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Psychosocial Factors in Medication Adherence and Diabetes Self-Management: Implications for Research and Practice

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Abstract

Diabetes is a chronic illness that places a significant self-management burden on affected individuals and families. Given the importance of health behaviors – such as medication adherence, diet, physical activity, blood glucose self-monitoring - in achieving optimal glycemic control in diabetes, interventions designed and delivered by psychologists hold promise in assisting children, adolescents and adults with diabetes in improving their health status and lowering their risk of serious complications. This paper first provides an overview of diabetes selfmanagement and associated challenges and burdens. Socioeconomic status factors that may influence diabetes management and outcomes are briefly highlighted. We then review the evidence base for select psychosocial factors that may be implicated in diabetes self-management. Modifiable targets of psychological intervention are presented across three overarching domains: 1) knowledge, beliefs and related cognitive constructs; 2) emotional distress and wellbeing; and 3) behavioral skills and coping. Important methodological issues facing future research are discussed, along with opportunities for psychologists in improving the care and treatment outcomes of individuals and families living with diabetes. In conclusion, we advocate for continued research emphasis on improving psychosocial aspects of living with diabetes, with greater attention to the situational context in which the self-regulatory processes underlying self-management occur. Psychologists have important roles to play in reducing emotional distress, improving patient knowledge, and providing training in behavioral skills to promote successful self-management and to support patient-centered diabetes care.

Keywords

Diabetes; Adherence; Self-management; Glycemic control; Psychosocial factors

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As the prevalence of type 1 (T1D) and type 2 diabetes (T2D) continues to rise in the United States and worldwide, more individuals and families are living with the challenge of integrating into their lives a demanding, complex and life-long regimen to control their progressive illness and prevent or delay diabetes complications. Despite the availability of effective treatments and landmark trials establishing the benefits of tight glycemic control (See: Hunter, this issue), many struggle with diabetes self-management and fail to achieve levels of risk-marker control that would significantly reduce their risk of serious complications and early mortality. In this review, from our vantage point as clinical health psychologists, we: 1) provide a brief snapshot of the problem of diabetes self-management, 2) touch on relevant socioeconomic and socio-cultural context, and 3) review recent literature on psychosocial factors associated with diabetes self-management, with an emphasis on modifiable targets of psychological intervention. The final section highlights methodological issues for future research and identifies important roles for psychologists in improving the health of those living with diabetes.

The Challenge of Diabetes Self-Management

Many individuals living with diabetes have difficulty achieving recommended standards for diabetes management. Long-term medication use and lifestyle change are necessary for the successful management of both T1D and T2D. In insulin-dependent T1D, exogenous insulin self-administration, via multiple daily injections or an insulin pump, is the focus of treatment. Individuals with T2D are increasingly treated with multiple-medication regimens, including oral medications and/or exogenous insulin. Weight loss is often an additional area of focus in T2D management (See: Hunter, this issue for more details). Although self-management demands differ significantly, problems meeting treatment goals in real world practice are common for both groups of patients. We review literature on T1D and T2D here but note that samples of 'adults with diabetes' often include far more individuals with T2D because of differences in prevalence.

About half of U.S. adults diagnosed with diabetes achieve targets for glycemic control, and similar proportions meet recommended blood pressure and cholesterol targets. Less than 1 in 5 adults reach recommended targets for all three risk biomarkers, the foundational 'ABCs' of diabetes care (Casagrande, Fradkin, Saydah, Rust, & Cowie, 2013). Although less stringent targets are recommended for youth with T1D, most still do not reach them. A registry-based study showed that 64% of children under 6 years of age, 43% of those 6 to 12 and only 21% of those 13–19 reached targets for glycemic control (Wood et al., 2013). This suggests that many patients will not reap the full health benefits of treatment and points to sub-optimal diabetes self-management as a target for behavioral interventions that can improve treatment outcomes.

The diverse behavioral requirements for diabetes self-management – including regular medication taking, self-monitoring of blood glucose (SMBG), changes in diet and physical activity, foot self-care and visits with healthcare providers – are detailed elsewhere in this issue (Hunter, 2015). Here, we use medication *adherence* to refer to the extent to which patients follow medication prescriptions from a health care provider. Measurement of adherence may involve comparing, for example, actual medication-taking frequency with

prescribed dosing frequency over a defined period. *Self-management* refers to regular performance of the broader set of diabetes self-care behaviors, including medication adherence. Successful self-management thus requires clear communication about the standards for self-care from providers and patient agreement with these goals. Nonadherence to recommendations can be unintentional or purposeful, reflecting patient decision-making that weighs anticipated treatment-related benefits and costs to health and quality of life (DiMatteo, 2004). Sub-optimal diabetes self-management is clearly associated with worse glycemic control (e.g., Feldman et al., 2014; Hood, Peterson, Rohan, & Drotar, 2009; Schectman, Nadkarni, & Voss, 2002) and increased risk for hospitalization, complications and mortality (e.g., Cho et al., 2011; Currie et al., 2012; Ho et al., 2006; Kuo et al., 2003). Thus, the consequences of poor diabetes self-management can be severe.

Available evidence suggests that sub-optimal diabetes self-management is common, especially for regimen aspects involving lifestyle change. A large multinational survey of adults with diabetes found that successful self-management rates were often sub-optimal – best for medication and lowest for physical activity, SMBG and regular self-examination of the feet (Nicolucci et al., 2013). This is consistent with evidence across chronic illnesses. A meta-analysis of 569 studies placed diabetes among the illnesses with the lowest levels of adequate self-management, likely reflecting the focus on lifestyle changes in diabetes care, relative to many other chronic illnesses (DiMatteo, 2004).

Lower rates of successful diabetes self-management also partially reflect the demands of a burdensome treatment regimen. Living with diabetes is best conceptualized as a chronic stressor for patients and families, affecting various life domains (Nicolucci et al., 2013). Self-management is time consuming: implementation of recommended behaviors has been estimated to take up two hours per day for an average adult with T2D (Russell, Suh, & Safford, 2005). These underappreciated time costs are accompanied by direct financial costs related to healthcare visits, medications and supplies. Medication regimens are often complex and cause side effects. Intensive treatment regimens raise the risk of hypoglycemia (Yudkin, Richter, & Gale, 2010), which, when severe, can result in physical injury, car accidents and death. Particular aspects of self-management, such as insulin injections for adults with T2D, are often appraised negatively by patients (Rubin, Peyrot, Kruger, & Travis, 2009) and are associated with increased patient distress (Baek, Tanenbaum, & Gonzalez, 2014). Thus, the demands and burdens of diabetes treatment provide an important situational context for any understanding of person-level psychosocial factors associated with suboptimal diabetes self-management.

Psychosocial Factors Related to Diabetes Self-Management

A large body of research has sought to identify psychosocial factors that could be targeted by interventions to improve diabetes self-management and treatment outcomes. Below, we briefly highlight the role of social disadvantage in diabetes self-management before reviewing relevant patient-level modifiable factors across three broad domains: 1) knowledge, beliefs and related cognitive constructs; 2) emotional distress and wellbeing; and 3) behavioral skills and coping. Developmental, family-context and social relationship factors are covered elsewhere in this issue (See: Wiebe, Helgeson, & Berg; Hilliard, Powell,

& Anderson). We also limit our examples of successful interventions to those tested in adults and refer readers to a comprehensive review of pediatric interventions in this special issue (See: Hilliard et al.).

The Socio-economic and Cultural Context of Diabetes Self-Management

Evidence clearly shows that socially disadvantaged individuals with diabetes benefit the least from available treatments, both in terms of glycemic control and risk for complications (Brown et al., 2004; Naranjo, Hessler, Deol, & Chesla, 2012). Costs are a common patient-reported barrier to self-management (e.g. Daly et al., 2009) and have been shown to reduce adherence (Roblin et al., 2005) and preventive care (Karter et al., 2003). For example, socially disadvantaged children with T1D are far less likely to be on insulin pump therapy (Lin et al., 2013), an alternative to multiple daily self-injections associated with improved control and less hypoglycemia (e.g., Johnson, Cooper, Jones, & Davis, 2013). A survey of 14,357 adults with T2D found that 16% of low-income adults experienced severe hypoglycemia in the prior year, compared with 8.8% of high-income adults (Berkowitz et al., 2014). Similar differences were found between those with low (11.9%) and high (8.9%) levels of education (Berkowitz et al., 2014). Thus, socioeconomic determinants of health outside the scope of medical practice have robust effects on diabetes treatment outcomes.

Ethnic minorities achieve relatively worse diabetes treatment outcomes; experience more emotional distress; and report lower quality of life than whites (Naranjo et al., 2012). However, although some studies report ethnic differences in self-management, population-based survey data suggest few differences; where they exist, they actually suggest better self-management among ethnic minorities (Johnson, Ghildayal, Rockwood, & Everson-Rose, 2014). Other data suggest that disparities may be most robust for SMBG and medication adherence, where SES likely plays an important role. For example, ethnic minorities, those with lower SES, those with difficulty communicating in English, and those with higher costs for test strips were significantly less likely to adequately perform SMBG (Karter, Ferrara, Darbinian, Ackerson, & Selby, 2000). Black adults with T2D were just as likely as whites to fill their medication prescription but almost twice as likely to discontinue over 10-years (Trinacty et al., 2009). SES often overlaps with ethnic minority status and may partially explain ethnic disparities. For example, epidemiological data suggest that about half of Latinos with diabetes do not have health insurance and link insurance status and SES to diabetes prevalence (Schneiderman, et al., 2014).

Cultural beliefs and norms may also play a role in ethnic disparities. Ethnic minorities with T2D may be more likely to worry about drug side-effects and medication dependency; they may also be more reluctant to accept treatment intensification when clinically indicated (Huang et al., 2009). Qualitative data suggest that low-income Blacks and Latinos with T2D can have doubts about the necessity of medication and may take less than prescribed to guard against negative effects (Lynch, Fernandez, Lighthouse, Mendenhall, & Jacobs, 2012). A number of small studies suggest that Latinos with T2D can have particularly negative views about insulin therapy, including fears that insulin causes blindness (Gutiérrez, Ferro, Caballero, 2015). Although cultural factors my influence diabetes self-management and treatment outcomes among ethnic minorities (Naranjo et al., 2012), research suggests that

the widest cultural gap is between patients and their diabetes care providers. Patients often endorse explanatory models for diabetes and its treatment that differ significantly from those underlying their physicians' approach to care; differences that persist even when national culture and language are shared (Weller, Baer, de Alba Garcia, & Salcedo Rocha, 2012). Thus, SES and socio-cultural factors should provide important context for the following patient-level constructs.

Patient Knowledge, Beliefs and Related Cognitive Factors

Knowledge, literacy and numeracy—Successful diabetes self-management requires considerable knowledge on the part of patients and families, including understanding of the effects of diabetes on the body, the goals of treatment, and the effects of various behaviors on glucose regulation. General intelligence consistently and robustly predicts a variety of health outcomes, seemingly independent of SES, and has been conceptualized as an important causal factor that influences health indirectly, through better health behavior and disease self-management (Gottfredson & Deary, 2004). In one study, social class and reading scores, an indicator of intelligence, from recently diagnosed adults with T1D independently predicted diabetes knowledge over time (Taylor, Frier, Gold, & Deary, 2003). Although it is difficult to separate intelligence effects from crudely measured indicators of SES, it seems quite plausible that one's general ability to learn, reason and solve problems would play a role in diabetes self-management. Specific aspects of neurocognitive functioning have been associated with better glycemic control, although at least part of this association likely reflects neurocognitive deficits resulting from poor control (See: Ryan, van Duinkerken, & Rosano, this issue).

Health literacy skills, including reading comprehension, writing, communicating and making decisions about healthcare, are often low among individuals treated for diabetes and could interfere with successful self-management. A review of 23 studies investigating the relation between health literacy and treatment adherence across chronic illnesses found mixed results: Only five studies found clear evidence of a relation with adherence (Ostini & Kairuz, 2014). A diabetes-specific review, focused primarily on adults with T1D and T2D, came to similar conclusions: While there is strong, consistent evidence that health literacy is related to diabetes knowledge, associations with self-management and treatment outcomes are inconsistent (Sayah, Majumdar, Williams, Robertson, & Johnson, 2013). In youth with T1D, higher caregiver literacy, but not child literacy, has been linked to improved glycemic control (Pulgaron et al., 2014; Sanders, Federico, Klass, Abrams, & Dreyer, 2009).

Numeracy skills include the ability to interpret and respond to numerical feedback (e.g. count carbs; recognize out-of-range numbers, understand medication dosages). Proficiency in these skills has been weakly related to glycemic control in adults with T1D or T2D (Cavanaugh et al., 2008). In one study of adolescents with T1D, parents' numeracy skills were not related to adolescent self-management (Janisse, Naar-King, & Ellis, 2009); another study found a relationship between parental numeracy and glycemic control (Pulgaron et al., 2014). Results from two randomized trials aiming to improve numeracy and literacy in adults demonstrated initial glycemic improvement that diminished by six months, with no observed group differences in diabetes self-management (Cavanaugh et al., 2009). Taken

together, findings on literacy and numeracy skills have not shown clear, consistent associations with diabetes self-management and control. Relationships may depend on other factors that vary across available studies.

National survey data also highlight basic knowledge gaps among many adults living with diabetes - less than 50% know their level of glycemic control, 63% know their blood pressure and only 22% know their cholesterol level; this basic knowledge is even less common among Mexican-Americans and those with lower SES (Casagrande et al., 2012). Guidelines emphasize that all patients should receive formal diabetes self-management education and ongoing support (American Diabetes Association, 2015) but less than 7% of privately insured adults receive self-management education and training within the first year after diagnosis (Li et al., 2014). Although these data highlight the need for better education, knowledge appears to be necessary but not sufficient for successful diabetes selfmanagement. A review of 72 self-management trials concluded that didactic interventions had positive effects on knowledge but were inconsistent on other outcomes; the authors concluded that factors other than knowledge are needed to achieve long-term change in selfmanagement (Norris, Engelgau, & Narayan, 2001). Similarly, a review of 24 interventions aimed at improving self-management and glycemic control in youth with T1D found little evidence to support the efficacy of educational programs (Murphy, Rayman, & Skinner, 2006). The importance of behavioral interventions that go beyond education to incorporate training in behavioral skills and strategies, with opportunities for practice, feedback, reinforcement and support, has long been recognized (e.g., Rubin, Peyrot, & Saudek, 1993). Effective T2D interventions tend to be longer, be delivered by teams of providers and reinforce information over time (Loveman, Frampton, & Clegg, 2008). Characteristics of successful educational youth interventions include parental involvement, self-efficacy promotion, and integration into routine clinical care (Murphy et al., 2006).

Beliefs about illness and treatment-Beyond knowledge, patient beliefs about illness and treatment have been a focus of various theoretical models for understanding health behavior. A recent review of health beliefs in diabetes concluded that Leventhal's Common Sense Model (CSM) of self-regulation (Leventhal, Diefenbach, & Leventhal, 1992) has a unique advantage among various health belief theoretical models in that it considers both cognitive and emotional processes involved in illness self-management (Harvey & Lawson, 2009). The CSM is a self-regulatory model that views patients as agents acting in a sociocultural context, their efforts guided by beliefs about illness - its *identity* (symptoms and label), perceived *cause*, expected *timeline*, *consequences*, and anticipated *controllability* – and further shaped by appraised feedback about the effects of their coping behaviors. Subsequent work has focused on beliefs about medication; meta-analysis of 94 of these studies in various illnesses found consistent evidence linking better adherence to greater perceptions of necessity of treatment and fewer concerns about adverse effects (Horne et al., 2013). Adults with diabetes who are younger, African American, or who have low health literacy may have more concerns about their medications (Aikens & Piette, 2009), perhaps contributing to medication non-adherence over time. Impoverished Latinos and African Americans may have commonsense but inaccurate beliefs, such as believing that

medications only need to be taken when blood glucose is high, and these beliefs are associated with non-adherence (Mann, Ponieman, Leventhal, & Halm, 2009).

CSM beliefs about diabetes are consistently associated with self-management, both concurrently and prospectively, in adults with T1D or T2D and adolescents with T1D (e.g., Hampson, Glasgow, & Foster, 1995; Nouwen, Urquhart Law, Hussain, McGovern, & Napier, 2009; Skinner & Hampson, 2001; Watkins et al., 2000). A meta-analysis showed that stronger identity (more symptoms and disease burden), perceptions of greater consequences of diabetes, lower personal control, a more unpredictable course, as well as more diabetes-related emotional distress, were consistently associated with poorer glycemic control in adults with T1D or T2D, with results suggesting 2–7% shared variance (McSharry, Moss-Morris, & Kendrick, 2011). Whether these associations indicate that inaccurate beliefs cause poorer self-management or whether they reflect interpretations of the lived experience of poorly controlled diabetes is difficult to ascertain from existing studies.

Evidence from CSM-informed interventions reviewed by McSharry and colleagues (2011) is limited but partially supportive. Of four trials that targeted glycemic control and measured CSM beliefs, two did not achieve changes in beliefs (French et al., 2008; George et al., 2008). Favorable changes, including better understanding of and greater perceived control over diabetes, were found in two trials that specifically targeted CSM beliefs (Davies et al., 2008; Keogh et al., 2011). One of these trials demonstrated an impact on glycemic control (Keogh et al., 2011), the other on smoking, weight and depression (Davies et al., 2008). Associated impact on these outcomes is promising, as is the pattern suggesting that studies that were most focused on changing CSM beliefs had the best effects. At its most basic level, this evidence suggests that intuitive but often inaccurate beliefs about diabetes and its treatment are common, likely implicated in problematic diabetes self-management and malleable to intervention.

Self-efficacy and perceived control—Patients may be fully confident in their ability to implement their diabetes self-management regimen (high self-efficacy), but if they do not believe that these efforts will affect outcomes of interest (low perceived control), they may be less motivated or consistent in their implementation. According to social cognitive theory, each of these beliefs influences task performance (Bandura & Wood, 1989) and a large literature has developed to study them, as well as a variety of related constructs (Skinner, 1996). We focus on self-efficacy and perceived control as the most extensively researched constructs in diabetes.

Observational studies of T1D and T2D in adults and adolescents have demonstrated associations between self-efficacy for diabetes self-management and some aspects of diabetes self-management (e.g., King et al., 2010; Nouwen et al., 2009; Sarkar, Fisher, & Schillinger, 2006). Beyond the CSM studies reviewed above, others also find greater perceived control over diabetes is associated with better self-management in adults with T2D (e.g., Macrodimitris & Endler, 2001; Surgenor, Horn, Hudson, Lunt, & Tennent, 2000; Walker et al., 2012). In adolescents with T1D, self-efficacy and perceived control were consistent correlates of all aspects of diabetes self-management, as well as glycemic control;

only perceived control was an independent predictor of diabetes self-management (Griva, Myers, & Newman, 2000). Among distressed adults with T2D, both perceived control and self-efficacy were significantly associated with better adherence, but only perceived control was independently significant. Furthermore, perceived control was independently related to glycemic control and accounted for a substantial portion of the variance shared by emotional distress and these outcomes (Gonzalez, Shreck, Psaros, & Safren, 2014). Perceived competence for diabetes tasks, a construct overlapping with self-efficacy and perceived control, also mediated the relationship between state affect and glycemic control in a study of adolescents with T1D (Fortenberry et al., 2009).

Along with preliminary evidence for intervention effects on perceived control, discussed in the previous section, there is strong evidence that self-efficacy can be increased through a variety of interventions. For example, a large trial evaluated the impact of a telemedicine approach to diabetes education, support and collaborative goal setting on glycemic control in 1,665 Medicare beneficiaries with T2D. Results showed the intervention improved glycemic control and self-efficacy; changes in self-efficacy and glycemic control were correlated, and self-efficacy was a partial mediator of intervention effects on glycemic control (Trief, Teresi, Eimicke, Shea, & Weinstock, 2009). Influential work has demonstrated enduring effects of a chronic disease self-management program on self-efficacy and health outcomes in various chronic illnesses, including adults with T2D (e.g., Lorig, Ritter, Villa, & Piette, 2008). Consistent with the CSM, these findings suggest that successful diabetes self-management requires confidence in ability, as well as evidence of impact: patients must be able to observe changes in relevant outcomes (feedback). These beliefs may be fruitful targets for psychological intervention that is sensitive to the context of diabetes, as well as the broader social context of structural barriers that can often pose significant challenges to sustaining these beliefs over time.

Emotional States and Distress

A large literature has explored emotions, mental health and psychiatric illness in relation to risk for the development of diabetes and treatment outcomes among those diagnosed with diabetes (See: deGroot, Golden, & Wagner, this issue). Here, we focus on the consistent link between depressive symptoms and poor diabetes self-management, which is significant in adults and children, and more robust when stronger measurement methods are used (Gonzalez et al., 2008). This association does not appear to be primarily explained by effects of comorbid psychopathology. Instead, emotional distress, which overlaps substantially with items on depression screening scales, appears to underlie these relationships. Diagnostic interviews for depression are rarely used but when they are, they show little evidence for a relation between Major Depressive Disorder (MDD) and diabetes self-management or glycemic control (Gonzalez, Fisher, & Polonsky, 2011; Fisher, Gonzalez, & Polonsky, 2014).

In contrast, elevations in depressive symptoms, even at subclinical levels that would not meet the diagnostic threshold for MDD, and distress related to the burdens of living with diabetes, or diabetes-related distress, are consistently associated with poorer self-management (Fisher et al., 2014). Diabetes-related distress generally shows a closer

association to glycemic control than depression (Fisher et al., 2014; Gonzalez et al., 2014; Schmitt, Reimer, Haak, Gahr, & Hermanns, 2014) and appears to be more common and chronic than depression in adults with T2D (Fisher et al., 2010). International survey data confirm this and suggest that emotional well-being is the domain of functioning most negatively affected by diabetes, second only to physical health (Nicolucci, et al., 2013). Diabetes also provides a situational context for several related emotional distress constructs implicated in self-management. For example, fear of hypoglycemia, measured via validated self-report, is common among parents, children and adults with T1D and can be associated with worse glycemic control (Wild et al., 2007). Worries and concerns about hypoglycemia may also be important among adults with T2D (Polonsky, Fisher, Hessler, Edelman, 2015). Parents often experience significant emotional distress related to their child's diabetes management (Streisand, Braniecki, Tercyak, & Kazak, 2001) and the perceived burden of treatment may explain the association between parent psychological distress and child glycemic control (Cunningham, Vesco, Dolan, & Hood, 2010).

While much of the literature on emotions in diabetes has focused on negative affective states, some studies have examined the role of positive emotions and resilience factors, including optimism, self-esteem, subjective well-being and sense of purpose (Celano, Beale, Moore, Wexler, & Huffman, 2013). However, evidence is generally not supportive of intention or behavior effects for positive affect manipulations (Cameron, Bertenshaw, & Sheeran, 2014). Similarly, although intervention studies for depression and distress have been mostly successful in affecting these negative affective targets, evidence does not support the hypothesis that their amelioration would on its own result in better diabetes self-management (Fisher et al., 2014; Markowitz, Gonzalez, Wilkinson, & Safren, 2011). Thus, rather than directly influencing diabetes outcomes, emotions likely play indirect causal roles, interact with other factors, or are outcomes of advancing illness and/or problematic diabetes self-management, rather than a cause.

Behavioral Skills, Coping, Self-Control and Self-Regulation

Problem-solving and coping—Cognitive and behavioral skills, involving the identification of problems, generating potential strategies for their resolution, selecting the most appropriate strategy, implementing it and evaluating its effectiveness, represent a foundational component of diabetes self-management, recognized by the American Association of Diabetes Educators (AADE, 2014). Given the dynamic nature of diabetes progression and treatment over time, problem-solving skills are largely developed in the course of day-to-day experience, outside of medical encounters. Although studies suggest that problem solving skill is associated with better self-management in adults with T2D (e.g., King et al., 2010) and adolescents with T1D (e.g., Mulvaney et al., 2014), a review of interventions targeting problem-solving skill in diabetes indicates considerable heterogeneity in content and weak and inconsistent effects on self-management for adults and adolescents; few trials measure problem-solving as an outcome or target these skills with sufficient potency (Fitzpatrick, Shumann, & Hill-Briggs, 2013).

Problem-solving skills share some overlap with problem-focused and approach-oriented coping strategies, which have been linked to better emotional adjustment and glycemic

control in adults with diabetes (Duangdao & Roesch, 2008). Coping research in youth with chronic illness, including T1D, emphasizes the central role of perceived control over stressors. Primary control strategies, aimed at changing one's situation, may be adaptive for certain aspects of self-management, but may be less well matched to other stressful aspects of living with T1D, such as feeling different from peers or fear of complications. Secondary control coping, involving efforts to adapt to stress through reappraisal, positive thinking, acceptance and distraction, is associated with better overall adjustment (Compas, Jaser, Dunn, & Rodriguez, 2012). Various effective interventions targeting coping in youth are reviewed in this issue (Hilliard et al.).

Self-control and self-regulation—Research in both adolescents and adults with diabetes has highlighted the importance of self-control in diabetes self-management. Selfcontrol involves one's ability to regulate emotions, behaviors and impulses as well as ability to delay gratification. One early and influential study of adults with T1D and T2D suggested that higher levels of self-control were associated with better glycemic control, in part due to better self-management (Peyrot, McMurry, & Kruger, 1999). In a study of adolescents with T1D, impulse control was significantly associated with better self-management, partially mediated by self-efficacy (Stupiansky, Hanna, Slaven, Weaver, & Fortenberry, 2013). Another study of adolescents with T1D showed that those with low self-control and infrequent use of emotion regulation strategies had the worst glycemic control (Hughes, Berg, & Wiebe, 2012). A further study suggests that self-control may mediate the relation between intelligence and better glycemic control in adolescents with T1D (Berg et al., 2014). In a set of preliminary studies, higher levels of self-control, measured by an objective handgrip test, were positively associated with weight loss, program attendance, and behavior change during a behavioral weight loss intervention for obese adults (Leahey, Xu, Unick, & Wing, 2014).

Self-regulatory models of health behavior encompass problem-solving, coping and selfcontrol but focus on the process of executive management of cognitions, emotions and behavior toward the attainment and maintenance of personal and interpersonal goals (Lansing & Berg, 2014; Maes & Karoly, 2005). Interventions that incorporate strategies aimed at improving self-regulation hold promise for influencing health behaviors relevant to diabetes self-management. For example, one study compared a single-session intervention of information plus self-regulation strategies - including goal identification, mental contrasting and recording of implementation intentions – against an information-only condition for effects on fruit and vegetable consumption in adult women without diabetes. Although both groups improved, by four months post-intervention the self-regulation group recorded significantly more fruits and vegetable consumption, a difference that persisted over two years of follow-up (Stadler, et al., 2010). Another intervention, based on self-monitoring, positive reinforcement, skills training and support, was successful at maintaining weight loss over 18-months. Self-weighing increased with intervention and was strongly associated with weight loss maintenance, emphasizing the importance of feedback in self-regulation (Wing, Tate, Gorin, Raynor, & Fava, 2006).

Study of the self-regulatory processes involved in diabetes self-management, as they occur over time, should be a priority for future behavioral diabetes research. Problem-solving,

coping and self-control in the service of diabetes self-management should be reinforced by monitored progress towards goals, or feedback (Harkin et al., 2015). However, diabetes provides multiple sources of sometimes competing feedback (e.g., emotional distress and side-effects vs. SMBG and glycemic control), which may complicate evaluations of goal progress and effects of self-management efforts (Tanenbaum et al., 2015). A process-oriented approach that views patients as actively engaged in a challenging and dynamic self-regulatory task provides a better fit with the realities of diabetes self-management than concepts such as *adherence*.

Conclusions and Implications for Science and Practice

Improving diabetes self-management among the growing number of children, adolescents and adults living with T1D and T2D would have a significant impact on treatment outcomes and public health. Psychologists should have a key role in meeting this challenge. Psychological factors related to patient knowledge and health beliefs, emotional states, and use of problem-solving and self-regulatory skills, core constructs relevant to psychological research and practice, have each been linked to diabetes self-management behavior. Improving our understanding of diabetes self-management could strengthen the broad evidence base for psychology.

It is useful to place the current brief review of such a large literature on psychosocial aspects of diabetes self-management in the context of prior reviews. One of the earliest reviews we could find focused on pediatric diabetes and was written by a pioneering health psychologist and future leader of the APA (Johnson, 1980). Three years later, a strong argument was made in American Psychologist for the study of behavioral aspects of diabetes as an important paradigm for the then-emerging field of health psychology (Surwit, Feinglos, & Scovern, 1983). The contemporary literature had been dominated by the psychosomatic perspective, which sought to identify psychogenic factors – primarily personality traits, family characteristics and life stress – that could impact diabetes onset and course. Both reviews were equally pessimistic about this approach, based on already available evidence. Studies focused on psychogenic factors were unable to rule out the influence of diabetes and its treatment on their psychosocial measures. They also tended to focus on only one or two self-reported factors, measured on a single occasion, and to assess general constructs rather than those specific to diabetes (Johnson, 1980). There has been much accomplished in the study of the psychosocial experience of diabetes patients since this time, as reviewed above. However, we close by echoing Johnson's still relevant "plea" for better measurement, as "first things are [still] first" (Johnson, 1980, p. 113).

One long noted measurement issue relates to studies that view glycemic control as a proxy for self-management. This is problematic because evidence suggests measures of self-management share 2.5–10% variance with concurrently measured glycemic control (Feldman et al., 2014; Hood, Peterson, Rohan, & Drotar, 2009; Schectman, Nadkarni, & Voss, 2002); and likely much less (e.g., 1.5–5%) with changes in control over time (Schectman et al., 2002; Houle et al., 2015). Self-management is one of many factors influencing glycemic control. Biological factors are also implicated, as are healthcare factors, such as access, cost, provider expertise, limited time for visits, increasing

complexity of medication regimens, limited use of SMBG data by physicians, and failure to intensify treatment when indicated (Vigersky, 2011). Thus, making inferences about self-management from glycemic control, in research and practice, will mostly involve error. Behavior is the primary outcome of behavioral interventions and should be the focus of behavioral science in diabetes. Furthermore, the value of sustained improvement in self-management goes beyond what is captured by glycemic control at a single time-point.

Better measurement of diabetes self-management is needed to advance the field. Accurate measurement can be difficult given the diversity of behaviors involved and their modest inter-correlation (e.g., Toobert, Hampson, & Glasgow, 2000). Furthermore, aspects of self-management not directly related to glycemic control are too often neglected. Foot self-care is particularly understudied considering the health and financial costs of foot complications in diabetes (Armstrong et al., 2013). Cardiovascular disease is the most significant health threat to adults with T2D and it is clear that efforts aimed at controlling blood pressure and cholesterol will have much larger effects on health outcomes than those focused only on glycemic control (Yudkin, Richter, & Gale, 2010). Technological advances provide a growing set of options for measuring self-management, particularly pill-taking, SMBG, insulin pump use and physical activity (Driscoll & Young-Hyman, 2014). As measurement error is relevant to all available methods, latent variable analytic models that pool shared variance across multiple methods and time-points of assessment represent a promising approach (Gonzalez & Schneider, 2011).

Greater attention to the situational context in which self-management occurs is also necessary. Even objective measures of self-management will be vulnerable to the "healthy adherer effect" – as they are often confounded by other health behaviors, SES, healthcare and social factors. For example, meta-analysis shows that adherence to placebo predicts reduced mortality, even when measured objectively, with an effect similar in magnitude to that of adherence to beneficial drug therapy (Simpson et al., 2006). Unraveling these "healthy adherer" effects from the causal effects of self-management should be prioritized. Covariate adjustment for crude indicators of contextual factors is likely to be insufficient. Despite these context-related measurement challenges, aspects of the work of diabetes selfmanagement (e.g., regular pill-taking, SMBG, appointment keeping) can be more accurately and easily quantified than many other behaviors of interest to psychologists. Thus, diabetes self-management provides an important paradigm for a psychological approach to health behavior change and maintenance.

Health psychology has played a major role in increasing the profile of psychological research in the medical and epidemiological literatures and has influenced practice standards regarding psychosocial aspects of diabetes care. However, the ghost of the psychogenic approach, focused on the identification of causal effects for single static characteristics such as, "diabetic personalities" and "psychosomatic families," on diabetic outcomes, which earlier reviewers all but declared dead more than 30 years ago (Johnson, 1980; Surwit et al., 1983), continues to haunt many studies that over-emphasize blood test results for glycemic control over behavioral outcomes. This narrow focus on glycemic control as a key outcome of diabetes is driven by important evidence on the population-level benefits of intensive treatment, as well as funding priorities. But it should be recognized that glycemic control,

while an important predictor of diabetes complications, is a surrogate outcome that has different meanings for risk of complications depending on patient age and other factors. When outcomes of intensive treatment are considered in terms of risk for macro-vascular (e.g., myocardial infarction and stroke) and micro-vascular (e.g., blindness and renal failure) complications of diabetes or life expectancy, benefits for patients can be modest and come with significant costs and raised risk of hypoglycemia (Yudkin et al., 2010). Health psychology researchers should be cautious about evaluating the importance of psychosocial factors or behavioral interventions solely in terms of glycemic control and other more distal health outcomes, especially when the bio-behavioral pathways that may explain these effects go unmeasured or fail to account for observed relations. Well-powered trials that go beyond surrogate outcomes to evaluate impact of psychological and behavioral interventions are needed to advance the field.

Should psychological interventions that improve patient quality of life, well-being, and selfmanagement, but have negligible or null effects on glycemic control, be considered failures unworthy of further research or dissemination? We think most patients and clinicians would disagree, but we are less sure about editors, reviewers, policy-makers and funders. Focusing on glycemic control as the most important outcome in behavioral research in diabetes is inconsistent with evidence-based, patient-centered care (Jones, Vallis, & Pouwer, 2014; Yudkin et al., 2010). At the same time that we build an evidence base for cost-effective benefits of psychological interventions in terms of diabetes treatment outcomes, we must also advocate for the evaluation of psychological factors and quality of life as essential outcomes of diabetes care. Behavioral science interventions that minimize the psychosocial burdens of diabetes and its treatment and improve health behaviors, diabetes selfmanagement, and functioning likely have value that is insufficiently captured by change in glycemic control from pre- to post-intervention.

The growing prevalence of diabetes points to an increasing need for psychologists competent in working with individuals living with diabetes and their families. In addition to improving the care of those with comorbid psychiatric conditions, psychologists should also have a role in expanding services to the many individuals and families struggling with diabetes without inaccurately casting their problems in the language of psychopathology and abnormality. Successful self-management involves making challenging changes in behavior and maintaining them over time, despite often confusing feedback and emotional distress. These changes run against powerful societal forces – limited preventive care, long work hours, sedentary lifestyle and unhealthy foods – and compete with other life demands and goals for daily prioritization.

To be effective in supporting children, adolescents, adults, and families in their efforts to effectively manage diabetes, clinicians must gain expert knowledge of diabetes and the goals of diabetes care. To accomplish this, training opportunities at doctoral, internship and post-doctoral levels should be formalized and expanded. Models of intervention delivery that can integrate psychological care with disease management delivered by interdisciplinary teams are likely to be most effective and efficient. Though evidence reviewed here and elsewhere (e.g., Markowitz et al., 2011) suggests psychological interventions can be effectively

delivered in the context of diabetes, targeting psychosocial factors in isolation is unlikely to be sufficient to improve self-management and health outcomes in diabetes. Interventions involving psycho-education, distress-management, problem-solving skills training and optimization of self-regulatory processes should also directly target the task of selfmanagement to have maximal impact. Successful interventions will be sensitive to the burdens of diabetes treatment, SES and socio-cultural context, supportive of patient-centered goals for diabetes care, and evidence-based in communicating expected costs and benefits of self-management for quality of life and health to patients, providers and policy makers.

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Biographies





