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| Chapter title | Subchapter | Lesson | Content |
| The role of patient engagement in diabetes management | Patient engagement in diabetes: what is it and why do we need it? | Patient engagement aims to educate and motivate individuals to be actively involved with their treatment plan | * Patient engagement – defined as the process of facilitating and supporting the active involvement of patients in their own care – was originally developed to improve clinical trial participation but now has broader applications in patient care. * Patient activation, defined as having the knowledge, skills and confidence to manage one’s own health, is a key part of patient engagement. * Ideally, patients are well informed and motivated to be involved in their own medical care. Therefore, patient engagement is increasingly identified as a key factor in the improvement of health behaviours and outcomes in the management of chronic diseases. * This is especially important for people with diabetes since management relies heavily on the ability of the affected individual to carry out daily self-care and self-management.      * Studies suggest patients with the lowest activation have the highest healthcare costs. Highly engaged patients, by contrast, are more likely to perform health-improving activities (e.g., dietary changes, physical activity), which correlate with better outcomes and lower long-term healthcare costs. |
| Many people with type 2 diabetes currently do not achieve their treatment goals | * Currently many people with type 2 diabetes do not meet their glycaemic, blood pressure or cholesterol targets.      * Around half of people with diabetes either achieve a blood pressure target of <130/80 mmHg or LDL cholesterol levels of <100 mg/dl. Less than 20% of adults with diabetes meet all three of their treatment targets (blood glucose, blood pressure, cholesterol).   Reflection question: How many of your patients achieve their treatment targets?   * There is a lack of global data on current engagement levels amongst individuals with type 2 diabetes. However, studies suggest that uptake and long-term maintenance of lifestyle interventions is low, despite awareness of the benefits. * Additional data suggest that amongst those with chronic conditions, such as diabetes, nearly 50% do not consistently follow recommended treatment regimens and lifestyle changes. * Patient activation is associated with a significant positive effect on glycaemic management and self-management behaviours (especially physical activity, healthy diet, foot care and regular blood glucose monitoring). * Therefore, improving patient engagement is likely to increase uptake and long-term maintenance of lifestyle interventions and improve long-term outcomes for people living with diabetes. |
| Engagement with diabetes has emotional, cognitive and behavioural components | * “Informed opinion and active co-operation on the part of the public are of the utmost importance in the improvement of the health of the people.” – the World Health Organization      * Engagement with health conditions such as diabetes is not a black-and-white process. Rather, there is a continuum on which individuals will fall, as outlined in the figure below. The aim of patient engagement is to drive all patients to become ‘eudaimonic’. Eudaimonia is a Greek word which translates to being in good health or spirit. |
| Barriers to patient engagement | There are many factors that affect patient engagement levels, some of which can be addressed by healthcare professionals | * A barrier to patient engagement is defined as a factor that prevents or reduces the likelihood of an individual using a service, adhering to a treatment plan or maintaining self-care practices. * Sustained beneficial behaviour change, as is required for optimal diabetes management, requires that a person with diabetes, with the support of their healthcare team, continuously makes appropriate choices. * An individual’s ability to do this is affected by many barriers, as outlined below.      * Many of these barriers are beyond the scope of being addressed by individual healthcare professionals (e.g. socioeconomics, education status, social stigma) and some are likely to be permanent, unchangeable barriers that cannot be addressed (e.g. physical disability, occupation, comorbidities). * Instead, patient engagement should focus on modifiable barriers that can be addressed by healthcare professionals (e.g. lack of knowledge, self-empowerment capacity, fears and concerns).   Reflection question: How often do you address modifiable barriers to self-care and engagement? |
| There are multiple emotional and psychological barriers to engagement that should be addressed | * Traditional diabetes care focuses on clinical outcomes such as glycaemic management, weight management and prevention of complications. Despite this, studies indicate that psychological well-being and quality of life are of equal importance to clinical outcomes for individuals with diabetes. * Positive psychological states, such as optimism and gratitude, are associated with improved outcomes including better glycaemic management and lower mortality rates. These positive psychological states are linked with positive health behaviours such as increased physical activity and a healthier diet. * Despite the benefits of good mental health, many people with diabetes experience poor mental well-being. |
| Diabetes distress is associated with worse outcomes and should be managed promptly | * Diabetes and its ongoing management is a significant burden which often results in distressing emotions including depression, diabetes distress and diabetes burnout.      * Diabetes distress and burnout are recognized consequences of the constant demands of diabetes management. Burnout is generally considered an extreme form of diabetes distress where the individual is typically no longer engaged with diabetes management. * Diabetes distress and burnout are associated with lack of engagement in self-care activities. It is important to identify and manage diabetes distress to prevent disengagement and poor glycaemic management. * Many people with type 2 diabetes also associate diabetes with a loss of freedom, which they may occasionally (or sometimes frequently) try to escape, often resulting in a lack of engagement with treatment. * Assessing psychological well-being is important in understanding patient engagement levels. Poor psychological well-being should be addressed with referral to specialist services where necessary. |
| Improving engagement for people with diabetes | Person-centred care is increasingly important in achieving engagement with diabetes management | * Person-centred care involves paying attention to all the various factors that are likely to influence an individual’s ability to be engaged in their health. * In diabetes management, person-centred care is important in improving engagement and is linked to small improvements in clinical outcomes. |
| Good communication from healthcare professionals is critical in boosting the patient experience | * Individuals with lived experience of diabetes should always be treated with dignity and respect. * The WHO advises that lived experience should be considered a form of expertise, alongside traditional forms of evidence in public health policy and practice. * Poor communication between healthcare professionals and patients is associated with misunderstandings about, and poor adherence to, treatment plans, which can result in poorer outcomes. * By contrast, effective communication is associated with improved quality of care and patient outcomes, improved patient experiences and reduced overall cost of healthcare. * To hear more about effective communication with patients, watch the video with Dr Roopa Mehta below.   **<<INSERT VIDEO HERE>>**   * Part of good communication includes consistently using inclusive, destigmatizing language (e.g. people with diabetes NOT diabetics, people living with obesity NOT obese person). |
| People with diabetes should have multiple means of engaging with their healthcare team | * We have established the importance of person-centred care and good communication with people with diabetes. * Part of this includes broadening the ways people with diabetes are involved in their care. For example:   + offering multiple ways of communicating, allowing individuals to choose from the options available the method that best suits their needs, lifestyle and preferences (e.g. face-to-face, telephone, email)   + facilitating access to medical records by people with diabetes   + supporting public awareness campaigns that educate on the importance of diabetes management   + involving patient advocates to support the engagement of people with diabetes   + providing information on support tools such as counselling, peer support groups and coaching   Reflection question: Do you encourage people with diabetes to be involved in their health care by offering multiple ways of communicating? |
| Bridging knowledge gaps is a key aspect of patient engagement | * Data suggest that around 50% of individuals with type 2 diabetes have doubts regarding their knowledge of the condition and have only ‘superficial’ knowledge of type 2 diabetes and its treatment. * Without adequate knowledge, it is unlikely that individuals with diabetes will understand the importance of glycaemic management nor the importance of regular self-management.      * As discussed in the chapter on Lifestyle management for people with diabetes, intensive self-management education (via educational booklets, videos, peer group discussions and follow-up telephone calls) is associated with significantly greater reductions in blood glucose levels and blood pressure versus standard care. * It is likely that this form of intensive self-management education improves patient engagement on multiple levels: emotional, cognitive and behavioural. * Where possible, all individuals with diabetes should be offered structured diabetes self-management education. |
| People with diabetes should have a personalized treatment plan with achievable goals | * Person-centred care means providing individualized, tailored care that considers an individual’s current situation and what they will ideally achieve. * A diabetes management plan should be developed in collaboration between healthcare professionals and individuals with diabetes to maximize the individual’s independence, engagement with healthcare and ability to carry out self-care. * Specific, realistic goals are an important part of any treatment plan for people with diabetes. |
| Peer support can improve outcomes for people with diabetes | * Many people with diabetes report feeling isolated from peers without diabetes. * Peer support is founded on the idea that people living with the same condition can draw on their shared experiences to help each other with knowledge, information and emotional support. * Peer support interventions significantly improved self-efficacy, confidence with diabetes management and self-management behaviours. * Peer support has been associated with a significantly greater decrease in blood glucose levels and improved self-management scores and quality of life compared with usual care. * Peer support activities appear to be particularly beneficial in settings where there is a shortage of healthcare professionals and financial resources. * Current evidence suggests that peer support does not affect the likelihood or severity of diabetes distress, which should be addressed with psychological interventions.      * There is no one correct model of peer support for diabetes – it can take many forms (e.g. weekly meetings, online forums, informal chats) and can include different numbers of people. * Increasingly, with widening access to technology, people with diabetes can take part in peer support online, which is likely to be more accessible for many people.   Reflection question: Do you offer your patients with diabetes the opportunity to access peer support? How could you incorporate this into your practice? |
| Friends and family can have a large impact on an individual’s engagement with diabetes management | * The majority of diabetes self-management is carried out within an individual’s family or social environment. Therefore, family and friends can strongly influence diabetes management, both positively and negatively. * Friends and family can actively support or negatively affect people with diabetes in their management.      * Providing diabetes education to only the individual with diabetes could hinder engagement with self-management, especially in scenarios where an individual does not have full control of their lifestyle habits (e.g. food shopping, meal preparation, presence of unhealthy foods). * Common misconceptions amongst family members regarding those with diabetes are that the individual with diabetes knows more about diabetes than they actually report. Family members frequently report not understanding the needs of their loved one with diabetes, highlighting the need for improved education. * Data support the inclusion of family members in patient education. A review of data across various chronic diseases found that interventions using a family-oriented approach were more beneficial than solely patient-oriented interventions. * A study of older individuals with diabetes found that including their spouse in a diabetes education programme resulted in greater improvements in knowledge, metabolic control and stress levels than individuals who participated alone. |
| Meet Kwame, a 70-year-old man with type 2 diabetes | Let’s reflect on what we have learnt so far in this chapter and begin to put learnings into practice.    Kwame is a 70-year-old retired man who was diagnosed with diabetes 8 years ago. He lives with his wife and has been married for 45 years. They have 3 adult children and 10 grandchildren who visit frequently. Kwame is currently treated with 2,000 mg metformin and 320 mg gliclazide once daily. Last time Kwame was in clinic, you discussed the importance of lifestyle changes and suggested implementing daily walks and reducing carbohydrate intake. He reports to clinic for a routine diabetes appointment. He reports feeling ‘fed up’ of diabetes management and that his family do not understand or accept his treatment and lifestyle changes. His mobility has decreased after a recent fall, and he reports struggling to gain interest to restart his usual physical activities. In recent clinic appointments, Kwame has experienced blood glucose values that are higher than expected. However, he is very reluctant to initiate insulin treatment, citing fear of needles, hypoglycaemia and the reaction of his family.  Vital signs  Weight: 101 kg  Height: 179 cm  BMI: 31.5 kg/m2  Fasting plasma glucose: 7.8 mmol/l (140 mg/dl)  HbA1c: 7.6% (60 mmol/mol)  **Family and personal history**   * No family history of diabetes or heart disease * Recent fall * Background retinopathy, under twice yearly review   **Reflection questions**   * Beyond clinical characteristics, what should you consider when reviewing Kwame in clinic? * Kwame mentions several barriers to engagement with his treatment plan. Which of these barriers could you address as his healthcare professional? * Where do you believe Kwame currently falls on the patient engagement continuum? * Do you feel that Kwame has adequate social and familial support? How could you address this? * Would you make any changes to his treatment plan?   **Now that you have reflected on these questions, see below for an example of how you could respond.**  An individual’s attitude towards self-care is important to consider when assessing the effectiveness of a management plan. Kwame reports feeling ‘fed up’ of diabetes management, which could be an indication of diabetes burnout and/or depression. Screen Kwame for diabetes burnout using the screening tool included in the Learn More section of this chapter. Work with Kwame to address the burden of diabetes management.  Kwame’s barriers to engagement include poor family support, lack of mobility following his fall, low motivation, and fear of treatment intensification. Kwame and his family could benefit from education to affirm the importance of managing diabetes and to address barriers to treatment intensification, such as fear of needles and stigma surrounding insulin use. While Kwame’s lack of mobility cannot be addressed, he can be supported in accessing appropriate physical activity, such as chair-based exercises.  Kwame appears to be in the adhesion stage of the patient engagement continuum where he is usually adherent to his treatment but struggles with the motivation to carry out the daily management tasks and lifestyle changes. Kwame reports taking his medication as prescribed, but his main challenge is applying recommended lifestyle changes (e.g., reducing carbohydrate intake and going for daily walks). At this stage of the continuum, Kwame could most benefit from empowerment and motivation.  Currently, it appears that Kwame is struggling and does not have enough familial support to deal with the demands of daily diabetes management. If possible, offer Kwame and his family a family-orientated education programme. Kwame may also benefit from connecting with other people living with diabetes. Refer him to a peer support group if available. |