

Empowerment: giving power to people with diabetes

Danny Meetoo and Harry Gopaul

ARTICLE POINTS

1 Education has long been recognised as the cornerstone of diabetes self-care management.

2 Healthcare professionals need to be aware that self-care management is a complex life-long undertaking by the person with diabetes.

3 Empowerment is an enabling process through which individuals make informed decisions about their own illness behaviour and to be fully responsible members of the healthcare team.

4 Those who are empowered are more likely to adhere to self-care management decisions, thus minimising the risk of micro- and macrovascular complications of diabetes.

KEY WORDS

- Diabetes
- Empowerment
- Education
- Self-care

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Introduction

Recent years have seen increasing calls for empowerment of both healthcare professionals and the people they serve. This article explores the concept of empowerment in the context of diabetes care. It discusses the limitations of the medical model with regard to empowerment, and the potential of the empowerment model to promote self-care. Finally, it demonstrates how the empowerment process can help individuals to make informed decisions in order to develop strategies for long-term management of their diabetes.

The 1989 St Vincent Declaration, an initiative resulting from collaboration between the World Health Organization and the International Diabetes Federation, and endorsed by the European Governments, recognised that diabetes mellitus poses major life-threatening problems (Krans et al, 1992). Its two general goals for people with diabetes were:

- Sustained improvement in health experience and a life approaching normal expectation in quality and quantity.
- Prevention and cure of diabetes and its complications by intensifying research effort.

It did, however, acknowledge that these targets would not be possible without the active participation of people with diabetes.

In the UK, this sentiment has been echoed in the *National Service Framework (NSF) for Diabetes: Standards* (Department of Health [DoH], 2001). One of its aims is:

'... to ensure that people with diabetes are empowered to enhance their personal control over the day-to-day management of their diabetes in a way that enables them to experience the best possible quality of life.'

Running parallel with this is the *NSF for Diabetes: Delivery Strategy* (DoH, 2003). This document emphasises the importance of developing and implementing a patient-held record incorporated within a care plan. It aims to enable people with diabetes and their professional team to closely monitor

the progress of the management of their diabetes. Achievement of any mutually agreed goals entered in the patient-held record will further motivate people with diabetes to become empowered to adhere to their self-care regimen.

Background to empowerment

The latter half of the 20th century has witnessed the rise of the 'empowerment movement' (Menon, 2002). This concept has emanated from the work of the Brazilian philosopher, Paulo Freire (1970). He developed a strategy to teach critical consciousness to the impoverished people of Brazil.

Freire's approach proposed a dialogue in which everyone participates as equals and co-learners. He stressed a relationship of equality and mutual respect between group members and facilitators who engaged the group in problem-posing dialogue designed to help them elucidate the root causes of problems they identified (Wallerstein and Berstein, 1999).

The empowerment model

In recent years, the healthcare arena has been characterised by increasing calls for empowerment of both healthcare employees and the community members they serve (Menon, 2002). The empowerment concept has therefore become very popular in the healthcare literature and setting (Wallerstein and Berstein, 1999). Within health care, the empowerment

philosophy of patient care is based on certain tenets (Gibson, 1991; Feste, 1992):

- Most healthcare consumers are responsible for making important and often complex decisions about their care.
- Patients are the ones who experience the consequences of both having and treating their illnesses, so they have the right to be the primary decision-makers regarding their medical condition.
- Healthcare professionals cannot empower people with diabetes: as empowerment is a process that takes place within the individual they can only create a climate in which a patient desires to be (or indeed, desires not to be) empowered (Falk-Rafael, 1995).
- Healthcare professionals need to surrender control for cooperation in order to create an environment that fosters understanding of beliefs, values and expectations.
- There needs to be mutual respect between the healthcare professional and the patient.
- Trust between the healthcare professional and the patient is a necessary condition if the health outcome is to be achieved (Mechanic, 1996).

Empowerment and the healthcare professional

Although the healthcare provider should be involved in the decision-making process, the final determination of what is best for the patient is both the right and responsibility of the individual (Gibson, 1991; Feste, 1992). As Lather (1991) notes, the concept of 'empowerment is a process one undertakes for oneself; it is not something done "to" or "for" someone'.

Consequently, Funnell et al (1991) state that the goal of empowering patients is to promote autonomous self-regulation in order to maximise the individual's potential for health and wellness. Patient empowerment is therefore an outcome. People with diabetes are empowered when they have the necessary knowledge, skills, attitudes and self-awareness to influence their behaviour and that of others in order to improve the quality of their lives. The enabling act of empowerment, therefore, begins with information and education.

This includes goal setting, which, according to Funnell and Anderson (2004), is a five-step process:

- The first two steps aim to define the problem and to ascertain whether the patient has any beliefs, thoughts or feelings that may support or hinder his/her efforts.
 - The third step is to identify long-term goals towards which the patient will work.
 - The fourth step enables the patient to choose and commit to a behavioural change that will help him/her to achieve the long-term goals.
 - The final step is for the patient to evaluate his/her efforts and to identify what he/she has learned in the process.
- This approach to empowerment eliminates the notion of success or failure. Instead, all efforts represent opportunities to learn more about the true nature of the problem, related feelings and barriers, and to continually develop effective strategies to achieve the set goals with ongoing support of the care provider.

Education has long been recognised as the cornerstone of the diabetes management regimen (Hurley and Shea, 1992). However, knowledge alone is an insufficient criterion for determining an individual's capability to incorporate the necessary behavioural changes. For example it has been reported that undertaking a self-care management regimen is more difficult than dealing with the diagnosis of diabetes (Anderson, 1985).

It is, therefore, important for the nurse to be aware of how complex the treatment regimen can be, particularly for individuals with type I diabetes mellitus. Their lives revolve around a temporal regularity in which insulin doses must be calculated and administered at precise times. Meals, exercise, rest and monitoring of blood glucose parameters must be planned and performed to match those times when insulin levels are expected to drop or peak.

In the context of diabetes education, the concept of empowerment is thus based on several assumptions:

- Diabetes care is provided by the person who lives with this condition on a day-to-day basis.
- Diabetes affects the emotional, spiritual, social, physical and cognitive aspects of a person's life.

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2 The goal of empowering patients is to promote autonomous self-regulation in order to maximise the individual's potential for health and wellness.

3 People with diabetes are empowered when they have the necessary knowledge, skills, attitudes and self-awareness to influence their behaviour and that of others to improve the quality of their lives.

4 Provision of information and education is the first step to empowering patients.

Table 1. Topics central to improving the knowledge of the person with diabetes

- Understanding diabetes
- Using medication such as insulin and oral antidiabetic agent (if applicable)
- Dietary advice
- Smoking cessation (if applicable)
- Physical exercise
- Effects of saturated fats
- Dietary modification
- Monitoring blood glucose
- Hyperglycaemia and hypoglycaemia
- Blood pressure control
- Complications: prevention, early identification, reporting and treatment
- Family planning and pregnancy
- Effects of other medication on diabetes control
- Lifestyle issues: driving, employment, travel and school
- Effects of other illnesses and infection on diabetes control
- Foot care
- Retinal screening

- People with diabetes experience both the burdens and benefits of their diabetes and self-care choices.
- Individuals diagnosed with diabetes need information about both the condition and themselves to make informed choices.

A helping hand

In order for people with diabetes to become actively involved in their own care, it is important for the nurse to equip them with the information needed for effective self-management. The person with diabetes also needs to understand the healthcare system and how to utilise it when necessary.

This can only be achieved if the education programme contains all the relevant topics to improve knowledge. As shown in the extended list (*Table 1*), these topics should include knowledge about diabetes, dietary composition (particularly with regard to reducing saturated fats), their impact on blood glucose levels, as well as the effect of other lifestyle issues such as exercise, smoking cessation, alcohol intake and illness. How and why insulin needs to be adjusted

to accommodate these factors also need to be explained. The importance of attending the diabetes clinic and eye appointments should be clearly emphasised. It could be argued that those who are thus empowered benefit both psychologically and in terms of maintaining long-term metabolic control.

This approach to diabetes management, as Cavan (2001) argues, shifts from a purely traditional medical model to the provision of effective educational interventions to facilitate successful self-care, with immediate medical needs met at diagnosis and at intervals thereafter (*Figure 1*).

However, not everyone with diabetes may be comfortable with taking responsibility for their lives. In such cases, the individual may prefer a more direct approach. As Funnell et al (1991) assert:

'These patients are transferring the power back to the health professionals, or empowering the health professional to make those decisions. The philosophy of empowerment should acknowledge and respect a person's wish to transfer power back to the healthcare professional. The choice remains with the patient, even when the choice is to decline power. Patients who choose to remain the passive recipients of care are responsible for that choice and its consequences.'

The medical model

In the medical model, treatment goals and plans often ignore the emotional, spiritual, social and cognitive aspects of living with a chronic disease such as diabetes (Arnold et al, 1995). Consultations – which are brief – are led by clinicians who, by questioning and assessing the person with diabetes, seek to identify clinical 'problems', and whose main focus is to ensure that eye and foot examinations have been undertaken.

During a medical visit, there may be opportunities to see a nurse or dietitian. Too often these encounters are based on referrals by the doctor, and on his/her terms rather than on the needs of the person with diabetes. Consequently, the medical model may well lead to conflict between healthcare professionals and people with diabetes. They may view each other as 'opponents', so that referral to a

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dietitian might be perceived on both sides as 'punishment' for being overweight, while referral to a nurse may be viewed as 'punishment' for having a high HbA_{1c} (Cavan, 2001).

Furthermore, the medical model does not necessarily meet the psychological needs of the person with diabetes. For example, the diagnosis of diabetes is often a shock and frequently devastating to the individual. Failure to effectively address this important aspect of psychological care may lead to poor self-esteem and low motivation to adopt self-care behaviour (Jacobson et al, 1997).

Moving towards empowerment

A major goal of patient empowerment is to improve adherence to agreed self-care regimens. People with diabetes are often unsure whether they can achieve the set goals. To become empowered, they need information, assurance, support and caring. The motivational interview model developed by Rollnick et al (1992) aims to assist healthcare professionals in helping patients manage their illness experience.

The adapted steps (see below), extracted from the work of Rollnick et al (1992), may be applied in full or in part, depending on where the individual is located in the process.

Open strategy: lifestyle

This strategy begins a conversation that encourages the person with diabetes to discuss his/her health beliefs. Consequently, an overall picture is presented, which may be used as a basis to determine whether the patient's lifestyle warrants change or modification.

A typical day

Knowing the person's typical day may help the nurse in several ways. It allows self-care strategies to be tailored to the person's daily routines. It may also help the nurse to understand how the person's daily routines may impact on his/her ability to manage the condition.

The good things and the less good things

This strategy assists the nurse in continuing

to build a rapport, and allows exploration of the person's perception of diabetes, knowledge base and concerns about the condition. Many people with diabetes have misconceptions about their condition. They may associate diabetes with complications and fatalistic outcome. Such information enables the nurse to respond in an empathic manner.

Exchanging information

The amount of information given to a person with diabetes should be based on assessment and negotiation. It makes no sense to try to tell the person more when he/she is not ready to hear it. When the person is ready for more information, it

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2 Failure to address this effectively may lead to poor self-esteem and low motivation to adopt self-care behaviour.

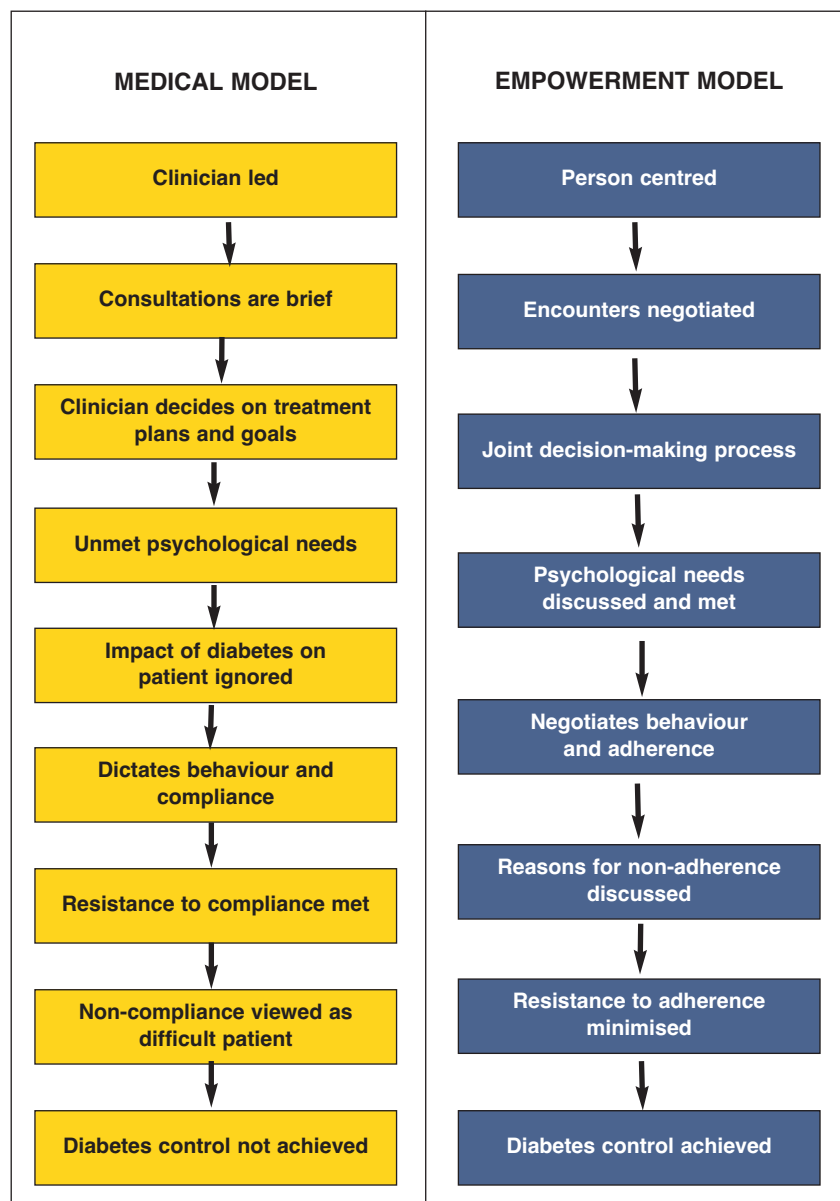


Figure 1. The medical model versus the empowerment model.

should be provided in an unbiased, non-judgmental manner. Where diabetes medications are concerned, their action, any possible side-effects, and storage should be explained in a style that is readily understood by the person with diabetes.

The present and the future

This strategy allows people with diabetes to discuss their expected outcomes as a result of undertaking the prescribed self-care activities. Expected outcomes may include weight loss, normal blood glucose level, and prevention of complications. Any concerns for the future should be addressed in a compassionate and non-judgmental manner.

Helping with decision-making

In achieving this step, the nurse might, for example, ask questions such as 'What are your thoughts about managing your diabetes?', as suggested by Squier (1990). It is very important to be patient when questioning the person with diabetes as he/she may vacillate between changing and staying the same. Although the approach to asking the questions is neutral and non-judgmental, they do not necessarily produce a desired outcome. For example, the patient may change by making a positive decision towards self-care management or he/she may choose to ignore the support on offer.

Conclusion

The empowerment philosophy clearly represents a shift in attitude for both patients and healthcare professionals. In the context of diabetes, there is perhaps an understandable apprehension that allowing people with this condition to learn about the care and education they should receive may give rise to an increasingly demanding population of patients.

It cannot be denied that healthcare professionals who routinely practice empowerment have seen the emergence of well-informed people with diabetes, who are aware of their rights. Frank and honest information about the lack of resources and other factors that impede the delivery of appropriate care will result in a better-informed population who have a significant effect on our healthcare providers and political figures. Consequently, people with

diabetes are our best allies in our fight to deliver the optimum level of care. Facilitating empowerment to people with diabetes and their families is therefore well worth the time and energy required to achieve it. ■

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1 The empowerment philosophy represents a shift in attitude for both patients and healthcare professionals.

2 Empowerment of patients has led to the emergence of a population of well-informed people with diabetes, who are aware of their rights.

3 Frank and honest information about the lack of resources and other factors that impede the delivery of appropriate care will result in a better-informed population.

4 This population could have a significant effect on our healthcare providers and political figures.

5 People with diabetes who are empowered are our best allies in our fight to deliver optimum level of care.