Methodology

Too often missing. Making emotional and psychological support routine in diabetes care.

DIABETES UK
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To get a broad view of the psychological and emotional difficulties faced by people living with diabetes, and to understand the need in this area, we spoke to as many people as we could about their experiences. This included people living with diabetes, parents and carers of people living with diabetes, and healthcare professionals working within diabetes services and primary care.

We adopted a mixed method approach to allow us to explore the need for emotional and psychological support; using quantitative surveys that included open-ended questions, and in-depth interviews. By speaking to both healthcare professionals and those affected by diabetes, we allowed consideration of both perspectives when gathering insight.

This briefing gives an overview of the methods of insight gathering used to inform the content and recommendations made within the policy report. If you would like more information please contact the Diabetes UK Policy team: policy@diabetes.org.uk

Overview of methodology used to gather insight

- Online survey: **Emotional support and diabetes** collected 2,667 responses including 351 from parents and carers.
- Online survey of psychological services for people living with diabetes, collected responses from 155 healthcare professionals involved in diabetes services.
- 32 in-depth face-to-face interviews were carried out with people living with or caring for (including parents of) someone living with diabetes. Conducted by research agency Magenta.
- GP poll, conducted by research agency ComRes, collected responses from over 1,000 GPs across the UK.
- Discussions with services providing emotional and psychological support for people living with diabetes.

Online survey – Emotional support and diabetes

- An online survey conducted by Diabetes UK for adults (18+) living with diabetes or caring for (including parents of) someone living with diabetes, called **Emotional support and diabetes**, ran from 2 August 2018 to 12 October 2018.
- Questions were devised by a project group with expertise in the topic, and cognitive testing was carried out on the questionnaire prior to the fieldwork. 10 face-to-face cognitive interviews were carried out through June and July 2018 with a mix of carers and people living with diabetes. This tested the language and terms used and understanding of the questions, in order to improve the survey.
- This survey explored how frequently people felt overwhelmed by diabetes, how often emotional wellbeing is discussed with healthcare professionals and the provision of, and ability to access, emotional support, including specialist and peer support.
- Before analysis of the survey results, the responses from people aged under 18 (51 people) and people with no connection to diabetes (49 people) were removed.

Quantitative analysis of Emotional support and diabetes survey – people living with diabetes

- For quantitative analysis of people living with diabetes, two separate analyses were undertaken. In one, the results were split by type of diabetes (Type 1 and Type 2 and other) and in the other analysis, all types of diabetes were grouped together for analysis.
- Results were weighted against the National Diabetes Audit 2016-17. Under 18 year olds were removed from the NDA population, to give us proportions matching the age-ranges of the survey population.
- 62 respondents were removed from the analysis as they had not provided demographic information, so were unable to be weighted. This left 2,154 living with diabetes included in the analysis.

- Where questions had a significantly lower response rate than the standard, the population was re-weighted against the NDA characteristics to remain representative.

Quantitative analysis of Emotional support and diabetes survey – parents/carers

- The parents and carers responses were analysed separately from the people living with diabetes comments. No weighting was applied to these results.
- One respondent was removed from the analysis as they had not responded to the question identifying whether they were a parent or carer of someone living with diabetes. This left 350 parents and carers included in the quantitative analysis.
- All parents and carers were grouped together for the analysis and when reporting the results.

Qualitative analysis of Emotional support and diabetes survey

- The open-ended question at the end of the Emotional support and diabetes survey 'Any other comments about emotional wellbeing and diabetes that haven't been covered in this survey?' was qualitatively analysed, using thematic analysis.
- For the 859 comments provided by people living with diabetes, three members of Diabetes UK staff individually read a sample (50 each) of the written feedback comments and developed potential codes. These were discussed and revised, and a list of agreed codes were applied to the entire dataset.
- Three staff members then regrouped to consider the overall themes representing the qualitative data as a whole, with consideration of any 'other' comments that had developed through the coding process. These themes were amended and revised as appropriate, to represent the data.
- The themes were written up in a slide deck, describing each theme and giving examples of where this was demonstrated:
- The five main themes; one of which had a number of sub-themes were:
  1. I need emotional support and so do those close to me.
  2. Need for improved awareness, acknowledgment and normalising of the impact diabetes can have on emotional wellbeing.
  3. I need support at diagnosis, but this is not the only time.
  4. What my service should look like
     - we need emotional support
     - not one size fits all
     - upskilling of staff and specialised services
     - structured education
     - better access to technology and treatments.
  5. Support does not have to come only from healthcare professionals: Social and Peer support.
- The list of codes for people living with diabetes, was applied to the 129 comments left by parents and carers, with any other codes identified being coded as 'other'. These were discussed in a group and themed as before, and presented within the same deck as people living with diabetes themes.
- Six main themes came from the parents and carers comments – with overlap between the theme from people living with diabetes:
  1. Families and support networks need emotional support too.
  2. Stigma and lack of understanding about diabetes impacts us.
  3. Our emotional need goes unnoticed by healthcare professionals.
  4. We don't bring up our emotional wellbeing with healthcare professionals.
  5. We want emotional support – but this is not one size fits all.
  6. Better support for us, means we provide better care to those living with diabetes.

Online survey – National survey of psychological services for people living with diabetes

- An online survey called the National survey of psychological services for people living with diabetes was conducted by Diabetes UK between 30 July 2018 and 12 October 2018.
- The aim of the survey was to identify the current provision of emotional and psychological support within the UK.
- The questions were based upon the Minding the Gap survey conducted in 2008[1]. In consultation with colleagues from the Royal College of Psychiatrists these were updated where necessary to be relevant for current provision.
- This was promoted through Diabetes UK colleagues with relationships to diabetes teams and through the NHS England diabetes networks.

Quantitative analysis of National survey of psychological services for people living with diabetes survey

- 155 professionals responded to the service survey.
- No weighting was applied to the services survey, and all respondents were included within the analysis as we were unable to identify duplicates responding from the same service, due to missing data.

Qualitative analysis of National survey of psychological services for people living with diabetes survey

- The services survey included an open-ended question 'In your own opinion, what gaps are there in services for people with diabetes, who have emotional, psychological or mental health problems' which was answered by all 155 of the respondents.
- These text comments were analysed by Diabetes UK staff.
- A small group from policy and analyst teams read through a third of the responses and developed initial codes. These were discussed as a group and an initial list of codes were decided. These codes were then applied to the whole dataset. The group came back together to finalise the overall themes that represent the codes and data set as a whole, with consideration of any 'other' codes that had come up. Final themes were agreed to be representative of the responses given and this was written up into a slide deck, giving descriptions of each theme.
- Final themes were as follows:
  - There are clear gaps in current provision for emotional and psychological support for people living with diabetes.
  - There are barriers in the current system that are preventing adequate emotional and psychological support for people living with diabetes.
  - The referral pathways for emotional and psychological support for diabetes patients are not clear, consistent or adequate.
  - Emotional and psychological support needs to be a routine part of diabetes care.
  - We need individualised, specialist support to meet the emotional and psychological needs of people living with diabetes.

1 Diabetes UK (2008) Minding the gap, the provision of psychological support and care for people with diabetes in the UK. https://diabetes-resources-production.s3-eu-west-1.amazonaws.com/diabetes-storage/migration/pdf/Minding_the_Gap_psychological_report.pdf

In-depth interviews with people affected by diabetes

- Research agency Magenta, conducted 32 two-hour face-to-face, in-depth interviews on behalf of Diabetes UK in October 2018.
- Prior to the interviews, participants completed a pre-interview screener questionnaire. All participants had self-declared within the screener as having experienced mild to moderate emotional problems, with a mixture of those that had received psychological support and those that had not.
- The interviews took place in London, Manchester and Glasgow and covered people of different age ranges, genders, types of diabetes, length of diabetes diagnosis, treatment types and ethnicities. Four of the 32 interviews were with parents and carers of people living with diabetes.
- The interview discussion guide focused on creating people's journey through life with diabetes. Topics covered included: the emotions experienced at different points of the journey living with diabetes or caring for someone with diabetes, the key people and support that they received, barriers to receiving appropriate support and their thoughts on the language used when talking about mental health and emotional wellbeing specifically in relation to diabetes.
- Magenta analysed the data gathered and produced a deck depicting the main themes and recommendations.

GP Polling

- ComRes surveyed 1,007 GPs in the UK via an online poll between 14 November 2018 and 25 November 2018 on behalf of Diabetes UK.
- Data was weighted to be regionally representative of UK GPs.
- Questions covered the likelihood and confidence of GPs having discussions about emotional wellbeing with their diabetes patients as well as their thoughts on the current provision for emotional and psychological support for this group.

Discussions with services providing emotional and psychological support for people living with diabetes

- We spoke to a number of services providing emotional and psychological support to people living with diabetes over the five-month period between October 2018 and February 2019, with the aim of learning more about current service provision.
- Services were identified through various means; including services that presented information at relevant conferences or had been previously included in publications highlighting emotional support for people living with diabetes – including those who had submitted evidence to the Diabetes All Party Parliamentary Group enquiry on diabetes and mental health. We also spoke to services identified through word-of-mouth from staff working at Diabetes UK, or other diabetes and mental health teams, highlighting other services doing work in this area.
- Where case studies have been used within the policy report as examples of current practice, the service provided us with a brief write up of their services and the final description within the report was agreed with the service themselves.

Find the full report and recommendations at:
www.diabetes.org.uk/emotional-wellbeing