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State of the art: understanding of, and integration in, the social context and diabetes care

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What's new?

- The biopsychosocial model and social ecological theory posit that understanding of the 'interpersonal context of illness' will lead to interventions that will improve health outcomes.
- The last 25 years of psychosocial research have shown that the social context of people with diabetes is of great importance to clinical, behavioural and psychological outcomes. Social support and resilience are beneficial, whereas stigma and discrimination negatively impact self-care, self-esteem and emotional well-being.
- Professionals should be mindful of the social context of diabetes throughout the lifespan. Development and implementation of research-based interventions are needed to support people with diabetes at the interpersonal and societal/environmental levels. Workplaces and diabetes services and organizations need to develop a culture of support for people with diabetes and strive to minimize stigmatization and foster stigma resistance.

Abstract

We review the past 25 years of research addressing challenges people living with diabetes experience in their daily lives related to social contexts, i.e. in their family, at work and in society at large, and identify research gaps. We found that young people with diabetes, as they develop through to adulthood, are exposed to considerable risks to their physical and mental health. Family-system interventions have had mixed outcomes. Research in this area would benefit from attention to ethnic/cultural diversity, and involving fathers and other family members. In adults with diabetes, social support relates to better diabetes outcomes. While family member involvement in care is likely to affect health and psychosocial outcomes of the person with diabetes, key elements and mediators of effective family interventions need to be identified. The challenges of diabetes management at work are under-researched; distress and intentional hyperglycaemia are common. When depression is comorbid with diabetes, there are increased work-related risks, e.g. unemployment, sickness absence and reduced income. Research to support people with diabetes at work should involve colleagues and employers to raise awareness and create supportive environments. Stigma and discrimination have

been found to be more common than previously acknowledged, affecting self-care, well-being and access to health services. Guidance on stigma-reducing choice of language has been published recently. Resilience, defined as successful adaptation to adversity such as stigma and discrimination, requires studies relevant to the specific challenges of diabetes, whether at diagnosis or subsequently. The importance of the social context for living well with diabetes is now fully recognized, but understanding of many of the challenges, whether at home or work, is still limited, with much work needed to develop successful interventions.

Introduction

'All three levels, biological, psychological and social, must be taken into account in every healthcare task.' [1] With these words, George Engel challenged the preeminent biomedical model of health and illness and introduced a revolutionary framework. He proposed that understanding illness requires an understanding of the complex interactions between biology (e.g. genes, viruses), psychology (e.g. mood, behaviour) and social factors [e.g. family, society; Reference S1 (Supporting Information)]; treatments must include attention to all of these domains. Urie Bronfenbrenner's social ecological theory also considered the social environments that we are exposed to as key to understanding human development and behaviour [2]. This model is so widely accepted (although it has its critics [3]) that the WHO adopted it as the foundation for its International Classification of Functioning, Disability and Health (ICF), the international standard to describe health and disability [3]. Stokols [4] applied this theory, and the biopsychosocial model, to focus on relationship influences on health, arguing that we must understand the 'interpersonal context of illness' to improve health outcomes. One important sphere of influence includes the family, partners and other relationships, including those in work life (Fig. 1), all of whom are the focus of this paper.

The interactions between individuals and their environments are reciprocal, and an individual's characteristics interact uniquely with their environment, creating a developmental context that is specific to that individual. This view helps to explain the differing developmental trajectories and outcomes of individuals with the same diagnosis of diabetes [2]. The level of congruence (or

compatibility) between people and their social context is viewed as an important predictor of physical as well as mental well-being [4].

When diagnosed with diabetes in childhood, the family plays an important role in the complex tasks of managing diabetes. These demands can disrupt family routines and change family climates. During adolescence and emerging adulthood, the social context shifts as parental responsibilities decline and peer influences increase. In addition, the relationships that families have with healthcare professionals shift from a triadic relationship between the parent, child and professionals, toward a dyadic patient–healthcare professional relationship [5].

The social context of diabetes management changes across the adult lifespan too. During emerging adulthood, the social context expands beyond parents and friends to include romantic relationships, some of which may become enduring and important sources of support for diabetes management, while conflict in others may undermine self-care. During late adulthood, spouses of those with diabetes may have to deal with the consequences of long-term complications of the disease [5].

Most adults spend a large proportion of time at work. Not only does work provide income, the workplace is also a key context in which social relations are developed and social identity is articulated. Diabetes management tasks and physical disabilities need to be balanced with work life. Throughout the lifespan, societal stigma can negatively affect individuals, impacting well-being, help-seeking and self-care (e.g. not injecting insulin to avoid attention in public).

In the present paper, we review the past 25 years of research on diabetes in the social context of youth, adult relationships, and diabetes management in the context of work life, stigma and resilience. For each section, we review 25 years of progress, beginning with what we knew in 1995, and what we have learned during the past 25 years. Given this scope, this paper will not discuss psychological correlates of diabetes (e.g. distress, depression), although we acknowledge these are important elements of understanding the importance of social context for diabetes. It should be noted that research has focused mostly on type 1 diabetes during childhood to emerging adulthood, and on type 2 diabetes during adulthood, consistent with the age at which diabetes is commonly diagnosed.

Although type 1 diabetes and type 2 diabetes require different treatment regimens, both create complex behavioural demands that can be challenging to the individual with diabetes and those in their social environment.

Diabetes in youth

What we knew in 1995

By 1995 the role of family behaviours and the family environment were identified as important in achieving optimal glycaemic control. A shift occurred in that period from the idea that psychological factors cause high HbA_{1c} levels primarily through physiological mechanisms to the theory that psychological factors do so through maladaptive behaviours. Bronfenbrenner's ecological model has been used to understand the impact a child's chronic illness has on the family [2]. Several studies showed that the family environment (e.g. family structure and socio-economic status) affects HbA_{1c}. The main psychosocial topics that were addressed concerned conflict and parental involvement regarding diabetes treatment; however, study samples were small and results conflicting. A developmental perspective was beginning to take shape, but the recommendation was that the transfer of responsibility for diabetes care to the child should take place at the beginning of adolescence.

The past 25 years

Since 1995, the benefits of continued involvement of parents in diabetes care throughout adolescence and into young adulthood have been well established [6] (Reference S2). Premature transition of responsibility could be detrimental [7]. Also, the way parents are involved in their child's diabetes management matters. Over-involvement, or unsupportive behaviours, could have adverse effects [8,9]. Parenting styles are important in these family dynamics. An authoritative and responsive style (i.e. high levels of expectation for self-management and of warmth and sensitivity) is associated with better self-management (e.g. checking blood glucose levels more frequently, making healthy food choices) and HbA_{1c}, and less overweight (therefore perhaps preventive for type 2 diabetes). More psychological control, conversely, is associated with poorer outcomes [10] (Reference S2). The benefits of an

authoritative parenting style transcend the boundaries of ethnicity, socio-economic status, and household composition [10].

Recent literature expanded the developmental perspective to cognitive functioning of youth, especially executive functioning. As the responsible brain areas are developing into young adulthood, close parental monitoring of self-management tasks requiring skills, such as problem-solving and impulse control, is warranted [11].

While the influence of conflicts in families on diabetes outcomes was somewhat unclear in 1995, research over the past 25 years has clearly shown its negative effect on HbA_{1c} levels and quality of life [6] (Reference S3). Family functioning has been strongly linked to adjustment in adolescents with type 1 diabetes, including both physiological and psychosocial functioning. A warm and accepting environment is associated with better outcomes [6,8].

Considering a family systems approach, parental well-being could affect outcomes in their children. Maternal depression is found to increase the risk of psychiatric disorders in their offspring, especially depression [12]. Recent research has indicated that fear of hypoglycaemia, in particular, in parents of younger children, and distress about caring for a child with diabetes, affect parental well-being. This could in turn affect parenting behaviours and thereby the child's HbA_{1c} levels and well-being [9](Reference S4).

Most research on the social context of youth with diabetes has focused on the family environment while, especially in adolescent years, peer relationships become more important. However, it is unclear whether friend involvement is helpful or harmful for diabetes management [13]. Supportive friends can complement parents' involvement in psychological outcomes [14] (Reference S5). By contrast, social conflict and extreme peer orientation is found to have a negative effect on diabetes outcomes [13,14].

Clinical implementation

The complexity of family systems has led to diabetes-specific theories. Leading theories for behavioural interventions are family systems theory, social cognitive theory and the social ecological model (with a diabetes-specific adaptation in the 'diabetes resilience' model) [15]. In their systematic

review, Feldman *et al.* [16] identified 25 randomized controlled trials examining family-based interventions. Behavioural family systems therapy and family teamwork interventions are most extensively researched. Behavioural family systems therapy is grounded in family systems and cognitive behavioural theories, maintaining a strong focus on adolescent development. Family teamwork interventions focus on increasing familial partnerships and responsibility-sharing in diabetes management. Based on social cognitive theory, coping skills training interventions teach adaptive communication, social problem-solving, cognitive restructuring, stress management and conflict resolution skills to improve self-efficacy and familial adjustment to a chronic illness. Multisystemic therapy is an intensive, community-based family therapy intervention, rooted in a social ecological framework that draws upon cognitive behavioural therapy, parent management and family systems theory [16]. To keep track of family dynamics in routine care, monitoring of child and parent quality of life to screen for potential problem areas needing attention could be helpful [9](Reference S4). The more recent focus on diabetes resilience offers new perspectives for interventions [15]. Yet, only two interventions have been studied, based on positive psychology and on self-determination theory, to support empowerment of families [16]. The growing body of behavioural intervention literature points towards a few well-developed, theory-based behavioural strategies with strong potential to effectively promote health and well-being outcomes [15,16].

Current gaps

Already in 1980, Anderson *et al.* [17] indicated the importance of including fathers and siblings in research with families with a child with diabetes; however, most studies include only one household member or caregiver, generally the mother. Although fathers are increasingly included as an additional family member in studies, a more comprehensive family system approach is warranted.

Type 1 diabetes has traditionally been studied as a chronic illness of childhood, but young adulthood is a critical time for the development and integration of lifelong diabetes management skills. Most young adults experience multiple transitions during this developmental period, including changes in lifestyle, healthcare, and shifting social relationships with family members, friends and intimate others. More longitudinal research is needed to track the psychosocial development into

young adulthood and beyond to identify key factors that influence diabetes management. Parents continue to play a crucial role in diabetes management during adolescence and emerging adulthood, but more research is needed to understand how other social relationships complement the involvement of parents (Reference S6). This research should include friends, romantic relationships and broader social settings, such as the school environment.

With the growing number of children diagnosed with type 2 diabetes showing generally poor outcomes, we need greater understanding of how their family systems impact their outcomes, and development of family-based interventions.

Although many behavioural interventions for young people with diabetes and their families have been developed, gaps remain. While most interventions have included the person with diabetes, this framework is not developmentally appropriate for families with very young children. Only two studies have examined parenting interventions in this age group, with small effects [16]. Also, interventions including friends and interventions for emerging adults are lacking. These should include technology, targeted education, and peer and parent support, with the goal of assisting young people with being autonomous in a supportive context (Reference S7).

Finally, implementation of evidence-based interventions in healthcare delivery settings have proven difficult. More effort should be put into their translation into routine care. The next step will be to develop more individualized interventions. E-(mental) health could be a helpful way to achieve this.

Diabetes and adult relationships

What we knew in 1995

In earlier years, family influences were primarily understood, and defined, under the broader construct of social support. In the 1970s and 1980s, an extensive, mostly cross-sectional literature reported that greater social support related to healthier biomedical and psychosocial outcomes. Social support appears to have direct main effects (e.g. positive affect, better immune system function), and indirect effects, by buffering the negative effects of stress on health. There was growing recognition that adult family relationships may exert influence in multiple ways, because they are unique, intimate, long-

lasting, and reciprocal. However, the few studies that have looked at family relationships and diabetes-related behaviours and outcomes focused exclusively on children with type 1 diabetes.

The past 25 years

In an important literature review of family influences on illness outcomes, Fisher *et al.* [18] brought attention to diabetes and identified four categories of family dynamics shown to have potential influences on health outcomes that should be studied for their relevance to diabetes outcomes. They include: 1) type of family relationship, including style of problem-solving, emotion management, and family structure; 2) patient and spouse/partner beliefs and agreements (e.g. about the meaning and course of disease, about relationships with healthcare providers); 3) current and foreseen family stressors (e.g. finances, parenting); and 4) allocation of disease management behaviours (i.e. who does what, when and how in managing diabetes). The authors strongly argued that assessment of these factors should first drive family assessments, and second lead to the development of family-tailored interventions. Importantly, they argued for this approach specifically for adults with diabetes.

In the 2000s, diabetes-focused researchers turned to the key domains that had been studied in other diseases, i.e. social support and family relationships, and extended them to diabetes. A systematic review of this literature (2000–2012) identified 37 papers that generally supported the link between social support and better diabetes outcomes [19]. This mostly cross-sectional research reported that social support has strong, positive relationships to HbA_{1c} levels, quality of life, self-care, and mortality. A second systematic review (2000–2011) reported that other aspects of family relationships may also affect diabetes-related outcomes. Greater marital satisfaction related to better self-care and quality of life, and greater marital stress related to higher HbA_{1c} and future depressive symptoms [20]. It is noteworthy that these studies primarily pertained to adults with type 2 diabetes, or mixed groups (type 1 and type 2 diabetes) that only included a small subsample of adults with type 1 diabetes.

Clinical implementation

In 2000, the US National Working Group on Family-Based Interventions in Chronic Disease called for expanding interventions to include aspects of family relationships that increased risk of, and enhanced protection against, poor health outcomes [21]. A systematic review of family interventions for people with diabetes (1994–2014) identified 26 clinical intervention trials in adults with type 2 diabetes (none in adults with type 1 diabetes) [22]. While these studies demonstrated that family interventions are acceptable and feasible, study design flaws (i.e. lack of a control group, lack of randomization, poor retention) make results difficult to interpret. One key element of a valid family intervention trial is the inclusion of an individual intervention control group that is comparable to the family intervention except does not involve a family member. Without this comparator arm one cannot attribute improved outcomes to the family member's involvement. The Diabetes Support Project, a practical, randomized controlled trial of a couple intervention, designed to foster collaborative coping for adults with type 2 diabetes and above-target HbA_{1c}, provided this test. In the Diabetes Support Project, all three arms (couple behavioural intervention, individual behavioural intervention, individual diabetes education intervention) achieved improved HbA_{1c} levels. However, when data were analysed by baseline HbA_{1c}, in the middle tertile [HbA_{1c} 66–77 mmol/mol (8.2–9.2%)], the couple intervention was the only arm showing improved HbA_{1c}. In the highest tertile [HbA_{1c} ≥ 78 mmol/mol (9.3%)], all arms improved, and in the lowest tertile [HbA_{1c} 58–66 mmol/mol (7.5–8.2%)] there was no significant improvement in any arm. Other outcomes also favoured the couple intervention arm [23].

Current gaps

The study of partner/family interventions for adults with diabetes that are high-quality, are theoretically based and include an individual intervention comparator has just begun, with many questions to study. First, if family involvement matters, how does it work and what are the mediators of the intervention's efficacy? For example, do partners help or hinder a patient's sense of self-efficacy, and thus affect outcomes? Second, what are the key elements of an effective intervention? For example, should we involve the family member in traditional behavioural diabetes interventions, or target the emotions and interpersonal dynamics of the unique family relationship? Third, for whom

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does a family intervention work best? These moderator analyses will assess whether, for example, people with high distress, or low relationship satisfaction, are more likely to benefit from family involvement. Fourth, we need studies that focus on adults with type 1 diabetes, noting that 85% of people with type 1 diabetes are adults, and they, and their partners, must manage complex behavioural regimens, demanding new technologies and unique diabetes-related stressors. They deserve specific attention in research and clinical interventions. Finally, since the family provides the frame for the potential effects of culture, race and ethnicity on disease outcomes, we need to better understand family influences on, and ways to engage family members of, diverse patient groups. The framework of family assessment and intervention in adults with diabetes described in 1998 remains relevant to, and lays out a roadmap for, 21st century research and clinical interventions [24].

Managing diabetes in the context of work life

What we knew in 1995

Around 1995, knowledge about the impact of work life on diabetes was limited and received little attention. However, work disability (i.e. being unable to work, usually because of a health condition) was found to be significantly higher for people with diabetes than for those without diabetes at all ages, resulting in significantly lower earnings [25]. Work disability was reported in the USA in 1987 by 25.6% of people with diabetes, compared with 7.8% of those without diabetes [25].

The past 25 years

During the past 25 years we have learned that, like many other chronic diseases, diabetes influences work life in several ways, mostly due to the impact of long-term sickness absences. For some chronic diseases, absences change over time, for some they decrease over the years (e.g. stroke). For diabetes, there is a pattern of continued long-term sickness absence, especially for men [26]. The onset of diabetes is associated with a substantial increase in sickness absence. And, compared to people without diabetes, people with diabetes have almost twice as many sickness absence days. Other work influences include evidence that childhood-onset type 1 diabetes influences later employment choice

and income [27] and that those with both diabetes and depression have an even higher risk of work absence [28]. Moreover, people with diabetes have an increased risk of unwanted early retirement compared to people without diabetes, and both men and women with diabetes have a higher amount of work limitations than people without diabetes. Diabetes thus has a significant impact on employees, employers, and society in terms of work loss, reduced employment, and work limitations [28].

Research shows that diabetes management is compromised in employed adults, which might be attributable to a reluctance to disclose at work that one has diabetes or to prioritize self-care at work over job demands [29]. Furthermore, employees with diabetes experience that managers have little knowledge of the effect of the workplace on their ability to manage diabetes at work [30]. Moreover, stigmatization and inappropriate treatment of the employee with diabetes affect both short-term and long-term complications of diabetes negatively [30]. A study from 2016 suggests that 70% of people with type 1 diabetes have experienced work-related diabetes distress and that work-related diabetes distress has a negative impact on HbA_{1c} levels [31].

People with diabetes and health professionals have identified five areas that affect the individual's sense of empowerment to cope with diabetes at work: their own ability to accept and cope, supportive health professionals, supportive work environments, work adaptation, and knowledge among colleagues and employers about diabetes management [32].

In general, work-specific issues related to diabetes self-care and the psychosocial burden of diabetes are not reflected in international guidelines and position statements. Recent studies on work life and diabetes have, however, highlighted how contextual factors influence diabetes self-care at work significantly, with the main strategies being to keep blood glucose levels higher than medically optimal to avoid hypoglycaemia. Doing so is unhealthy and increases the risk of complications. Hansen *et al.* [33] stated in 2018 that work life and diabetes can be characterized as a matter of containment: '... the assemblage of practices and mental and emotional work required to keep diabetes at the level of a side-involvement and maintain proper situational involvement in work life' [33]. They also argue that people with type 1 diabetes commonly report experiencing stigma at work [34]. The fears of being seen as less worthy as an employee and of being discriminated against force some

people with diabetes to work while being sick to overcome these biases and compensate for sickness absence related to diabetes [34]. Another study, however, shows a high disclosure rate of having type 2 diabetes in the workplace [35]. Hansen *et al.* [34] conclude that the psychosocial burden of diabetes in work life among people with type 1 diabetes should be considered to fall within the spectrum of psychosocial diabetes care and research.

Translation/implementation

There are consistent findings through the last 25 years of the negative influence of diabetes on work life and of work life on self-care; diabetes has an impact on, and is often experienced as a burden on, work life, and work life has an impact on, and is often experienced as a burden on, self-management. Thus, there is a high demand for research-based interventions to facilitate and support good work life conditions for people with diabetes, but very little knowledge about this in the literature. It can be a huge challenge to be a diligent employee and simultaneously to be proficient in managing diabetes. Given the lack of literature about measures, interventions and implementation of support, this is a largely neglected burden at the workplace as well as in the clinic and in diabetes research.

Current gaps

There is a need for available and valid measures of the psychosocial burden of diabetes in work life, including measurements of experience of discrimination and stigma. Currently, only a few scales are available, and the present measures are of limited use because of language barriers. We need more research into valid measures capturing diabetes care in the work life setting as well as the psychosocial burden related to work life for both people with type 1 diabetes and those with type 2 diabetes.

Work life and diabetes could be addressed in the clinic (psychosocial and technical support, empowerment) and at the workplace (psychosocial, practical and technical support, appropriate conditions, knowledge and understanding) as well as in diabetes research (further exploration, valid measurements, development and evaluation of interventions). As an example, people with diabetes and depression represent a large percentage of diabetes-related sickness absences. Improvement of

tools and systems to identify people with diabetes at high risk of depression and applying early prevention and intervention is an important research area. Discrimination and stigma, not least among people with type 2 diabetes and obesity, seem to be a serious problem in work life. Research into the prevention of stigmatization and the development of empowerment methods for people with diabetes to be able to cope better with stigma and discrimination in the workplace are also important areas for further research.

Stigma and resilience in the social context

What we knew in 1995

While earlier sections have focused on developmental stages (young people and adults/family context, respectively) and work life, this section will focus on two cross-cutting and potentially linked themes that were hardly addressed until the early 2000s. Stigma, especially related to dietary restrictions and insulin injections, and discrimination at work because of health and safety regulations were noted but not addressed in systematic research; resilience was an unknown concept in diabetes research in these years.

The past 25 years

Stigma and resilience have been studied for some time in other fields, such as mental health, HIV/AIDS, and developmental trauma research [36,37]. Diabetes research has been catching up since the early 2010s. Stigma and resilience are concepts with multiple meanings, no clearly identifiable research traditions in diabetes, but frequently alluded to in non-technical papers and social media.

The first substantive review in the field of diabetes, drawing on sociological and psychological theories, proposed that stigma relates to negative social evaluations (appraisal) of people living with diabetes [38], reflecting negative stereotypes and prejudices. The same authors, adopting a social psychological perspective, proposed a framework to understand diabetes-related stigma focused on experiences and consequences of stigma, including putative causes and mechanisms. They developed

relevant questionnaires to assess the experience of stigma separately for type 1 and 2 diabetes (References S8,S9). People with type 2 diabetes report being blamed/shamed for bringing the condition upon themselves (e.g. being lazy, eating too much), whereas those with type 1 diabetes report being stigmatized by association with type 2 diabetes as the public often does not understand differences in aetiology. Experiences of anger vs shame about stigmatization are contrasting experiences of people with type 1 vs type 2 diabetes, respectively [39](References S10,S11).

The multinational Diabetes, Attitudes, Wishes and Needs survey (DAWN2) asked health professionals about the need to improve 'accepting people with diabetes as equal members of society'; this need was affirmed by 30% of health professionals, with huge variation between countries, from 11% in Canada to 80% in Algeria [40]. In a large US survey, 76% and 52% of participants with type 1 and type 2 diabetes, respectively, report experiencing stigma [41]. Stigma or discrimination, sometimes used interchangeably, can take severe forms; a review of 17 studies summarizes themes under 'rejected for marriage', diabetes being seen as 'self-inflicted' or 'contagious', and the person with diabetes being labelled 'drunk' or a 'drug abuser' [42].

Resilience is typically understood as successful adaptation to adversity, an active process which may lead to profound positive life changes, referred to as 'flourishing' [43]. While a number of studies on resilience and diabetes have been carried out, these studies rarely assessed the nature of the adversity. Diagnosis of diabetes can be traumatic, and subsequent living with the condition can be a major challenge, not to mention the many serious comorbidities. However, some observational studies provide only limited information on these challenges [44,45]. The focus is on resilience components, statistically identified from questionnaire data. While less resilience is linked to poor coping [44] and poor HbA_{1c} levels [45], this approach, at odds with resilience research in other fields, which considers resilience as a set of components including self-efficacy, self-esteem and social support (Reference S12) has added little to earlier stress-focused studies. Longitudinal studies, clearly identifying the experienced adversities, are required.

Qualitative studies have addressed adversity explicitly or implicitly. Walker *et al.* [46] provide a very apt example of a resilient response by a young man with type 1 diabetes, using photographic

methods: 'Diabetes is like a "speed bump". It slows you down for an instance but doesn't stop you from reaching your final destination' [46]. Resilience research can be expected to enhance our understanding of stigma resistance (Reference S13), linking self-esteem as a major component of resilience to successfully deal with stigma and discrimination.

Stigma and resilience are fundamentally social issues. Exposure to stigma is linked to the social environment, and successful adjustment to diabetes, whether at diagnosis or later, is fundamentally dependent not only on the strengths of the person with diabetes, but on those of family, peers and health professionals.

Implications for clinical practice and societal representations of diabetes

Research has highlighted the importance of choice of language as a way of reducing stigma [47] and improving engagement with health services. The use of person-first language was recommended by guidance provided by NHS England (Reference S14), and systematically reviewed, summarized and addressed in two editorials in *Diabetic Medicine* [48] (References S12,15), highlighting the importance of the choice of words. An important recommendation is to avoid labelling people as their condition ('a diabetic'). Terms which are judgemental or reinforcing of negative stereotypes, such as 'failing', 'control' and 'compliance', should also be avoided. The importance of the quality of relationships and the overall approach to communication forms an important background within which the choice of words needs to be situated [49] (Reference S12).

Interventions

Interventions to reduce stigma have had mixed results, some show clinical benefits, some show the potential to cause harm by increasing stigma. Future studies will benefit from psychometrically validated questionnaires on diabetes stigma (References S8,9). Thornicroft *et al.* [50], in a systematic review, explored the role of social-contact-based interventions, probably the most widely studied approach, particularly in mental health (relevant to diabetes with its prevalence of comorbid poor mental health), and identified benefits; however, the picture is complex, and there is a risk that

interventions do harm as focusing on the condition may trigger and intensify stigma [50]. Targeting health professionals has been suggested as an important step in a review of intervention studies for a number of health conditions, except for diabetes (Reference S16).

Interventions to foster resilience are available for young people and adults, frequently prioritizing focusing on strengths and resources (Reference S17). These interventions are not specific to diabetes; they tend to focus on mental health and were developed by mental health and HIV/AIDS researchers. The influence of this work is reflected in a shift in focus to positive aspects of adaptation to diabetes, rather than avoidance of failure. Resilience interventions for diabetes are still in their infancy. Efforts to build on existing strengths and create supportive environments have shown potential. It should be possible to extend and adapt these interventions for people with diabetes.

Current gaps

Research on stigma in diabetes could benefit from working with other disciplines and follow the WHO recommendation for cross-condition research on stigma, on the basis that stigma is fundamentally shaped within social structures of power differentials and responding to the 'differentness' of the person with a health condition (Reference S18). A similar argument can be put forward for resilience research. Additionally, high-quality research is needed to lay the foundations for effective interventions. A focus on successful adaptation to diabetes, described as flourishing, might inform public health and clinical interventions, adopting strength-based approaches to supporting people with diabetes.

Experience of stigma and fostering of resilience are intrinsically linked to the social environment; relationships can be helpful in reducing the effects of stigma and supporting resilience, but also the opposite. Stigma, as understood and measured in diabetes, possibly underestimates the role of power relationships, particularly for disadvantaged groups with their typically higher prevalences of diabetes and its complications, but also the potential for stigma resistance (Reference

S13). A focus on those flourishing with or despite their disease and those most vulnerable should produce useful insights.

Conclusion

The social context of people with diabetes has proven to be of great importance to diabetes-related outcomes, including diabetes management, quality of life, HbA_{1c} levels and other emotional, behavioural and clinical outcomes. Research has provided insights into the character and prevalence of effects of key interpersonal relationships on diabetes outcomes, and the reciprocal effects of living with diabetes on these social contexts. These effects contribute to the significant psychosocial burden of diabetes; however, little is known about evidence-based, effective support interventions to provide the crucial social support that is needed within families with children with diabetes, among adult partners when one has diabetes, and in the workplace where colleagues and employers interact with people with diabetes. Healthcare professionals may have little knowledge about the emotional and behavioural support needed by people with diabetes. The stigma and discrimination that people with diabetes experience may negatively impact self-care and access to health services, and impact their wider life experiences, including social participation.

There is very little research about how to guide people with diabetes to cope with challenging environments, whether experienced within their family relationships, in education or in the workplace. Similarly, there is limited knowledge about how to empower families, partners and workplace peers to understand the biopsychosocial burden of diabetes, and create positive family and work environments to promote positive health and well-being. Implementation and testing of such interventions have been limited. There are (at least) two ways to proceed: to empower people with diabetes to address issues within their social contexts (i.e. foster resilience), and to empower others to support people with diabetes. Ideally, this is a two-way street, and people provide mutual support within the family, in the workplace, in the healthcare setting and within professional organizations, to work to minimize stigma, dispel myths and promote resilience.

The next steps regarding comprehensive diabetes care should include increased attention to the social contexts of people with diabetes and the development and implementation of research-based support and care interventions. People with diabetes, their families, partners, colleagues and employers should be involved in design and implementation processes to ensure that the interventions are relevant, acceptable and practicable in real-life settings.

To sum up and conclude: a substantive body of knowledge about the social context of diabetes care has accumulated, relevant above all to high-income countries, but similar efforts are needed for low- and middle-income countries, with often very powerful family influences and high levels of discrimination. Interventions that are effective and deliverable at scale will need to be a primary focus for the coming years. We still have a long way to go in extending support to people with diabetes at the interpersonal and societal/environmental levels, but we have a clear path forward.

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Competing interests

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References

1. Engel GL. The biopsychosocial model and the education of health professionals. *Ann N Y Acad Sci* 1978;**310**:169–187.
2. Bronfenbrenner U. Measuring environment across the life span: Emerging methods and concepts. Friedman SL, Wachs TD, editors. Washington, DC: American Psychological Association Press; 1999.
3. Borrell-Carrio F, Suchman AL, Epstein RM. The biopsychosocial model 25 years later: principles, practice, and scientific inquiry. *Ann Fam Med* 2004; **2**:576–582.
4. Stokols D. Translating social ecological theory into guidelines for community health promotion. *Am J Health Promot* 1996;**10**:282–298.
5. Wiebe DJ, Helgeson V, Berg CA. The social context of managing diabetes across the life span. *Am Psychol* 2016;**71**:526–538.
6. Markowitz JT, Garvey KC, Laffel LM. Developmental changes in the roles of patients and families in type 1 diabetes management. *Curr Diabetes Rev* 2015;**11**:231–238.
7. Anderson BJ. Behavioral research in pediatric diabetes: putting the evidence to work for advocacy and education. *Pediatr Diabetes* 2012;**13**:77–80.
8. Jaser SS. Family interaction in pediatric diabetes. *Curr Diab Rep* 2011;**11**:480–485.
9. Eilander MMA, Snoek FJ, Rotteveel J, Aanstoot HJ, Bakker-van Waarde WM, Houdijk E *et al*. Parental Diabetes Behaviors and Distress Are Related to Glycemic Control in Youth with Type 1 Diabetes: Longitudinal Data from the DINO Study. *J Diabetes Res* 2017; **2017**:1462064.
10. Anderson BJ. Parenting styles and parenting practices in pediatric diabetes. *Diabetes Care* 2011;**34**:1885–1886.
11. Vloemans AF, Eilander MMA, Rotteveel J, Bakker-van Waarde WM, Houdijk E, Nuboer R *et al*. Youth With Type 1 Diabetes Taking Responsibility for Self-Management: The Importance of Executive Functioning in Achieving Glycemic Control: Results From the Longitudinal DINO Study. *Diabetes Care* 2019;**42**:225–231.

12. Kovacs M, Obrosky DS, Goldston D, Drash A. Major depressive disorder in youths with IDDM. A controlled prospective study of course and outcome. *Diabetes Care* 1997; **20**:45–51.
13. Palladino DK, Helgeson VS. Friends or foes? A review of peer influence on self-care and glycemic control in adolescents with type 1 diabetes. *J Pediatr Psychol* 2012;**37**:591–603.
14. Raymaekers K, Oris L, Prikken S, Moons P, Goossens E, Weets I *et al.* The Role of Peers for Diabetes Management in Adolescents and Emerging Adults With Type 1 Diabetes: A Longitudinal Study. *Diabetes Care* 2017;**40**:1678–1684.
15. Hilliard ME, Powell PW, Anderson BJ. Evidence-based behavioral interventions to promote diabetes management in children, adolescents, and families. *Am Psychol* 2016;**71**:590–601.
16. Feldman MA, Anderson LM, Shapiro JB, Jedraszko AM, Evans M, Weil LEG *et al.* Family-Based Interventions Targeting Improvements in Health and Family Outcomes of Children and Adolescents with Type 1 Diabetes: a Systematic Review. *Curr Diab Rep* 2018;**18**:15.
17. Anderson BJ, Auslander WF. Research on diabetes management and the family: a critique. *Diabetes Care* 1980;**3**:696–702.
18. Fisher L, Chesla CA, Bartz RJ, Gilliss C, Skaff MA, Sabogal F *et al.* The family and type 2 diabetes: a framework for intervention. *Diabetes Educ* 1998;**24**:599–607.
19. Strom JL, Egede LE. The impact of social support on outcomes in adult patients with type 2 diabetes: a systematic review. *Curr Diab Rep* 2012;**12**:769–781.
20. Rintala TM, Jaatinen P, Paavilainen E, Astedt-Kurki P. Interrelation between adult persons with diabetes and their family: a systematic review of the literature. *J Fam Nurs* 2013;**19**:3–28.
21. Fisher L, Weihs KL. Can addressing family relationships improve outcomes in chronic disease? Report of the National Working Group on Family-Based Interventions in Chronic Disease. *J Fam Pract* 2000;**49**:561–566.
22. Trief PM, Fisher LM, R H. Family Therapies for Adults with Diabetes. In: Delamater A, D M, eds. Behavioral Diabetes: Ecological Perspectives for Pediatric and Adult Populations: Springer Publishing Co., 2018

23. Trief PM, Fisher L, Sandberg J, Cibula DA, Dimmock J, Hessler DM *et al.* Health and Psychosocial Outcomes of a Telephonic Couples Behavior Change Intervention in Patients With Poorly Controlled Type 2 Diabetes: A Randomized Clinical Trial. *Diabetes Care* 2016;**39**:2165–2173.
24. Marrero DG, Ard J, Delamater AM, Peragallo-Dittko V, Mayer-Davis EJ, Nwankwo R *et al.* Twenty-first century behavioral medicine: a context for empowering clinicians and patients with diabetes: a consensus report. *Diabetes Care* 2013;**36**:463–470.
25. Von Korff M, Katon W, Lin EH, Simon G, Ciechanowski P, Ludman E *et al.* Work disability among individuals with diabetes. *Diabetes Care* 2005;**28**:1326–1332.
26. Nexø MA, Carlsen K, Pedersen J, Hetland ML, Watt T, Hansen SM *et al.* Long-term sickness absence of 32 chronic conditions: a Danish register-based longitudinal study with up to 17 years of follow-up. *BMJ Open* 2018;**8**:e020874.
27. Persson S, Dahlquist G, Gerdtham UG, Steen Carlsson K, Swedish Childhood Diabetes Study G. Why childhood-onset type 1 diabetes impacts labour market outcomes: a mediation analysis. *Diabetologia* 2018; **61**:342–353.
28. Breton MC, Guenette L, Amiche MA, Kayibanda JF, Gregoire JP, Moisan J. Burden of diabetes on the ability to work: a systematic review. *Diabetes Care* 2013;**36**:740–749.
29. O'Neil A, Williams ED, Browne JL, Horne R, Pouwer F, Speight J. Associations between economic hardship and markers of self-management in adults with type 2 diabetes: results from Diabetes MILES - Australia. *Aust N Z J Public Health* 2014;**38**:466–472.
30. Ruston A, Smith A, Fernando B. Diabetes in the workplace - diabetic's perceptions and experiences of managing their disease at work: a qualitative study. *BMC Public Health* 2013;**13**:386.
31. Hakkarainen P, Moilanen L, Hanninen V, Heikkinen J, Rasanen K. Work-related diabetes distress among Finnish workers with type 1 diabetes: a national cross-sectional survey. *J Occup Med Toxicol* 2016;**11**:11.
32. Detaille SI, Haafkens JA, Hoekstra JB, van Dijk FJ. What employees with diabetes mellitus need to cope at work: views of employees and health professionals. *Patient Educ Couns* 2006;**64**:183–190.

33. Hansen UM, Cleal B, Willaing I, Tjornhoj-Thomsen T. Managing type 1 diabetes in the context of work life: A matter of containment. *Soc Sci Med* 2018;**219**:70–77.
34. Hansen UM, Olesen K, Willaing I. Diabetes stigma and its association with diabetes outcomes: A cross-sectional study of adults with type 1 diabetes. *Scand J Public Health* 2019;.
35. Olesen K, Cleal B, Skinner T, Willaing I. Characteristics associated with non-disclosure of Type 2 diabetes at work. *Diabet Med* 2017;**34**:1116–1119.
36. Rutter M. Resilience in the face of adversity. Protective factors and resistance to psychiatric disorder. *Br J Psychiatry* 1985;**147**:598–611.
37. Goffman E. Stigma: Notes on the Management of Spoiled Identity. Cliffs E, ed. Upper Saddle River, NJ: Prentice-Hall, 1963.
38. Schabert J, Browne JL, Mosely K, Speight J. Social stigma in diabetes : a framework to understand a growing problem for an increasing epidemic. *Patient* 2013;**6**:1–10.
39. Stuckey HL, Mullan-Jensen CB, Reach G, Kovacs Burns K, Piana N, Vallis M *et al.* Personal accounts of the negative and adaptive psychosocial experiences of people with diabetes in the second Diabetes Attitudes, Wishes and Needs (DAWN2) study. *Diabetes Care* 2014;**37**:2466–2474.
40. Holt RI, Nicolucci A, Kovacs Burns K, Escalante M, Forbes A, Hermanns N *et al.* Diabetes Attitudes, Wishes and Needs second study (DAWN2): cross-national comparisons on barriers and resources for optimal care—healthcare professional perspective. *Diabet Med* 2013;**30**:789–798.
41. Liu NF, Brown AS, Folias AE, Younge MF, Guzman SJ, Close KL *et al.* Stigma in People With Type 1 or Type 2 Diabetes. *Clin Diabetes* 2017;**35**:27–34.
42. Abdoli S, Doosti Irani M, Hardy LR, Funnell M. A discussion paper on stigmatizing features of diabetes. *Nurs Open* 2018;**5**:113–119.
43. Charney DS. Psychobiological mechanisms of resilience and vulnerability: implications for successful adaptation to extreme stress. *Am J Psychiatry* 2004;**161**:195–216.
44. Yi-Frazier JP, Smith RE, Vitaliano PP, Yi JC, Mai S, Hillman M *et al.* A Person-Focused Analysis of Resilience Resources and Coping in Diabetes Patients. *Stress Health* 2010;**26**:51–60.

45. Yi-Frazier JP, Yaptangco M, Semana S, Buscaino E, Thompson V, Cochrane K *et al.* The association of personal resilience with stress, coping, and diabetes outcomes in adolescents with type 1 diabetes: variable- and person-focused approaches. *J Health Psychol* 2015;**20**:1196–1206.
46. Walker AF, Johnson C, Schatz DA, Silverstein JH, Lyles S, Rohrs HJ. Using photography as a method to explore adolescent challenges and resilience in type 1 diabetes. *Diabetes Spectr* 2015;**28**:92–98.
47. Dickinson JK, Guzman SJ, Maryniuk MD, O'Brian CA, Kadohiro JK, Jackson RA *et al.* The Use of Language in Diabetes Care and Education. *Diabetes Care* 2017;**40**:1790–1799.
48. Lloyd CE, Wilson A, Holt RIG, Whicher C, Kar P; Language Matters Group. Language matters: a UK perspective. *Diabet Med* 2018; **35**:1635–1641.
49. Huber JW, Browne JL, Fang ML, Waroquier L. Diabetes stigma: a neglected issue. *Diabetes Update* 2015;Spring:28–31.
50. Thornicroft G, Mehta N, Clement S, Evans-Lacko S, Doherty M, Rose D *et al.* Evidence for effective interventions to reduce mental-health-related stigma and discrimination. *Lancet* 2016;**387**:1123–1132.

Supporting information

Additional Supporting Information may be found in the online version of this article:

Supplementary References.

FIGURE 1 Social ecological theory (based on Bronfenbrenner, 1999 and Stokols, 1996).

