Four Theories and a Philosophy: Self-Management Education for Individuals Newly Diagnosed With Type 2 Diabetes

T. Chas Skinner, PhD; Sue Cradock, RGN, DipN, MSc; Francesca Arundel, RGN, BSc; and William Graham

Many reviews of educational interventions for people with diabetes have criticized the lack of reported theory in the development or descriptions of these programs.^{1,2} Yet these reviews seem to ignore a fundamentally more important omission in the self-management education and behavior change literature—a lack of reporting of the projects' philosophies of care. A program that is designed to persuade or motivate individuals with diabetes to do what health care professionals think they should do, for example, is substantially different from a program built on the philosophy of supporting individuals to achieve their own goals for diabetes management. This issue of philosophy is of fundamental importance because it influences the theories that may be used, the educators' attitudes (cognitive, affective, and behavioral), and the content and style of any educational material and interaction.

This article reports on the development of a series of self-management education workshops for individuals newly diagnosed with type 2 diabetes. It focuses on how different theories from health psychology have been used to guide the development of the workshops and how these theories have been implemented in delivering the workshops.

Context

The Health District of Portsmouth, U.K., has a population of 560,000, an estimated 17,000–18,000 of whom have diabetes (3% prevalence). To develop diabetes services for this population, the Diabetes Service Advisory Group, which represents all of the primary and secondary care organizations involved in delivering diabetes services locally, held a workshop facilitated by the local Health Authority (governing body for the Health District). Workshop participants, including health care professionals,

commissioners of health services, and people with diabetes, were asked to set priorities for the delivery of better health care for people with diabetes in the locality. "Patient education at diagnosis" topped the resulting list of priorities.

One of the primary care groups, which served a population of 190,000, then highlighted diabetes as one of a set of priorities within its own Health Improvement Plan for the locality and funded an education initiative to provide workshops aimed at individuals newly diagnosed with type 2 diabetes. The goals of this initiative were:

- to provide individuals with information regarding the causes, effects, and management of type 2 diabetes;
- to enable newly diagnosed individuals to discuss and explore their experiences, frustrations, and successes in living with diabetes;
- to ensure that those living with type 2 diabetes are aware of their specific health risks for developing the complications of diabetes;
- to provide an expert forum for participants to discuss methods of reducing their identified risk factors; and
- to support individuals in developing their own diabetes management plan.

Philosophy

As part of the initial workshop development process, project team members agreed on a core set of philosophical principles against which they could judge all of their work on the initiative. This was done through the team members describing their core principles of care and what they felt the workshops should provide for participants. Through discussing and clarifying these initial aspirations, team members reached the following consensus on their underlying philosophy for the workshops:

- All workshop facilitators acknowledge and accept that people with diabetes are completely responsible for their condition and that this responsibility is nonnegotiable, indivisible, and inescapable.
- 2. All participants will make decisions that move them toward a direction of best possible physical and emotional health, as they understand it.
- 3. Individuals with diabetes will be given an open, honest, and complete picture of diabetes.
- Individuals will be supported in processing and understanding this information.
- 5. Health care professionals will view all individuals with the utmost respect and unconditional positive regard. Empathy, warmth, and enacted equality of all individuals present are essential for the success of any educational interaction.

In essence, team members summarized their philosophy as that of "informed choice," which they felt is the key to empowerment,^{3,4} based on a humanistic view of the individual.

A review of the literature failed to identify any programs for those newly diagnosed with type 2 diabetes that espoused or fit with such a philosophy. Therefore, the workshops were developed from scratch.

Given the principles listed above, the project team—a health psychologist, two diabetes nurse specialists, and an individual with type 2 diabetes who had recently started using insulin—set out to develop daylong workshops using an iterative process. The team developed an initial outline and workshop booklet, which was then implemented in two pilot workshops. Different team members facilitated different sections of the workshops, trying out their own ideas for engaging the group while adhering to the underlying philosophical principles. The team then reviewed the pilot

efforts, focusing on those elements that seemed to work well and developing these further. This process was repeated in another series of workshops until all group members were happy with the format, which was then followed as the standard for all subsequent workshops.

Four Theories

After reviewing the pilot workshops, team members agreed that it was of fundamental importance for the workshops not to be guided by an overarching philosophy, but also to encompass sound theoretical principles for effective self-management education and the development of individuals' motivation and sense of control over their diabetes. Toward this end, four key theories were used to guide the delivery of the workshops.

Self-Regulation Theory⁵ focuses on individuals' illness representation or personal model of diabetes as a key determinant of their behavioral and emotional responses to illness.

Research in this field has identified five core elements, across cultures, that form our illness representations:

- Identity (What is diabetes? What symptoms are experienced? What is actually wrong?)
- Cause (What caused my diabetes?)
- Timeline (How long will this last?)
- Consequences (How will diabetes affect me now and in the future?)
- Treatment effectiveness (How good is my treatment at controlling or curing my diabetes?)

Research in adults and adolescents with diabetes has consistently demonstrated that individuals hold a diverse set of illness beliefs that do not fit the medical view of diabetes and that these beliefs are robust and proximal determinants of patients' emotional well-being and self-care behavior. 6,7 Individuals often have relatives or know people who have diabetes, have seen media portrayals of people with diabetes, and have heard about some of the complications of diabetes. Therefore, individuals come to the workshops already having a personal model of diabetes. However, these beliefs are not necessarily accurate, up-to-date, or complete.

The Portsmouth workshops seek to elicit individuals' beliefs and knowledge about diabetes so that misunder-

standings and misconceptions can be addressed and revised. One of the benefits team members have noticed from this exercise is that individuals who have not been aware of any symptoms of diabetes recognize retrospectively that they have been experiencing these symptoms without attributing them to their diagnosis of diabetes. The exercise has also revealed that some participants hold very interesting beliefs about their illness, such as the woman who said, "I don't think it is diabetes. I just think the walls of my womb are falling in because I am peeing so much of the time."

Dual Process Theory⁸ was used to guide the process of education and addressing individuals' current understanding of diabetes. Dual process theory makes a distinction between heuristic and systematic processing.

Much patient education relies predominantly on heuristic processing, through which patients have a rather passive role, mostly listening to health care professionals telling them about their illness. In such instances, health care professionals are seen as experts who should be listened to and whose advice should be followed. However, the information provided is usually generic and usually easily rationalized as not relevant to the individual.

Where attitudes do change, they tend

to be surface changes and susceptible to further change in light of other, contradictory information from other "experts," be they health care professionals, relatives, friends with diabetes, or the media.

To overcome these issues, dual process theory emphasizes the need to actively involve individuals in the learning process. This means providing individuals with the least possible information from which to learn. The workshops note, for example, that the problem in type 2 diabetes is insulin resistance. Then, through good questioning and analogies (the workshops use the analogy that having insulin resistance is a bit like having a rusty lock on your front door), facilitators support individuals in working out how this information relates to what is happening in their bodies now and in the future (e.g., that because they are resistant to insulin, their pancreas needs to work harder and may then get tired out and start being inefficient). Figure 1 provides an example of a picture that the group generates at the workshops, with only the two highlighted pieces of information provided to them. This more active learning leads to changes in beliefs that are more resistant to the influences of contradictory information. It equips Continued on p. 78

What is type 2 diabetes?

- Glucose provides cells with energy.
- Glucose must go through gate in cell wall to enter cells.
- *Insulin is the key that unlocks these gates.*
- *The locks in the gate are not working well.*
- Because the locks in the gate are not working well...
- insulin has to work harder to open the gate,
- so the pancreas has to work harder to produce insulin.
- With time, the pancreas gets too tired and stops making insulin.

What can you do about it?

- Change amount of food.
- · Change type of food.
- Stop food being digested.
- Stop food being stored.
- Stop food being stored.
 Stop liver releasing sugar.
- Make pancreas work harder.
- Make panereas work narder.
 Make insulin locks on cell work.
- Expend more energy.

*The only information provided to participants.

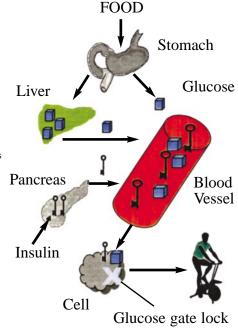


Figure 1. The model of type 2 diabetes created by the individuals participating in the workshop.

Continued from p. 76 individuals with principles by which new information can be explored and tested. And, because it helps individuals understand how the information relates to what is happening in their own bodies, it makes this information more difficult to rationalize away.

As a result of this approach, individuals who have participated in a program evaluation up to a year after attending a workshop have been able to give amazingly detailed descriptions of the workshop. This is in stark contrast to individuals' recall of one-on-one consultations.⁹

Self-Determination Theory¹⁰ focuses on the difference between controlled and autonomous motivation. Controlled motivation means doing things for extrinsic reasons, such as to make others happy or to receive a

contingent reward. Autonomous motivation, in contrast, means doing things for intrinsic reasons or for one-self. This type of motivation is predictive of successful self-care, weight loss, and glycemic control. 11,12

To support the development of autonomous motivation for diabetes self-care, the individuals in these workshops conduct their own health assessments and record the results on their own health profiles (Figure 2). This serves to further the processing of the information they have received, but also helps them make informed choices about their diabetes and what they wish to do for the future. At the end of the daylong workshops, individuals set their own goals based on their health assessments and management plans. This emphasizes participants' autonomy

and encourages them to make their own decisions about their diabetes management.

To facilitate a better understanding of their individual health risks, workshop participants take part in measuring many of the tests and assessments that are usually performed on them. This not only helps to identify their individual health risks, but also helps them to see the relevance of the tests they will have as a regular part of their future health assessments and understand how these measurements affect their risk of developing complications. Project team members continue to be amazed at how many people being treated for hypertension do not know what blood pressure is, let alone what their own blood pressure levels are or what they should be. Although this process of gaining an

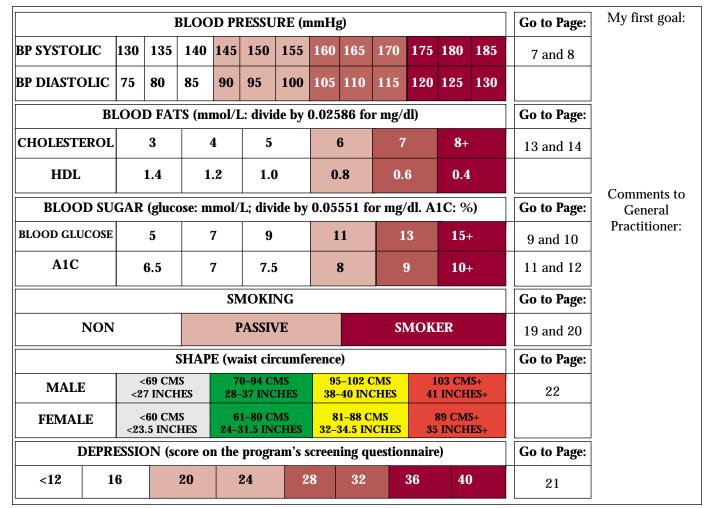


Figure 2. Health profile used in workshops to help people make diabetes management decisions. The shading is designed to give a visual representation of the increase in risk for coronary heart disease and the treatment targets (to try to get everything into the white and keep it there). The "go to page" column gives the page numbers in the patient handbook that provide more information about each risk factor and what self-management tasks will influence the risk factor.

insight into potential risks could lead to anxiety, it is a necessary part of understanding the nature of diabetes, and it acts as a motivator for behavior change. Understanding what their individual health risks are naturally leads participants to the question, "What can I do about it?"

Social Learning Theory¹³ focuses on individuals' perceptions of their ability to enact behaviors and follow through on action plans. In psychological terms, this is referred to as self-efficacy, but it is very similar to the concept of self-confidence. Self-efficacy has been shown to be one of the most consistent predictors of successful self-care behavior and has been incorporated into most health psychology models.¹⁴

The Portsmouth workshops support the development of participants' sense of self-efficacy throughout their daylong agenda. This is done by reinforcing the message that any changes, no matter how small, have benefits for improving health. At the end of the workshops, facilitators support participants in setting "SMART goals": specific, measurable, action goals that are realistic and time-limited. The range of goals and strategies set by participants has been stunning, from talking to a doctor about depression to exploring low-fat cooking options, to moving salt from the table to the refrigerator to discourage overuse when it is close at hand. This structured session at the end of the workshops also encourages individuals to anticipate barriers to achieving their goals and uses structured problem solving to help them overcome these potential barriers.

As part of their health assessments, workshop participants complete a depression screening questionnaire. Depression is more prevalent among people with diabetes, decreases self-efficacy, and is a major barrier to behavior change and successful glycemic control. More than one-third of the workshop participants score at about the clinical cutoff point on the depression screening questionnaire.

The Workshops

All individuals within the Portsmouth City Primary Care Trust who have newly diagnosed type 2 diabetes are booked into a workshop on confirma-

tion of diagnosis. A sufficient number of workshops is offered to ensure that individuals can attend within 1 month of diagnosis. Because each daylong workshop is structured with the "bad news" about diabetes coming in the morning before the "good news" about self-management in the afternoon, availability for the whole day is confirmed, and participants are rescheduled if they cannot attend the entire workshop. Each workshop is limited to 10 participants, plus their partners, to provide sufficient time to address collective and individual needs.

Table 1 provides an outline of the entire workshop. After the introductions, participants are invited to tell their stories of how they were diagnosed with diabetes and what they already know about diabetes. Participants' responses are noted on flip charts at the front of the room, so that this information can be reviewed later. Both individuals with diabetes and their partners are also asked to identify one thing they would like to get from the workshop. The facilitator then works through the symptoms and causes of diabetes. This supports participants in understanding what insulin resistance is and what insulin does so that they can then work through how this relates to their own symptoms and causal beliefs.

After coffee, the next section focuses on the complications of diabetes

Table 1. Workshop Outline

- · Welcome and introductions
- · What is diabetes? Patient stories
- What is diabetes? Professional stories

Morning Break

- What are my risks? Blood pressure, cholesterol, depression, blood glucose
- Health profile
- Lay facilitator's personal story and insulin injection demonstration

Shared Lunch

- · What can you do? Diet
- · What can you do? Activity
- · What can you do? Medication

Afternoon Break

- Review
- What are you going to do?
- Outstanding questions
- Finish (one-on-one sessions)

and the health assessments that participants' diabetes care team will be doing on a regular basis. Again using dual process theory, participants are supported in working out what blood pressure, total cholesterol, HDL cholesterol, and blood glucose are and how these relate to the different complications of diabetes that were identified in the first session.

The group then dissipates to rotate through various workstations around the room, where they can take their blood pressure; get their total and HDL cholesterol checked; learn how to use a blood glucose meter and perform a blood glucose check; complete the depression screening questionnaire; self-assess their current diet against nutritional guidelines; and self-assess their risks of developing complications of the feet and eyes. This process is supported by two health care professionals and a layperson with diabetes, who shows participants how to check their blood glucose levels. Participants use the information they gather to complete a health profile (Figure 1), which they will use later in the day to facilitate goal setting.

The lay facilitator then tells the group his personal story of living with type 2 diabetes for more than 20 years and gives himself his lunchtime insulin injection to help people understand that insulin therapy can be a positive and near-painless experience. This can help dispel participants' fears about insulin.

After lunch, the sessions focus on the various dietary recommendations, breaking them down into key messages and exploring how each recommendation or change would affect the different measures that were discussed and assessed in the morning. The workshops take a similar approach with regard to current recommendations for physical activity and how this influences patients' health. The group also discusses issues related to medication taking, blood glucose monitoring, and, where appropriate, smoking.

The final session supports participants as they review the day, first by encouraging them to generate a list of all the things they can do to influence their diabetes, such as change the amount of food they eat, the types of

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fat they include in their diets, and so forth. The group then links each of these behaviors to the various elements of their health profile, which are, in turn, linked to the complications of diabetes.

Participants then use their health profile and the day's learning to identify something they want to change and develop a behavioral goal and action plan. This plan identifies which risk factor they want to change, which behavior they must change to do this, what their exact goal is, and how they plan to achieve this goal. These plans are written down in patients' workshop handbooks, and copies are sent to their primary care provider for follow-up.

Finally, the group works through the list of questions participants wanted to address, and any outstanding questions are answered. This question/answer period concludes the group portion of the workshop. Participants are then given an opportunity to have a brief, private one-onone chat with one of the facilitators.

Conclusions

These workshops are a relatively new initiative in the United Kingdom. The only other model currently in use (in Bournemouth, U.K.) provides patient education at diagnosis in a specialist diabetes center.

The Portsmouth workshops were designed to provide self-management education for people with newly diagnosed type 2 diabetes, and this goal has been achieved with a substantial degree of success. The general practitioners who refer their patients to these workshops have reported that the programs make their jobs of providing care for these patients easier and allow them to have conversations with patients that they have never had before.

These workshops are now embedded into routine care provided by the Portsmouth Trust and, being run in a local community center, are accessible to all individuals. They are cost-effective and financially sustainable, costing about \$80 U.S. per person, including all assays, refreshments and lunch, staffing, room rental fees, and sta-

tionery. Initial evaluation indicates these workshops result in significant changes in self-management behavior and are accompanied by significant reductions in hemoglobin A_{1c} , total cholesterol, and body mass index. 15

This workshop model is now also being used to provide self-management education for newly diagnosed patients in two neighboring primary health care organizations and for screen-detected patients in another city in England that has a substantial (24%) South Asian ethnic population. It is also being reviewed by several other health care providers around England. Experience to date has indicated that the workshops can address multicultural patient education, but that, for some ethnic or religious groups, single-sex workshops or workshops conducted in participants' native languages are needed. These workshops are also now used by the local primary care trust as part of community nurses' continuing professional development.

Workshop organizers are convinced that group self-management education that is grounded in an empowerment philosophy and psychological theory and attended by individuals when told it is part of their diabetes care is enjoyed by patients and professionals, is effective in changing beliefs about diabetes and initiating lifestyle change, is easily integrated into diabetes care pathways, and is sustainable and affordable.

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T. Chas Skinner, PhD, is a health psychologist in the Department of Diabetes and Endocrinology at Leicester Royal Infirmary in Leicester, U.K. Sue Cradock, RGN, DipN, MSc, is a consultant nurse in diabetes, and Francesca Arundel, RGN, BSc, is a diabetes nurse specialist at the Portsmouth Diabetes Centre & Portsmouth City Primary Care Trust in Portsmouth, U.K. William Graham is the lay facilitator for the Portsmouth, U.K., diabetes workshops.