neither should we be doing so for people with diabetes unless there are specific diagnoses that require input from these services."

Dr Dorothy Frizelle, Mid Yorkshire Hospitals NHS Trust

Examples of integrated services include:

1) In Tower Hamlets, London, a Diabetes Clinical Psychologist is embedded in the specialist Diabetes Service working into GP networks and the Type 1 diabetes pathways. The CCG has also accepted a business case to pilot putting a Clinical Psychologist into the GP networks to work specifically with people whose glycaemic control is off target and skill up primary care staff in working with well-being issues.

2) In NHS Grampian, Scotland, the diabetes service has been redesigned to embed psychology within the team. Psychologists carry out clinical work focusing on emotional distress and diabetes specific self-management outcomes, service redesign and initiate innovative approaches to care delivery.

3) In West Hertfordshire, the Children and Young People's team has a Clinical Psychologist integrated into the MDT, who is present in the multi-disciplinary clinics and provides guidance on the team's approach and interaction with children with complex emotional needs in the clinic setting. Work is also underway to bring together adult diabetes and mental health services across the patch.

4) The North West London Collaboration of CCGs Diabetes Transformation Programme's approach aims to create seamless pathways across all levels of psychological needs. This involves mapping current provision and

providing support for commissioners and providers to work towards the pathways.

5) At King's, London, the award winning Three Dimension for Diabetes (3DFD) service integrated a psychiatrist and a community worker into the diabetes teams. This led to significant improvements in blood glucose, as well as reductions in A&E visits and hospital admissions. The diabetes psychology unit is now developing effective interventions for people with Type 1 diabetes and eating disorders.

Routine assessment to identify people who need support

There are too many missed opportunities for identifying people with diabetes who need additional psychological support. Implementing screening tools and assessment practices could improve this and is recommended as standard practice internationally. The American Diabetes Association's position statement on psychosocial support sets out that routine monitoring and screening for diabetes distress, depression, anxiety, eating issues, and appropriate levels of social and family support are clearly indicated[27].

"Awareness-raising about the role of mental health issues for people with diabetes can take place by asking screening questions at annual diabetes care-planning sessions."

Dr Sonya Frearson, Barts Health NHS Trust

Assessment of psychosocial wellbeing should already be an integral part of paediatric diabetes care. For adults, the Health Innovation Network's Type 1 consultation tool supports clinicians in Type 1 diabetes services to implement diabetes distress screening at annual reviews[28]. For General Practice, Diabetes UK has produced a mood information prescription which healthcare professionals can use to support patients to talk about how they feel and set goals to improve their diabetes management and emotional wellbeing[29].

Hospitalisation for diabetic ketoacidosis (DKA) also presents an opportunity to assess for emotional or psychological problems.

"We [the psychology service] see all people with Type 1 diabetes admitted for DKA two or more times in a 12 month period during their admission to conduct assessments and to try to avert further acute crises."

Dr Kirsty MacLennan, NHS Grampian

Providing more training to Healthcare Assistants and Practice Nurses to increase their skills and confidence in asking about psychological and emotional wellbeing in annual care planning sessions could also help people with Type 2 diabetes who are managed in primary care. In Tower Hamlets, this is being carried out by a Psychologist who also offers case discussions to practice staff regarding people they are struggling to support.

However, without appropriate resource and integration of psychological expertise within the diabetes team it is very difficult to effectively implement screening measures. There are concerns that screening should not be carried out if there are no appropriate services to refer people with identified needs on to, or if waiting lists are extensively long. This shows the need to develop clear pathways of support which can be implemented at the local level.

[27] Young-Hyman D, de Groot M, Hill-Briggs F et al (2016) Psychosocial Care for People with Diabetes: A Position Statement of the American Diabetes Association. Diabetes Care 39(12):2126-2140.

[28] Health Innovation Network. Type 1 Consultation (T1C) Tool User Guide https://healthinnovationnetwork.com/wp-content/uploads/2017/01/Type-1-Consultation-Tool-User-Guide.pdf

29 Diabetes UK. Mood Information Prescription https://www.diabetes.org.uk/professionals/resources/resources-to-improve-your-clinical-practice/information-prescriptions-qa/information-prescription---diabetes-and-mood-

Designing services to cater to different needs

"There is a whole range of needs from adjusting to the diagnosis and diabetes distress to psychosis and dementia and the service model we are developing will look at all of those level of need."

North West London Diabetes Transformation Programme Team

A 'one-size-fits-all' approach is not appropriate for diabetes psychological support. Services need to be designed so that they cater for different levels of need and the diversity of the diabetes population. There is a case for tailoring support offers for people with Type 1 and Type 2 diabetes, during transition to adult services, through pregnancy, and for people from BAME communities.

The APPG received evidence about innovative pilot programmes which targeted specific groups of people in need, such as the Long-Term Conditions Psychology in General Practice Pilot Project in Tower Hamlets for people with Type 2 diabetes.

"In Tower Hamlets we have 740 residents registered as living with Type 1 diabetes and 15,795 registered as living with Type 2 diabetes. Of those living with Type 2 diabetes, 10.3 per cent (1,627) are under the age of 40 years old. Very little attention is paid to providing specialist interventions and offering psychological support to them, even though the complications associated with not having an HbA1c in target range can be life-threatening."

Dr Amy-Kate Hurrell, Specialised Clinical Psychologist

Many services operate on a self-referral basis, and some allow people with diabetes to bring along family or carers to appointments.

Skilling up diabetes professionals

While there are clear issues with the lack of specialist psychological services, more people with diabetes could get the support they need if members of the diabetes team were able to provide it. The APPG heard that it is often most appropriate for a person with diabetes' psychological needs to be addressed by those who usually provide their care.

In many cases, Diabetes Specialist Nurses (DSNs) already give a significant amount of emotional support to their patients – often without specialist training. One respondent referred to DSNs as the 'untrained psychologists of diabetes care'. Training DSNs about psychological therapies has been shown to improve blood glucose control for people with Type 1 diabetes[30].

"In the current financial climate, it is not realistic to employ lots of psychologists to support these 40 per cent of people who are struggling, so we need to think more broadly as how best to support this population to engage in health behaviour change."

Dr Kirsty MacLennan, NHS Grampian

"We have shown in a randomised controlled trial (RCT) that training DSNs in diabetes focused cognitive behaviour therapy (motivational interviewing and CBT) led to

[30] Ismail, K et al. Motivational enhancement therapy with and without cognitive behaviour therapy to treat type 1 diabetes Annals of Internal Medicine 2008;149:,708-719.

improvements in blood glucose control in Type 1 diabetes."

Prof Khalida Ismail, King's College London

The diabetes counselling course at Knuston Hall in Northamptonshire is an exemplar training programme which combines training in communication skills and empowerment to support healthcare professionals to put person-centred care into practice. Though the nature of the course restricts the number of participants, there is scope to develop means for delivering this sort of course content more widely, including as e-learning[31].

Members of other professions who regularly come into contact with people with diabetes, such as pharmacists and podiatrists, also suggested they could take on a greater role in identifying and signposting people with potential psychological needs.

Maximising opportunities for peer support

The APPG heard that peer support can take many different forms and cater for varying levels of emotional and psychological need. From organised groups facilitated by psychologists to residential weekends away at Center Parcs for younger people, people with diabetes say they find great value in meeting and speaking with others with the condition, and this can help them to form long-lasting networks of support. Demand exists for more help to develop peer support networks for all ages, for example, for women with diabetes who are pregnant.

"Through the psychotherapist, we formed a group of three of us and since our first meeting we have become very close friends, and we meet very regularly. We have planned to extend our group to more people to turn it into a support group for all ages. It really helps to have people to talk to who know what you're going through and you can relate to as it really helps to know that you're not alone."

Young person with Type 1 diabetes

"Local Diabetes UK support group, which I'm involved in, provides great support. Sometimes there's nothing better than talking things through with someone who understands the condition, because they live with it themselves. No doctor or nurse, however well intentioned, and mine are very good, is going to be able to properly understand in the same way."

Person with Type 2 diabetes

Making psychosocial support a key part of diabetes education

Good psychological wellbeing should be seen as a necessary condition for good diabetes-management, much in the same way that diabetes education is. Linking up psychological support and structured diabetes education can be beneficial for a number of reasons, from facilitating reciprocal referrals, to providing information about wellbeing, to helping patients to make lasting supportive peer relationships. Research shows that psycho-education interventions are effective for reducing diabetes distress[32].

"It was only when I attended the education sessions, 18 months after diagnosis, that I realised it wasn't just me and other people felt as desperate and alone as I did."

[31] Kilvert A, Fox C (2017) Course focus The diabetes counselling course at Knuston Hall: A 30-year journey. Practical Diabetes 34(10);25-27.

[32] Sturt, J., Dennick, K., Hessler, D., M. Hunter, B., Oliver, J., & Fisher, L. (2015). Effective interventions for reducing Diabetes Distress: systematic review and meta-analysis. International Diabetes Nursing . DOI: 10.1179/2057332415Y.0000000004.

Person with diabetes

"All patients attending the structured education programmes are informed of the Psychology Service and provided with self-referral forms should they wish to access the service. Those attending the education programme for newly diagnosed Type 2 Diabetes are screened for depression and given the opportunity to self-refer. All patients attending Type 1 education have a psychological health session embedded into the programme and an opportunity to self–refer to psychology if needed."

Samina Hassan, Hackney Diabetes Centre

Empowering people with digital and data

As with diabetes education, digital providers are increasingly offering interventions which could support people with lower levels of psychological need. For example, Changing Health combines X-Pert diabetes education content and access to lifestyle coaches who can provide one-to-one telephone advice.

In NHS Grampian, psychologists developed a self-help web-based intervention to help people with Type 2 better self-manage their condition. An evaluation by Health Improvement Scotland indicated that ACT Now! is markedly more cost effective than drug treatments, has no know side effects, results in objective improvements in self-management and was found to be enjoyable and transformative for participants.

"Based on the clinical evidence, if patients are offered accessible, easy-to-understand help and ongoing support to reach goals, they will live happier and healthier lives."

Professor Mike Trenell, Changing Health

People with diabetes who submitted evidence to the APPG inquiry often mentioned the support they had received from online forums and social media. Barriers to accessing support include the lack of availability outside of working hours, so evidence-based digital solutions could help to address this issue as well as providing some initial support to those on waiting lists.

"Online support out of office hours or even the option to have a trained person in my appointments with my consultant would help, that way I wouldn't have to take additional time off work to access the support I've needed."

Person with diabetes

Improving the data available to clinicians and people with diabetes could also play an important role in embedding psychology as a core part of diabetes care and encouraging more partnership and collaborative working in the doctor-patient relationship. The Scottish Care Information Diabetes Collaboration (SCI-Diabetes) provides a fully integrated shared electronic patient record to support treatment of NHS Scotland patients with diabetes. This allows all patients to have access to their clinical information, including results of psychological screening where this is carried out.

Conclusion

There is much that needs to be done to break down the historic divide between physical and mental health in diabetes care. The APPG's evidence shows that there are significant barriers to overcome if all local areas are to provide an adequate standard of psychological support to people with diabetes and their families. Achieving systemic change requires sustained effort and investment. Though this is a considerable task, the long-term impact on the health and wellbeing of people with diabetes should not be underestimated and the examples of good practice heard by the APPG show it can be done.

"I will always wonder how much happier and healthier I would have been if I had seen someone qualified to talk with."

Person with Type 1 diabetes

"The chance to have support from someone who is dedicated to emotional and psychological support has just been so valuable. Where was she when I was 17 years old? Will she be there if I have a bad patch again, in 5 or 30 years…?"

Person with Type 1 diabetes

Recommendations

The APPG has found that there are significant barriers to people with diabetes getting the support they need. In both adults and children's services, demand for specialist psychological support seems to be outstripping supply, and there is a concurrent need to grow the psychological skills of diabetes teams. The APPG therefore makes the following recommendations:

NHS England should:

1) Ensure the NHS spending review targets additional national investment at growing the psychological expertise of diabetes multi-disciplinary teams and bringing down waiting times. This could be achieved through future diabetes transformation funding, as a new stream or as part of the investment in treatment targets.

2) Develop and endorse clear pathways for psychological support for people with diabetes.

3) Ensure that the strategy which supersedes the Five Year Forward View for Mental Health builds on the roll out of IAPT-LTC and considers the menu of options which are required to support the integration of mental and physical health for people with long-term conditions. This should be informed by the latest evidence on clinical and psychosocial outcomes, as well as cost-effectiveness.

4) Work with NHS Digital to establish meaningful datasets around diabetes and mental health and explore opportunities for promoting person-centred care by ensuring people with diabetes and healthcare professionals have access to their clinical data.

5) Take urgent action to address the lack of effective interventions for people with diabetes and eating disorders, for example, through supporting pilots of

service models and ensuring there is adequate provision across the country.

Local decision makers:

1) Adopt pathways of psychological support for people with diabetes across all levels of need and for different demographics. This should be based on a robust mapping of local provision and gaps in support.

2) Implement the NHS RightCare Diabetes Pathway, which sets out that all people with diabetes should have access to psychological support and that Type 1 diabetes services should have access to a diabetes trained clinical psychologist[33].

3) Consider how psychosocial KPIs could be incorporated into monitoring and evaluation of diabetes services.

4) Develop the existing local diabetes structured education offer to provide opportunities for accessible emotional and psychological support.

Health Education England should:

1) Develop a plan for building the psychological skills of diabetes teams. For example, through supporting the development of learning packages around diabetes distress and how to recognise it, or support DSNs to receive additional training in psychological interventions.

2) Review whether the training available to IAPT-LTC practitioners gives them a sufficient grounding in diabetes.

The National Institute for Health Research should:

1) Fund more research on supporting people with diabetes with their mental health, for example, by looking into interventions that are effective in improving both depressive symptoms and glycaemic control.

Healthcare professionals working in diabetes should:

1) Ensure that in every contact with their patients they consider the emotional and psychological impact of living with diabetes on them and those close to them, and ask them how they are feeling.

2) Consider the use of psychological screening tools and Diabetes UK information prescriptions.

3) Signpost to local or digital peer support.

4) Establish clear communication with and referral pathways to mental health and/or psychological wellbeing services and refer as appropriate.

5) Treat people with diabetes as true partners in their diabetes care.

[33] NHS RightCare Pathway: Diabetes [updated version: June 2018]. https://www.england.nhs.uk/rightcare/wp-content/uploads/sites/40/2018/06/rightcare-pathway-diabetes-june-update.pdf

Past publications:

Reversing Type 2 Diabetes (2018)
Diabetes and Podiatry (2018)
Emotional and Psychological Support for people with Diabetes (2018)
Next Steps for Childhood Obesity Plan (2018)
The Future of Inpatient Diabetes Care (2017)
Safety and Inclusion of Children with Medical Conditions at School (2017)
Industry Action on Obesity and Type 2 Diabetes (2017)
Levelling up: Tackling Variation in Diabetes Care (2016)
Taking Control: Supporting People to Self-Manage their Diabetes (2015)

ALL PARTY PARLIAMENTARY GROUP FOR DIABETES