

Diabetes UK Position Statements

Transforming mental well-being for people with diabetes: research recommendations from Diabetes UK's 2019 Diabetes and Mental Well-Being Workshop

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Accepted 6 June 2019

Abstract

Aims To identify key gaps in the research evidence base that could help to improve the mental well-being of people with diabetes, and to provide recommendations to researchers and research funders on how best to address them.

Methods A 2-day international research workshop was conducted, bringing together research experts in diabetes and in mental health, people living with diabetes and healthcare professionals.

Results The following key areas needing increased financial investment in research were identified: understanding the mechanisms underlying depression; understanding the multifactorial impact of social stigma; improving the language used by healthcare professionals; supporting people who find it difficult to engage with their diabetes; supporting significant others; supporting people with diabetes and eating disorders; improving models of care by learning from best practice; the potential benefits of screening and managing diabetes distress in routine diabetes care pathways; primary prevention of mental health issues at the time of diagnosis of diabetes; establishing the effectiveness of diabetes therapies on mood and other mental health issues; and understanding the impact of current diabetes technologies on mental health. Research recommendations as to how to address each of these priority areas were also developed.

Conclusions This inaugural position statement outlines recommendations to address the urgent unmet need related to the mental well-being of people living with diabetes, and calls on the research community and funders to develop research programmes and strategies to reduce this need.

Diabet. Med. 36, 1532–1538 (2019)

Introduction

Extensive insight gathered from people with diabetes, healthcare professionals and researchers has highlighted mental well-being as one of the most significant areas of UK diabetes care in need of improvement.

In order to make these improvements, the diabetes Clinical Studies Groups (CSGs), established by Diabetes UK in 2016, have identified a number of research gaps and priority areas

under the umbrella of diabetes and mental well-being. The CSGs bring together people with diabetes, healthcare professionals and researchers to examine the research landscape, amplify the voice of people living with diabetes, and identify research priorities and practical actions to move forward research in areas of unmet clinical need.

Alongside this, more than 9000 people with diabetes shared their experiences as part of Diabetes UK's Future of Diabetes report in 2017 [1], highlighting that living with diabetes can be exhausting and that individuals need more support for their emotional and psychological health. At the same time, 4000 people with Type 2 diabetes and healthcare professionals contributed to the Type 2 diabetes James Lind Alliance Priority Setting Partnership, with 'psychological and social support' and 'understanding the impact of positive

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In memory of Dr Carlo Acerini (1962–2019).

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What's new?

- There is an increased prevalence of psychological and psychiatric disorders in people with diabetes which impairs quality of life.
- Research prioritization exercises have identified mental well-being as an area in which further research is needed.
- Diabetes UK convened a workshop that identified 11 areas for future research.

mental well-being' both featured in the top 10 research priorities [2]. Furthermore, the Diabetes All Party Parliamentary Group Report on diabetes and mental health highlighted how a lack of emotional and psychological support impacts on the ability of people with diabetes to effectively manage their condition and recommended that routine psychological support be integrated into diabetes care [3].

With the need for further research made clear, the CSGs called for an international research workshop, the first of its kind in the UK, to establish how most effectively to move this field forward, bringing together research experts in diabetes and in mental health, people living with diabetes and healthcare professionals (Appendix 1).

Diabetes UK convened an expert advisory group to determine the scope of the workshop. While the group acknowledged the wide range of conditions that affect mental well-being, such as severe mental illness and dementia, they recommended focusing this workshop's remit on depression [4,5], eating disorders [6–9] and diabetes distress [10,11]. This decision was supported by the evidence of the high prevalence of these three conditions in people with diabetes, the need for effective, evidence-based interventions [12], and the interplay between them.

The workshop aimed to identify key gaps in the evidence base for the links between diabetes and mental health, particularly depression, eating disorders and diabetes distress, and how best to address them in order to improve the mental well-being of people with diabetes. Eleven key areas in need of increased research investment and focus were identified. This report sets out the outputs from those discussions and recommendations to both researchers and research funders.

Research priorities and recommendations

Understanding the mechanisms underlying depression

Context

The prevalence of depression is increased twofold in people with diabetes compared to the general population [3,4]. The relationship between diabetes and depression is bi-directional: while people with diabetes are at increased risk of

depression, people with depression are also at increased risk of Type 2 diabetes [13]. Research has also suggested that there is a complex relationship between depression, the complications of diabetes and long-term health outcomes. Comorbid depression increases the risk of both microvascular and macrovascular complications and shortens life expectancy, while the development of diabetes complications increases the risk of depression [14–16].

People with diabetes may be at increased risk of depression because of the psychological burden of living with diabetes or owing to underlying shared biological pathways [17]. Environmental risk factors include poor diet and physical inactivity, as well as the effects of some psychotropic medications. The emerging theories of biological mechanisms along the life course that are shared by depression and Type 2 diabetes include genetic vulnerabilities and activation of the innate inflammatory response [18].

There is a need to understand these mechanisms better and establish what are the most effective interventions to reduce the adverse effects of the bilateral association between depression and Type 2 diabetes.

Research recommendations

- Establish the common biological, social and psychological pathways underpinning depression and diabetes.
- Reach a consensus on the most effective markers for depression in people with diabetes. This should be supported by bringing together scientists to interrogate 'big data' gathered from people with diabetes and by conducting more proof-of-concept and mechanistic studies.

Understanding the multifactorial impact of social stigma

Context

There is limited understanding of how social stigma (disapproval of, or discrimination against, people based on a characteristic that distinguishes them from others in society) affects the lives and mental well-being of people living with diabetes, but it clearly exists. Those who have experienced social stigma report that it negatively affects the social, emotional and diabetes management aspects of their lives [19]. A much greater understanding of stigma in diabetes is needed in order to develop strategies to reduce or prevent its impact.

Research recommendations

- Perform national surveys to understand the extent and impact of stigma using questionnaires such as the validated Type 1 and Type 2 Diabetes Stigma Assessment Scales [20,21].
- Explore issues relating to stigma in more detail through qualitative research, recognizing both the similarities and differences in how stigma affects people with different types of diabetes.

- Identify interventions designed to reduce stigma, learning from existing successful stigma reduction interventions for other conditions [22–24].
- Research in this area should be conducted with sensitivity.

Improving the language used by healthcare professionals

Context

A recently published position statement and review of scientific literature, supported by NHS England and Diabetes UK, highlighted the importance of the use of language in the care of people with diabetes. In particular, the way healthcare professionals talk about diabetes and the impact language may have on both the mental well-being of people with diabetes and social stigma [25,26]. However, the full impact of language is not well understood.

Research in this area could support the design of interventions to improve attitudes and upskill current healthcare professionals and the next generation to use language effectively, in order to reduce stigma and improve the mental well-being of people with diabetes.

Research recommendations

- Review the current literature investigating the effect of the use of language in healthcare on mental well-being, particularly around diagnosis, for both diabetes and other conditions such as cancer [25], where a substantial amount of research has been undertaken.
- Assess the impact of wording used in National Health Service (NHS) referral or screening letters and position statements on mental well-being.
- Consider that language can be interpreted in different ways by different cultures, and that research should not focus solely on the English language.

Supporting people who find it difficult to engage with their diabetes

Context

Not all people with diabetes who find it difficult to engage with their condition experience diabetes distress, and there are other reasons why they may struggle to manage their diabetes. Clinicians at the workshop reported that they had cared for people with diabetes who find the process of engagement distressing, and choose to adopt different coping strategies. While they may appear to have a positive mental well-being at present, their lack of engagement may negatively affect their mental well-being in the future, as a result of having a higher risk of diabetes-related complications [27].

Strategies are needed to help people who are finding it difficult to engage with their condition and manage their

blood glucose levels, without negatively affecting their mental well-being.

Research recommendations

- Identify people with diabetes who have low diabetes distress scores and high blood glucose levels and carry out qualitative interviews to understand their experiences.
- When recruiting individuals, consider the use of community outreach programmes, clinical referrals or databases, and incentives for participants, recognizing the challenge of identifying and reaching out to these individuals.
- Co-design research with people with diabetes who experience low diabetes distress and high blood glucose levels, to ensure that their needs and the potential barriers are considered.

Supporting significant others

Context

The second Diabetes Attitudes Wishes and Needs (DAWN2) study has shown that diabetes can have a profound negative impact on the lives of significant others, friends and families of people living with the condition [28]. In turn, this can have a further negative impact on the individuals with diabetes. For example, research has shown that people experiencing complications, such as hypoglycaemia unawareness, have expressed concern that they may become 'a burden' to family members [29]. To date, research has not fully explored how to reduce this impact for both the person with diabetes and their wider support network.

A greater understanding of this area could lead to future interventions to support and empower the significant others of people with diabetes, and ensure that diabetes has limited negative impact on their mental well-being.

Research recommendations

- Review existing literature and available resources to establish the current evidence base to inform a survey of the significant others of people with diabetes, in order to investigate the impact of diabetes and its complications on these individuals. This could potentially build on the methodology used in the DAWN2 study [24].
- Explore issues in more depth, potentially through a programme of research using focus groups and a narrative approach, sharing examples of helpful or unhelpful events.

Supporting people with diabetes and eating disorders

Context

There is a significant lack of understanding of how and why people with diabetes develop eating disorders, and

importantly, how to best care for them when they do [30]. Studies have found that 30% of women with Type 1 diabetes may take less insulin than they need in order to manage their weight [31] and that disordered eating behaviours have been observed in as many as 20% of people with Type 2 diabetes [7–9]. We need to better understand how these conditions arise in people with diabetes in order to treat them effectively [32].

Research recommendations

- Analyse all studies testing interventions to improve biomedical and psychological outcomes in people with diabetes and disordered eating (in the broadest terms) to understand which approaches show potential effectiveness.
- Analyse existing databases and real-world data to establish how common eating disorders and insulin omission are in people with diabetes and identify risk and prognostic factors.
- Establish detailed definitions and an understanding of insulin omission and eating disorders in people with diabetes, to enable more accurate diagnosis and phenotyping.
- Develop complex interventions for people with diabetes and eating disorders. These should be co-designed with people affected by these conditions and informed by existing interventions for eating disorders not specific to people with diabetes.
- Give equal weight to mental and physical health when using endpoints to establish the success of any intervention.
- Focus on each type of diabetes separately, given the varied experiences of people with different forms of diabetes and the potential impact of stigma.

Improving models of care by learning from best practice

Context

Too often, the care and support people with diabetes receive does not consider their mental well-being. There are a number of examples, both within the UK and worldwide, of successfully integrating care for people with diabetes and their mental well-being into a single care pathway [33,34]. It is important that effective examples are identified and spread beyond the centres that develop them.

As existing programmes are improved and rolled out, two important factors need to be considered: the time constraints placed on healthcare providers and the additional workload such integration may require, and the lack of existing knowledge diabetes and mental health specialists may have about each other's fields.

Research recommendations

- Identify existing best practice in integrated mental and physical healthcare approaches, both in the UK and particularly internationally.
- Test the most effective examples of best practice with feasibility studies in the UK. The results of these studies could then inform future clinical trials, to establish the effectiveness of integrated approaches on both physical and mental health and quality of life.

Potential benefits of screening and managing diabetes distress in routine diabetes care pathways

Context

Services or pathways which could help to improve the mental well-being of people with diabetes distress exist in some areas of the UK [35], but consistent and effective services have yet to be implemented across the UK as a whole. While there is a need to expand existing interventions and ensure they reach those who might benefit, there is also a need to establish robust evidence on which approaches would be most effective at treating diabetes distress.

This knowledge would inform and enable the national rollout of effective therapies to support people with diabetes distress in the future.

Research recommendations

- Better define both diabetes distress and depression in order to ensure that people receive the treatment they need.
- Formally evaluate the effectiveness of existing programmes for diabetes distress [35] to inform future improvements and innovation.
- Explore the barriers to implementing and accessing these programmes, to help inform how future programmes should be implemented within new locations.
- Establish well-defined study populations and focus on the further development of existing tools.

Primary prevention of mental health issues at the time of diagnosis of diabetes

Context

There is an acknowledgement that how a diagnosis of diabetes is delivered may affect the mental well-being of people with diabetes, even many years later, but there is little research evidence in this area. There is a need to understand the impact of the delivery of a diagnosis, identify the hallmarks of a positive diagnosis experience, find factors which could reduce the stress or trauma of diagnosis, and spot signs of any future decline in mental well-being.

Understanding how to diagnose diabetes in order to minimize shock or trauma, and implementing this, would reduce the risk of the diagnosis experience having a subsequent negative effect on future mental well-being.

Research recommendations

- Systematically review the current research evidence in this area, before exploring the features of diagnosis that may help or harm subsequent mental well-being through qualitative research.
- Involve people with diabetes in co-designing interventions to improve the process of diagnosis: implementing the identified positives and limiting the negatives.
- Consider how people of different cultures and languages experience diagnosis, as well as the impact of diabetes type and age.
- Design studies comparing new approaches to diagnosis with existing processes, to assess the potential benefits. Studies should explore ways to use existing healthcare interventions, such as structured education programmes [36,37], as a test bed for new approaches.

Establishing the effectiveness of diabetes therapies on mood and other mental health issues

Context

There is a need to understand whether specific drugs currently used to treat Type 2 diabetes may improve the mood of those taking them, independent of effects on glycaemic control or weight loss [38]. This may potentially occur through effects on the brain, but the phenomenon is not well described.

Research in this area could help to define the full effects of Type 2 diabetes therapies, enabling healthcare professionals to make more informed decisions when treating people with Type 2 diabetes and mental health conditions.

Research recommendations

- Define a core set of mental health outcomes that should be measured in trials evaluating Type 2 diabetes medications.
- Establish the effects of Type 2 diabetes medications on the mental well-being of people living with the condition and identify the underlying mechanisms involved.
- Include neuroimaging and inflammatory marker analyses to establish the effects of the drugs within the brain and the mechanisms involved.
- Focus on therapies that have already been suggested to have a potential positive effect on mental well-being.

Understanding the impact of current diabetes technologies on mental health

Context

A new generation of technology designed to assist in the management of diabetes, such as continuous glucose monitoring and insulin pumps, now exists and is being used primarily in the management of Type 1 diabetes. Whilst research has started to examine the impact of this technology on mental well-being [39] and how to ensure it is as positive as possible [40], more research is needed. In particular, there is a need to understand how the design and use of technology may affect the long-term mental well-being of children, young adults and families.

More understanding of how and why technology affects the mental well-being of people with diabetes will enable us to maximize the benefit these devices can provide to their users.

Research recommendations

- Review existing research evidence and gather the views of people who have used technology through qualitative research.
- Develop and test tools to better deliver technology to users, such as education programmes, to enable people with diabetes to use the devices to gain the most benefit to their glycaemic control and mental well-being.
- Develop tools to help healthcare professionals to identify people with diabetes whose mental well-being may be most likely to benefit from technologies.
- Consider the fast moving pace of technology and look beyond existing trial outcome measures to patient-reported outcome measures.

Conclusions

Diabetes UK's international research workshop was the first step towards tackling the urgent unmet need related to the mental well-being of people living with diabetes. Now we must ensure that these questions are addressed. Diabetes UK calls on the research community, partner organizations and funders to establish how we can work together to achieve this.

Funding sources

Financial support for the workshop was provided by Diabetes UK.

Competing interests

R.I.G.H. has received honoraria for speaker engagements, advisory panel membership or conference attendance from

the following: Astra Zeneca, Boehringer Ingelheim, Eli Lilly, Janssen, Menarini, Mylan, NAPP, Novo Nordisk, Otsuka, Roche, Sanofi. K.I. has received honoraria for educational lectures for Eli Lilly, Novo Nordisk, Sanofi and Janssen.

Acknowledgements

Facilitation for the workshop was provided by the Collective Facilitation Ltd. Our thanks go to MQ: Transforming Mental Health and the Juvenile Diabetes Research Foundation for their support.

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Appendix Workshop attendees

Workshop Attendees

The authors are grateful to the following for attending and/or contributing to the workshop: Dr Carlo Acerini (University of Cambridge), Dr Ramzi Ajjan (University of Leeds), Professor Stephanie Amiel (King's College London), Associate Professor Rob Andrews (University of Exeter), Dr Rachel Connor (JDRE, Advisory Group Member), Dr David Chaney (Diabetes UK), Professor Mary de Groot (Indiana University, Speaker) Sophie Dix (MQ: Transforming Mental Health, Advisory Group Member), Dr Mark Evans (University of

Cambridge), Professor Andrew Farmer (University of Oxford, Advisory Group Member), Professor Christina van der Feltz-Cornelis (University of York), Professor Lawrence Fisher (University of California, San Francisco, Speaker), Rosanna Flury (Diabetes UK), Professor Eric F. van Furth (Leiden University Medical Center), Dr Christopher Garrett (Bart's Health and East London Foundation Trust), Sarah Gibbs (Expert by Experience), Professor Linda Gonder-Frederick (University of Virginia), Professor Simon Heller (University of Sheffield), Dr Christel Hendrieckx (The Australian Centre for Behavioural Research in Diabetes, Diabetes Victoria and Deakin University), Professor Norbert Hermanns (Research Institute Diabetes Academy Mergentheim), Professor Richard Holt (University of Southampton, Speaker and Advisory Group Member), Professor Jörg Huber (University of Brighton), Professor Khalida Ismail (King's College London, Speaker and Advisory Group Member), Nikki Joule (Diabetes UK), Professor Cathy Lloyd (The Open University), Bekki Millar (Expert by Experience, Advisory Group Member), Anna Morris (Diabetes UK), Professor Arie Nouwen (Middlesex University), Professor Frans Pouwer (University of Southern Denmark), Professor John Petrie (University of Glasgow), Dr William Polonsky (University of California, San Diego, Speaker), Professor Gerry Rayman (Ipswich Hospital), Professor Rebecca Reynolds (University of Edinburgh, Advisory Group Member), Dr Faye Riley (Diabetes UK), Dr Elizabeth Robertson (Diabetes UK), Dr Chandrabala Shah (Diabetes UK), Kamini Shah (Diabetes UK), Professor Timothy Skinner (University of Copenhagen), Professor Daniel Smith (University of Glasgow, Advisory Group Member), Professor Jane Speight (The Australian Centre for Behavioural Research in Diabetes, Diabetes Victoria and Deakin University), Professor Falko Sniehotta (Newcastle University), Dr Marietta Stadler (King's College London, Speaker), Professor Jackie Sturt (King's College London), Robin Swindell (Expert by Experience, Advisory Group Member), Dr Gemma Traviss-Turner (University of Leeds), Katie Trigg (Expert by Experience), John Turner (Expert by Experience), Dr Benjamin Underwood (University of Cambridge), Elisabeth Warren (Expert by Experience, Advisory Group Member), Dr Kirsty Winkley (King's College London), Professor Susan Wong (Cardiff University, Advisory Group Member) and Dr Thomas Wylie (Diabetes UK).