Diabetes Self-management: A Lifetime of Work

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Abstract
The International Diabetes Federation indicated diabetes self-management education is the right of all people with diabetes. Diabetes self-management is hard, relentless work and is required throughout the person's life. People require individualised education and health professional and family support to effectively manage their diabetes. Self-management education is more likely to be effective if it is implemented as part of a comprehensive care plan, takes account of the individual's situation and actively involves them in care decisions. Significantly, people with diabetes who never received diabetes education have a fourfold increased risk of complications compared to those who received education.

Introduction

Lifelong self-management is an essential component of optimal diabetes care. Self-management embodies the key values of autonomy, informed-decisions, person-centred care and the right to self-determination. The person with diabetes is expected to be an active participant in his or her care with an interdisciplinary team of health professionals (HPs). Thus, effective self-management depends on the individual acquiring and applying the relevant knowledge and skills and positive attitudes to set goals, problem-solve and make informed decisions about their care. However, there is a wide gap between this self-management rhetoric and actual practice[1].
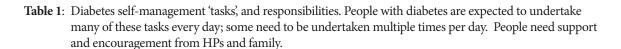
What is self-management?

Self-management is practised in some form by almost everybody, well or otherwise, but is particularly expected of people with chronic diseases such as diabetes. Self-management is also an important aspect of managing inter-current illnesses and minor injuries and pain, and is also a key component of health maintenance and prevention. Many people use complementary therapies (CAM) for this purpose[2]. Significantly, self-management is under the control of the individual: HPs do not recommend, or even know about, many of the self-management activities people undertake.

The UK Department of Health (DOH)[3] defined self-management as:

The actions individuals and carers take for themselves, their children, their families and others to stay fit and maintain good physical and mental health; meet psychological needs; prevent illness or accidents; care for minor ailments and long term conditions, and maintain health and wellbeing after an acute illness or discharge from hospital.

The UK definition is particularly relevant to diabetes because it focuses on wellness and positions the individual within their social context. It is also consistent with the self-management tasks people with diabetes are expected to perform (see Table 1). The International Diabetes Federation (IDF)[4] stated that diabetes education is necessary to achieve effective self-management, is a right of all people with diabetes and, further, indicated that governments need to integrate diabetes self-management education into their national diabetes policies.

Table 1: Diabetes self-management 'tasks', and responsibilities. People with diabetes are expected to undertake many of these tasks every day; some need to be undertaken multiple times per day. People need support and encouragement from HPs and family.

- Integrate diabetes into their daily lives and find a balance.
- Monitor blood glucose including interpreting the result and using it to plan care such as insulin doses, meals and activity regimens.
- Manage multiple medicines (polypharmacy is common), in itself a complex activity.
- Eat healthy, regular meals.
- Exercise/undertake activity regularly.
- Monitor body cues and recognise changes such as hypo-and hyperglycaemia and be able to self-treat these conditions.
- Learn to recognise how diabetes affects their feelings, emotions and moods and the impact negative emotions can have on their short and long term health and their relationships.
- Carry glucose if they are using insulin or sulphonylureas.
- Attend HP appointments.
- Take steps to reduce the risk of short and long term diabetes complications including having regular complications assessments and undertaking foot checks.
- Be able to recognise and manage hypo- and hyperglycaemia and intercurrent illnesses appropriately.
- Know when and how to seek HP advice.
- Wear identification in case of emergency.
- Inform relevant authorities they have diabetes e.g. driving license authorities.
- Attend HP appointments and take their blood glucose monitoring records and other relevant information to the appointment.
- Attend diabetes education programs and make the recommended 'behaviour changes.'

Any discussion of self-management involves considering the individual's behaviours, general and health-related beliefs, and health capability, which encompasses literacy and numeracy, and what the individual wants to achieve for his or her health. HPs need to realise that their own attitudes, beliefs and assumptions can affect the outcome of diabetes education and clinical care encounters (see Table 2).

Table 2: Strategies that support diabetes self-management. There is evidence for the effectiveness of these strategies[7] but they need to be tailored to suit the individual. A co-created approach between the individual and the health professional is more likely to meet the learning needs of the individual.

- Developing effective relationship with individuals.
- Involving the individual in care decisions and supporting their involvement using patient held records, telephone coaching, written and electronic information.
- Using problem-solving and the individual's experience.
- Assisting the individual to set goals and following up on progress towards meeting goals.
- Promoting healthy lifestyles. However, HPs need to be appropriate role models in their own lifestyle (self-management) behaviours.
- Valuing people's self-care efforts e.g. blood glucose testing and helping them interpret the results and use them in their self-care.
- Providing opportunities to share with and learn from other people with diabetes through group education programs and support groups.
- Identifying the individual's stage of change and working with them to effect change.
- Providing personalised written information and decision support tools.
- Enhancing learning and clinical environment.

When diabetes is diagnosed the person needs to:

- Accept and understand the diagnosis.
- Adapt to their changed health status, often difficult in the absence of symptoms, which is often the case in type 2 diabetes.
- Adapt to other changes over time, for example type 2 diabetes is a progressive disease and insulin is required by more than 50% of individuals over time[5]. Thus, self-management capability and tasks are likely change over time

Self-management: a complex set of tasks

Self-management is complex. It becomes increasingly complicated and difficult with a longer duration of diabetes and the development of physical and mental complications. Combined evidence suggests strategies that support self-efficacy and behaviour change can improve self-management capacity, encourage behaviour change, reduce unnecessary service utilisation[6,7] and improve quality of life[8] but the outcomes of individual studies are mixed for a number of outcome measures[9,10a,10b.]

It is difficult to separate the complex inter-related activities that comprise self-management. In addition, an individual's knowledge may not be applied to self-management and may be abstract rather than acquired through experience[11,12]. Many studies are too short to measure knowledge development and retention or determine whether it is integrated into self-management. Thus, knowledge might increase but not be applied to self-care; therefore, knowledge tests might have limited applicability to self-management and health outcomes[12]. Alternatively, the outcome measures and processes might be appropriate, but be undertaken at an inappropriate time/s. Measurement time frames are often constrained by available resources and funding in research projects.

However, most self-management is assessed and measured in clinical practice rather than in research settings but such information is not regarded as 'evidence.' 'Learning health care' initiatives suggest the care of individuals can be improved by using information about other people with similar conditions which is available in the growing body of linked databases. Learning health care may play an increasing role in generating evidence and management decisions in the future[13].

Self-management education and support need to be implemented as part of a comprehensive care plan that takes account of the individual's health status, social situation, beliefs, culture and goals. Table 1 depicts some of the usual day-to-day diabetes self-management tasks. Many of these tasks are performed multiple times each day. Table 3 illustrates some of the factors that can affect self-management.

Table 3: The inter-related factors that affect self-management either positively or negatively. People with positive attitudes tend to achieve better outcomes than those with negative outcomes. Health professionals could reflect on these issues when assessing and discussing an individual's self-management behaviours.

Person with diabetes	Diabetes	Therapy	Health professional
Does/does not follow the care plan.	• Long duration of diabetes associated with beta cell decline in type 2 leading to reduced insulin secretion and the need for insulin over time.	• Appropriate/inappropriate prescriptions: medicine choice, dose, dose interval, duration, timely change e.g. from oral agents to insulin in type 2.	• Adequate/ inadequate knowledge and competence
Adequate/Inadequate health capability, knowledge and/or skills—may not understand what is said or required, may have low health literacy and/or numeracy.	• Hypoglycaemia • Many people with type1 develop hypoglycaemia unawareness over time • Temporary cognitive changes affect decision-making • Hypoglycaemia creates fear: some people 'run their blood glucose high' to prevent hypoglycaemia (reduce their risk).	• Reduced absorption, distribution and metabolism due to renal and/or liver disease	• Beliefs, attitudes and diabetes explanatory models
Beliefs, attitudes and diabetes explanatory models.	-	-	-
Socioeconomic factors such as access to resources and support	-	-	• Behaviour-role model to other HPs and people with diabetes

Person with diabetes	Diabetes	Therapy	Health professional
Stress and illness	• Hyperglycaemia in the short term reduces mood and causes lethargy in the long term has significant effects on organ and tissues and mental health	• Diabetogenic medicines especially corticosteroids and antipsychotics	• Assumptions about individual that can be influenced by the opinions of other HPs
Genetic makeup	• Long term complications such as cardiovascular disease, renal disease, neuropathy and vision defect,	• Inappropriate, conflicting or no information	• Positive/negative orientation
Presence/absence of complications.	-	-	• Available resources and other support
Age	-	-	• Age
Positive/negative orientation	-	-	• Health status
Presence of other comorbidities such as arthritis	-	-	• Culture
Culture	-	-	-

Strategies to support diabetes self-management range from passive activities such as providing oral and written information, to initiatives that actively involve the individual in care decisions, for example motivational interviewing, coaching and cognitive and behavioural therapies. In addition, education needs to be relevant to the individual's age and health literacy and numeracy, thus, other people such as parents and carers may be involved in supporting self-management. Just providing information is unlikely to result in effective self-management[7]. Importantly, people with diabetes who never received diabetes education have a four-fold risk of complications compared to those who received education.

Self-management is hard work

Self-management is hard, relentless, often frustrating work that can lead to 'diabetes burnout' in the longer term. People with diabetes:

• are anxious about gaining weight: many diabetes medicines contribute to weight gain (for example, sulphonylureas, thiazolidinediones, insulin);

• worry about having to cope all the time is hard; 'there are no holidays from diabetes';

• are fearful of hypoglycaemia and developing other complications that affect their well-being and independence;

• often 'do not feel any different,' even when they undertake self-management

• feel HPs do not provide sufficient support or recognise or understand their emotional distress; and

• often do not recognise the depressing effect of living with a chronic illness[14].

Thus, self-management is often 'inadequate' by HP standards and people are described as 'non-compliant' or 'non-adherent'. Some of the inter-related reasons that influence self-management are depicted in Table 3.

Importance of supportive relationships

Establishing a supportive relationship with the individual with diabetes is important to achieving optimal outcomes[15] and has a significant effect on outcomes. HPs must have the knowledge and skills to establish and maintain a relationship with the individual. In addition, people with diabetes often value the support of other people with diabetes in formal and informal scenarios[16].

Measuring the outcomes of self-management

A primary aim of clinical care is to monitor the individual's health status and self-management capacity. Research often compares 'standard' education with various other models and measures a range of outcomes, which may or may not reflect the individual's goals or health status. One could ask whether structured guidelines and metabolic targets derived from such evidence is consistent with current patient-centred, holistic, empowerment self-management models. Holistic theory suggests we should measure the individual's outcomes according to his or her self-selected goals and health status[12,7].

Clinical assessments are undertaken using formal measures such as tests of cognitive function, quality of life (QOL), depression, knowledge and skills and laboratory data such as HbA1c and lipids. Many valid

general and diabetes-specific tools are used to measure these parameters and are also used as outcome indicators in research projects. A great deal of information about individuals can be obtained through observation, asking questions, and from their families and medical records, for example, self-blood glucose monitoring. Significantly, most clinicians and researchers only measure one part of the education/relationship: the person with diabetes' performance. While clinicians often measure 'patient satisfaction' with services, they rarely measure their ability to teach and establish a supportive relationship or actively reflect on how their behaviours, attitudes and assumptions impact on people with diabetes[17].

Common outcome measures used to assess self-management

Commonly used self-management outcome measures include:

• Knowledge change before and after an education program: however, the way individuals use information may not be measured, and frequently such measures do not reflect knowledge development or account for experiential learning;

• Behaviour change such as adhering to recommended dietary and activity advice;

• Quality of life and psychological measure;

• Indicators of metabolic control such as HbA1c and lipids, which can be affected by factors besides self-management and need to be considered as part of the whole picture;

• Adherence to medicines regimen such as having prescriptions filled, using medicines 'as directed,' HbA1c, lipids and blood pressure;

• Presence of short- and long-term complications;

• Service use including presentations to hospitals/emergency, occasions of service an d waiting times;

• Patient satisfaction; and

• Mortality rates.

Summary

Self-management is very important to optimising outcomes for people with diabetes. It is measured in various ways to address the needs of various stakeholders. There are two inter-related overall measurement processes: research and clinical practice. Compilations of individual data extracted from linked data bases will have an increasing influence on self-management education and diabetes care in the future. Most existing measurement tools can be used in both

research and clinical settings. However, we need to recognise that the HPs' performance affects self-management outcomes and the measurement of HP's performance as a key component of care—doing so is a challenge.

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