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Back to the future: 25 years of ‘Guidelines for encouraging psychological well-being’ among people affected by diabetes

J. Speight\textsuperscript{1,2,3}, C. Hendrieckx\textsuperscript{1,2}, F. Pouwer\textsuperscript{1,3,4}, T. C. Skinner\textsuperscript{5,6} and F. J. Snoek\textsuperscript{7}

\textsuperscript{1}School of Psychology, Deakin University, Geelong and \textsuperscript{2}The Australian Centre for Behavioural Research in Diabetes, Diabetes Victoria, Melbourne, Australia, \textsuperscript{3}Department of Psychology, University of Southern Denmark and \textsuperscript{4}STENO Diabetes Centre, Odense, \textsuperscript{5}Department of Psychology, University of Copenhagen and \textsuperscript{6}STENO Diabetes Centre, Copenhagen, Denmark, and \textsuperscript{7}Department of Medical Psychology, Amsterdam University Medical Centers, Vrije Universiteit Amsterdam, The Netherlands

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In a special issue of this Journal in 1994, a Working Group of the WHO IDF St Vincent’s Declaration Action Programme for Diabetes published a seminal guideline [1] that made seven recommendations for encouraging psychological well-being among people living with diabetes (Table 1). Our key observation is that the guideline has stood the test of time, and is as commendable today as it was 25 years ago.

Most, if not all, contemporary clinical diabetes guidelines include a focus on psychological care (Table 2). However, whereas the 1994 guideline focused on encouraging and monitoring ‘psychological well-being’, today’s guidelines focus on psychological problems. The key exception is the International Diabetes Federation (IDF) publication Global Guideline for Type 2 Diabetes [2]. Perhaps, it is the nature of resource-limited health systems to take a problem-focused approach. However, as the World Health Organization (WHO) observed over 70 years ago, health is ‘a state of complete physical, mental and social well-being and not merely the absence of [problems]’ [3]. Some might argue that this is a subtle difference in interpretation, but it is noteworthy. If we aim only for an absence of psychological problems, how can we hope to achieve a state of complete psychological well-being? And, if we only monitor problems, how can we tell if psychological well-being is achieved? We believe it is important to adopt a ‘positive, affirmative approach to the psychosocial needs of the person with diabetes’ [4]. Psychological well-being is not only an important outcome in its own right, it is a pre-requisite for optimal diabetes self-management. Furthermore, the lack of uptake, in contemporary guidelines, of the 1994 recommendation to assess treatment satisfaction is noteworthy, particularly given its relevance for maintaining behaviours (e.g. medication taking, glucose monitoring) that impact biomedical outcomes.
Regardless of whether the focus should be on psychological well-being or problems, it remains the case that monitoring and improving biomedical outcomes is revered and prioritized over psychological outcomes. Back in 1994, this may have been a function of the lack of evidence underpinning the guideline, but this is no longer the case. The past 25 years of psychosocial research in diabetes care has established irrefutably that the psychological well-being of many people with diabetes is impaired. Numerous systematic reviews demonstrate that many people experience clinically relevant symptoms of depression, anxiety, disordered eating [5], and elevated levels of diabetes distress [6,7] and fear of hypoglycaemia [8,9]; the number varying naturally with measurement, populations and settings. It is also clear that psychological problems can hamper diabetes self-care and increase the risk of suboptimal HbA1c, incident diabetes complications and increased mortality rates [10–12]. There is also an emerging evidence base for managing many of these problems [13–17]. Consequently, several professional organizations have published specific recommendations for the psychosocial care of people with diabetes [4,18]. Importantly, unlike the 1994 guideline, most contemporary guidelines – except those of the IDF and American Diabetes Association (ADA) – do not provide detailed guidance on how to assess and address psychological problems, or recommend the use of specific assessment tools, which may be hindering their implementation. Thus, the International Consortium for Health Outcomes Measurement (ICHOM) Diabetes Standard Set [19] is a welcome development.

The 1994 guideline highlights that diabetes care should be ‘responding to individuals’ differing needs’, ‘helping patients learn about their own individual responses’ and ‘helping to motivate self-care’ (recommendations 3 to 5). Arguably, these directives have been adopted most widely, appearing in nearly every contemporary diabetes care guideline, standard and policy, subsumed under the rubrics of ‘patient-centred care’ and ‘diabetes self-management education and support’. For example, the joint EASD-ADA consensus on the Management of
Hyperglycaemia in Type 2 Diabetes asserts that ‘providers and health care systems should prioritize the delivery of patient-centered care’ [20]. This involves evaluating ‘the impact of any suggested intervention, including self-care regimens, in the context of cognitive impairment, limited literacy, distinct cultural beliefs, and individual fears or health concerns’. Further, it asserts that structured self-management education should be ‘individualized to the needs of the person’ and ‘support the person and their family in developing attitudes, beliefs, knowledge, and skills to self-manage diabetes’. Similar assertions are found in many (inter)national guidelines [2]. Thus, these three recommendations have become the expected standard of contemporary diabetes care. However, the limited studies examining the delivery of person-centred care and the fidelity with which structured education curricula are implemented suggest we have a long way to go [21,22].

In terms of communication and protecting the self-esteem of people with diabetes (recommendations 1 and 2), there are no data against which to benchmark, but it is likely that the problem is worse than it was 25 years ago. Contemporary data show people with diabetes perceive and experience a social stigma surrounding their condition [23,24], with 55% of people with type 1 diabetes, and 25% of people with type 2 diabetes, reporting being blamed for bringing their condition on themselves [25,26]. This is undoubtedly due to, or exacerbated by, the widespread and indiscriminate public health messaging that ‘diabetes is preventable’ since seminal trials concluded that up to 58% of cases of type 2 diabetes can be prevented [27]. Most alarmingly, this blaming of people with diabetes for their condition or their complications appears widespread among healthcare professionals, with an apparent lack of compassion for those struggling to manage this relentless condition [23,24,28]. Stigma and discrimination are even more prevalent in non-Western countries than Western countries [29,30]. Importantly, in recent years, several (inter)national diabetes organizations have published guidance on how to improve communication with and about people with diabetes.
[31–33]. It is clearly an issue that resonates with many people with diabetes, as they have raised their collective voice across social media, but it is yet to translate into a widespread change in practice.

Fundamentally, the 1994 guideline implies that psychological care should be an integrated part of holistic diabetes care. This approach is highly valued by people with diabetes [16,17,34,35], has positive impacts on their psychological well-being [16,34], and can improve metabolic outcomes [36], particularly in those with severe diabetes distress. However, it would seem that the organizational shift to a place where psychological assessment and care is integrated in routine diabetes care (recommendation 7) still needs to happen. Diabetes UK’s 2019 campaign highlights that psychological care is #TooOftenMissing. Health professionals are often reluctant to provide psychological care, citing several barriers, such as feeling unskilled, lacking confidence, no incentives or reimbursement, and the prevailing focus on medical outcomes [37,38]. Although some training programmes and resources exist [39,40], there are still not sufficient training options available to meet the need.

While much has been achieved in the past 25 years, there is still more to do. Funding for psychological research in diabetes remains woefully inadequate [41], and this may be key to the lack of progress in clinical practice. Importantly, in four of the 20 research priorities for type 1 or type 2 diabetes identified by people with these conditions in the Diabetes UK–James Lind Alliance priority-setting partnership, psychological care was explicit, while several others included elements of psychological care [42,43]. Further, Diabetes UK recently convened a workshop and published 11 research priorities to promote the psychological well-being of people with diabetes [44]. We hope that more funding bodies will follow suit. It is also encouraging that the workshop was convened at the behest of seven clinical study groups, each of which independently identified psychological well-being as the key barrier to
optimizing diabetes outcomes in their specialist areas. So, what will be the reflection 25 years from now? Hopefully, that psychological well-being is widespread among people with diabetes. Unfortunately, optimism alone is not enough. It will require dedicated funding to progress psychological research, and clinicians and health systems prioritizing attention to the psychological aspects of living with diabetes. We all have a responsibility and role to play in ensuring that the challenges laid down in 1994 are resolved in the next 25 years.

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**Competing interests**

JS and CH are authors of the *Diabetes & Emotional Health* handbook and toolkit, published by Diabetes Australia/National Diabetes Services Scheme (NDSS) in 2016, and the UK adaptation of this published by Diabetes UK in 2019. JS is the leader of, and CH is a consultant to the Diabetes Australia/NDSS Diabetes and Mental Health National Priority Area. FJS led the development of the psychology chapter for the *IDF Global Guideline for Type 2 Diabetes* in 2006. All other authors have no competing interests to declare.
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1 diabetes improve psychosocial well-being: a randomized controlled trial. *Diabetes Care* 2008; **31**: 1521–1526.


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Table 1. The 1994 recommendations for ‘encouraging psychological well-being’ among people living with diabetes

1. Improve communication
2. Protect the self-esteem of people affected by diabetes
3. Respond to individuals’ differing needs
4. Help people with diabetes to learn about their own individual responses
5. Help to motivate self-care
6. Monitor psychological well-being
7. Organizational changes to optimize psychosocial aspects of diabetes care

Table 2. Contemporary guidelines for the psychological care of people living with diabetes

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<th>For both type 1 and type 2 diabetes</th>
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<td>American Association of Clinical Endocrinologists and American College of Endocrinology, 2015</td>
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<td>American Diabetes Association, 2019</td>
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validated tools at the initial visit, at periodic intervals, and where there is a change in disease, treatment, or life circumstance.

Routinely monitor people with diabetes for diabetes distress, particularly when treatment targets are not met and/or at the onset of diabetes complications. Psychosocial care should be integrated with a collaborative, patient-centered approach and provided to all people with diabetes, with the goals of optimizing health outcomes and health-related quality of life.

All individuals should be regularly screened for the presence of diabetes-related psychological distress and psychiatric disorders by validated self-report questionnaire or clinical interview.

People with diabetes are assessed for psychological problems, which are then managed appropriately.

Regular assessment of a broad range of psychological and behavioural problems in adults with [type 1 and type 2] diabetes is recommended. This should include anxiety, depression and eating disorders.
Refer those with significant psychological problems to services or colleagues with expertise in this area.

**For type 1 diabetes only**

Australian Paediatric Endocrine Group and Australian Diabetes Society, 2011

Clinicians should be aware that the co-occurrence of psychological disorders in type 1 diabetes is common…. Consider the co-occurrence of psychological disorders, including clinical and subthreshold eating disorders, when assessing people with type 1 diabetes and suboptimal glycaemic control, insulin omission, disordered eating behaviours, unexplained weight loss or recurrent admissions for diabetic ketoacidosis…. Diabetes care teams should have appropriate access to mental health professionals to support them in (1) the assessment of psychological functioning, (2) the delivery of psychological support.

**For type 2 diabetes only**

International Diabetes Federation, 2014

Adopt a whole person approach and respect that person’s central role in their care…. Explore the social situation, attitudes, beliefs and worries related to diabetes and self-care issues. Assess well-being (including mood
and diabetes distress), periodically, by questioning or validated measures (e.g. WHO-5). Discuss the outcomes and clinical implications with the person with diabetes, and communicate findings to other team members where appropriate. Counsel the person with diabetes in the context of ongoing diabetes education and care. Refer to a mental healthcare professional with a knowledge of diabetes when indicated.

Patients with diabetes can be assessed for mental health issues, social isolation/networks and family or work stress. Consider assessment of diabetes distress through the use of the PAID questionnaire and depression with the Patient Health Questionnaire-2 (PHQ-2). Enquire about possible diabetes complications as well as known co-morbid conditions including psychological stress and/or depression.

PAID, Problem Areas in Diabetes scale.