

Diabetes self-management

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The burden of diabetes is growing, with 347 million people currently affected worldwide,¹ and that number is projected to increase to 552 million by 2030.² Complications of diabetes range from an increased risk of heart attack, stroke, and amputation to blindness and kidney damage: a 60-year-old man, newly diagnosed with type 2 diabetes (without pre-existing cardiovascular disease) can expect to lose 8–10 years of life if his diabetes is poorly controlled.³ The need for effective, safe strategies in managing diabetes to reduce the risk of complications and improve life expectancy is evidently important.

The question then arises about how we facilitate improvements in patient care. There are biological markers that predict future complications in diabetes,⁴ but achieving significant reductions in those targets in practice is often difficult.⁵ There is a growing body of evidence that supports the idea that improving self-care improves outcomes – including the clinically important biological outcomes, and the cognitive and emotional aspects of diabetes that need to be managed for the individual to achieve a sense of control and wellbeing, while living with this chronic illness.⁶

Diabetes and self-management

Improving self-care is likely to be an important strategy in the future for improving the safety of patients with diabetes. However, it is clear that diabetes self-care presents some risks to patient safety. These risks include:

- Not self-monitoring glucose levels when on hypoglycaemic agents like insulin
- Not taking hypoglycaemic medication at prescribed times
- Incorrectly changing doses of insulin to compensate for missed medication or acute illness
- Failing to examine feet regularly for injuries, especially in the context of diabetic neuropathy.

These risks can be avoided by the patient adopting a disciplined approach to the management of their diabetes, and patient education programmes can help instil the routines that are at the foundation of safe self-management.

Corbin and Strauss described three distinct elements of coping with a chronic illness⁷:

- 1 Medical/behavioural management: for example, diet, exercise, taking medication, attending follow-up
- 2 Role management: for example taking on the ‘patient’ role, the effect on relationships, ideally becoming an equal partner in managing the illness
- 3 Emotional management: dealing with the fear, anxiety, stress, anger, frustration, or depression that may accompany living with a chronic illness.

Lorig and Holman used this model as a basis to describe six skills required for self-management⁸:

- 1 Problem solving
- 2 Decision making
- 3 Resource utilisation
- 4 Formation of a patient–provider partnership
- 5 Action planning/behaviour change
- 6 Self-tailoring.

Diabetes self-management education (DSME) is a formal term used to describe the on-going process of facilitating the knowledge, skill, and ability necessary for diabetes self-care.⁹ Domains of self-care particularly likely to have an impact on the safety of patients with diabetes include problem solving and self-tailoring around the use of high risk medication such as insulin, and self-directed behavioural change.

The evidence for diabetes self-management education

Patients who receive no education about their diabetes appear to be four times as likely to develop complications as those who do,¹⁰ so the need for patient education is well established. Several evidence based programmes to improve self-care are already widely used, and examples of these DSME programmes include:

- The Diabetes Education and Self Management for Ongoing and Newly Diagnosed (DESMOND) programme

for people with newly diagnosed type 2 diabetes¹¹

- The Dose Adjustment For Normal Eating (DAFNE) programme for people with type 1 diabetes¹²
- The Diabetes X-PERT Programme for people with type 2 diabetes.¹³

Examples of general patient self-management programmes include:

- The Chronic Disease Self Management Programme (CDSMP)¹⁴
- The Expert Patient Programme (EPP)¹⁵

The programmes listed above are complex interventions,¹⁶ with several interacting components. They are often heterogeneous and targeted at different populations, so synthesising the evidence on diabetes self-management is difficult to do and not easy to interpret. However, there are a number of excellent reviews in this area.¹⁷

As expected, these programmes do increase patient knowledge and skill in managing their diabetes, thereby reducing the risk of patients experiencing harm secondary to their diabetes, with those programmes of longer duration achieving greater success. While patient knowledge and skill improve over the time observed (≤ 1 year), success in weight loss and metabolic control appear to fade over time, with improvements in blood sugar control peaking at one to six months and declining after six months. Depression and quality of life scores improve with these programmes, however, and these gains do not seem to diminish over time.

Challenges faced by current face-to-face interventions

1 Complexity and limitation

These are complex interventions and the “active ingredients” that make them effective are not yet known. A recent meta-analysis of diabetic education programmes commented that the quality of reporting of important design issues was often ‘limited and vague’, making them difficult to compare or reproduce, and very little psychological research had been implemented in their design.¹⁸

2 Setting and convenience

Most education programmes are delivered in the clinical setting and there is less evidence on the use of DSME programmes in other locations; however, a review found evidence to support their use in community gathering places for adults with type 2 diabetes, and at home for adolescents with type 1 diabetes,¹⁹ so there appears to be potential for self-management interventions outside traditional clinical settings. However this would have cost implications for face-to-face self-management training.

The ability to offer patient education at any time the patient desires might also be important for increasing uptake; for example a survey by the Pew Internet & American Life Project, reported by Strecher,²⁰ found that ‘93% of those using the Internet for health information thought it was important to obtain the information at any hour’ – not a feasible option for traditional face-to-face education programmes.

3 Duration of effect

Another issue appears to be that many of the benefits of DSME programmes diminish rapidly after the interventions have ended, with duration being a predictor of a programme’s success.²¹ The American Diabetes Association (ADA) guidelines specify the need for continuing diabetes self-management support, which it defines as ‘activities to assist the individual with diabetes to implement and sustain the on-going behaviours needed to manage their illness.’⁹

4 Cost

Economic data for these programmes is not well documented, but a review for NICE found cost estimates ranged from £66 per person attending a diabetes centre based teaching programme for three afternoons, to £545 for the DAFNE programme.²² However, if we take into account the need for ongoing diabetes self-management support, these costs would significantly increase.

5 Uptake

ADA guidelines on self-management education advise that DSME is a critical element of care for *all* people with diabetes and is necessary in

order to improve patient outcomes.⁹ However, actual provision of diabetes education is patchy. For example, a survey in the UK for the Healthcare Commission in 2006 noted that only 11% of people with type 2 diabetes self-reported that they had been offered a structured education programme.²³ In the USA, previous surveys have shown that only between 35% and 45% of patients received DSME.^{24,25}

6 Equity

In American patients with type 2 diabetes, exposure to DSME has been shown to be associated with younger age, black race, residence in the Midwest, higher level of education, presence of diabetes complications, and higher income.²⁴ Existing interventions do not appear effectively to target the whole spectrum of patients with diabetes. Similarly, early implementation studies of the UK based (generic) Expert Patient Programme courses tended to draw in people who were already committed to self-management, and who tended to be white, middle class, and well educated.²⁶ Improving equity and thereby reducing variation in the care patients receive is critical to improving patient safety.

7 Changing needs

Tailored interventions in which programmes are individualised by patient characteristics and adapted to patient needs are potentially more effective at behaviour change.²⁷ Group based DSME interventions have limited flexibility in how much they can be adapted to suit the individual needs of different patients. Any changes to the intervention are potentially complicated and expensive to implement and disseminate; change may involve reprinting large volumes of written information, retraining staff, or recruiting new staff with different language abilities.

8 Barriers to implementation

A national survey of access to DSME programmes in the U.S.A. highlighted a number of barriers identified by educators, physicians, and patients.²⁸

- Educators of people with diabetes felt that some barriers were related to the referring doctors: physicians did not educate patients

about the importance of DSME, did not recognise programme quality, did not want to lose control of their patients, did not know how to refer, or did not believe that DSME interventions were effective.

- Physicians' beliefs that were barriers included feeling that patients were told things the physicians did not agree with, patients were not interested in DSME, there were not enough referral sources, or the referral process was not easy.
- Patient beliefs that hampered access to DSME included ideas that their doctor told them everything they needed to know, they already knew what they needed to know, they felt that their doctor did not think DSME was important, or they did not need it because they did not have any problems.
- Both educators and physicians believed that some of the barriers to DSME were that patients did not think they needed DSME, they would not be able to fit it into their schedules, it would not be covered by insurance, or it was too expensive.

While not all of the opinions described above would affect every patient or health system, it is important to consider the relevant ones that resonate with prevalent attitudes that might hinder uptake of education programmes.

9 Time taken

As mentioned above, structured education programmes require a significant investment of time from the patient, ranging from six hours (DESMOND) to one week (DAFNE). Integrating that sort of commitment into a busy life can be too much of a barrier for some. Given the burden of care needed to manage a chronic lifelong illness, clinical interventions need to be 'minimally disruptive'²⁹ and require their providers to have flexible and varied methods for their delivery.

The potential for new technology

New technology offers some exciting new opportunities to expand on the success of DSME programmes and counter some of the difficulties.³⁰ Desktop, laptop, and handheld computers and mobile phones have the processing power and connectivity

to allow remote access to information and algorithms that may be able to target most of the components of existing face-to-face DSME programmes. The programmes also have the potential to be relatively cheap, easily distributable, delivered at multiple locations (clinical, community based, at home, or on the move) at times convenient for patients, offer patients as many interventions as they need or want, offer continuing support, send out automatic reminders, and present information in an attractive, tailored format to suit patients' needs. Such connectivity also allows easy formation of social networking and peer support groups beyond traditional clinical settings.

Face-to-face diabetes self-management interventions often show evidence of short term benefits that fade over time.³¹ Computer based interventions have the potential to provide ongoing self-management support to reinforce the benefits over time. However, a recent Cochrane review of computer based diabetes self-management interventions showed small, short term improvements in HbA1c that appeared to fade over time like those of face-to-face interventions.³²

In order to improve the care of patients with diabetes, self-management strategies need to be developed. Using new technology may offer opportunities to overcome challenges in supporting self-management. However, the efficacy of these technologies is yet to be proved.

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