

Chapter 12

Diabetes

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Diabetes: Prevalence and Trajectories

Diabetes affects 382 million people in 2013, which is just below 10 % of the global population, meanwhile an additional 175 million people remained undiagnosed (International Diabetes Federation, 2013). In the USA, there are currently over 24 million people being diagnosed with diabetes and nearly seven million undiagnosed cases. The International Diabetes Federation (IDF) projected the number of people with diabetes to increase to 600 million in the next two decades. About 90 % of people with diabetes have type 2 diabetes with the remaining having type 1 diabetes or gestational diabetes (International Diabetes Federation, 2013). Type 1 diabetes is an autoimmune disease that results in β cells of the pancreatic islets unable to produce insulin. The majority of type 1 diabetes is diagnosed during childhood. Type 2 diabetes is a metabolic disease caused by impaired insulin secretion and resistance to insulin. Type 2 diabetes generally occurs later in life; however, there is a growing prevalence among adolescents (Cameron & Wherrett, 2015). Gestational diabetes develops during pregnancy and is a risk factor for type 2 diabetes. Lastly, there is a small proportion of diabetes that is due to other causes (American Diabetes Association, 2014). Although there are differences in the etiology of diabetes types, their long term impact and psychological demands on daily life are quite similar.

Diabetes is responsible for 5.1 million premature deaths in 2013 (International Diabetes Federation, 2013). Furthermore IDF estimated that global health expenditure will increase significantly from \$548 billion in 2013 to \$627 billion in 2035 (International Diabetes Federation, 2013). At an individual level, the costs of care

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double once the person with diabetes develops diabetes-related complications (Baker IDI Heart and Research Institute et al., 2012). The burden of disease from diabetes and its complications, all of which are potentially preventable, has been steadily increasing. The second Diabetes Attitudes, Wishes and Needs (DAWN-2) study surveyed 8596 adults with diabetes from 17 countries and found that depression (WHO-5 Well-Being Index score ≤ 28) and poor quality of life (negative impact of diabetes on physical health, psychological health, social relationships, and environment as measured by WHOQOL-BREF) are common among this population (Holt & Kalra, 2013). The study also reported lack of knowledge among caregivers and healthcare professionals to support people to self-manage their diabetes.

Quality evidence-based care is critical to address these challenges. Understanding diabetes trajectories and the impact of diabetes on life demands is fundamental. The three critical timepoints in engaging patients are at diagnosis, during the initiation of treatment and in the ongoing monitoring of treatment. Step by step care and various practical ways clinicians can engage people with diabetes in their treatment over the course of the disease are presented next. Some strategies can be undertaken by individual clinicians with their patients (micro-level), or in partnerships within the care organization level (meso-level) and finally in the wider healthcare system and funding support (macro-level). The American Diabetes Association (ADA) issued standards of care based on the Chronic Care Model of holistic and comprehensive diabetes care (Standards of Medical Care in Diabetes-2016: Summary of Revisions, 2016). The standards are continually being updated as new research evidence emerges.

At Diagnosis Phase

The ADA states one of the following measures to diagnose diabetes (American Diabetes Association, 2014):

- **Glycated hemoglobin** (hemoglobin A1c) at or above 6.5% (≥ 48 mmol/mol)
- Fasting plasma glucose level at or above 126 mg/dL (7.0 mmol/L)
- Two-hour **plasma** glucose at or above 200 mg/dL (11.1 mmol/L) during oral **glucose tolerance test**
- A random plasma glucose at or above 200 mg/dL (11.1 mmol/L) with symptoms of hyperglycemia or hyperglycemic crisis

Despite diagnosing diabetes as being a relatively straightforward task, how the diagnosis being conveyed to the patient and their family matters. There is evidence that illness beliefs are developed soon after diagnosis is made and then these persist over the course of the disease (Skinner et al., 2014). These early illness beliefs have been found to negatively impact longer term stress and depression (Skinner et al., 2014). The following section illustrates patients' negative psychosocial accounts when they were diagnosed with diabetes. This will provide a context on the underlying strategies needed to engage patients prior to the initiation of their diabetes treatment.

Type 1 Diabetes

It is all happening within a short timeframe: from the moment a child is unwell, being referred to a hospital to visit a specialist, being diagnosed with type 1 diabetes, receiving an abundance of information and sympathy from healthcare professionals, and having to adjust to a new routine at home; this situation can be overwhelming for both parents and their children (Barnard & Lloyd, 2012). Parents often feel shock, scared, and angry about the diagnosis and there is also a sense of guilt and self-blame because their genes cause their children to suffer this condition for the rest of their lives (Barnard & Lloyd, 2012). At diagnosis, children commonly do not understand the seriousness of the disease but have to take greater responsibility of administering their insulin therapy. There is a fear of “being different” from peers at school, fear of death if insulin is not administered correctly, feeling of being a burden to the family, embarrassment in the social situation and isolation (Barnard & Lloyd, 2012). Indeed, public stigma surrounds type 1 diabetes exists, often labeling children as “lazy, unhealthy, fat, obese, lacking exercise, and having eating disorders” (Vishwanath, 2014).

Type 2 Diabetes

Similar accounts of shock, anger, denial, guilt, emotional distress, and fear of death were reported by people when they were being diagnosed with type 2 diabetes (Furler et al., 2008; Stuckey et al., 2014). The psychological reactions can persist years after diagnosis is made. Participants of the DAWN-2 Study reported that diabetes diagnosis means they are denied enjoyment in life such as favored foods and worry about the uncertainty of their future (Stuckey et al., 2014). While for some, the diagnosis is inevitable because they have one or more diabetes risk factors such as obesity, physical inactivity, poor nutrition, or family history, for others they believe that the underlying emotional distress due to major life events, such as the loss of loved ones or life trauma, cause their diabetes. Patients’ views on their diabetes symptoms, concerns, impact, and management are relatively stable over time. On the other hand, high emotional reactions upon diagnosis diminish as the disease progresses and instead being replaced with a sense of appreciation and understanding of their disease (Lawson, Bundy, & Harvey, 2008).

Stepped Care to Engage Patients Early in Their Disease Progression

Diagnosis stage presents a critical opportunity for clinicians to engage patients early in the course of their diabetes treatment. The ADA recommends tailoring approach to the individual circumstances, orienting towards patient-centered care and goals beyond glycemic control (American Diabetes Association, 2014). This is critical as

patient engagement is a continuum process of blackout, arousal, adhesion, and eudaimonic phases (Graffigna, Barello, Libreri, & Bosio, 2014). The blackout phase occurs at diagnosis when patients often feel isolated and in denial and therefore would benefit from psychological support. In the arousal phase, patients accept the diagnosis but find difficulty in understanding all the information from healthcare professionals about the new treatment and prescribed lifestyle modifications, and they often have limited access to learn new skills from their peers. In the adhesion phase, the doctor-patient relationship is key to ongoing patient motivation to engage in diabetes treatment. In the eudaimonic phase, patients are able to embed diabetes management into their daily life routine; however, they express specific needs for practical support from the wider healthcare system.

Although diabetes diagnosis is generally made by physicians (primary care physician, endocrinologists, or diabetologists), diabetes care requires interdisciplinary and collaborative approach involving the person with diabetes and their family, diabetes educators, nurse practitioners, nurses, dietitians, pharmacists, and mental healthcare professionals with expertise in diabetes (American Diabetes Association, 2014). The following practical strategies should be tailored to meet patients' circumstances and preferences as there will not be "one size fits all" approach in diabetes treatment engagement.

Clinicians' Factors

The first step in engaging patients at diagnosis and early in their treatment is to evaluate the clinicians' own personal beliefs, knowledge, and skills related to diabetes that may influence the interaction with patients and their families. Furthermore, understanding the healthcare system, funding mechanisms, and support structures available to patients are critical to facilitate successful patient engagement in their diabetes treatment.

Patient-Centered Care

Patient-centered care is about reorienting the healthcare system to support patients to become an active as well as to effectively manage their conditions (Von Korff, Glasgow, & Sharpe, 2002). Provision of structured and tailored educational information to empower people with diabetes can enhance the level of patient activation and strengthen patient treatment engagement (Gillani, Nevill, & Singh, 2015).

Communication Skills

The DAWN-2 study found that half of the 5000 healthcare professionals surveyed reported having a lack of communication skills with people with diabetes and with other diabetes team members (Holt et al., 2013). Effective communication skills

include the ability to actively listen, to address patients' concerns, to offer sufficient consultation time, to understand patients' circumstances, and to encourage patient active participation in their management plan (Corbin & Rosen, 2005). Effective communication also means positive language use (Speight, Conn, Dunning, & Skinner, 2012). Some words such as "diabetic sufferer," "noncompliant," or "failure" are known to have negative impact on people with diabetes (Speight et al., 2012). Effective communication skills may change patient's disease perception and influence outcomes (Nam, Chesla, Stotts, Kroon, & Janson, 2011). The way information is being conveyed and received determines patient's view of their diabetes at diagnosis and beyond (Lawson et al., 2008). Good relationships and therapeutic alliance between patients and clinicians is integral to diabetes treatment (Furler et al., 2008).

Attitude, Beliefs, and Knowledge

One in five healthcare professionals in the DAWN-2 study never had any postgraduate level of diabetes education or training (Holt et al., 2013). The various level of knowledge on diabetes management influences healthcare professionals' confidence to support people with diabetes and work with other diabetes care team member (Blackberry et al., 2013). Clinicians' attitudes and beliefs at diagnosis directly influence how patients perceive the seriousness of their disease and how patients engage with their diabetes treatment regime (Dietrich, 1996; Puder & Keller, 2003). Clinicians' attitudes and beliefs also influence how they manage their diabetes patients (Nam et al., 2011).

Motivational Interviewing (MI) Approach

The Motivational Interviewing (MI) approach refers to "*a directive, client-centered counseling style for eliciting behavior change by helping clients to explore and resolve ambivalence*" (Miller & Rollnick, 2002). The MI provides a framework for clinicians to build rapport and support people with diabetes to be in control, to be empowered, and to choose their own goals (Carrier, 2009). Training for clinicians is available; however, practice and feedback are as important to embed the delivery of MI approach in routine practice (Miller & Rollnick, 2002). MI has been shown to be effective in promoting patient-centered care and improving health outcomes in diabetes including glucose level, self-efficacy, physical activity, diet, and body weight are also reported (Martins & McNeil, 2009).

Stages of Change/Transtheoretical Model (TTM) of Behavior Change

The TTM has six stages of change including pre-contemplation, contemplation, preparation, action, maintenance, and termination (Prochaska, DiClemente, & Norcross, 1992). This model has been widely applied in behavior change research

and offers framework to match treatment according to the individual's stages of behavior change (Prochaska & Velicer, 1997). Evidence from a systematic review shows that behavior interventions, including those moderated by behavior change theories or models, are effective in improving glycated hemoglobin, objective and self-reported physical activity and body mass index among people with type 2 diabetes (Avery, Flynn, van Wersch, Sniehotta, & Trenell, 2012; Guicciardi et al., 2014). The TTM model of change intervention also reduces smoking rates among people with diabetes in primary care by 26% over 12 months (Perez-Tortosa et al., 2015).

Collaborative Care

Quality of relationships between patients and their healthcare providers is key; however, collaboration between multiple healthcare providers to better meet patients' needs as their care becomes progressively complex is just as important (Funnell, 2006). There are several ways to integrate collaborative care in usual practice. For example a psychologist within a comprehensive multidisciplinary care team provides psychological services to support overall health and well-being of patients and their carers (Kichler, Harris, & Weissberg-Benchell, 2015). Evidence on the significant benefits of collaborative care among patients with coexisting depression on reduced depressive symptoms, enhanced self-management, and satisfaction with care and glycemia is emerging (Atlantis, Fahey, & Foster, 2014; Coventry et al., 2015; Johnson et al., 2014; Richards et al., 2013). While what constitutes collaborative care model varies, common factors include case management or care coordination, behavioral activation, treat to target, regular monitoring, and individualized patient-centered care. Training, ongoing support, professional and personal qualities of the case manager and preexisting relationships facilitate successful delivery of diabetes collaborative care models (Wozniak et al., 2015)

Patients' Factors

Every patient reacts differently upon receiving a diabetes diagnosis hence there is no one strategy that is superior or more effective than others. Treatment engagement should be individualized based on patient's health literacy, coping skills, and support services.

Health Literacy

There is a strong evidence on the positive association between health literacy and diabetes knowledge particularly in the US primary care (Al Sayah, Majumdar, Williams, Robertson, & Johnson, 2013; Bailey et al., 2014; van der Heide et al., 2014). People with high levels of health literacy are more likely to self-manage their

diabetes (van der Heide et al., 2014) while those with low literacy levels develop more diabetes complications and hypoglycemia (Bailey et al., 2014). The relationship between health literacy and other outcomes including glycemic control, quality of life, health care utilization, or patient–provider interaction is less clear (Al Sayah et al., 2013; Bailey et al., 2014).

Healthcare professionals always need to assess their patients' health literacy level when conveying diabetes diagnoses or treatment plans and adjust their communication level accordingly (Parker, 2000). Some practical ways clinicians can engage patients with limited health literacy include using visual materials, avoid jargon or complex medical terms, simple instructions, and involving care givers or family members in the discussion. It is important to check patients' understanding of the diagnosis and treatment plans by asking them to repeat and demonstrate.

Attitude, Beliefs, Culture, and Knowledge

Apart from health literacy level, attitude, beliefs, culture and knowledge influence patients' ability to accept diabetes diagnoses and undertake self-management (Nam et al., 2011). Misconceptions and stigma regarding diabetes still exist widely in the community. Despite global health promotion and awareness on diabetes, public understanding of the etiology of type 1, type 2, gestational diabetes, and other type of diabetes is still poor. The lack of knowledge often influences public beliefs and attitudes that diabetes regardless of its type is caused by overeating, obesity, and sedentary lifestyle (Vishwanath, 2014). Likewise diverse cultural factors can play a pivotal role in forming people's perception on how or why people have diabetes. In some cultures, people believe that type 2 diabetes is caused by emotional distress and trauma rather than poor lifestyle choices (Furler et al., 2008; Stuckey et al., 2014). Cultural beliefs are commonly shaped by patients' personal experience with diabetes in their family and local community.

Illness beliefs including how patients view the seriousness of diabetes and perceived impact of diabetes on their lives are developed early and these beliefs remain for at least 3 years after diagnoses are made (Skinner et al., 2014). Personal models of diabetes including beliefs about symptoms, treatment effectiveness, consequences, and emotional responses to possible complications are influenced by the way the diagnosis is communicated by healthcare professionals rather than patient's personality traits (Lawson et al., 2008). Illness beliefs are associated with the development of psychological distress and depression (Skinner et al., 2014). Understanding patients' culture, beliefs, and knowledge about diabetes at diagnosis enhance patient-centeredness to diabetes treatment engagement.

Psychosocial and Peer Support

Findings from nearly 9000 adults with type 1 diabetes and type 2 diabetes in the DAWN-2 study reported psychosocial issues such as anxiety, fear, worry about hypoglycemia and complications of diabetes, depression, and negative moods or

hopelessness. The study also found that discrimination at work and public misunderstanding about diabetes exist (Stuckey et al., 2014). For example, in the workplace the study found people with diabetes were dismissed because of their diminished capacity to perform or do shift work; or taking medical leaves which could be costly to the employer. Participants reported resilience and being positive as a coping mechanism. Moreover, receiving psychosocial support through a caring and compassionate family, caregivers, healthcare professionals, and peers are regarded as important. There is emerging evidence that peer support programs such as Peer for Progress benefits people with diabetes by offering psychosocial support (Fisher et al., 2015).

Patient Education and Self-Management

Evidence shows that group-based structured diabetes self-management education or training (DSME) in people with type 2 diabetes has favorable effects in clinical, lifestyle, and psychosocial outcomes (Steinsbekk, Rygg, Lisulo, Rise, & Fretheim, 2012). There are various DSME programs with contents covering diabetes disease progression, lifestyle modification, diabetes treatment options, blood glucose monitoring, identifying diabetes complications, and personal goals/targets to achieve (Haas et al., 2012). DSME should be offered to people being newly diagnosed with diabetes (American Diabetes Association, 2015). Yet only half of the Australian National Diabetes Support Scheme (NDSS) members with type 2 diabetes were offered structured DSME (Speight et al., 2011). In the US, less than 7% of privately insured patients with new diabetes diagnosis completed DSME within 12 months of diagnosis (Li et al., 2014). The low proportion of people receiving structured education is alarming given that illness beliefs form early following diagnosis and impact on health outcomes as diabetes progresses (Skinner et al., 2014).

During the Initiation of Diabetes Treatment

The ADA and the European Association for the Study of Diabetes (EASD) have made a joint position statement and guidelines on the best practice management of diabetes (Inzucchi et al., 2012). Multiple dose insulin or continuous subcutaneous insulin infusion is the recommended therapy for type 1 diabetes (American Diabetes Association, 2014). Unlike type 1 diabetes, gestational diabetes, or Latent Autoimmune Disease of Adults (LADA), there is less sense of urgency to initiate and intensify treatment in type 2 diabetes. Disease severity at diagnosis can also vary greatly between one person to another as diagnosis can be made early through health screening or later in the disease progression when symptoms are more pronounced or diabetes complications have emerged. Lifestyle modification with metformin is commonly the first line therapy with step by step clinical guidelines leading to insulin therapy in type 2 diabetes (Inzucchi et al., 2012).

Lifestyle modification is an integral part of type 1 and type 2 diabetes care regardless of pharmacological regime. Research evidence shows that lifestyle modification on diet, exercise, and body weight as well as getting interpersonal support from family and friends remains challenging for people with diabetes (Schroeder et al., 2015). In addition, there is often a mismatch between the healthcare professionals' perception and the actual ability of the patient to undertake self-care activities (Peyrot et al., 2005). This section describes strategies to engage all patients with diabetes to make lifestyle changes and self-care activities as well as to initiate glucose lowering agents.

Stepped Care to Engage Patients Upon Initiation and Intensification of Diabetes Treatment

Cognitive, behavioral, and emotional dimensions each play a part in forming patients' experience to living with diabetes on a day to day basis and the way they manage their diet, physical activity, therapy, and patient–doctor relationship (Graffigna et al., 2014). Patients who have limited understanding of the rationale of therapeutic regime and ineffective support from healthcare professionals, tend to avoid healthcare encounters and a review of their diabetes therapy. Over time patients become ambivalent about their diabetes and disconnected with their healthcare professionals. Assessing and monitoring individual patient experience enables healthcare professionals to engage with their patients during their diabetes treatment.

Person-Centered Care

Person-centered care (PCC) is the underlying strategy to engage patients in their diabetes treatment, individualized treatment to reach normoglycemic target and prevent micro and macrovascular complications according to their individual circumstances. PCC needs to take into account factors such as age, gender, education, life experience, socioeconomic, cultural diversity, social support, environment, communication skills, relationships with healthcare professionals, and coping behavior. PCC requires clinicians to express genuine concern and empathy towards patients.

In type 1 diabetes, the three key elements underpinned PCC include forming long-term relationships with patients and their families; setting up multidisciplinary team care arrangement; and maintaining records of how care is delivered over time (Wigert & Wikstrom, 2014). Training for healthcare professionals, patients, and their families is vital to ensure PCC is embedded in the delivery diabetes care because soon after diagnosis, treatment options need to be discussed and treatment decisions made. Patients and their families require significant support from healthcare professionals to understand what the diagnosis means for them psychologically, to manage the demand of insulin regime and monitoring as well as to learn to adjust their lifestyle (Malik & Taplin, 2014).

In a large cohort of people with newly diagnosed type 2 diabetes in the US, an oral hypoglycemic agent was introduced within a year of diagnosis in younger population while among people aged 65 years and over it took in excess of 2 years (Zhang et al., 2012). The significant time difference to the initiation of treatment also reflected in almost two thirds of younger patients as opposed to less than half of older people were on treatment 2 years post diagnosis. The study also found that older people were less likely to receive antihyperglycemic therapy. Similar findings were found in the UK that at 2 years post diagnosis only one in two patients with newly diagnosed type 2 diabetes was prescribed hypoglycemic agents. Initiation of therapy was associated with younger age at diagnosis and worse glycemic control (Sinclair, Alexander, Davies, Zhao, & Mavros, 2012).

Delay in intensification of therapy after the initiation of oral hypoglycemic agents also occurs in type 2 diabetes. The addition of the second or third oral agents ranged from 1.6 years to over 7 years despite elevated glycemia (HbA1c $\geq 7.0\%$ or ≥ 53 mmol/mol) (Khunti, Wolden, Thorsted, Andersen, & Davies, 2013). Furthermore, a significant proportion, of the 80,000 UK patients with type 2 diabetes, never had their treatment intensified during the 7 years study follow-up period. Overall, the studies highlight *clinical inertia*, a failure to intensify treatment despite persistent hyperglycemia, as well as a substantial lack of ongoing patient engagement to achieve optimal glycemia in type 2 diabetes once the diagnosis was made.

Shared Decision-Making

Shared decision-making (SDM) is a partnership between patients and clinicians to achieve agreement on an evidence-based treatment option that suits patient's circumstances and preferences (Tamhane, Rodriguez-Gutierrez, Hargraves, & Montori, 2015). Patient-centered care is the underlying principle of SDM.

SDM facilitates exchange of information between clinicians on the risks and benefits of treatment and patients to express their values and preferences (Barry & Edgman-Levitan, 2012). SDM relies on clinicians' communication skills to respond to patient's health literacy level. The end result is a shared responsibility of the decision being made. SDM becomes more prominent in healthcare policy although yet to be part of routine clinical practice (Barry & Edgman-Levitan, 2012).

Diabetes is a chronic but progressive condition that necessitates patient to constantly juggle diabetes care with other life demands and other competing comorbidities. SDM in diabetes care enables patients to be the main player to adjust and prioritize their diabetes management with help from their clinicians (Frosch, 2015). Adults with late onset type 1 diabetes report having to make decisions very rapidly after diagnosis occurred. The diagnosis made a significant impact on their lives. To enable people to have SDM, they need knowledge, respect from others on their individual choices and support to make decisions on day to day basis (Jull, Witteman, Ferne, Yoganathan, & Stacey, 2016).

The Patient Health Engagement is a new model of consumer engagement based on patient's own experience with their health management to facilitate shared a

decision making process regarding available health services and sustainable engagement in preventive action and healthy behaviors (Graffigna et al., 2014). Discussion between prescribing clinicians and patients about the choice of diabetes treatment and therapeutic regime needs to occur soon after diagnosis. Once prescribing is completed, it is far too late to engage patients in their therapy. Even multiple follow-up from pharmacists or nurse-directed outreach service makes no difference in improving primary medication adherence (Fisher et al., 2015).

Psychological Barriers

Almost half of people with diabetes participated in the DAWN study reported poor psychological well-being that has negative impact on their ability to self-manage their condition (Peyrot et al., 2005). Despite clinicians recognizing this issue, only one in ten patients received psychological therapy with lack of resources in clinical practice cited as the most common reason (Peyrot et al., 2005). Identifying and addressing the underlying psychological barriers after diagnosis is made and factors that may attribute to the effectiveness of therapy is therefore essential.

Health Illness Beliefs

Education enhances knowledge and training improves skills in self-management. Yet for many people with diabetes continues to struggle with adhering to diabetes self-care behaviors and treatment recommendations. Health illness beliefs influence patients' adherence to self-care and diabetes treatment (Harvey & Lawson, 2009). There are many models and theories to explore the relationship between health beliefs and behaviors. One model that has been widely developed to understand and predict health behaviors is Leventhal's Self-Regulatory Model (also called the Illness Perceptions Model, the Illness Representations Model, the Parallel Process Model, or the Common-Sense Model) that takes into account patients' dynamic and parallel processes of emotional and cognitive response to illness such as how patients make sense of their diabetes and how they develop their coping mechanism (Leventhal, Brissette, & Leventhal, 2003). Perceived threat on the severity and vulnerability to complications as well as belief in treatment effectiveness and the value of care from healthcare professionals play a major part on optimal diabetes outcomes (Harvey & Lawson, 2009). Psychological theory-based interventions offer healthcare professionals the greatest prospect to engage their patients in diabetes self-care behavior and treatment (Harvey & Lawson, 2009).

Treatment Goals and Goal Setting

There are various clinical (blood glucose control, blood pressure, weight loss, exercise) and psychosocial (quality of life, depression, self-efficacy, satisfaction, knowledge) outcomes in diabetes treatment; however, most research regardless of the type

of intervention and clinical practice focus on blood glucose control as the primary outcome. Indeed, glycemic control is important in diabetes for improving health outcomes. Hyperglycemia causes vascular complications through glycation and oxidation of proteins, and lipids, inflammation and disturbed angiogenesis. A period of poor glycemic control can cause tissue and organ damage well past the period of hyperglycemia, well recognized as the *legacy effect* (Holman, Paul, Bethel, Matthews, & Neil, 2008). For every 1% reduction in HbA1c, the relative risk for microvascular complications, diabetes-related mortality, and myocardial infarction decreased by 37%, 21% and 14% respectively over the course of the disease (Holman et al., 2008; Stratton et al., 2000).

In a systematic review of comprehensive behavioral intervention trials incorporating problem solving, goal setting, and health promotion, only a modest improvement of glycated hemoglobin (HbA1c) is observed (Medical Advisory Secretariat 2009). Similarly, clinicians often measure their treatment's effectiveness only on clinical parameters with little regards to patients' own treatment goals and how they would like to achieve treatment goals given their capacity, circumstances, and priorities in their life (Frosch, 2015). For example a nurse continued coaching a patient according to the coaching intervention schedule to achieve optimal diabetes control despite the patient experiencing bereavement (Walker et al., 2011).

Motivational Interviewing

MI principles and techniques underpin clinical encounters between clinicians and their patients. MI is proposed as one effective method to engage patients in diabetes therapy (Martins & McNeil, 2009). Yet evidence from real-world clinical practice remains inconclusive. Integration of MI principles within structured nurse-led diabetes care was ineffective in improving glycemic control or lifestyle modification among people with type 2 diabetes (Jansink et al., 2013). Better outcomes on MI were generally associated with longer consultation time with MI-trained nurses, greater opportunity to discuss lifestyle modification and increased patients' readiness to change. However, introduction of MI to intensify therapy among people with out of target glycemia and lipids had little effect. In fact, patients randomly allocated to the MI intervention group were less engaged in the study compared to usual care (Pladevall, Divine, Wells, Resnicow, & Williams, 2015). These findings raise doubts whether MI principles are appropriate, or clinicians' failure in properly implementing MI principles attributed to the lack of success (Jansink et al., 2013).

Patient Education and Self-Management

Patient education on self-management needs to be considered as part of an ongoing diabetes therapy. Data from US Commercial and Medicare payer-derived claims showed that participation in diabetes self-management education or training within accredited or recognized programs by diabetes educators reduced healthcare costs.

Furthermore, multiple and ongoing attendance produced better quality of care and adherence to medication regime (Duncan et al., 2011).

In parents and young people with type 1 diabetes, higher knowledge, understanding, confidence, and motivation were associated with attendance in group-structured self-management education program delivered by trained members of pediatric diabetes services (Christie et al., 2014). However the program was ineffective in improving glycemia over 2 years. Despite evidence on the benefits of self-management education, integrating self-management programs into routine care and engaging people with diabetes and their families to participate in the program remains a challenge. Low uptake in type 1 diabetes program has been attributed to difficulties juggling other life demands or finding suitable time to fit the group education schedule (Christie et al., 2014). Training multidisciplinary team to support patients with type 1 diabetes and their families is key. Establishing a transitional care between pediatric and adult diabetes services is vital to ensure the continuity of care given that older teenagers are more likely to disengage in their healthcare and the alarming rate of complications under 40 years of age (Winocour, 2014).

In type 2 diabetes, self-management education motivates people to continue their self-care activities and engagement with their healthcare professionals. Reasons for participation in self-management programs include desire to stay healthy, being independent, achieve better quality of life, avoid complications, and reduce utilization of health services (Newton, Asimakopoulou, & Scambler, 2015). There are various types of programs available to meet the needs of people with type 2 diabetes. This includes programs for people with newly diagnosed, within few years of being diagnosed and longstanding duration. There is also generic self-management support that takes into account the presence of multimorbidity and support in chronic diseases in general. The Stanford Chronic Disease Self-Management Program developed by Lorig is one example. The program is available in various format, delivery, and adaptation to various cultures and languages (Lorig, 2015). The Peer for Progress is another form of self-management support that was originated in the US and have been adapted globally (Fisher et al., 2015). In the UK, the Diabetes Education and Self-Management for ongoing and newly diagnosed type 2 diabetes (DESMOND) program has been running for the past decade (Davies et al., 2008; Skinner et al., 2014).

Stepped Care to Engage Patients During Transition to Insulin Therapy

A decision to commence insulin often produces negative psychological impact such as grief, loss of independence, stress, blame, and anger. Strategies discussed in the previous section when initiating and intensifying treatment are relevant and can be applied. This section elaborates some areas that are pertinent to how patients deal with the decision to commence insulin. A particular focus is for healthcare professionals to receive adequate training to support patients psychologically and to

dedicate sufficient time to engage patients to safely and independently administered and titrate their insulin regime.

In type 1 diabetes, transition to insulin occurs soon after diagnosis. Ensuring children/adolescent and their families are able to cope and make an adjustment is important. Stigma, communication, disclosure, balancing the children's feeling of being different to their peers and restriction to normal daily activities needs to be addressed (Lambert & Keogh, 2015). Stress, burnout, time pressure, social support, parental autonomy support, and stigma influence glycemic control (Mulvaney et al., 2011). Patient-centered care principles need to underpin care as each patient will have various psychosocial circumstances, health literacy, and maturity. To successfully engage patient and their families in treatment, healthcare professionals also need to explore barriers stem from complex insulin initiation and adjustment regimens. Simplifying therapy as well as close support and monitoring how the patients and their families respond to prescribing regimens and adjust therapy accordingly are necessary (Santer, Ring, Yardley, Geraghty, & Wyke, 2014). Collaborative and integrated pediatric care by trained multidisciplinary team is warranted.

Use of insulin is critical in achieving glycemic control but often delayed in type 2 diabetes. While patient-centered education and self-management are important (Norris, Lau, Smith, Schmid, & Engelgau, 2002), pharmacotherapy is a key aspect of type 2 diabetes therapy. There are increasing pharmacological options, including GLP-1 agonist therapy; however, insulin remains the most efficacious medication to achieve glycemic target. Despite the importance of tight glycemic control and strong evidence of the use of insulin, *clinical inertia* remains an issue particularly in primary care (Khunti, Wolden, Thorsted, Andersen, & Davies, 2013). This may stem from misunderstanding the benefits of tight glycemic control, lack of confidence about insulin initiation and up-titration, or problematic interpretation of blood glucose patterns. Concerns about hypoglycemia and confusion about target levels for HbA1c also may play a role. Barriers also exist at the health or practice system and patient level (Kuritzky, 2009). Healthcare professionals may set unrealistic goals (Wolpert & Anderson, 2001) or neglect discussing insulin in ways that engage patients (e.g. improve energy, better quality of life, reduce complication risk). Given the epidemic of type 2 diabetes, the majority of cases and initiation of insulin will need to be managed in primary care.

Initiation and intensification of insulin regime in type 2 diabetes is often delayed particularly in primary care. Patients reported having “*psychological insulin resistance*”, worry that insulin will make life inconvenient and less flexible, and feelings of being failure and self-blame (Holmes-Truscott, Pouwer, & Speight, 2014). The average HbA1c level prior to insulin initiation range between 8.3% or 67 mmol/mol (Best et al., 2012) and 9.4% or 79 mmol/mol (Davis, Davis, & Bruce, 2006). A large clinical practice data from 11,696 patients with type 2 diabetes in the UK showed that between 2004–2013 only one in three had their basal insulin regime intensified within a median time of 4 years (Khunti et al., 2016). Clinical inertia was attributed to older age, longer duration of diabetes, use of oral antihyperglycemic agent and presence of comorbidities. The same study also found that a third of patients with out of target glycemia ceased their insulin therapy. Guidelines and clinical algorithm

to initiate insulin in primary care is available. However increased primary care-based insulin initiation remains a challenge that requires greater clarification of the role of each interdisciplinary team member, integration into routine care, and ongoing quality assurance (Sunaert et al., 2014). A model of care, of primary care physician and nurse team with training and mentoring support from a diabetes educator and a diabetologist, embedded within the primary care systems with simple algorithm and education for patients may facilitate uptake of insulin (Furler et al., 2014).

Monitoring

Monitoring is essential in diabetes care to review the effect of therapy and to examine disease control and progression. Blood glucose monitoring include patient's self-monitoring of blood glucose (SMBG), HbA1c, point of care testing, and continuous glucose monitoring (Standards of Medical Care in Diabetes-2016: Summary of Revisions, 2016). Clinicians should consider the rationale for testing blood glucose using each of these options, and review the result based on the individualized target and recommended clinical guidelines.

Evidence around the benefits of glucose monitoring in patients on insulin therapy is robust while it is less clear for patients with type 2 diabetes not on insulin (Standards of Medical Care in Diabetes-2016: Summary of Revisions, 2016). In type 1 diabetes, a large proportion of adult patients and caregivers of children reported only 20–40% downloaded their SMBG data four times or more in the past 12 months (Wong, Neinstein, Spindler, & Adi, 2015). Furthermore, less than a third reviewed their SMBG data. Those who regularly reviewed their SMBG data had significantly better glycemic control. Meanwhile a review of people with type 2 diabetes over 12 months duration who were not on insulin found that SMBG had no effect on glycemia, patient satisfaction, well-being, or health-related quality of life (Malanda et al., 2012).

Continuous glucose monitoring (CGM) examines instantaneous real-time or retrospective glucose level and glycemic variability. The CGM technology has improved significantly in the past few years to enable online data sharing. Overall CGM is underutilized in clinical practice mainly due to lack of affordability. CGM is primarily used in type 1 diabetes together with an insulin pump and is essential for a closed-loop artificial pancreas (Rodbard, 2016). CGM is particularly useful for patients with a history of hypoglycemia or hypoglycemia unawareness. Among patients with type 2 diabetes on insulin, CGM can be a powerful educational and motivational tool for both patients and their healthcare professionals (Blackberry et al., 2014).

HbA1c is generally reviewed twice yearly; however, when patients are out of glycemic target or have their therapy modified, HbA1c tests are performed every 3 months. HbA1c level is strongly related with risks of developing diabetes complications. Apart from monitoring blood glucose level, ADA recommends regular screening and treatment of macro- and microvascular complications in routine clinical care (Standards of Medical Care in Diabetes-2016: Summary of Revisions, 2016).

The Role of Technology in Patient Treatment Engagement

There have been massive technological advances in diabetes care besides CGM and insulin pumps. Various types of eHealth interventions are available to improve clinical outcomes and patient engagement. Online patient self-management and support tool has the potential to supplement the traditional one-on-one patient clinical encounter (Kaufman, 2010). Web-based tools enable healthcare professionals to service a large number of patients in glucose monitoring, medication review, lifestyle counseling, and social support as well as promoting greater partnerships between patients and their healthcare professionals. Some of the functionalities that have been found useful in engaging people with diabetes include:

- Online self-management support where patients can input and monitor their lifestyle modification, blood pressure, mood, blood sugar against their individualized goals
- Web-based learning, sharing of online information between patients and their healthcare professionals and remote monitoring can facilitate more efficient and timely review and individualized actions
- A “virtual coach” or monitor “virtual support groups or chat rooms or blogs” to offer round the clock support.

Evidence on the use of eHealth in facilitating better health outcomes, capacity of self-manage diabetes, or health service utilization is unequivocal (de Jongh, Gurol-Urganci, Vodopivec-Jamsek, Car, & Atun, 2012). A review of 16 trials covering clinic-based, Internet-based, and mobile phone-based interventions found that mobile phone-based performed better than computer based self-management interventions in improving HbA1c (Pal et al., 2013). However overall benefits in clinical outcomes, mental health, quality of life, health behavior, and resource utilization is limited.

Despite showing great potential to complement or enhance current diabetes care, evidence on how technologies can be used as a patient engagement tool is lacking (Barello et al., 2015). User experience and functionality of the technologies are rarely evaluated in research to date (Lyles, Sarkar, & Osborn, 2014). Furthermore, there is often a mismatch of expectations between patients and their healthcare professionals. For example, patients found Personalized Decision Aid (PDA) to be simple and can offer practical information in their diabetes management. Meanwhile, healthcare professionals viewed PDA as too complex and burdensome for patients (Lee et al., 2016).

A recent study highlights the importance of healthcare professionals’ perceived ability in motivating, engaging, and activating patients in their self-management using mHealth and eHealth devices. Patient engagement is a mediator of healthcare professionals’ ability to motivate patients with type 2 diabetes and patients being activated or taking actions. The ability to motivate patients’ autonomy is also a much stronger predictor of treatment adherence than increased frequency of mHealth and eHealth use (Graffigna, Barello, Bonanomi, & Menichetti, 2016).

Conclusions

Diabetes is a metabolic as much as a psychological disease. It is a progressive disease that requires lifelong commitment to a therapeutic regime and significant lifestyle modification. There is often a mismatch between clinicians focusing on diabetes treatment solely to achieve glycemic targets and patients' dealing with psychosocial issues and competing life demands. The Chronic Care Model provides a useful framework for clinicians to deliver comprehensive and holistic diabetes care.

“...resources (should be) allocated to proactive psychological care that encourages (diabetes) patients to be engaged and goal orientated” (Kirby, 2015).

One strategy does not fit all in people with diabetes. Patient engagement in diabetes treatment needs to start early in the course of the disease and be maintained across life span. Treatment approaches should be individualized and based on patient-centered care particularly given that the bulk of the care lies with the patient. Successful patient treatment engagement requires ongoing support, monitoring, and review. Different types of interventions should be offered at various stages of the disease progression and be adjusted to patients' individual circumstances. Support from trained healthcare professionals and accredited programs are widely available. Additionally, support and networking opportunities online and face-to-face with peers exist and should be recommended. Clinicians need to be responsive to enhanced standards of medical care in diabetes, healthcare system reform, new therapies, and more importantly greater complexity in the disease profile as people with diabetes live longer.

“It must be emphasized that clinical evidence and expert recommendations alone cannot improve patients' lives, but must be effectively translated into clinical management” (American Diabetes Association, 2014).

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