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WHAT HAPPENS WHEN PATIENTS KNOW MORE THAN THEIR DOCTORS?

Diabetics’ experiences of health interactions after patient education: a qualitative patient-led study

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Article Summary

Article focus

1. To explore the impact of patient education on the lives of people with chronic disease, including the post-intervention effect on interactions with healthcare professionals.

Key Messages

1. Patients who have taken part in intensive education courses are given practical condition-specific biomedical knowledge that exceeds that taught to all but the most specialist healthcare professionals.
2. The knowledgeable, self-managing patient created by such education can encounter obstacles in a health system that is not always prepared for them to take such an independent role. This can obstruct patients' efforts to manage their own condition, and can impair health outcomes.
3. Patient education alone cannot solve problems rooted in healthcare power structures and attitudes towards patient expertise. There is a role for those supporting and training healthcare professionals to recognise generic issues that arise when a population becomes self-efficacious and health literate, and ensure patient self-management is not undermined.

Strengths and Limitations

Studies of patient education have been dominated by medical perspectives, resulting in an emphasis on questions about compliance and biomedical markers, with less attention paid to the impact on other parts of patients' lives. A strength of this study was its user-led focus, with a researcher from the diabetic community supported and advised by others from that community. The project fits the NIHR INVOLVE definition of research for patient benefit: "research 'with' or 'by' people who use services rather than 'to', 'about' or 'for' them."

This qualitative study allowed a rich in-depth exploration of a particular education intervention, but this approach has inherent limitations; we cannot assume some of the condition-specific details are necessarily representative of other populations and other conditions. However, the broader findings of the study are applicable across the board: it has offered a new insight into the potential difficulties faced by highly health-literate patients, and suggests a need for serious reflection on existing practices, power hierarchies and training paradigms within healthcare.

Abstract

Objective

To explore the impact of patient education on the lives of people with diabetes, including the effect on interactions with doctors and other healthcare professionals.

Design

Qualitative user-led study using longitudinal interviews and 146 hours of participant observation. Data were analysed using a narrative approach.

Participants

21 patients with Type 1 diabetes, those either about to attend a patient education course or those who had completed the course in the previous 10 years.

Setting

Established patient education centres in three UK teaching hospitals.

Results

Both post-course and several years later, most participants spoke of the experience of taking part in education as life-changingly positive. It helped them understand how to gain control over a very complex disease and freed them from dependence on medical advice and restrictive regimes. However, interactions within the health system following patient education could be fraught. Participants emerged from the course with greater condition-specific knowledge than many of the healthcare professionals they encountered. When these professionals did not understand what their patients were trying to do and were uncomfortable trusting their expertise, there could be serious consequences for these patients' ability to continue effective self-management.

Conclusions

Patients who have in-depth knowledge of their condition encounter problems when their expertise is seen as inappropriate in standard healthcare interactions, and expertise taught to patients in one branch of medicine can be considered non-compliant by those who are not specialists in that field. Although patient education can give people confidence in their own self-management skills, it cannot solve the power imbalance that remains when a generalist healthcare professional, however well-meaning, blocks access to medication and supplies needed to manage chronic disease successfully. There is a role for those involved in primary and hospital care, including those supporting and training healthcare professionals, to recognise these problems and find ways to acknowledge and respect chronic patients' biomedical and practical expertise.

What is already known and what this study adds

Research on patient education has looked mainly at cost-effectiveness and clinically defined outcomes. In diabetes, for example, structured education has been shown to improve quantitative scores for average blood glucose and quality of life. These outcomes, while important, have to date been researched and interpreted entirely by healthcare personnel within a medical perspective. This study, driven and carried out by people with Type 1 diabetes, is the first to explore several unaddressed areas, including the impact patient education has on people's overall life stories, and consequences for their healthcare interactions in the longer term.

Patients who have taken part in intensive education courses are given practical condition-specific biomedical knowledge that exceeds that taught to all but the most specialist healthcare professionals. Our findings suggest that the knowledgeable, self-managing patient created by such education can encounter obstacles in a health system that is not always prepared for patients to take such an independent role. This power imbalance can obstruct patients' efforts to manage their own condition, and can impair health outcomes.

Keywords:

Diabetes mellitus, Type 1; Health education; Professional-patient relations; Delivery of health care; Disease management

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4 **Introduction**

5 For more than two decades the UK has been developing and refining effective patient education
6 programmes in order to help those with long-term conditions to take responsibility for their own self-
7 management and avoid unnecessary hospitalisation.^{1 2} Diabetes care has a particularly strong track
8 record, with over 70 regional courses in England alone, and national programmes now being adopted
9 abroad, such as DAFNE (Dose Adjustment for Normal Eating) and DESMOND (Diabetes Education
10 and Self-Management for Ongoing and Newly Diagnosed).^{3 4} Randomised controlled trials have
11 shown improvements in specific health outcomes and condition-related quality of life measurements,
12 and NICE recommends that all people with diabetes should have access to this kind of structured
13 education.^{5 6 7}

14 For the patients themselves, however, these clinical outcomes are only one part of living with a
15 chronic condition. Our study, the first entirely patient-led research undertaken in this field, explores
16 several unaddressed areas: the role created for the patient during education, what it means to take
17 part, and consequences for patients' lives long-term. This paper draws on that research, looking
18 specifically at the experience of attending DAFNE and how it affects post-course interactions with the
19 health system.

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28 **Methods**

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30 **Influence of service users**

31 Service users with Type 1 diabetes were involved at every stage of the project, including choice of
32 topic, formulation of research question, design, development and conducting of the investigation, as
33 well as analysis and writing up. The James Lind Alliance (<http://www.lindalliance.org/>), INVOLVE
34 (<http://www.involve.org.uk/>), and the entirely patient-led Diabetes.co.uk Forum
35 (<http://www.diabetes.co.uk>) advised on the development of and recruitment to an Advisory Group for
36 the study. The final membership comprised 15 people who, between them, had more than 400 years
37 of living with diabetes, and experience of a variety of treatment regimes and patient education
38 initiatives. Some had never attended patient education, some were DAFNE trained and some had had
39 experience of non-DAFNE programmes. The Advisory Group shared experiences to help inform the
40 kinds of interview topics of relevance to diabetics, gave feedback on patient information sheets, and
41 three members participated in pilot interviews, on which they gave feedback. RS, herself a user-
42 researcher with Type 1 diabetes, had overall responsibility for the research design and
43 implementation, including data collection, analysis, and writing up.

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51 **Design**

52 The study took an interpretive, qualitative approach. Those attending or teaching DAFNE courses
53 acted as respondents or informants for the study, and a range of methods – interviewing,
54 observations, and course participation – were used. Semi-structured interviews were conducted in
55 order to allow these respondents' stories to emerge and give insight into the impact of the course on
56 their overall lives, including their health-related interactions with others. Open-ended questions
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allowed interviewees to direct large parts of the interview to follow the narrative they wished to tell.⁸⁻¹¹ The study also involved a longitudinal dimension, in that interviews were conducted with new DAFNE students before and after the course.^{12 13} This meant that changes in people's perceptions of their situation and their own and others' levels of expertise could be observed and discussed, and the impact on their overall life narrative noted. Observations and course documentation were included as part of the data making up the narratives in the study.¹⁴ Finally, in order to explore how patients' narratives might change over a longer time-frame, DAFNE "graduates" (those who had completed the course several years previously) were asked for a single interview. Although the majority of interview data were collected in formal, recorded sessions with a topic guide, less formal discussion and exploration of ideas with students and educators also took place during observations.

Participant selection and setting

DAFNE centres are externally audited to ensure that students get the same quality of education wherever they attend the course.¹⁵ This consistency, along with DAFNE's national reach, was one of the reasons behind the choice of this programme for the research study over other patient education projects with more localised or internal variation. Several different study sites were included to increase the diversity of participants and venues, rather than specifically to compare and contrast different experiences from one DAFNE centre to another. Each site ran the course over 5 consecutive days, with specially trained teams of two healthcare professionals, a Diabetes Specialist Nurse (DSN) and a dietitian, doing the teaching.

Participants were recruited from established DAFNE centres in three UK hospitals. All three were teaching hospitals with specialist Diabetes Clinics that continued to support patients along DAFNE principles post-course. The study thus looked at the journey taken by a group of perhaps the country's most expert patients – those with one of the most complex conditions to manage, taught in one of the most comprehensive education programmes, administered by some of the most experienced programme leaders.

Patient education is open to everyone with established Type 1 diabetes, and is recommended for all.⁶ Anyone enrolling onto a DAFNE course at the study sites during the study period (September 2011 to January 2012) was considered a potential participant in the "new student" group and approached to take part; 11 were interviewed. DAFNE graduates were recruited from course follow-up sessions (n=4), ordinary clinic appointments (n=4), and field contacts (n=2), with the aim of recruiting as heterogeneous sample as possible in terms of diagnosis era, stage of life at diagnosis, current age, educational level, type of work, ethnicity and gender. Nobody who was approached to take part declined, although two people had to cancel the arranged interviews because of health or family problems and so were not in the end included in the study.

Longitudinal narrative interviews were conducted with 11 new students before their course; they were observed during education, and re-interviewed three months post-course. Retrospective narratives were collected from ten former students of DAFNE, and additional information gathered from seven teaching staff. In all, data were gathered from 32 interviews with patients and 146 hours of

observations, including five days of complete participation in DAFNE by a user-researcher with Type 1 diabetes, RS.

Transcripts and field notes were coded using NVivo 9, using a mixture of thematic and structural narrative analysis.^{16 17} The ideal patient role and narrative being taught on DAFNE was compared with students' personal life stories, and with their stories of others' expectations of them once the course was over.

Results

Expectations: the role of the expert patient

Consistently across all observed courses, students were encouraged by tutors to adopt certain ideals. Among these were concepts of empowerment, expertise, and independence. These principles are keystones of much patient education in the last couple of decades.^{1 23} As can be seen in the extract below, when students made statements suggesting blind compliance or dependence on doctors, they were gently challenged to think of themselves differently; as an empowered and expert patient, no longer dependent on doctors for decisions, but able to talk about their treatment requirements with healthcare professionals as an equal:

Student: "My consultant told me to [take insulin at a certain time]."

Tutor: "You'll all be DAFNE trained by the end of the week, you will be having a discussion with your doctors about your insulins!"

Observation field notes

The structure and complexity of DAFNE course content has been written about in depth elsewhere, including the benefits for patients in terms of blood glucose control; but the amount of knowledge imparted, and the quantity of self-management work, is not always emphasised.^{5 18} Students in this study were expected to learn how to take control of their own treatment regime at a very high level, interpreting complex patterns of blood glucose results over time in order to make constant alterations to insulin dose and timing. This included understanding not only how to count carbohydrates, but also the action and interaction of different kinds of insulin, the interaction of foods to create an overall glycaemic index of a meal, the impact of hormones, stress, alcohol, different kinds of exercise, travelling across time zones, managing pregnancy and breast-feeding, and how to self-manage specific problems such as dawn phenomenon, rising blood glucose during various severities of illness, and hypoglycaemia unawareness.

In the DAFNE narrative, the patient is not a passive victim of circumstance. In the following extract, a student's summary of previous experience as an inpatient is listened to, then a more active, independent role is suggested for the future:

Student: "Whenever I've gone to hospital, because I'm diabetic, they put me on a drip, everything."

Tutor replies that the Sick Day Rules [specific self-management guidelines] are there "to help you avoid that situation".

Observation field notes

In summary, the ideal DAFNE graduate is empowered, knowledgeable and independent.

Experience – taking on the new role

Participating in the kind of detailed, comprehensive self-management education offered by DAFNE had a very positive impact on the personal lives of nearly everyone in the study. Participants from all groups talked of “life-changing” experiences on the course, and of having been freed from the “shackles” of a confusing or restrictive treatment regime by being given “the tools of the trade” to manage a central aspect of their own lives.

“I mean I really have nothing but praise for [DAFNE], it has been properly transformative in ... in a *fundamental* way, I've got a fundamentally better understanding of what it is that's actually wrong with me. Um... and that, yeah, that just allows me to be a lot freer.”

Harry, new student, speaking in post-DAFNE interview

Those who had already built up self-management expertise pre-course talked about “fine-tuning” or solving a specific problem that had been causing them difficulty; nobody was entirely negative about attending DAFNE.

In short, students were largely comfortable with the new patient role being offered them via DAFNE. Knowledge, and independence from doctors and restrictive regimes, were mostly valued, although support from DAFNE specialists post-course was very much appreciated by some. The relationship of students to “empowerment” was slightly less clear cut; although power and control over diabetes was hugely enhanced by DAFNE, empowerment within the health system was more problematic, as we describe below.

Consequences – a clash of roles

Post-course, participants were often cast into ambiguous roles in healthcare interactions; frequently, the condition-specific biomedical and practical information they had learnt was far greater than that of their doctors or nurses. It was clear that in many health interactions, patients and healthcare professionals frequently struggled to manage the tensions that arose from the partial role-reversal of expertise after self-management education. In some cases basic or even inaccurate information was imposed on patients, who on the whole swallowed their annoyance in silence:

I went to a nurse [...] for like, I can't remember what even for, a flu jab or something, um ... and, um [...] she started giving me advice about my blood sugars and it *really*, it really got on my nerves, because they were just completely, completely counter to everything that I'd just been taught. And, and obviously not *right*?

Interviewer: What did you say?

I, I didn't, I didn't say anything. I just left it.

Interviewer: So she didn't know that you... what you were thinking?

No. There's no point getting into an argument.

James, new student, speaking in post-DAFNE interview

Where this tension became more serious was in situations where a less knowledgeable doctor had considerable power over the expert patient. This was most often seen in interactions with GPs, who restricted prescriptions, sometimes surreptitiously, when they did not understand the importance of blood testing to the patient's self-management regime. Using DAFNE principles, students learn how to achieve tighter, smoother blood glucose control by performing blood tests at least four times a day, using the results to make decisions about insulin dosage as well as ensuring that dangerously high or low blood sugars could be avoided. For some, this meant a considerable increase in test strip requirements as they took on the extra work to improve blood glucose control. Although course tutors provided letters for GPs explaining the necessity for these adjustments, interviewees reported having to be "quite tough" to successfully negotiate with primary care teams who were reluctant to absorb the rise in short-term costs. Even when changes had apparently been agreed, they were sometimes reversed by healthcare staff without explanation or warning.

Julia's story, below, is an example of the kind of interaction that could arise in these circumstances. Although her GP did not refuse the prescription request outright, the dispensary simply reduced the amount asked for without explanation:

"So I went to pick up my prescription, I'd asked for four boxes, so I went to pick up my prescription when they were ready to go and pick it up, my husband got it and there were only two.

So I rang them up. I said: 'There are only two boxes.'

'- That's all you need.'

So I said: 'Oh right. Why's that?'

So she said, um: 'Well you only do two tests a day, and that will last you for months.'

[..]

So I said: 'So, as you can see on {the letter from the diabetes specialist tutors} they're asking for me to have adequate supplies to do x number of blood tests a week.'

'- Well I think it's quite ridiculous, you don't need that many.'

Julia, diabetic 50 years, new student speaking post-DAFNE.

Phil, mentioned earlier, was another typical example. He recontacted RS six months after data collection ended, with an update: his GP, who had originally agreed to prescribe blood test strips, had subsequently taken the strips off repeat prescription and insisted on Phil taking time off work every month to come into the surgery and justify the next month's supply. Since this was not always possible to do, he had had to reduce his testing and his blood glucose had begun to rise again. As Phil put it, his doctor did not "win the battle" because of superior medical knowledge; the GP simply had more power, and chose to exercise it.

Healthcare professionals who were reluctant to trust patients' expertise in daily management could also cause difficulties. For example, one participant told of being sent to hospital when her blood glucose happened to be high because of an infection (something she had been taught to self-manage at home using DAFNE principles):

I don't go to my GP for *anything* to do with my diabetes, because they mainly deal with Type 2 diabetics. [...My GP] sent me to hospital when I had my blood sugar... I went in

to see him about something and my blood sugar was 18, which was not unusual. And he called an ambulance and I said to him he was being O.T.T., because not many Type 2 diabetics would go to A&E.

Interviewer: Did he listen or did he still call the ambulance?

"He listened, but he still called the ambulance."

Interviewer: And then what happened?

Well I was in hospital for two days! [...] And then I had trouble getting out of hospital, because I didn't meet the criteria and I'm saying to them 'please, just let me go home, this is unnatural, you know, I'm stuck in bed, my blood sugars aren't coming down because I'm stressed, I've got an infection, it's no good putting me on...' you know, because I was on a sliding scale, I said 'you don't understand, you don't understand, you don't understand...'

Mary, DAFNE graduate, talking nine years post-course

Although the GP and hospital staff meant well, they had failed to appreciate not just the emotional but also the physical impact on the patient of their actions. Mary gave her account with great emphasis. She described her unnecessary hospitalisation and subsequent events as "frightening" because of the lack of power she was allowed over her own body; she could only watch her blood sugar rise needlessly without being able to use her own skills and expertise to keep herself safe. During the experience of being put on a "sliding scale" (intravenous insulin and glucose administered in hospital), the patient completely loses control over his or her diabetes, surrendering management to hospital staff who are unlikely to be diabetes specialists. The National Diabetes Inpatient Audit has shown that in more than a third of cases this results in medication errors, which can lead to coma and occasionally death.¹⁹

Discussion

Principal findings

People graduating from intensive patient education courses such as DAFNE emerge with disease-specific biomedical, experiential and practical knowledge that exceeds that of many healthcare professionals. From the stories told by participants in this study, it was clear that many generalist and even specialist doctors and nurses were not comfortable with patients who had a high level of self-management expertise. While this has been noted elsewhere in more general terms,^{20 21} this is the first study to confirm these findings in terms of healthcare professionals' reactions to formally trained Expert Patients. Although some healthcare teams were happy to support course graduates and even learn from them, this attitude could not be counted on, particularly when patients made budgetary demands that the budget-holders did not fully understand, such as requests for home blood testing equipment. Expertise taught to patients in one branch of medicine can be considered non-compliant by those who are not specialists in that field, and in some circumstances, such as inpatient care, self-management may be greatly discouraged or even forbidden by hospital policy.

Patient education has the potential to change people's lives for the better in a way that is perhaps not fully captured by standard clinical and quality of life outcome assessments. As well as offering

practical information, DAFNE teaches people with diabetes to consider a new role as expert, independent, and empowered patients. Participants in this study found that hugely helpful, not only in terms of biomedical improvements, but also in terms of taking control over their own lives with chronic disease. However, there is evidence that having learnt how to self-manage successfully, patients find it frustrating, at best, and frightening, at worst, to have access to self-management resources denied them; in some cases problems with post-course interactions may be hindering patients' ability to hit biomedical targets and stay healthy.

Strengths and limitations

Traditionally, studies of patient education have been dominated by medical perspectives, with very little formal research conducted by patients themselves. This has resulted in emphasis on questions about compliance and biomedical markers, with less attention paid to the impact of educational interventions on other parts of patients' lives. A strength of this study was its user-led focus, with a researcher from the diabetic community supported and advised by others from that community. The project fits wholly within the NIHR and INVOLVE definition of research for patient benefit: "research 'with' or 'by' people who use services rather than 'to', 'about' or 'for' them."²²

The choice of a narrative methodology and relatively unstructured topic guide allowed patients to choose what to emphasise in stories they told about themselves, but this approach had its inherent limitations too, as did the decision to restrict the research to a single chronic illness and just one patient education course. The small sample size allowed in-depth qualitative analysis to take place, but both sample size and the particular challenges involved in managing Type 1 diabetes mean that we cannot assume disease-specific findings are representative of other populations and other conditions. However, the broader findings of the study are applicable across the board: it has offered a new insight into the potential difficulties faced by newly educated patients, and suggests a need for serious reflection on existing practices, power hierarchies and training paradigms within healthcare. There may be local differences in different populations, but the paradox remains: patients are being given expertise and confidence to self-manage, but there remains no pathway to having these skills recognised or valued more generally by those with power and access to resources. At best, this leaves patients vulnerable; at worst, it can undermine their hard work and health status.

Studies of post-education health interactions have been rather limited to date. Some evaluations have hinted at potential conflicts between knowledgeable patients and less knowledgeable health professionals, and the potential for this conflict to erode health outcomes over time,^{5 24} but has rarely been a focus of research. Previous qualitative work in diabetes education has identified the importance of ongoing support from healthcare professionals in patients' ability to self-manage along the lines taught on the course.²⁵⁻²⁷ However, these studies focus on the relationship between the specialist and patient rather than interactions with generalist healthcare professionals. In our study we found important differences in interactions in primary and hospital care compared with those in specialist clinics. This suggests that the power held by GP prescribers should not be overlooked when considering patients' ability to self-manage successfully.

Implications and future research

Although patient education is recommended for those with chronic conditions in general,^{1 28} the implications for the education of healthcare professionals are not currently considered in parallel. While modern medical and nursing education focuses on patient-centred care,^{29 30} it does not prepare healthcare students for situations in which their patients have more biomedical and practical knowledge than they do about a specific treatment regime or illness.³¹ When the role of the patient in a healthcare interaction is ambiguous and contested, problems arise on both sides, and extra work is required by both patient and professional. There are limits to the extent to which patient education can mitigate these problems. In the districts where this study took place, work was already being done to help support DAFNE graduates who needed to go into hospital, and to ensure they got letters to enhance their authority when asking for supplies from primary care. Findings from this study would suggest that this work is very much needed. However, even when this support was in place, graduates continued to encounter disempowering practices from healthcare staff who were not DAFNE-aware. When healthcare practitioners do not understand the patient's self-management requirements or trust their ability, they may put up obstacles to improved health outcomes by limiting medical supplies or insisting on unnecessary hospitalisation. As more chronic illness care is put into the hands of generalists, such situations are likely to arise more and more often; the importance of teaching strategies to cope with patient expertise, rather than see it as a threat, is of increasing relevance.

Although this study has provided an insight into the kinds of issues encountered by patients after formal education, further research is needed to establish how widespread these problems are on a national level, and whether similar issues are faced by patients with other kinds of chronic conditions following other styles of Expert Patient Programme.

Conclusions

Healthcare professionals cannot become experts in the detailed management of every complex condition; gathering specialist input from others has long been an important part of treatment decision-making. Doctors, nurses and others whose attitudes impact on patient care must be supported to extend that model of shared expertise to work with those who have chronic illnesses, seeing the patient as part of the healthcare team, and the patient's condition-specific biomedical knowledge as a valuable resource, not a threat.

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RS designed and carried out the research, and drafted the paper. She is guarantor. JS and CH supervised research, reviewed and edited the paper.

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Data Sharing:

The presented data are anonymised and risk of identification is low. Extra data is available by emailing RS.

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WHAT HAPPENS WHEN PATIENTS KNOW MORE THAN THEIR DOCTORS?

Diabetics' experiences of health interactions after patient education: a qualitative patient-led study

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Article Summary

Article focus

1. To explore the impact of patient education on the lives of people with chronic disease, including the post-intervention effect on interactions with healthcare professionals.

Key Messages

1. Patients who have taken part in intensive education courses are given practical condition-specific biomedical knowledge that exceeds that taught to all but the most specialist healthcare professionals.
2. The knowledgeable, self-managing patient created by such education can encounter obstacles in a health system that is not always prepared for them to take such an independent role. This can obstruct patients' efforts to manage their own condition, and can impair health outcomes.
3. Patient education alone cannot solve problems rooted in healthcare power structures and attitudes towards patient expertise. There is a role for those supporting and training healthcare professionals to recognise generic issues that arise when a population becomes self-efficacious and health literate, and ensure patient self-management is not undermined.

Strengths and Limitations

Studies of patient education have been dominated by medical perspectives, resulting in an emphasis on questions about compliance and biomedical markers, with less attention paid to the impact on other parts of patients' lives. A strength of this study was its user-led focus, with a researcher from the diabetic community supported and advised by others from that community. The project fits the NIHR INVOLVE definition of research for patient benefit: "research 'with' or 'by' people who use services rather than 'to', 'about' or 'for' them."

This qualitative study allowed a rich in-depth exploration of a particular education intervention, but this approach has inherent limitations; we cannot assume some of the condition-specific details are necessarily representative of other populations and other conditions. However, the broader findings of the study are applicable across the board: it has offered a new insight into the potential difficulties faced by highly health-literate patients, and suggests a need for serious reflection on existing practices, power hierarchies and training paradigms within healthcare.

Abstract

Objective

To explore the impact of patient education on the lives of people with diabetes, including the effect on interactions with doctors and other healthcare professionals.

Design

Qualitative user-led study using longitudinal interviews and 146 hours of participant observation. Data were analysed using a narrative approach.

Participants

21 patients with Type 1 diabetes, those either about to attend a patient education course or those who had completed the course in the previous 10 years.

Setting

Established patient education centres in three UK teaching hospitals.

Results

Both post-course and several years later, most participants spoke of the experience of taking part in education as life-changingly positive. It helped them understand how to gain control over a very complex disease and freed them from dependence on medical advice and restrictive regimes.

However, interactions within the health system following patient education could be fraught.

Participants emerged from the course with greater condition-specific knowledge than many of the healthcare professionals they encountered. When these professionals did not understand what their patients were trying to do and were uncomfortable trusting their expertise, there could be serious consequences for these patients' ability to continue effective self-management.

Conclusions

Patients who have in-depth knowledge of their condition encounter problems when their expertise is seen as inappropriate in standard healthcare interactions, and expertise taught to patients in one branch of medicine can be considered non-compliant by those who are not specialists in that field.

Although patient education can give people confidence in their own self-management skills, it cannot solve the power imbalance that remains when a generalist healthcare professional, however well-meaning, blocks access to medication and supplies needed to manage chronic disease successfully.

There is a role for those involved in primary and hospital care, including those supporting and training healthcare professionals, to recognise these problems and find ways to acknowledge and respect chronic patients' biomedical and practical expertise.

Comment [RS1]: Conclusions section rewritten to emphasise why these findings are relevant outside patient education; patients cannot address these obstacles to care themselves because of existing power imbalances

What is already known and what this study adds

Research on patient education has looked mainly at cost-effectiveness and clinically defined outcomes. In diabetes, for example, structured education has been shown to improve quantitative scores for average blood glucose and quality of life. These outcomes, while important, have to date been researched and interpreted entirely by healthcare personnel within a medical perspective. This study, driven and carried out by people with Type 1 diabetes, is the first to explore several unaddressed areas, including the impact patient education has on people's overall life stories, and consequences for their healthcare interactions in the longer term.

Patients who have taken part in intensive education courses are given practical condition-specific biomedical knowledge that exceeds that taught to all but the most specialist healthcare professionals. Our findings suggest that the knowledgeable, self-managing patient created by such education can encounter obstacles in a health system that is not always prepared for patients to take such an independent role. This power imbalance can obstruct patients' efforts to manage their own condition, and can impair health outcomes.

Keywords:

Diabetes mellitus, Type 1; Health education; Professional-patient relations; Delivery of health care; Disease management

Comment [RS2]: Sentence altered to emphasise power relationship

Introduction

For more than two decades the UK has been developing and refining effective patient education programmes in order to help those with long-term conditions to take responsibility for their own self-management and avoid unnecessary hospitalisation.^{1 2} Diabetes care has a particularly strong track record, with over 70 regional courses in England alone, and national programmes now being adopted abroad, such as DAFNE (Dose Adjustment for Normal Eating) and DESMOND (Diabetes Education and Self-Management for Ongoing and Newly Diagnosed).^{3 4} Randomised controlled trials have shown improvements in specific health outcomes and condition-related quality of life measurements, and NICE recommends that all people with diabetes should have access to this kind of structured education.^{5 6 7}

For the patients themselves, however, these clinical outcomes are only one part of living with a chronic condition. Our study, the first entirely patient-led research undertaken in this field, explores several unaddressed areas: the role created for the patient during education, what it means to take part, and consequences for patients' lives long-term. This paper draws on that research, looking specifically at the experience of attending DAFNE and how it affects post-course interactions with the health system.

Methods

Influence of service users

Service users with Type 1 diabetes were involved at every stage of the project, including choice of topic, formulation of research question, design, development and conducting of the investigation, as well as analysis and writing up. The James Lind Alliance (<http://www.lindalliance.org/>), INVOLVE (<http://www.involve.org.uk/>), and the entirely patient-led Diabetes.co.uk Forum (<http://www.diabetes.co.uk>) advised on the development of and recruitment to an Advisory Group for the study. The final membership comprised 15 people who, between them, had more than 400 years of living with diabetes, and experience of a variety of treatment regimes and patient education initiatives. Some had never attended patient education, some were DAFNE trained and some had had experience of non-DAFNE programmes. The Advisory Group shared experiences to help inform the kinds of interview topics of relevance to diabetics, gave feedback on patient information sheets, and three members participated in pilot interviews, on which they gave feedback. RS, herself a user-researcher with Type 1 diabetes, had overall responsibility for the research design and implementation, including data collection, analysis, and writing up.

Design

The study took an interpretive, qualitative approach. Those attending or teaching DAFNE courses acted as respondents or informants for the study, and a range of methods – interviewing, observations, and course participation – were used. Semi-structured interviews were conducted in order to allow these respondents' stories to emerge and give insight into the impact of the course on their overall lives, including their health-related interactions with others. Open-ended questions

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allowed interviewees to direct large parts of the interview to follow the narrative they wished to tell.⁸⁻¹¹ The study also involved a longitudinal dimension, in that interviews were conducted with new DAFNE students before and after the course.^{12 13} This meant that changes in people's perceptions of their situation and their own and others' levels of expertise could be observed and discussed, and the impact on their overall life narrative noted. Observations and course documentation were included as part of the data making up the narratives in the study.¹⁴ Finally, in order to explore how patients' narratives might change over a longer time-frame, DAFNE "graduates" (those who had completed the course several years previously) were asked for a single interview. Although the majority of interview data were collected in formal, recorded sessions with a topic guide, less formal discussion and exploration of ideas with students and educators also took place during observations.

Participant selection and setting

DAFNE centres are externally audited to ensure that students get the same quality of education wherever they attend the course.¹⁵ This consistency, along with DAFNE's national reach, was one of the reasons behind the choice of this programme for the research study over other patient education projects with more localised or internal variation. Several different study sites were included to increase the diversity of participants and venues, rather than specifically to compare and contrast different experiences from one DAFNE centre to another. Each site ran the course over 5 consecutive days, with specially trained teams of two healthcare professionals, a Diabetes Specialist Nurse (DSN) and a dietitian, doing the teaching.

Participants were recruited from established DAFNE centres in three UK hospitals. All three were teaching hospitals with specialist Diabetes Clinics that continued to support patients along DAFNE principles post-course. The study thus looked at the journey taken by a group of perhaps the country's most expert patients – those with one of the most complex conditions to manage, taught in one of the most comprehensive education programmes, administered by some of the most experienced programme leaders.

Patient education is open to everyone with established Type 1 diabetes, and is recommended for all.⁶ Anyone enrolling onto a DAFNE course at the study sites during the study period (September 2011 to January 2012) was considered a potential participant in the "new student" group and approached to take part; 11 were interviewed. DAFNE graduates were recruited from course follow-up sessions (n=4), ordinary clinic appointments (n=4), and field contacts (n=2), with the aim of recruiting as heterogeneous sample as possible in terms of diagnosis era, stage of life at diagnosis, current age, educational level, type of work, ethnicity and gender. Nobody who was approached to take part declined, although two people had to cancel the arranged interviews because of health or family problems and so were not in the end included in the study.

Longitudinal narrative interviews were conducted with 11 new students before their course; they were observed during education, and re-interviewed three months post-course. Retrospective narratives were collected from ten former students of DAFNE, and additional information gathered from seven teaching staff. In all, data were gathered from 32 interviews with patients and 146 hours of

observations, including five days of complete participation in DAFNE by a user-researcher with Type 1 diabetes, RS.

Transcripts and field notes were coded using NVivo 9, using a mixture of thematic and structural narrative analysis.^{16 17} The ideal patient role and narrative being taught on DAFNE was compared with students' personal life stories, and with their stories of others' expectations of them once the course was over.

Results

Expectations: the role of the expert patient

Consistently across all observed courses, students were encouraged by tutors to adopt certain ideals. Among these were concepts of empowerment, expertise, and independence. These principles are keystones of much patient education in the last couple of decades.^{1 23} As can be seen in the extract below, when students made statements suggesting blind compliance or dependence on doctors, they were gently challenged to think of themselves differently; as an empowered and expert patient, no longer dependent on doctors for decisions, but able to talk about their treatment requirements with healthcare professionals as an equal:

Student: "My consultant told me to [take insulin at a certain time]."

Tutor: "You'll all be DAFNE trained by the end of the week, you will be having a discussion with your doctors about your insulins!"

Observation field notes

The structure and complexity of DAFNE course content has been written about in depth elsewhere, including the benefits for patients in terms of blood glucose control; but the amount of knowledge imparted, and the quantity of self-management work, is not always emphasised.^{5 18} Students in this study were expected to learn how to take control of their own treatment regime at a very high level, interpreting complex patterns of blood glucose results over time in order to make constant alterations to insulin dose and timing. This included understanding not only how to count carbohydrates, but also the action and interaction of different kinds of insulin, the interaction of foods to create an overall glycaemic index of a meal, the impact of hormones, stress, alcohol, different kinds of exercise, travelling across time zones, managing pregnancy and breast-feeding, and how to self-manage specific problems such as dawn phenomenon, rising blood glucose during various severities of illness, and hypoglycaemia unawareness.

In the DAFNE narrative, the patient is not a passive victim of circumstance. In the following extract, a student's summary of previous experience as an inpatient is listened to, then a more active, independent role is suggested for the future:

Student: "Whenever I've gone to hospital, because I'm diabetic, they put me on a drip, everything."

Tutor replies that the Sick Day Rules [specific self-management guidelines] are there "to help you avoid that situation".

Observation field notes

Comment [RS3]: Paragraph rewritten to illustrate the links between diabetes-specific courses and other forms of patient education.

In summary, the ideal DAFNE graduate is empowered, knowledgeable and independent.

Experience – taking on the new role

Participating in the kind of detailed, comprehensive self-management education offered by DAFNE had a very positive impact on the personal lives of nearly everyone in the study. Participants from all groups talked of “life-changing” experiences on the course, and of having been freed from the “shackles” of a confusing or restrictive treatment regime by being given “the tools of the trade” to manage a central aspect of their own lives.

“I mean I really have nothing but praise for [DAFNE], it has been properly transformative in ... in a *fundamental* way, I've got a fundamentally better understanding of what it is that's actually wrong with me. Um... and that, yeah, that just allows me to be a lot freer.”

Harry, new student, speaking in post-DAFNE interview

Those who had already built up self-management expertise pre-course talked about “fine-tuning” or solving a specific problem that had been causing them difficulty; nobody was entirely negative about attending DAFNE.

In short, students were largely comfortable with the new patient role being offered them via DAFNE. Knowledge, and independence from doctors and restrictive regimes, were mostly valued, although support from DAFNE specialists post-course was very much appreciated by some. The relationship of students to “empowerment” was slightly less clear cut; although power and control over diabetes was hugely enhanced by DAFNE, empowerment within the health system was more problematic, as we describe below.

Consequences – a clash of roles

Post-course, participants were often cast into ambiguous roles in healthcare interactions; frequently, the condition-specific biomedical and practical information they had learnt was far greater than that of their doctors or nurses. It was clear that in many health interactions, patients and healthcare professionals frequently struggled to manage the tensions that arose from the partial role-reversal of expertise after self-management education. In some cases basic or even inaccurate information was imposed on patients, who on the whole swallowed their annoyance in silence:

I went to a nurse [...] for like, I can't remember what even for, a flu jab or something, um ... and, um [...] she started giving me advice about my blood sugars and it *really*, it really got on my nerves, because they were just completely, completely counter to everything that I'd just been taught. And, and obviously not *right*?

Interviewer: What did you say?

I, I didn't, I didn't say anything. I just left it.

Interviewer: So she didn't know that you... what you were thinking?

No. There's no point getting into an argument.

James, new student, speaking in post-DAFNE interview

Comment [RS4]: A section here describing another positive experience on the course has been cut to allow more space for quotes about consequences of patient education.

Comment [RS5]: Section cut here to allow to rewritten expansion of themes on role clash, order to illustrate the relevance of this problem to generalist healthcare staff

Where this tension became more serious was in situations where a less knowledgeable doctor had considerable power over the expert patient. This was most often seen in interactions with GPs, who restricted prescriptions, sometimes surreptitiously, when they did not understand the importance of blood testing to the patient's self-management regime. Using DAFNE principles, students learn how to achieve tighter, smoother blood glucose control by performing blood tests at least four times a day, using the results to make decisions about insulin dosage as well as ensuring that dangerously high or low blood sugars could be avoided. For some, this meant a considerable increase in test strip requirements as they took on the extra work to improve blood glucose control. Although course tutors provided letters for GPs explaining the necessity for these adjustments, interviewees reported having to be "quite tough" to successfully negotiate with primary care teams who were reluctant to absorb the rise in short-term costs. Even when changes had apparently been agreed, they were sometimes reversed by healthcare staff without explanation or warning.

Julia's story, below, is an example of the kind of interaction that could arise in these circumstances.

Although her GP did not refuse the prescription request outright, the dispensary simply reduced the amount asked for without explanation:

"So I went to pick up my prescription, I'd asked for four boxes, so I went to pick up my prescription when they were ready to go and pick it up, my husband got it and there were only two.

So I rang them up. I said: 'There are only two boxes.'

'- That's all you need.'

So I said: 'Oh right. Why's that?'

So she said, um: 'Well you only do two tests a day, and that will last you for months.'

[..]

So I said: 'So, as you can see on {the letter from the diabetes specialist tutors} they're asking for me to have adequate supplies to do x number of blood tests a week.'

'- Well I think it's quite ridiculous, you don't need that many.'

Julia, diabetic 50 years, new student speaking post-DAFNE.

Phil, mentioned earlier, was another typical example. He recontacted RS six months after data collection ended, with an update: his GP, who had originally agreed to prescribe blood test strips, had subsequently taken the strips off repeat prescription and insisted on Phil taking time off work every month to come into the surgery and justify the next month's supply. Since this was not always possible to do, he had had to reduce his testing and his blood glucose had begun to rise again. As Phil put it, his doctor did not "win the battle" because of superior medical knowledge; the GP simply had more power, and chose to exercise it.

Healthcare professionals who were reluctant to trust patients' expertise in daily management could also cause difficulties. For example, one participant told of being sent to hospital when her blood glucose happened to be high because of an infection (something she had been taught to self-manage at home using DAFNE principles):

I don't go to my GP for *anything* to do with my diabetes, because they mainly deal with Type 2 diabetics. [...My GP] sent me to hospital when I had my blood sugar... I went in

Comment [RS6]: "Julia's story" is a new addition in response to the request for more participant quotes of relevance to this finding on obstacles to self-management.

to see him about something and my blood sugar was 18, which was not unusual. And he called an ambulance and I said to him he was being O.T.T., because not many Type 2 diabetics would go to A&E.

Interviewer: Did he listen or did he still call the ambulance?

"He listened, but he still called the ambulance."

Interviewer: And then what happened?

Well I was in hospital for two days! [...] And then I had trouble getting out of hospital, because I didn't meet the criteria and I'm saying to them 'please, just let me go home, this is unnatural, you know, I'm stuck in bed, my blood sugars aren't coming down because I'm stressed, I've got an infection, it's no good putting me on...' you know, because I was on a sliding scale, I said 'you don't understand, you don't understand, you don't understand...'

Mary, DAFNE graduate, talking nine years post-course

Although the GP and hospital staff meant well, they had failed to appreciate not just the emotional but also the physical impact on the patient of their actions. Mary gave her account with great emphasis. She described her unnecessary hospitalisation and subsequent events as "frightening" because of the lack of power she was allowed over her own body; she could only watch her blood sugar rise needlessly without being able to use her own skills and expertise to keep herself safe. During the experience of being put on a "sliding scale" (intravenous insulin and glucose administered in hospital), the patient completely loses control over his or her diabetes, surrendering management to hospital staff who are unlikely to be diabetes specialists. The National Diabetes Inpatient Audit has shown that in more than a third of cases this results in medication errors, which can lead to coma and occasionally death.¹⁹

Discussion

Principal findings

People graduating from intensive patient education courses such as DAFNE emerge with disease-specific biomedical, experiential and practical knowledge that exceeds that of many healthcare professionals. From the stories told by participants in this study, it was clear that many generalist and even specialist doctors and nurses were not comfortable with patients who had a high level of self-management expertise. While this has been noted elsewhere in more general terms,^{20 21} this is the first study to confirm these findings in terms of healthcare professionals' reactions to formally trained Expert Patients. Although some healthcare teams were happy to support course graduates and even learn from them, this attitude could not be counted on, particularly when patients made budgetary demands that the budget-holders did not fully understand, such as requests for home blood testing equipment. Expertise taught to patients in one branch of medicine can be considered non-compliant by those who are not specialists in that field, and in some circumstances, such as inpatient care, self-management may be greatly discouraged or even forbidden by hospital policy.

Patient education has the potential to change people's lives for the better in a way that is perhaps not fully captured by standard clinical and quality of life outcome assessments. As well as offering

Comment [RS7]: Paragraph rewritten to explain more clearly why this incident is important to safe patient care

practical information, DAFNE teaches people with diabetes to consider a new role as expert, independent, and empowered patients. Participants in this study found that hugely helpful, not only in terms of biomedical improvements, but also in terms of taking control over their own lives with chronic disease. However, there is evidence that having learnt how to self-manage successfully, patients find it frustrating, at best, and frightening, at worst, to have access to self-management resources denied them; in some cases problems with post-course interactions may be hindering patients' ability to hit biomedical targets and stay healthy.

Strengths and limitations

Traditionally, studies of patient education have been dominated by medical perspectives, with very little formal research conducted by patients themselves. This has resulted in emphasis on questions about compliance and biomedical markers, with less attention paid to the impact of educational interventions on other parts of patients' lives. A strength of this study was its user-led focus, with a researcher from the diabetic community supported and advised by others from that community. The project fits wholly within the NIHR and INVOLVE definition of research for patient benefit: "research 'with' or 'by' people who use services rather than 'to', 'about' or 'for' them."²²

The choice of a narrative methodology and relatively unstructured topic guide allowed patients to choose what to emphasise in stories they told about themselves, but this approach had its inherent limitations too, as did the decision to restrict the research to a single chronic illness and just one patient education course. The small sample size allowed in-depth qualitative analysis to take place, but both sample size and the particular challenges involved in managing Type 1 diabetes mean that we cannot assume disease-specific findings are representative of other populations and other conditions. However, the broader findings of the study are applicable across the board: it has offered a new insight into the potential difficulties faced by newly educated patients, and suggests a need for serious reflection on existing practices, power hierarchies and training paradigms within healthcare. There may be local differences in different populations, but the paradox remains: patients are being given expertise and confidence to self-manage, but there remains no pathway to having these skills recognised or valued more generally by those with power and access to resources. At best, this leaves patients vulnerable; at worst, it can undermine their hard work and health status.

Studies of post-education health interactions have been rather limited to date. Some evaluations have hinted at potential conflicts between knowledgeable patients and less knowledgeable health professionals, and the potential for this conflict to erode health outcomes over time,^{5 24} but has rarely been a focus of research. Previous qualitative work in diabetes education has identified the importance of ongoing support from healthcare professionals in patients' ability to self-manage along the lines taught on the course.²⁵⁻²⁷ However, these studies focus on the relationship between the specialist and patient rather than interactions with generalist healthcare professionals. In our study we found important differences in interactions in primary and hospital care compared with those in specialist clinics. This suggests that the power held by GP prescribers should not be overlooked when considering patients' ability to self-manage successfully.

Comment [RS8]: Section rewritten to explain the general principles that apply beyond diabetes

Implications and future research

Although patient education is recommended for those with chronic conditions in general,^{1 28} the implications for the education of healthcare professionals are not currently considered in parallel. While modern medical and nursing education focuses on patient-centred care,^{29 30} it does not prepare healthcare students for situations in which their patients have more biomedical and practical knowledge than they do about a specific treatment regime or illness.³¹ When the role of the patient in a healthcare interaction is ambiguous and contested, problems arise on both sides, and extra work is required by both patient and professional. There are limits to the extent to which patient education can mitigate these problems. In the districts where this study took place, work was already being done to help support DAFNE graduates who needed to go into hospital, and to ensure they got letters to enhance their authority when asking for supplies from primary care. Findings from this study would suggest that this work is very much needed. However, even when this support was in place, graduates continued to encounter disempowering practices from healthcare staff who were not DAFNE-aware. When healthcare practitioners do not understand the patient's self-management requirements or trust their ability, they may put up obstacles to improved health outcomes by limiting medical supplies or insisting on unnecessary hospitalisation. As more chronic illness care is put into the hands of generalists, such situations are likely to arise more and more often; the importance of teaching strategies to cope with patient expertise, rather than see it as a threat, is of increasing relevance.

Although this study has provided an insight into the kinds of issues encountered by patients after formal education, further research is needed to establish how widespread these problems are on a national level, and whether similar issues are faced by patients with other kinds of chronic conditions following other styles of Expert Patient Programme.

Conclusions

Healthcare professionals cannot become experts in the detailed management of every complex condition; gathering specialist input from others has long been an important part of treatment decision-making. Doctors, nurses and others whose attitudes impact on patient care must be supported to extend that model of shared expertise to work with those who have chronic illnesses, seeing the patient as part of the healthcare team, and the patient's condition-specific biomedical knowledge as a valuable resource, not a threat.

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Comment [RS9]: Section rewritten to emphasise the limited role of the patient educator, and thus the importance of this topic outside that field

Competing Interests and Funding:

All authors have completed the Unified Competing Interest form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare that (1) RS has support from the National Institute for Health Research (NIHR) for the submitted work; (2) RS, CH and JS have no relationships with any company that might have an interest in the submitted work in the previous 3 years; (3) their spouses, partners, or children have no financial relationships that may be relevant to the submitted work; and (4) RS, CH and JS have no non-financial interests that may be relevant to the submitted work.

Contributorship statement:

RS designed and carried out the research, and drafted the paper. She is guarantor. JS and CH supervised research, reviewed and edited the paper.

Ethics Statement:

This study was supported by a National Institute for Health Research grant, awarded to RS as an independent researcher. Ethics approval was obtained from the NHS NRES Committee [REC reference 11/LO/0819] and from the relevant Research and Development Departments from the hospital NHS Trusts before the study began. All identifying details of participants have been removed and all names are pseudonyms.

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Data Sharing:

The presented data are anonymised and risk of identification is low. Extra data is available by emailing RS.

Word Count:

5,433

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What happens when patients know more than their doctors?
Diabetics' experiences of health interactions after patient education: a qualitative patient-led study

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WHAT HAPPENS WHEN PATIENTS KNOW MORE THAN THEIR DOCTORS?

Diabetics’ experiences of health interactions after patient education: a qualitative patient-led study

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Abstract

Objective

To explore the impact of patient education on the lives of people with diabetes, including the effect on interactions with doctors and other healthcare professionals.

Design

Qualitative user-led study using longitudinal interviews and 146 hours of participant observation. Data were analysed using a narrative approach.

Participants

21 patients with Type 1 diabetes, those either about to attend a patient education course or those who had completed the course in the previous 10 years.

Setting

Established patient education centres in three UK teaching hospitals teaching the DAFNE course (Dose Adjustment for Normal Eating).

Results

Both post-course and several years later, most participants spoke of the experience of taking part in education as life-changingly positive. It helped them understand how to gain control over a very complex disease and freed them from dependence on medical advice and restrictive regimes. However, interactions within the health system following patient education could be fraught. Participants emerged from the course with greater condition-specific knowledge than many of the healthcare professionals they encountered. When these professionals did not understand what their patients were trying to do and were uncomfortable trusting their expertise, there could be serious consequences for these patients' ability to continue effective self-management.

Conclusions

Patients who have in-depth knowledge of their condition encounter problems when their expertise is seen as inappropriate in standard healthcare interactions, and expertise taught to patients in one branch of medicine can be considered non-compliant by those who are not specialists in that field.

Although patient education can give people confidence in their own self-management skills, it cannot solve the power imbalance that remains when a generalist healthcare professional, however well-meaning, blocks access to medication and supplies needed to manage chronic disease successfully. There is a role for those involved in primary and hospital care, including those supporting and training healthcare professionals, to recognise these problems and find ways to acknowledge and respect chronic patients' biomedical and practical expertise.

Article Summary

Article focus

1. To explore the impact of patient education on the lives of people with chronic disease, including the post-intervention effect on interactions with healthcare professionals.

Key Messages

1. Patients who have taken part in intensive education courses are given practical condition-specific biomedical knowledge that exceeds that taught to all but the most specialist healthcare professionals.
2. The knowledgeable, self-managing patient created by such education can encounter obstacles in a health system that is not always prepared for them to take such an independent role. This can obstruct patients' efforts to manage their own condition, and can impair health outcomes.
3. Patient education alone cannot solve problems rooted in healthcare power structures and attitudes towards patient expertise. There is a role for those supporting and training healthcare professionals to recognise generic issues that arise when a population becomes self-efficacious and health literate, and ensure patient self-management is not undermined.

Strengths and Limitations

- Studies of patient education have been dominated by medical perspectives, resulting in an emphasis on questions about compliance and biomedical markers, with less attention paid to the impact on other parts of patients' lives. A strength of this study was its user-led focus, with a researcher from the diabetic community supported and advised by others from that community.
- The project fits the NIHR INVOLVE definition of research for patient benefit: "research 'with' or 'by' people who use services rather than 'to', 'about' or 'for' them."
- This qualitative study allowed a rich in-depth exploration of a particular education intervention, but this approach has inherent limitations; we cannot assume some of the condition-specific details are necessarily representative of other populations and other conditions.
- However, the broader findings of the study are applicable across the board: it has offered a new insight into the potential difficulties faced by highly health-literate patients, and suggests a need for serious reflection on existing practices, power hierarchies and training paradigms within healthcare.

What is already known and what this study adds

Research on patient education has looked mainly at cost-effectiveness and clinically defined outcomes. In diabetes, for example, structured education has been shown to improve quantitative scores for average blood glucose and quality of life. These outcomes, while important, have to date been researched and interpreted entirely by healthcare personnel within a medical perspective. This study, driven and carried out by people with Type 1 diabetes, is the first to explore several unaddressed areas, including the impact patient education has on people's overall life stories, and consequences for their healthcare interactions in the longer term.

Patients who have taken part in intensive education courses are given practical condition-specific biomedical knowledge that exceeds that taught to all but the most specialist healthcare professionals. Our findings suggest that the knowledgeable, self-managing patient created by such education can encounter obstacles in a health system that is not always prepared for patients to take such an independent role. This power imbalance can obstruct patients' efforts to manage their own condition, and can impair health outcomes.

Keywords:

Diabetes mellitus, Type 1; Health education; Professional-patient relations; Delivery of health care; Disease management

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4 **Introduction**

5 For more than two decades the UK has been developing and refining effective patient education
6 programmes in order to help those with long-term conditions to take responsibility for their own self-
7 management and avoid unnecessary hospitalisation.^{1 2} Diabetes care has a particularly strong track
8 record, with over 70 regional courses in England alone, and national programmes now being adopted
9 abroad, such as DAFNE (Dose Adjustment for Normal Eating) and DESMOND (Diabetes Education
10 and Self-Management for Ongoing and Newly Diagnosed).^{3 4} Randomised controlled trials have
11 shown improvements in specific health outcomes and condition-related quality of life measurements,
12 and NICE recommends that all people with diabetes should have access to this kind of structured
13 education.^{5 6 7}

14 For the patients themselves, however, these clinical outcomes are only one part of living with a
15 chronic condition. Our study, the first entirely patient-led research undertaken in this field, explores
16 several unaddressed areas: the role created for the patient during education, what it means to take
17 part, and consequences for patients' lives long-term. This paper draws on that research, looking
18 specifically at the experience of attending DAFNE and how it affects post-course interactions with the
19 health system.

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28 **Methods**

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31 **Influence of service users**

32 Service users with Type 1 diabetes were involved at every stage of the project, including choice of
33 topic, formulation of research question, design, development and conducting of the investigation, as
34 well as analysis and writing up. The James Lind Alliance (<http://www.lindalliance.org/>), INVOLVE
35 (<http://www.involve.org.uk/>), and the entirely patient-led Diabetes.co.uk Forum
36 (<http://www.diabetes.co.uk>) advised on the development of and recruitment to an Advisory Group for
37 the study. The final membership comprised 15 people who, between them, had more than 400 years
38 of living with diabetes, and experience of a variety of treatment regimes and patient education
39 initiatives. Some had never attended patient education, some were DAFNE trained and some had had
40 experience of non-DAFNE programmes. The Advisory Group shared experiences to help inform the
41 kinds of interview topics of relevance to diabetics, gave feedback on patient information sheets, and
42 three members participated in pilot interviews, on which they gave feedback. RS, herself a user-
43 researcher with Type 1 diabetes, had overall responsibility for the research design and
44 implementation, including data collection, analysis, and writing up.

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51 **Design**

52 The study took an interpretive, qualitative approach. Those attending or teaching DAFNE courses
53 acted as respondents or informants for the study, and a range of methods – interviewing,
54 observations, and course participation – were used. Semi-structured interviews were conducted in
55 order to allow these respondents' stories to emerge and give insight into the impact of the course on
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their overall lives, including their health-related interactions with others. Open-ended questions (such as “tell me how you have learnt to manage diabetes”) allowed interviewees to direct large parts of the interview to follow the narrative they wished to tell.⁸⁻¹¹ The study aimed to look at changes in people’s perceptions of their situation and their own and others’ levels of expertise, so interviews with new DAFNE students before and after the course, observations and course documentation were included as part of the data making up the narratives in the study.¹²⁻¹⁴ This meant that changes connected with course attendance could be observed as they happened, and the immediate impact on participants’ overall life narrative noted. Roughly half the participants fell into this “new student” group. However, in order to explore how patients’ narratives might change over a longer time-frame, the rest of the participants were recruited from DAFNE “graduates” (those who had completed the course several years previously), who were asked for retrospective narratives in a single interview. Although the majority of interview data were collected in formal, recorded sessions with a topic guide, less formal discussion and exploration of ideas with students and educators also took place during observations.

Participant selection and setting

DAFNE centres are externally audited to ensure that students get the same quality of education wherever they attend the course.¹⁵ This consistency, along with DAFNE’s national reach, was one of the reasons behind the choice of this programme for the research study over other patient education projects with more localised or internal variation. Several different study sites were included to increase the diversity of participants and venues, rather than specifically to compare and contrast different experiences from one DAFNE centre to another. Each site ran the course over 5 consecutive days, with specially trained teams of two healthcare professionals, a Diabetes Specialist Nurse (DSN) and a dietitian, doing the teaching.

Participants were recruited from established DAFNE centres in three UK hospitals. All three were teaching hospitals with specialist Diabetes Clinics that continued to support patients along DAFNE principles post-course. The study thus looked at the journey taken by a group of perhaps the country’s most expert patients – those with one of the most complex conditions to manage, taught in one of the most comprehensive education programmes, administered by some of the most experienced programme leaders.

Patient education is open to everyone with established Type 1 diabetes, and is recommended for all.⁶ For this study, potential participants for the “new student” group were considered to be anyone accepted onto a DAFNE course at the chosen study sites during the study period (September 2011 to January 2012); 11 were interviewed. DAFNE graduates were recruited from course follow-up sessions (n=4), ordinary clinic appointments (n=4), and field contacts (n=2), with the aim of recruiting a purposive sample, as heterogeneous as possible in terms of diagnosis era, stage of life at diagnosis, current age, educational level, type of work, ethnicity and gender. Participants in the “graduate” group had taken part in DAFNE between three and eleven years previously, with a mean and median of seven years since completing the course. Nobody who was approached to take part

declined, although two people had to cancel the arranged interviews because of health or family problems and so were not in the end included in the study.

A breakdown of the participants' demographics can be found in Table 1.

Table 1: Demographics of participants

Decade of diagnosis	
<i>Pre 1970</i>	5 participants
<i>1970s</i>	3 participants
<i>1980s</i>	4 participants
<i>1990s</i>	2 participants
<i>Post 2000</i>	7 participants
Stage of life at diagnosis	
<i>Child</i>	8 participants
<i>Teenager</i>	2 participants
<i>Young adult (under 25)</i>	3 participants
<i>Adult (25 and over)</i>	8 participants
Age at time of first interview	
<i>20s</i>	3 participants
<i>30s</i>	3 participants
<i>40s</i>	7 participants
<i>50s</i>	4 participants
<i>60s</i>	4 participants

Employment situation

<i>Full time (standard hours)</i>	10 participants
<i>Full time (shift work)</i>	2 participants
<i>Part time</i>	3 participants
<i>Student</i>	2 participants
<i>Unemployed/ on sick leave</i>	2 participants
<i>Retired</i>	2 participants

Last educational qualification taken

<i>None</i>	2 participants
<i>GCSE or equivalent</i>	3 participants
<i>A level or equivalent</i>	8 participants
<i>Degree level or equivalent</i>	5 participants
<i>Postgraduate level</i>	3 participants

Gender

<i>Male</i>	9 participants
<i>Female</i>	12 participants

Ethnicity

<i>White British</i>	17 participants
<i>White Other</i>	1 participant
<i>Black Caribbean</i>	3 participants

In summary, longitudinal narrative interviews were conducted with 11 new students before their course; they were observed during education, and re-interviewed three months post-course. Retrospective narratives were collected from ten former students of DAFNE, and additional information gathered from seven teaching staff. In all, data were gathered from 32 interviews with patients and 146 hours of observations, including five days of complete participation in DAFNE by a user-researcher with Type 1 diabetes, RS.

Analysis

Transcripts and field notes were coded using NVivo 9, using a mixture of thematic and structural narrative analysis.^{16 17} The ideal patient role and narrative being taught on DAFNE was compared with students' personal life stories, and with their stories of others' expectations of them once the course was over. The DAFNE curriculum document, patient-facing course booklet, and field notes from observations and participant observation were analysed along with transcribed interviews and notes of classroom discussions. Following a thematic narrative approach, whole stories rather than fragments of data were coded by theme, using *in vivo* codes derived directly from the actual words used in observations or documentation. This allowed story themes, woven through several days or even across observations, to be collected and compared. For students' individual narratives, interview transcripts were used as one set of data; for the new student group, this was supplemented by sections in observations where they had told personal stories. Each participant was coded separately, and a précis document created for each to summarise the elements important to their story. This final version could then be compared, not only with each other but with the roles and themes taught on the DAFNE course (the DAFNE narrative). Participants' post-course stories of diabetes-related interactions were examined to gain an insight into the metanarratives they were encountering and the cultural expectations with which they had to live; in other words, to discover the ways healthcare professionals and laypeople responded to graduates' status and knowledge in their new, post-DAFNE patient role.

Results

Expectations: the role of the expert patient

Consistently across all observed courses, students were encouraged by tutors to adopt certain ideals. Among these were concepts of empowerment, expertise, and independence. These principles are keystones of much patient education in the last couple of decades.^{1 25} As can be seen in the extract below, when students made statements suggesting blind compliance or dependence on doctors, they were gently challenged to think of themselves differently; as an empowered and expert patient, no longer dependent on doctors for decisions, but able to talk about their treatment requirements with healthcare professionals as an equal:

Student: "My consultant told me to [take insulin at a certain time]."

Tutor: "You'll all be DAFNE trained by the end of the week, you will be having a discussion with your doctors about your insulins!"

Observation field notes

The structure and complexity of DAFNE course content has been written about in depth elsewhere, including the benefits for patients in terms of blood glucose control; but the amount of knowledge imparted, and the quantity of self-management work, is not always emphasised.^{5 18} Students in this study were expected to learn how to take control of their own treatment regime at a very high level, interpreting complex patterns of blood glucose results over time in order to make constant alterations to insulin dose and timing. This included understanding not only how to count carbohydrates, but also the action and interaction of different kinds of insulin, the interaction of foods to create an overall glycaemic index of a meal, the impact of hormones, stress, alcohol, different kinds of exercise, travelling across time zones, managing pregnancy and breast-feeding, and how to self-manage specific problems such as dawn phenomenon, rising blood glucose during various severities of illness, and hypoglycaemia unawareness.

In the DAFNE narrative, the patient is not a passive victim of circumstance. In the following extract, a student's summary of previous experience as an inpatient is listened to, then a more active, independent role is suggested for the future:

Student: "Whenever I've gone to hospital, because I'm diabetic, they put me on a drip, everything."

Tutor replies that the Sick Day Rules [specific self-management guidelines] are there "to help you avoid that situation".

Observation field notes

In summary, the DAFNE graduate is taught not only key information, but also to accept a new role for him- or herself in the health system and the wider world: as empowered, knowledgeable and independent.

Experience – taking on the new role

Participating in the kind of detailed, comprehensive self-management education offered by DAFNE had a very positive impact on the personal lives of nearly everyone in the study. Participants from all groups talked of "life-changing" experiences on the course, and of having been freed from the "shackles" of a confusing or restrictive treatment regime by being given "the tools of the trade" to manage a central aspect of their own lives.

"I mean I really have nothing but praise for [DAFNE], it has been properly transformative in ... in a *fundamental* way, I've got a fundamentally better understanding of what it is that's actually wrong with me. Um... and that, yeah, that just allows me to be a lot freer."

Harry, new student, speaking in post-DAFNE interview

Those who had already built up self-management expertise pre-course talked about “fine-tuning” or solving a specific problem that had been causing them difficulty; nobody was entirely negative about attending DAFNE.

In short, students were largely comfortable with the new patient role being offered them via DAFNE. Knowledge, and independence from doctors and restrictive regimes, were mostly valued, although support from DAFNE specialists post-course was very much appreciated by some. The relationship of students to “empowerment” was slightly less clear cut; although power and control over diabetes was hugely enhanced by DAFNE, empowerment within the health system was more problematic, as we describe below.

Consequences – a clash of roles

Post-course, participants were often cast into ambiguous roles in healthcare interactions. Both the new student and the graduate groups had similar experiences; frequently, the condition-specific biomedical and practical information they had learnt was far greater than that of their doctors or nurses.

This was not necessarily a problem for everyone. Jane, below, described a positive experience with a primary care doctor who was keen to learn more and trusted her expertise:

I had an insect, I had a mozzie bite that closed my eye, bit me on the eye just here, the soft bit above the eye. And my eye swelled up, and I went to a walk-in clinic. And they wanted to give me steroids, which obviously push your blood sugar up, and I said ‘well I *know* that’s going to happen, I can manage my blood sugar if it does shoot up, I can increase my insulin and I use the DAFNE, do you have DAFNE?’ and I had to go step by step through with [this doctor] how it worked. And he wrote *loads of notes*; it was really interesting, he wrote *loads and loads of notes*.

Jane, DAFNE graduate, talking six years post-course

Some participants simply avoided less specialist healthcare professionals if they could, relying instead on advice from their DAFNE tutors. However, this was not always possible, and in many health interactions, patients and healthcare professionals struggled to manage the tensions that arose from the partial role-reversal of expertise after self-management education. In some cases basic or even inaccurate information was imposed on patients, who on the whole swallowed their annoyance in silence:

I went to a nurse [...] for like, I can’t remember what even for, a flu jab or something, um ... and, um [...] she started giving me advice about my blood sugars and it *really*, it really got on my nerves, because they were just completely, completely counter to everything that I’d just been taught. And, and obviously not *right*?

Interviewer: What did you say?

I, I didn’t, I didn’t say anything. I just left it.

Interviewer: So she didn’t know that you... what you were thinking?

No. There’s no point getting into an argument.

James, new student, speaking in post-DAFNE interview

Where this tension became more serious was in situations where a less knowledgeable doctor had considerable power over the expert patient. This was most often seen in interactions with GPs, who restricted prescriptions, sometimes surreptitiously, when they did not understand the importance of blood testing to the patient's self-management regime. Using DAFNE principles, students learn how to achieve tighter, smoother blood glucose control by performing blood tests at least four times a day, using the results to make decisions about insulin dosage as well as ensuring that dangerously high or low blood sugars could be avoided. For some, this meant a considerable increase in test strip requirements as they took on the extra work to improve blood glucose control. Although course tutors provided letters for GPs explaining the necessity for these adjustments, interviewees reported having to be "quite tough" to successfully negotiate with primary care teams who were reluctant to absorb the rise in short-term costs. Even when changes had apparently been agreed, they were sometimes reversed by healthcare staff without explanation or warning.

Julia's story, below, is an example of the kind of interaction that could arise in these circumstances. Although her GP did not refuse the prescription request outright, the dispensary simply reduced the amount asked for without explanation:

"So I went to pick up my prescription, I'd asked for four boxes, so I went to pick up my prescription when they were ready to go and pick it up, my husband got it and there were only two.

So I rang them up. I said: 'There are only two boxes.'

'- That's all you need.'

So I said: 'Oh right. Why's that?'

So she said, um: 'Well you only do two tests a day, and that will last you for months.'

[..]

So I said: 'So, as you can see on {the letter from the diabetes specialist tutors} they're asking for me to have adequate supplies to do x number of blood tests a week.'

'- Well I think it's quite ridiculous, you don't need that many.'

Julia, diabetic 50 years, new student speaking post-DAFNE.

Phil, mentioned earlier, was another typical example. He recontacted RS six months after data collection ended, with an update: his GP, who had originally agreed to prescribe blood test strips, had subsequently taken the strips off repeat prescription and insisted on Phil taking time off work every month to come into the surgery and justify the next month's supply. Since this was not always possible to do, he had had to reduce his testing and his blood glucose had begun to rise again. As Phil put it, his doctor did not "win the battle" because of superior medical knowledge; the GP simply had more power, and chose to exercise it.

Healthcare professionals who were reluctant to trust patients' expertise in daily management could also cause difficulties. For example, one participant told of being sent to hospital when her blood glucose happened to be high because of an infection (something she had been taught to self-manage at home using DAFNE principles):

I don't go to my GP for *anything* to do with my diabetes, because they mainly deal with Type 2 diabetics. [...My GP] sent me to hospital when I had my blood sugar... I went in to see him about something and my blood sugar was 18, which was not unusual. And he called an ambulance and I *said* to him he was being O.T.T., because not many Type 2 diabetics would go to A&E.

Interviewer: Did he listen or did he still call the ambulance?

"He listened, but he still called the ambulance."

Interviewer: And then what happened?

Well I was in hospital for two days! [...] And then I had trouble getting out of hospital, because I didn't meet the criteria and I'm saying to them 'please, just let me go home, this is unnatural, you know, I'm stuck in bed, my blood sugars aren't coming down because I'm stressed, I've got an infection, it's no good putting me on...' you know, because I was on a sliding scale, I said 'you don't understand, you don't understand, you don't understand...'

Mary, DAFNE graduate, talking nine years post-course

Although the GP and hospital staff meant well, they had failed to appreciate not just the emotional but also the physical impact on the patient of their actions. Mary gave her account with great emphasis. She described her unnecessary hospitalisation and subsequent events as "frightening" because of the lack of power she was allowed over her own body; she could only watch her blood sugar rise needlessly without being able to use her own skills and expertise to keep herself safe. During the experience of being put on a "sliding scale" (intravenous insulin and glucose administered in hospital), the patient completely loses control over his or her diabetes, surrendering management to hospital staff who are unlikely to be diabetes specialists. The National Diabetes Inpatient Audit has shown that in more than a third of cases this results in medication errors, which can lead to coma and occasionally death.¹⁹

Discussion

Principal findings

People graduating from intensive patient education courses such as DAFNE emerge with disease-specific biomedical, experiential and practical knowledge that exceeds that of many healthcare professionals. From the stories told by participants in this study, it was clear that serious obstacles to self-management arose when generalist and even specialist doctors and nurses were not comfortable with patients who had a high level of expertise. While this has been noted elsewhere in more general terms,^{20 21} this is the first study to confirm these findings in terms of healthcare professionals' reactions to formally trained Expert Patients. Although some healthcare teams were happy to support course graduates and even learn from them, this attitude could not be counted on, particularly when patients made budgetary demands that the budget-holders did not fully understand, such as requests for home blood testing equipment. Expertise taught to patients in one branch of medicine can be considered non-compliant by those who are not specialists in that field, and in some circumstances,

such as inpatient care, self-management may be greatly discouraged or even forbidden by hospital policy.

Patient education has the potential to change people’s lives for the better in a way that is perhaps not fully captured by standard clinical and quality of life outcome assessments. As well as offering practical information, DAFNE teaches people with diabetes to consider a new role as expert, independent, and empowered patients. Participants in this study found that hugely helpful, not only in terms of biomedical improvements, but also in terms of taking control over their own lives with chronic disease. However, there is evidence that having learnt how to self-manage successfully, patients find it frustrating, at best, and frightening, at worst, to have access to self-management resources denied them; in some cases problems with post-course interactions may be hindering patients’ ability to hit biomedical targets and stay healthy.

Strengths and limitations

Traditionally, studies of patient education have been dominated by medical perspectives, with very little formal research conducted by patients themselves. This has resulted in emphasis on questions about compliance and biomedical markers, with less attention paid to the impact of educational interventions on other parts of patients’ lives. A strength of this study was its user-led focus, with a researcher from the diabetic community supported and advised by others from that community. The project fits wholly within the NIHR and INVOLVE definition of research for patient benefit: “research ‘with’ or ‘by’ people who use services rather than ‘to’, ‘about’ or ‘for’ them.”²²

Of potential concern in this study is the issue of the reification of one user-researcher’s experience at the expense of other people’s stories.²³ Several steps were taken to mitigate this potential problem. Although the project was designed and conducted by a single user-researcher, RS, the Advisory Group described above provided a wider range of perspectives on living with diabetes, acted as a sounding-board for ideas, and helped to develop, refine and pilot the interview schedule and topic guide. Practical help was also enlisted from others in order to mitigate issues associated with RS being the only investigator conducting interviews. JS and CH checked transcripts, advised with analysis, and confirmed the extent to which respondents were allowed to tell their own stories. In addition, the opportunity to observe students on DAFNE and then conduct follow-up interviews meant that a rapport was built up over time, and it was possible to return to previous stories and statements for clarification or expansion if necessary.

Some researchers recommend the use of respondent validation or “member checking”, where participants are asked to comment on findings and the conclusions made from those findings, although the benefit of this as proof of a study’s validity is contested.²⁴ A limited form of this practice was used in this study. Although there was no formal process for gathering feedback on the findings from every participant, general concepts and emerging theories were discussed post-interview with those participants who expressed interest in the turns the study was taking, and the insights gained in these discussions were invaluable.

The choice of a narrative methodology and semi-structured topic guide allowed patients to choose what to emphasise in stories they told about themselves, but this approach had its inherent limitations too, as did the decision to restrict the research to a single chronic illness and just one patient education course. The small sample size allowed in-depth qualitative analysis to take place, but both sample size and the particular challenges involved in managing Type 1 diabetes mean that we cannot assume disease-specific findings are representative of other populations and other conditions. However, the broader findings of the study are applicable across the board: it has offered a new insight into the potential difficulties faced by newly educated patients, and suggests a need for serious reflection on existing practices, power hierarchies and training paradigms within healthcare. There may be local differences in different populations, but the paradox remains: patients are being given expertise and confidence to self-manage, but there remains no pathway to having these skills recognised or valued more generally by those with power and access to resources. At best, this leaves patients vulnerable; at worst, it can undermine their hard work and health status.

Studies of post-education health interactions have been rather limited to date. Some evaluations have hinted at potential conflicts between knowledgeable patients and less knowledgeable health professionals, and the potential for this conflict to erode health outcomes over time,^{5 26} but has rarely been a focus of research. Previous qualitative work in diabetes education has identified the importance of ongoing support from healthcare professionals in patients' ability to self-manage along the lines taught on the course.²⁷⁻²⁹ However, these studies focus on the relationship between the specialist and patient rather than interactions with generalist healthcare professionals. In our study we found specific problems with interactions in primary and hospital care. This suggests that the power held by GP prescribers should not be overlooked when considering patients' ability to self-manage successfully.

Implications and future research

Although patient education is recommended for those with chronic conditions in general,^{1 30} the implications for the education of healthcare professionals are not currently considered in parallel. While modern medical and nursing education focuses on patient-centred care,^{31 32} it does not prepare healthcare students for situations in which their patients have more biomedical and practical knowledge than they do about a specific treatment regime or illness.³³ When the role of the patient in a healthcare interaction is ambiguous and contested, problems arise on both sides, and extra work is required by both patient and professional. Although courses like DAFNE could include sessions preparing students for post-course interactions, there are limits to the extent to which patient education can mitigate these problems. In the districts where this study took place, work was already being done to help support DAFNE graduates who needed to go into hospital, and to ensure they got letters to enhance their authority when asking for supplies from primary care. Findings from this study would suggest that this work is very much needed. However, even when this support was in place, graduates continued to encounter disempowering practices from healthcare staff who were not DAFNE-aware. When healthcare practitioners do not understand the patient's self-management

requirements or trust their ability, they may put up obstacles to improved health outcomes by limiting medical supplies or insisting on unnecessary hospitalisation. As more chronic illness care is put into the hands of generalists, such situations are likely to arise more and more often; the importance of teaching strategies to cope with patient expertise, rather than see it as a threat, is of increasing relevance.

Although this study has provided an insight into the kinds of issues encountered by people after formal education, further research with both patients and healthcare professionals is needed to establish how widespread these problems are on a national level, and whether similar issues are faced by patients with other kinds of chronic conditions following other styles of Expert Patient Programme.

Conclusions

Healthcare professionals cannot become experts in the detailed management of every complex condition; gathering specialist input from others has long been an important part of treatment decision-making. Doctors, nurses and others whose attitudes impact on patient care must be supported to extend that model of shared expertise to work with those who have chronic illnesses, seeing the patient as part of the healthcare team, and the patient's condition-specific biomedical knowledge as a valuable resource, not a threat.

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RS designed and carried out the research, and drafted the paper. She is guarantor. JS and CH supervised research, reviewed and edited the paper.

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The presented data are anonymised and risk of identification is low. Extra data is available by emailing RS.

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WHAT HAPPENS WHEN PATIENTS KNOW MORE THAN THEIR DOCTORS?

Diabetics' experiences of health interactions after patient education: a qualitative patient-led study

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Abstract

Objective

To explore the impact of patient education on the lives of people with diabetes, including the effect on interactions with doctors and other healthcare professionals.

Design

Qualitative user-led study using longitudinal interviews and 146 hours of participant observation. Data were analysed using a narrative approach.

Participants

21 patients with Type 1 diabetes, those either about to attend a patient education course or those who had completed the course in the previous 10 years.

Setting

Established patient education centres in three UK teaching hospitals **teaching the DAFNE course (Dose Adjustment for Normal Eating)**.

Results

Both post-course and several years later, most participants spoke of the experience of taking part in education as life-changingly positive. It helped them understand how to gain control over a very complex disease and freed them from dependence on medical advice and restrictive regimes. However, interactions within the health system following patient education could be fraught. Participants emerged from the course with greater condition-specific knowledge than many of the healthcare professionals they encountered. When these professionals did not understand what their patients were trying to do and were uncomfortable trusting their expertise, there could be serious consequences for these patients' ability to continue effective self-management.

Conclusions

Patients who have in-depth knowledge of their condition encounter problems when their expertise is seen as inappropriate in standard healthcare interactions, and expertise taught to patients in one branch of medicine can be considered non-compliant by those who are not specialists in that field.

Although patient education can give people confidence in their own self-management skills, it cannot solve the power imbalance that remains when a generalist healthcare professional, however well-meaning, blocks access to medication and supplies needed to manage chronic disease successfully. There is a role for those involved in primary and hospital care, including those supporting and training healthcare professionals, to recognise these problems and find ways to acknowledge and respect chronic patients' biomedical and practical expertise.

Article Summary

Article focus

1. To explore the impact of patient education on the lives of people with chronic disease, including the post-intervention effect on interactions with healthcare professionals.

Key Messages

1. Patients who have taken part in intensive education courses are given practical condition-specific biomedical knowledge that exceeds that taught to all but the most specialist healthcare professionals.
2. The knowledgeable, self-managing patient created by such education can encounter obstacles in a health system that is not always prepared for them to take such an independent role. This can obstruct patients' efforts to manage their own condition, and can impair health outcomes.
3. Patient education alone cannot solve problems rooted in healthcare power structures and attitudes towards patient expertise. There is a role for those supporting and training healthcare professionals to recognise generic issues that arise when a population becomes self-efficacious and health literate, and ensure patient self-management is not undermined.

Strengths and Limitations

- Studies of patient education have been dominated by medical perspectives, resulting in an emphasis on questions about compliance and biomedical markers, with less attention paid to the impact on other parts of patients' lives. A strength of this study was its user-led focus, with a researcher from the diabetic community supported and advised by others from that community.
- The project fits the NIHR INVOLVE definition of research for patient benefit: "research 'with' or 'by' people who use services rather than 'to', 'about' or 'for' them."
- This qualitative study allowed a rich in-depth exploration of a particular education intervention, but this approach has inherent limitations; we cannot assume some of the condition-specific details are necessarily representative of other populations and other conditions.
- However, the broader findings of the study are applicable across the board: it has offered a new insight into the potential difficulties faced by highly health-literate patients, and suggests a need for serious reflection on existing practices, power hierarchies and training paradigms within healthcare.

What is already known and what this study adds

Research on patient education has looked mainly at cost-effectiveness and clinically defined outcomes. In diabetes, for example, structured education has been shown to improve quantitative

scores for average blood glucose and quality of life. These outcomes, while important, have to date been researched and interpreted entirely by healthcare personnel within a medical perspective. This study, driven and carried out by people with Type 1 diabetes, is the first to explore several unaddressed areas, including the impact patient education has on people's overall life stories, and consequences for their healthcare interactions in the longer term.

Patients who have taken part in intensive education courses are given practical condition-specific biomedical knowledge that exceeds that taught to all but the most specialist healthcare professionals. Our findings suggest that the knowledgeable, self-managing patient created by such education can encounter obstacles in a health system that is not always prepared for patients to take such an independent role. This power imbalance can obstruct patients' efforts to manage their own condition, and can impair health outcomes.

Keywords:

Diabetes mellitus, Type 1; Health education; Professional-patient relations; Delivery of health care; Disease management

Introduction

For more than two decades the UK has been developing and refining effective patient education programmes in order to help those with long-term conditions to take responsibility for their own self-management and avoid unnecessary hospitalisation.^{1 2} Diabetes care has a particularly strong track record, with over 70 regional courses in England alone, and national programmes now being adopted abroad, such as DAFNE (Dose Adjustment for Normal Eating) and DESMOND (Diabetes Education and Self-Management for Ongoing and Newly Diagnosed).^{3 4} Randomised controlled trials have shown improvements in specific health outcomes and condition-related quality of life measurements, and NICE recommends that all people with diabetes should have access to this kind of structured education.^{5 6 7}

For the patients themselves, however, these clinical outcomes are only one part of living with a chronic condition. Our study, the first entirely patient-led research undertaken in this field, explores several unaddressed areas: the role created for the patient during education, what it means to take part, and consequences for patients' lives long-term. This paper draws on that research, looking specifically at the experience of attending DAFNE and how it affects post-course interactions with the health system.

Methods

Influence of service users

Service users with Type 1 diabetes were involved at every stage of the project, including choice of topic, formulation of research question, design, development and conducting of the investigation, as well as analysis and writing up. The James Lind Alliance (<http://www.lindalliance.org/>), INVOLVE (<http://www.involve.org.uk/>), and the entirely patient-led Diabetes.co.uk Forum (<http://www.diabetes.co.uk>) advised on the development of and recruitment to an Advisory Group for the study. The final membership comprised 15 people who, between them, had more than 400 years of living with diabetes, and experience of a variety of treatment regimes and patient education initiatives. Some had never attended patient education, some were DAFNE trained and some had had experience of non-DAFNE programmes. The Advisory Group shared experiences to help inform the kinds of interview topics of relevance to diabetics, gave feedback on patient information sheets, and three members participated in pilot interviews, on which they gave feedback. RS, herself a user-researcher with Type 1 diabetes, had overall responsibility for the research design and implementation, including data collection, analysis, and writing up.

Design

The study took an interpretive, qualitative approach. Those attending or teaching DAFNE courses acted as respondents or informants for the study, and a range of methods – interviewing, observations, and course participation – were used. Semi-structured interviews were conducted in order to allow these respondents' stories to emerge and give insight into the impact of the course on

their overall lives, including their health-related interactions with others. Open-ended questions (such as “tell me how you have learnt to manage diabetes”) allowed interviewees to direct large parts of the interview to follow the narrative they wished to tell.⁸⁻¹¹ The study aimed to look at changes in people’s perceptions of their situation and their own and others’ levels of expertise, so interviews with new DAFNE students before and after the course, observations and course documentation were included as part of the data making up the narratives in the study.¹²⁻¹⁴ This meant that changes connected with course attendance could be observed as they happened, and the immediate impact on participants’ overall life narrative noted. Roughly half the participants fell into this “new student” group. However, in order to explore how patients’ narratives might change over a longer time-frame, the rest of the participants were recruited from DAFNE “graduates” (those who had completed the course several years previously), who were asked for retrospective narratives in a single interview. Although the majority of interview data were collected in formal, recorded sessions with a topic guide, less formal discussion and exploration of ideas with students and educators also took place during observations.

Participant selection and setting

DAFNE centres are externally audited to ensure that students get the same quality of education wherever they attend the course.¹⁵ This consistency, along with DAFNE’s national reach, was one of the reasons behind the choice of this programme for the research study over other patient education projects with more localised or internal variation. Several different study sites were included to increase the diversity of participants and venues, rather than specifically to compare and contrast different experiences from one DAFNE centre to another. Each site ran the course over 5 consecutive days, with specially trained teams of two healthcare professionals, a Diabetes Specialist Nurse (DSN) and a dietitian, doing the teaching.

Participants were recruited from established DAFNE centres in three UK hospitals. All three were teaching hospitals with specialist Diabetes Clinics that continued to support patients along DAFNE principles post-course. The study thus looked at the journey taken by a group of perhaps the country’s most expert patients – those with one of the most complex conditions to manage, taught in one of the most comprehensive education programmes, administered by some of the most experienced programme leaders.

Patient education is open to everyone with established Type 1 diabetes, and is recommended for all.⁶ For this study, potential participants for the “new student” group were considered to be anyone accepted onto a DAFNE course at the chosen study sites during the study period (September 2011 to January 2012); 11 were interviewed. DAFNE graduates were recruited from course follow-up sessions (n=4), ordinary clinic appointments (n=4), and field contacts (n=2), with the aim of recruiting a purposive sample, as heterogeneous as possible in terms of diagnosis era, stage of life at diagnosis, current age, educational level, type of work, ethnicity and gender. Participants in the “graduate” group had taken part in DAFNE between three and eleven years previously, with a mean and median of seven years since completing the course. Nobody who was approached to take part

declined, although two people had to cancel the arranged interviews because of health or family problems and so were not in the end included in the study.

A breakdown of the participants' demographics can be found in Table 1.

Table 1: Demographics of participants

Decade of diagnosis	
<i>Pre 1970</i>	5 participants
<i>1970s</i>	3 participants
<i>1980s</i>	4 participants
<i>1990s</i>	2 participants
<i>Post 2000</i>	7 participants
Stage of life at diagnosis	
<i>Child</i>	8 participants
<i>Teenager</i>	2 participants
<i>Young adult (under 25)</i>	3 participants
<i>Adult (25 and over)</i>	8 participants
Age at time of first interview	
<i>20s</i>	3 participants
<i>30s</i>	3 participants
<i>40s</i>	7 participants
<i>50s</i>	4 participants
<i>60s</i>	4 participants

Employment situation

<i>Full time (standard hours)</i>	10 participants
<i>Full time (shift work)</i>	2 participants
<i>Part time</i>	3 participants
<i>Student</i>	2 participants
<i>Unemployed/ on sick leave</i>	2 participants
<i>Retired</i>	2 participants

Last educational qualification taken

<i>None</i>	2 participants
<i>GCSE or equivalent</i>	3 participants
<i>A level or equivalent</i>	8 participants
<i>Degree level or equivalent</i>	5 participants
<i>Postgraduate level</i>	3 participants

Gender

<i>Male</i>	9 participants
<i>Female</i>	12 participants

Ethnicity

<i>White British</i>	17 participants
<i>White Other</i>	1 participant
<i>Black Caribbean</i>	3 participants

In summary, longitudinal narrative interviews were conducted with 11 new students before their course; they were observed during education, and re-interviewed three months post-course. Retrospective narratives were collected from ten former students of DAFNE, and additional information gathered from seven teaching staff. In all, data were gathered from 32 interviews with patients and 146 hours of observations, including five days of complete participation in DAFNE by a user-researcher with Type 1 diabetes, RS.

Analysis

Transcripts and field notes were coded using NVivo 9, using a mixture of thematic and structural narrative analysis.^{16 17} The ideal patient role and narrative being taught on DAFNE was compared with students' personal life stories, and with their stories of others' expectations of them once the course was over. The DAFNE curriculum document, patient-facing course booklet, and field notes from observations and participant observation were analysed along with transcribed interviews and notes of classroom discussions. Following a thematic narrative approach, whole stories rather than fragments of data were coded by theme, using *in vivo* codes derived directly from the actual words used in observations or documentation. This allowed story themes, woven through several days or even across observations, to be collected and compared. For students' individual narratives, interview transcripts were used as one set of data; for the new student group, this was supplemented by sections in observations where they had told personal stories. Each participant was coded separately, and a précis document created for each to summarise the elements important to their story. This final version could then be compared, not only with each other but with the roles and themes taught on the DAFNE course (the DAFNE narrative). Participants' post-course stories of diabetes-related interactions were examined to gain an insight into the metanarratives they were encountering and the cultural expectations with which they had to live; in other words, to discover the ways healthcare professionals and laypeople responded to graduates' status and knowledge in their new, post-DAFNE patient role.

Results

Expectations: the role of the expert patient

Consistently across all observed courses, students were encouraged by tutors to adopt certain ideals. Among these were concepts of empowerment, expertise, and independence. These principles are keystones of much patient education in the last couple of decades.^{1 25} As can be seen in the extract below, when students made statements suggesting blind compliance or dependence on doctors, they were gently challenged to think of themselves differently; as an empowered and expert patient, no longer dependent on doctors for decisions, but able to talk about their treatment requirements with healthcare professionals as an equal:

Student: "My consultant told me to [take insulin at a certain time]."

Tutor: "You'll all be DAFNE trained by the end of the week, you will be having a discussion with your doctors about your insulins!"

Observation field notes

The structure and complexity of DAFNE course content has been written about in depth elsewhere, including the benefits for patients in terms of blood glucose control; but the amount of knowledge imparted, and the quantity of self-management work, is not always emphasised.^{5 18} Students in this study were expected to learn how to take control of their own treatment regime at a very high level, interpreting complex patterns of blood glucose results over time in order to make constant alterations to insulin dose and timing. This included understanding not only how to count carbohydrates, but also the action and interaction of different kinds of insulin, the interaction of foods to create an overall glycaemic index of a meal, the impact of hormones, stress, alcohol, different kinds of exercise, travelling across time zones, managing pregnancy and breast-feeding, and how to self-manage specific problems such as dawn phenomenon, rising blood glucose during various severities of illness, and hypoglycaemia unawareness.

In the DAFNE narrative, the patient is not a passive victim of circumstance. In the following extract, a student's summary of previous experience as an inpatient is listened to, then a more active, independent role is suggested for the future:

Student: "Whenever I've gone to hospital, because I'm diabetic, they put me on a drip, everything."

Tutor replies that the Sick Day Rules [specific self-management guidelines] are there "to help you avoid that situation".

Observation field notes

In summary, the DAFNE graduate is taught not only key information, but also to accept a new role for him- or herself in the health system and the wider world: as empowered, knowledgeable and independent.

Experience – taking on the new role

Participating in the kind of detailed, comprehensive self-management education offered by DAFNE had a very positive impact on the personal lives of nearly everyone in the study. Participants from all groups talked of "life-changing" experiences on the course, and of having been freed from the "shackles" of a confusing or restrictive treatment regime by being given "the tools of the trade" to manage a central aspect of their own lives.

"I mean I really have nothing but praise for [DAFNE], it has been properly transformative in ... in a *fundamental* way, I've got a fundamentally better understanding of what it is that's actually wrong with me. Um... and that, yeah, that just allows me to be a lot freer."

Harry, new student, speaking in post-DAFNE interview

Those who had already built up self-management expertise pre-course talked about “fine-tuning” or solving a specific problem that had been causing them difficulty; nobody was entirely negative about attending DAFNE.

In short, students were largely comfortable with the new patient role being offered them via DAFNE. Knowledge, and independence from doctors and restrictive regimes, were mostly valued, although support from DAFNE specialists post-course was very much appreciated by some. The relationship of students to “empowerment” was slightly less clear cut; although power and control over diabetes was hugely enhanced by DAFNE, empowerment within the health system was more problematic, as we describe below.

Consequences – a clash of roles

Post-course, participants were often cast into ambiguous roles in healthcare interactions. Both the new student and the graduate groups had similar experiences; frequently, the condition-specific biomedical and practical information they had learnt was far greater than that of their doctors or nurses.

This was not necessarily a problem for everyone. Jane, below, described a positive experience with a primary care doctor who was keen to learn more and trusted her expertise:

I had an insect, I had a mozzie bite that closed my eye, bit me on the eye just here, the soft bit above the eye. And my eye swelled up, and I went to a walk-in clinic. And they wanted to give me steroids, which obviously push your blood sugar up, and I said ‘well I know that’s going to happen, I can manage my blood sugar if it does shoot up, I can increase my insulin and I use the DAFNE, do you have DAFNE?’ and I had to go step by step through with [this doctor] how it worked. And he wrote loads of notes; it was really interesting, he wrote loads and loads of notes.

Jane, DAFNE graduate, talking six years post-course

Some participants simply avoided less specialist healthcare professionals if they could, relying instead on advice from their DAFNE tutors. However, this was not always possible, and in many health interactions, patients and healthcare professionals struggled to manage the tensions that arose from the partial role-reversal of expertise after self-management education. In some cases basic or even inaccurate information was imposed on patients, who on the whole swallowed their annoyance in silence:

I went to a nurse [...] for like, I can’t remember what even for, a flu jab or something, um ... and, um [...] she started giving me advice about my blood sugars and it really, it really got on my nerves, because they were just completely, completely counter to everything that I’d just been taught. And, and obviously not right?

Interviewer: What did you say?

I, I didn’t, I didn’t say anything. I just left it.

Interviewer: So she didn’t know that you... what you were thinking?

No. There’s no point getting into an argument.

James, new student, speaking in post-DAFNE interview

Where this tension became more serious was in situations where a less knowledgeable doctor had considerable power over the expert patient. This was most often seen in interactions with GPs, who restricted prescriptions, sometimes surreptitiously, when they did not understand the importance of blood testing to the patient's self-management regime. Using DAFNE principles, students learn how to achieve tighter, smoother blood glucose control by performing blood tests at least four times a day, using the results to make decisions about insulin dosage as well as ensuring that dangerously high or low blood sugars could be avoided. For some, this meant a considerable increase in test strip requirements as they took on the extra work to improve blood glucose control. Although course tutors provided letters for GPs explaining the necessity for these adjustments, interviewees reported having to be "quite tough" to successfully negotiate with primary care teams who were reluctant to absorb the rise in short-term costs. Even when changes had apparently been agreed, they were sometimes reversed by healthcare staff without explanation or warning.

Julia's story, below, is an example of the kind of interaction that could arise in these circumstances. Although her GP did not refuse the prescription request outright, the dispensary simply reduced the amount asked for without explanation:

"So I went to pick up my prescription, I'd asked for four boxes, so I went to pick up my prescription when they were ready to go and pick it up, my husband got it and there were only two.

So I rang them up. I said: 'There are only two boxes.'

'- That's all you need.'

So I said: 'Oh right. Why's that?'

So she said, um: 'Well you only do two tests a day, and that will last you for months.'

[..]

So I said: 'So, as you can see on {the letter from the diabetes specialist tutors} they're asking for me to have adequate supplies to do x number of blood tests a week.'

'- Well I think it's quite ridiculous, you don't need that many.'

Julia, diabetic 50 years, new student speaking post-DAFNE.

Phil, mentioned earlier, was another typical example. He recontacted RS six months after data collection ended, with an update: his GP, who had originally agreed to prescribe blood test strips, had subsequently taken the strips off repeat prescription and insisted on Phil taking time off work every month to come into the surgery and justify the next month's supply. Since this was not always possible to do, he had had to reduce his testing and his blood glucose had begun to rise again. As Phil put it, his doctor did not "win the battle" because of superior medical knowledge; the GP simply had more power, and chose to exercise it.

Healthcare professionals who were reluctant to trust patients' expertise in daily management could also cause difficulties. For example, one participant told of being sent to hospital when her blood glucose happened to be high because of an infection (something she had been taught to self-manage at home using DAFNE principles):

I don't go to my GP for *anything* to do with my diabetes, because they mainly deal with Type 2 diabetics. [...My GP] sent me to hospital when I had my blood sugar... I went in to see him about something and my blood sugar was 18, which was not unusual. And he called an ambulance and I *said* to him he was being O.T.T., because not many Type 2 diabetics would go to A&E.

Interviewer: Did he listen or did he still call the ambulance?

"He listened, but he still called the ambulance."

Interviewer: And then what happened?

Well I was in hospital for two days! [...] And then I had trouble getting out of hospital, because I didn't meet the criteria and I'm saying to them 'please, just let me go home, this is unnatural, you know, I'm stuck in bed, my blood sugars aren't coming down because I'm stressed, I've got an infection, it's no good putting me on...' you know, because I was on a sliding scale, I said 'you don't understand, you don't understand, you don't understand...'

Mary, DAFNE graduate, talking nine years post-course

Although the GP and hospital staff meant well, they had failed to appreciate not just the emotional but also the physical impact on the patient of their actions. Mary gave her account with great emphasis. She described her unnecessary hospitalisation and subsequent events as "frightening" because of the lack of power she was allowed over her own body; she could only watch her blood sugar rise needlessly without being able to use her own skills and expertise to keep herself safe. During the experience of being put on a "sliding scale" (intravenous insulin and glucose administered in hospital), the patient completely loses control over his or her diabetes, surrendering management to hospital staff who are unlikely to be diabetes specialists. The National Diabetes Inpatient Audit has shown that in more than a third of cases this results in medication errors, which can lead to coma and occasionally death.¹⁹

Discussion

Principal findings

People graduating from intensive patient education courses such as DAFNE emerge with disease-specific biomedical, experiential and practical knowledge that exceeds that of many healthcare professionals. **From the stories told by participants in this study, it was clear that serious obstacles to self-management arose when generalist and even specialist doctors and nurses were not comfortable with patients who had a high level of expertise.** While this has been noted elsewhere in more general terms,^{20 21} this is the first study to confirm these findings in terms of healthcare professionals' reactions to formally trained Expert Patients. Although some healthcare teams were happy to support course graduates and even learn from them, this attitude could not be counted on, particularly when patients made budgetary demands that the budget-holders did not fully understand, such as requests for home blood testing equipment. Expertise taught to patients in one branch of medicine can be considered non-compliant by those who are not specialists in that field, and in some circumstances,

such as inpatient care, self-management may be greatly discouraged or even forbidden by hospital policy.

Patient education has the potential to change people's lives for the better in a way that is perhaps not fully captured by standard clinical and quality of life outcome assessments. As well as offering practical information, DAFNE teaches people with diabetes to consider a new role as expert, independent, and empowered patients. Participants in this study found that hugely helpful, not only in terms of biomedical improvements, but also in terms of taking control over their own lives with chronic disease. However, there is evidence that having learnt how to self-manage successfully, patients find it frustrating, at best, and frightening, at worst, to have access to self-management resources denied them; in some cases problems with post-course interactions may be hindering patients' ability to hit biomedical targets and stay healthy.

Strengths and limitations

Traditionally, studies of patient education have been dominated by medical perspectives, with very little formal research conducted by patients themselves. This has resulted in emphasis on questions about compliance and biomedical markers, with less attention paid to the impact of educational interventions on other parts of patients' lives. A strength of this study was its user-led focus, with a researcher from the diabetic community supported and advised by others from that community. The project fits wholly within the NIHR and INVOLVE definition of research for patient benefit: "research 'with' or 'by' people who use services rather than 'to', 'about' or 'for' them."²²

Of potential concern in this study is the issue of the reification of one user-researcher's experience at the expense of other people's stories.²³ Several steps were taken to mitigate this potential problem. Although the project was designed and conducted by a single user-researcher, RS, the Advisory Group described above provided a wider range of perspectives on living with diabetes, acted as a sounding-board for ideas, and helped to develop, refine and pilot the interview schedule and topic guide. Practical help was also enlisted from others in order to mitigate issues associated with RS being the only investigator conducting interviews. JS and CH checked transcripts, advised with analysis, and confirmed the extent to which respondents were allowed to tell their own stories. In addition, the opportunity to observe students on DAFNE and then conduct follow-up interviews meant that a rapport was built up over time, and it was possible to return to previous stories and statements for clarification or expansion if necessary.

Some researchers recommend the use of respondent validation or "member checking", where participants are asked to comment on findings and the conclusions made from those findings, although the benefit of this as proof of a study's validity is contested.²⁴ A limited form of this practice was used in this study. Although there was no formal process for gathering feedback on the findings from every participant, general concepts and emerging theories were discussed post-interview with those participants who expressed interest in the turns the study was taking, and the insights gained in these discussions were invaluable.

The choice of a narrative methodology and semi-structured topic guide allowed patients to choose what to emphasise in stories they told about themselves, but this approach had its inherent limitations too, as did the decision to restrict the research to a single chronic illness and just one patient education course. The small sample size allowed in-depth qualitative analysis to take place, but both sample size and the particular challenges involved in managing Type 1 diabetes mean that we cannot assume disease-specific findings are representative of other populations and other conditions. However, the broader findings of the study are applicable across the board: it has offered a new insight into the potential difficulties faced by newly educated patients, and suggests a need for serious reflection on existing practices, power hierarchies and training paradigms within healthcare. There may be local differences in different populations, but the paradox remains: patients are being given expertise and confidence to self-manage, but there remains no pathway to having these skills recognised or valued more generally by those with power and access to resources. At best, this leaves patients vulnerable; at worst, it can undermine their hard work and health status.

Studies of post-education health interactions have been rather limited to date. Some evaluations have hinted at potential conflicts between knowledgeable patients and less knowledgeable health professionals, and the potential for this conflict to erode health outcomes over time,^{5 26} but has rarely been a focus of research. Previous qualitative work in diabetes education has identified the importance of ongoing support from healthcare professionals in patients' ability to self-manage along the lines taught on the course.²⁷⁻²⁹ However, these studies focus on the relationship between the specialist and patient rather than interactions with generalist healthcare professionals. In our study we found specific problems with interactions in primary and hospital care. This suggests that the power held by GP prescribers should not be overlooked when considering patients' ability to self-manage successfully.

Implications and future research

Although patient education is recommended for those with chronic conditions in general,^{1 30} the implications for the education of healthcare professionals are not currently considered in parallel. While modern medical and nursing education focuses on patient-centred care,^{31 32} it does not prepare healthcare students for situations in which their patients have more biomedical and practical knowledge than they do about a specific treatment regime or illness.³³ When the role of the patient in a healthcare interaction is ambiguous and contested, problems arise on both sides, and extra work is required by both patient and professional. Although courses like DAFNE could include sessions preparing students for post-course interactions, there are limits to the extent to which patient education can mitigate these problems. In the districts where this study took place, work was already being done to help support DAFNE graduates who needed to go into hospital, and to ensure they got letters to enhance their authority when asking for supplies from primary care. Findings from this study would suggest that this work is very much needed. However, even when this support was in place, graduates continued to encounter disempowering practices from healthcare staff who were not DAFNE-aware. When healthcare practitioners do not understand the patient's self-management

requirements or trust their ability, they may put up obstacles to improved health outcomes by limiting medical supplies or insisting on unnecessary hospitalisation. As more chronic illness care is put into the hands of generalists, such situations are likely to arise more and more often; the importance of teaching strategies to cope with patient expertise, rather than see it as a threat, is of increasing relevance.

Although this study has provided an insight into the kinds of issues encountered by people after formal education, further research with both patients and healthcare professionals is needed to establish how widespread these problems are on a national level, and whether similar issues are faced by patients with other kinds of chronic conditions following other styles of Expert Patient Programme.

Conclusions

Healthcare professionals cannot become experts in the detailed management of every complex condition; gathering specialist input from others has long been an important part of treatment decision-making. Doctors, nurses and others whose attitudes impact on patient care must be supported to extend that model of shared expertise to work with those who have chronic illnesses, seeing the patient as part of the healthcare team, and the patient's condition-specific biomedical knowledge as a valuable resource, not a threat.

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RS designed and carried out the research, and drafted the paper. She is guarantor. JS and CH supervised research, reviewed and edited the paper.

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The presented data are anonymised and risk of identification is low. Extra data is available by emailing RS.

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What happens when patients know more than their doctors?
Diabetics' experiences of health interactions after patient education: a qualitative patient-led study

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WHAT HAPPENS WHEN PATIENTS KNOW MORE THAN THEIR DOCTORS?

Diabetics’ experiences of health interactions after patient education: a qualitative patient-led study

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Abstract

Objective

To explore the impact of patient education on the lives of people with diabetes, including the effect on interactions with doctors and other healthcare professionals.

Design

Qualitative user-led study using longitudinal interviews and 146 hours of participant observation. Data were analysed using a narrative approach.

Participants

21 patients with Type 1 diabetes, those either about to attend a patient education course or those who had completed the course in the previous 10 years.

Setting

Established patient education centres in three UK teaching hospitals teaching the DAFNE course (Dose Adjustment for Normal Eating).

Results

Both post-course and several years later, most participants spoke of the experience of taking part in education as life-changingly positive. It helped them understand how to gain control over a very complex disease and freed them from dependence on medical advice and restrictive regimes. However, interactions within the health system following patient education could be fraught. Participants emerged from the course with greater condition-specific knowledge than many of the healthcare professionals they encountered. When these professionals did not understand what their patients were trying to do and were uncomfortable trusting their expertise, there could be serious consequences for these patients' ability to continue effective self-management.

Conclusions

Patients who have in-depth knowledge of their condition encounter problems when their expertise is seen as inappropriate in standard healthcare interactions, and expertise taught to patients in one branch of medicine can be considered non-compliant by those who are not specialists in that field.

Although patient education can give people confidence in their own self-management skills, it cannot solve the power imbalance that remains when a generalist healthcare professional, however well-meaning, blocks access to medication and supplies needed to manage chronic disease successfully. There is a role for those involved in primary and hospital care, including those supporting and training healthcare professionals, to recognise these problems and find ways to acknowledge and respect chronic patients' biomedical and practical expertise.

Article Summary

Article focus

1. To explore the impact of patient education on the lives of people with chronic disease, including the post-intervention effect on interactions with healthcare professionals.

Key Messages

1. Patients who have taken part in intensive education courses are given practical condition-specific biomedical knowledge that exceeds that taught to all but the most specialist healthcare professionals.
2. The knowledgeable, self-managing patient created by such education can encounter obstacles in a health system that is not always prepared for them to take such an independent role. This can obstruct patients' efforts to manage their own condition, and can impair health outcomes.
3. Patient education alone cannot solve problems rooted in healthcare power structures and attitudes towards patient expertise. There is a role for those supporting and training healthcare professionals to recognise generic issues that arise when a population becomes self-efficacious and health literate, and ensure patient self-management is not undermined.

Strengths and Limitations

- Studies of patient education have been dominated by medical perspectives, resulting in an emphasis on questions about compliance and biomedical markers, with less attention paid to the impact on other parts of patients' lives. A strength of this study was its user-led focus, with a researcher from the diabetic community supported and advised by others from that community.
- The project fits the NIHR INVOLVE definition of research for patient benefit: "research 'with' or 'by' people who use services rather than 'to', 'about' or 'for' them."
- This qualitative study allowed a rich in-depth exploration of a particular education intervention, but this approach has inherent limitations; we cannot assume some of the condition-specific details are necessarily representative of other populations and other conditions.
- However, the broader findings of the study are applicable across the board: it has offered a new insight into the potential difficulties faced by highly health-literate patients, and suggests a need for serious reflection on existing practices, power hierarchies and training paradigms within healthcare.

What is already known and what this study adds

Research on patient education has looked mainly at cost-effectiveness and clinically defined outcomes. In diabetes, for example, structured education has been shown to improve quantitative scores for average blood glucose and quality of life. These outcomes, while important, have to date been researched and interpreted entirely by healthcare personnel within a medical perspective. This study, driven and carried out by people with Type 1 diabetes, is the first to explore several unaddressed areas, including the impact patient education has on people's overall life stories, and consequences for their healthcare interactions in the longer term.

Patients who have taken part in intensive education courses are given practical condition-specific biomedical knowledge that exceeds that taught to all but the most specialist healthcare professionals. Our findings suggest that the knowledgeable, self-managing patient created by such education can encounter obstacles in a health system that is not always prepared for patients to take such an independent role. This power imbalance can obstruct patients' efforts to manage their own condition, and can impair health outcomes.

Keywords:

Diabetes mellitus, Type 1; Health education; Professional-patient relations; Delivery of health care; Disease management

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4 **Introduction**

5 For more than two decades the UK has been developing and refining effective patient education
6 programmes in order to help those with long-term conditions to take responsibility for their own self-
7 management and avoid unnecessary hospitalisation.^{1 2} Diabetes care has a particularly strong track
8 record, with over 70 regional courses in England alone, and national programmes now being adopted
9 abroad, such as DAFNE (Dose Adjustment for Normal Eating) and DESMOND (Diabetes Education
10 and Self-Management for Ongoing and Newly Diagnosed).^{3 4} Randomised controlled trials have
11 shown improvements in specific health outcomes and condition-related quality of life measurements,
12 and NICE recommends that all people with diabetes should have access to this kind of structured
13 education.^{5 6 7}

14 For the patients themselves, however, these clinical outcomes are only one part of living with a
15 chronic condition. Our study, the first entirely patient-led research undertaken in this field, explores
16 several unaddressed areas: the role created for the patient during education, what it means to take
17 part, and consequences for patients' lives long-term. This paper draws on that research, looking
18 specifically at the experience of attending DAFNE and how it affects post-course interactions with the
19 health system.

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28 **Methods**

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30 **Influence of service users**

31 Service users with Type 1 diabetes were involved at every stage of the project, including choice of
32 topic, formulation of research question, design, development and conducting of the investigation, as
33 well as analysis and writing up. The James Lind Alliance (<http://www.lindalliance.org/>), INVOLVE
34 (<http://www.involve.org.uk/>), and the entirely patient-led Diabetes.co.uk Forum
35 (<http://www.diabetes.co.uk>) advised on the development of and recruitment to an Advisory Group for
36 the study. The final membership comprised 15 people who, between them, had more than 400 years
37 of living with diabetes, and experience of a variety of treatment regimes and patient education
38 initiatives. Some had never attended patient education, some were DAFNE trained and some had had
39 experience of non-DAFNE programmes. The Advisory Group shared experiences to help inform the
40 kinds of interview topics of relevance to diabetics, gave feedback on patient information sheets, and
41 three members participated in pilot interviews, on which they gave feedback. RS, herself a user-
42 researcher with Type 1 diabetes, had overall responsibility for the research design and
43 implementation, including data collection, analysis, and writing up.

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51 **Design**

52 The study took an interpretive, qualitative approach. Those attending or teaching DAFNE courses
53 acted as respondents or informants for the study, and a range of methods – interviewing,
54 observations, and course participation – were used. Semi-structured interviews were conducted in
55 order to allow these respondents' stories to emerge and give insight into the impact of the course on
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their overall lives, including their health-related interactions with others. Open-ended questions (such as “tell me how you have learnt to manage diabetes”) allowed interviewees to direct large parts of the interview to follow the narrative they wished to tell.⁸⁻¹¹ If that initial narrative did not already include stories of interactions with others, they were prompted to think about times when they had had to discuss diabetes with friends, family, work colleagues, and healthcare professionals of all kinds. Post-DAFNE, participants were asked to reflect on their initial answers and consider how (and whether) they would fit DAFNE into the story of how they learnt to self-manage. They were also asked to consider any changes to the way they interacted with others about diabetes following the course.

The study aimed to look at changes in people’s perceptions of their situation and their own and others’ levels of expertise, so interviews with new DAFNE students before and after the course, observations and course documentation were included as part of the data making up the narratives in the study.¹²⁻¹⁴ This meant that changes connected with course attendance could be observed as they happened, and the immediate impact on participants’ overall life narrative noted. Roughly half the participants fell into this “new student” group. However, in order to explore how patients’ narratives might change over a longer time-frame, the rest of the participants were recruited from DAFNE “graduates” (those who had completed the course several years previously), who were asked for retrospective narratives in a single interview. Although the majority of interview data were collected in formal, recorded sessions with a topic guide, less formal discussion and exploration of ideas with students and educators also took place during observations.

Participant selection and setting

DAFNE centres are externally audited to ensure that students get the same quality of education wherever they attend the course.¹⁵ This consistency, along with DAFNE’s national reach, was one of the reasons behind the choice of this programme for the research study over other patient education projects with more localised or internal variation. Several different study sites were included to increase the diversity of participants and venues, rather than specifically to compare and contrast different experiences from one DAFNE centre to another. Each site ran the course over 5 consecutive days, with specially trained teams of two healthcare professionals, a Diabetes Specialist Nurse (DSN) and a dietitian, doing the teaching.

Participants were recruited from established DAFNE centres in three UK hospitals. All three were teaching hospitals with specialist Diabetes Clinics that continued to support patients along DAFNE principles post-course. The study thus looked at the journey taken by a group of perhaps the country’s most expert patients – those with one of the most complex conditions to manage, taught in one of the most comprehensive education programmes, administered by some of the most experienced programme leaders.

Patient education is open to everyone with established Type 1 diabetes, and is recommended for all.⁶ For this study, potential participants for the “new student” group were considered to be anyone accepted onto a DAFNE course at the chosen study sites during the study period (September 2011 to January 2012); 11 were interviewed. DAFNE graduates were recruited from course follow-up

sessions (n=4), ordinary clinic appointments (n=4), and field contacts (n=2), with the aim of recruiting a purposive sample, as heterogeneous as possible in terms of diagnosis era, stage of life at diagnosis, current age, educational level, type of work, ethnicity and gender. Participants in the “graduate” group had taken part in DAFNE between three and eleven years previously, with a mean and median of seven years since completing the course. Nobody who was approached to take part declined, although two people had to cancel the arranged interviews because of health or family problems and so were not in the end included in the study.

A breakdown of the participants’ demographics can be found in Table 1.

Table 1: Demographics of participants

Decade of diagnosis	
<i>Pre 1970</i>	5 participants
<i>1970s</i>	3 participants
<i>1980s</i>	4 participants
<i>1990s</i>	2 participants
<i>Post 2000</i>	7 participants
Stage of life at diagnosis	
<i>Child</i>	8 participants
<i>Teenager</i>	2 participants
<i>Young adult (under 25)</i>	3 participants
<i>Adult (25 and over)</i>	8 participants
Age at time of first interview	
<i>20s</i>	3 participants
<i>30s</i>	3 participants
<i>40s</i>	7 participants
<i>50s</i>	4 participants
<i>60s</i>	4 participants

Employment situation

<i>Full time (standard hours)</i>	10 participants
<i>Full time (shift work)</i>	2 participants
<i>Part time</i>	3 participants
<i>Student</i>	2 participants
<i>Unemployed/ on sick leave</i>	2 participants
<i>Retired</i>	2 participants

Last educational qualification taken

<i>None</i>	2 participants
<i>GCSE or equivalent</i>	3 participants
<i>A level or equivalent</i>	8 participants
<i>Degree level or equivalent</i>	5 participants
<i>Postgraduate level</i>	3 participants

Gender

<i>Male</i>	9 participants
<i>Female</i>	12 participants

Ethnicity		White Other	1 participant
White British	17 participants	Black Caribbean	3 participants

In summary, longitudinal narrative interviews were conducted with 11 new students before their course; they were observed during education, and re-interviewed three months post-course. Retrospective narratives were collected from ten former students of DAFNE, and additional information gathered from seven teaching staff. In all, data were gathered from 32 interviews with patients and 146 hours of observations, including five days of complete participation in DAFNE by a user-researcher with Type 1 diabetes, RS.

Analysis

Transcripts and field notes were coded using NVivo 9, using a mixture of thematic and structural narrative analysis.^{16 17} The ideal patient role and narrative being taught on DAFNE was compared with students' personal life stories, and with their stories of others' expectations of them once the course was over. The DAFNE curriculum document, patient-facing course booklet, and field notes from observations and participant observation were analysed along with transcribed interviews and notes of classroom discussions. Following a thematic narrative approach, whole stories rather than fragments of data were coded by theme, using *in vivo* codes derived directly from the actual words used in observations or documentation. This allowed story themes, woven through several days or even across observations, to be collected and compared. For students' individual narratives, interview transcripts were used as one set of data; for the new student group, this was supplemented by sections in observations where they had told personal stories. Each participant was coded separately, and a précis document created for each to summarise the elements important to their story. This final version could then be compared, not only with each other but with the roles and themes taught on the DAFNE course (the DAFNE narrative). Participants' post-course stories of diabetes-related interactions were examined to gain an insight into the metanarratives they were encountering and the cultural expectations with which they had to live; in other words, to discover the ways healthcare professionals and laypeople responded to graduates' status and knowledge in their new, post-DAFNE patient role.

Reflexivity

Of potential concern in this study is the issue of the reification of one user-researcher's experience at the expense of other people's stories.²³ Several steps were taken to mitigate this potential problem. Although the project was designed and conducted by a single user-researcher, RS, the Advisory Group described above provided a wider range of perspectives on living with diabetes, acted as a sounding-board for ideas, and helped to develop, refine and pilot the interview schedule and topic guide. Practical help was also enlisted from others in order to mitigate issues associated with RS being the only investigator conducting interviews. JS and CH checked transcripts, advised with analysis, and confirmed the extent to which respondents were allowed to tell their own stories. In

addition, the opportunity to observe students on DAFNE and then conduct follow-up interviews meant that a rapport was built up over time, and it was possible to return to previous stories and statements for clarification or expansion if necessary.

Some researchers recommend the use of respondent validation or “member checking”, where participants are asked to comment on findings and the conclusions made from those findings, although the benefit of this as proof of a study’s validity is contested.²⁴ A limited form of this practice was used in this study. Although there was no formal process for gathering feedback on the findings from every participant, general concepts and emerging theories were discussed post-interview with those participants who expressed interest in the turns the study was taking, and the insights gained in these discussions were invaluable.

Results

Expectations: the role of the expert patient

Consistently across all observed courses, students were encouraged by tutors to adopt certain ideals. Among these were concepts of empowerment, expertise, and independence. These principles are keystones of much patient education in the last couple of decades.^{1 25} As can be seen in the extract below, when students made statements suggesting blind compliance or dependence on doctors, they were gently challenged to think of themselves differently; as an empowered and expert patient, no longer dependent on doctors for decisions, but able to talk about their treatment requirements with healthcare professionals as an equal:

Student: “My consultant told me to [take insulin at a certain time].”
Tutor: “You’ll all be DAFNE trained by the end of the week, you will be having a discussion with your doctors about your insulins!”
Observation field notes

The structure and complexity of DAFNE course content has been written about in depth elsewhere, including the benefits for patients in terms of blood glucose control; but the amount of knowledge imparted, and the quantity of self-management work, is not always emphasised.^{5 18} Students in this study were expected to learn how to take control of their own treatment regime at a very high level, interpreting complex patterns of blood glucose results over time in order to make constant alterations to insulin dose and timing. This included understanding not only how to count carbohydrates, but also the action and interaction of different kinds of insulin, the interaction of foods to create an overall glycaemic index of a meal, the impact of hormones, stress, alcohol, different kinds of exercise, travelling across time zones, managing pregnancy and breast-feeding, and how to self-manage specific problems such as dawn phenomenon, rising blood glucose during various severities of illness, and hypoglycaemia unawareness.

In the DAFNE narrative, the patient is not a passive victim of circumstance. In the following extract, a student’s summary of previous experience as an inpatient is listened to, then a more active, independent role is suggested for the future:

Student: "Whenever I've gone to hospital, because I'm diabetic, they put me on a drip, everything."

Tutor replies that the Sick Day Rules [specific self-management guidelines] are there "to help you avoid that situation".

Observation field notes

In summary, the DAFNE graduate is taught not only key information, but also to accept a new role for him- or herself in the health system and the wider world: as empowered, knowledgeable and independent.

Experience – taking on the new role

Participating in the kind of detailed, comprehensive self-management education offered by DAFNE had a very positive impact on the personal lives of nearly everyone in the study. Participants from all groups talked of "life-changing" experiences on the course, and of having been freed from the "shackles" of a confusing or restrictive treatment regime by being given "the tools of the trade" to manage a central aspect of their own lives.

"I mean I really have nothing but praise for [DAFNE], it has been properly transformative in ... in a *fundamental* way, I've got a fundamentally better understanding of what it is that's actually wrong with me. Um... and that, yeah, that just allows me to be a lot freer."

Harry, new student, speaking in post-DAFNE interview

Those who had already built up self-management expertise pre-course talked about "fine-tuning" or solving a specific problem that had been causing them difficulty; nobody was entirely negative about attending DAFNE.

In short, students were largely comfortable with the new patient role being offered them via DAFNE. Knowledge, and independence from doctors and restrictive regimes, were mostly valued, although support from DAFNE specialists post-course was very much appreciated by some. The relationship of students to "empowerment" was slightly less clear cut; although power and control over diabetes was hugely enhanced by DAFNE, empowerment within the health system was more problematic, as we describe below.

Consequences – a clash of roles

Post-course, participants were often cast into ambiguous roles in healthcare interactions. Both the new student and the graduate groups had similar experiences; frequently, the condition-specific biomedical and practical information they had learnt was far greater than that of their doctors or nurses.

This was not necessarily a problem for everyone. Jane, below, described a positive experience with a primary care doctor who was keen to learn more and trusted her expertise:

I had an insect, I had a mozzie bite that closed my eye, bit me on the eye just here, the soft bit above the eye. And my eye swelled up, and I went to a walk-in clinic. And they wanted to give me steroids, which obviously push your blood sugar up, and I said 'well I

1
2
3 *know* that's going to happen, I can manage my blood sugar if it does shoot up, I can
4 increase my insulin and I use the DAFNE, do you have DAFNE?' and I had to go step
5 by step through with [this doctor] how it worked. And he wrote *loads of notes*; it was
6 really interesting, he wrote *loads and loads* of notes.

7
8 *Jane, DAFNE graduate, talking six years post-course*

9
10 Some participants simply avoided less specialist healthcare professionals if they could, relying instead
11 on advice from their DAFNE tutors. However, this was not always possible, and in many health
12 interactions, patients and healthcare professionals struggled to manage the tensions that arose from
13 the partial role-reversal of expertise after self-management education. In some cases basic or even
14 inaccurate information was imposed on patients, who on the whole swallowed their annoyance in
15 silence:

16
17
18 I went to a nurse [...] for like, I can't remember what even for, a flu jab or something, um
19 ... and, um [...] she started giving me advice about my blood sugars and it *really*, it
20 really got on my nerves, because they were just completely, completely counter to
21 everything that I'd just been taught. And, and obviously not *right*?

22
23 *Interviewer: What did you say?*

24
25 I, I didn't, I didn't say anything. I just left it.

26
27 *Interviewer: So she didn't know that you... what you were thinking?*

28
29 No. There's no point getting into an argument.

30
31 *James, new student, speaking in post-DAFNE interview*

32
33 Where this tension became more serious was in situations where a less knowledgeable doctor had
34 considerable power over the expert patient. This was most often seen in interactions with GPs, who
35 restricted prescriptions, sometimes surreptitiously, when they did not understand the importance of
36 blood testing to the patient's self-management regime. Using DAFNE principles, students learn how
37 to achieve tighter, smoother blood glucose control by performing blood tests at least four times a day,
38 using the results to make decisions about insulin dosage as well as ensuring that dangerously high or
39 low blood sugars could be avoided. For some, this meant a considerable increase in test strip
40 requirements as they took on the extra work to improve blood glucose control. Although course tutors
41 provided letters for GPs explaining the necessity for these adjustments, interviewees reported having
42 to be "quite tough" to successfully negotiate with primary care teams who were reluctant to absorb the
43 rise in short-term costs. Even when changes had apparently been agreed, they were sometimes
44 reversed by healthcare staff without explanation or warning.

45
46
47 Julia's story, below, is an example of the kind of interaction that could arise in these circumstances.
48 Although her GP did not refuse the prescription request outright, the dispensary simply reduced the
49 amount asked for without explanation:

50
51
52 "So I went to pick up my prescription, I'd asked for four boxes, so I went to pick up my
53 prescription when they were ready to go and pick it up, my husband got it and there
54 were only two.

55
56 So I rang them up. I said: 'There are only two boxes.'

57
58 '- That's all you need.'

So I said: 'Oh right. Why's that?'

So she said, um: 'Well you only do two tests a day, and that will last you for months.'

[..]

So I said: 'So, as you can see on {the letter from the diabetes specialist tutors} they're asking for me to have adequate supplies to do x number of blood tests a week.'

'- Well I think it's quite ridiculous, you don't need that many.'

Julia, diabetic 50 years, new student speaking post-DAFNE.

Phil, mentioned earlier, was another typical example. He recontacted RS six months after data collection ended, with an update: his GP, who had originally agreed to prescribe blood test strips, had subsequently taken the strips off repeat prescription and insisted on Phil taking time off work every month to come into the surgery and justify the next month's supply. Since this was not always possible to do, he had had to reduce his testing and his blood glucose had begun to rise again. As Phil put it, his doctor did not "win the battle" because of superior medical knowledge; the GP simply had more power, and chose to exercise it.

Healthcare professionals who were reluctant to trust patients' expertise in daily management could also cause difficulties. For example, one participant told of being sent to hospital when her blood glucose happened to be high because of an infection (something she had been taught to self-manage at home using DAFNE principles):

I don't go to my GP for *anything* to do with my diabetes, because they mainly deal with Type 2 diabetics. [...My GP] sent me to hospital when I had my blood sugar... I went in to see him about something and my blood sugar was 18, which was not unusual. And he called an ambulance and I *said* to him he was being O.T.T., because not many Type 2 diabetics would go to A&E.

Interviewer: Did he listen or did he still call the ambulance?

"He listened, but he still called the ambulance."

Interviewer: And then what happened?

Well I was in hospital for two days! [...] And then I had trouble getting out of hospital, because I didn't meet the criteria and I'm saying to them 'please, just let me go home, this is unnatural, you know, I'm stuck in bed, my blood sugars aren't coming down because I'm stressed, I've got an infection, it's no good putting me on...' you know, because I was on a sliding scale, I said 'you don't understand, you don't understand, you don't understand...'

Mary, DAFNE graduate, talking nine years post-course

Although the GP and hospital staff meant well, they had failed to appreciate not just the emotional but also the physical impact on the patient of their actions. Mary gave her account with great emphasis. She described her unnecessary hospitalisation and subsequent events as "frightening" because of the lack of power she was allowed over her own body; she could only watch her blood sugar rise needlessly without being able to use her own skills and expertise to keep herself safe. During the experience of being put on a "sliding scale" (intravenous insulin and glucose administered in hospital), the patient completely loses control over his or her diabetes, surrendering management to hospital

staff who are unlikely to be diabetes specialists. The National Diabetes Inpatient Audit has shown that in more than a third of cases this results in medication errors, which can lead to coma and occasionally death.¹⁹

Discussion

Principal findings

People graduating from intensive patient education courses such as DAFNE emerge with disease-specific biomedical, experiential and practical knowledge that exceeds that of many healthcare professionals. From the stories told by participants in this study, it was clear that serious obstacles to self-management arose when generalist and even specialist doctors and nurses were not comfortable with patients who had a high level of expertise. While this has been noted elsewhere in more general terms,^{20 21} this is the first study to confirm these findings in terms of healthcare professionals' reactions to formally trained Expert Patients. Although some healthcare teams were happy to support course graduates and even learn from them, this attitude could not be counted on, particularly when patients made budgetary demands that the budget-holders did not fully understand, such as requests for home blood testing equipment. Expertise taught to patients in one branch of medicine can be considered non-compliant by those who are not specialists in that field, and in some circumstances, such as inpatient care, self-management may be greatly discouraged or even forbidden by hospital policy.

Patient education has the potential to change people's lives for the better in a way that is perhaps not fully captured by standard clinical and quality of life outcome assessments. As well as offering practical information, DAFNE teaches people with diabetes to consider a new role as expert, independent, and empowered patients. Participants in this study found that hugely helpful, not only in terms of biomedical improvements, but also in terms of taking control over their own lives with chronic disease. However, there is evidence that having learnt how to self-manage successfully, patients find it frustrating, at best, and frightening, at worst, to have access to self-management resources denied them; in some cases problems with post-course interactions may be hindering patients' ability to hit biomedical targets and stay healthy.

Strengths and limitations

Traditionally, studies of patient education have been dominated by medical perspectives, with very little formal research conducted by patients themselves. This has resulted in emphasis on questions about compliance and biomedical markers, with less attention paid to the impact of educational interventions on other parts of patients' lives. A strength of this study was its user-led focus, with a researcher from the diabetic community supported and advised by others from that community. The project fits wholly within the NIHR and INVOLVE definition of research for patient benefit: "research 'with' or 'by' people who use services rather than 'to', 'about' or 'for' them."²²

The choice of a narrative methodology and semi-structured topic guide allowed patients to choose what to emphasise in stories they told about themselves, but this approach had its inherent limitations too, as did the decision to restrict the research to a single chronic illness and just one patient education course. The small sample size allowed in-depth qualitative analysis to take place, but both sample size and the particular challenges involved in managing Type 1 diabetes mean that we cannot assume disease-specific findings are representative of other populations and other conditions. However, the broader findings of the study are applicable across the board: it has offered a new insight into the potential difficulties faced by newly educated patients, and suggests a need for serious reflection on existing practices, power hierarchies and training paradigms within healthcare. There may be local differences in different populations, but the paradox remains: patients are being given expertise and confidence to self-manage, but there remains no pathway to having these skills recognised or valued more generally by those with power and access to resources. At best, this leaves patients vulnerable; at worst, it can undermine their hard work and health status.

Studies of post-education health interactions have been rather limited to date. Some evaluations have hinted at potential conflicts between knowledgeable patients and less knowledgeable health professionals, and the potential for this conflict to erode health outcomes over time,^{5 26} but this has rarely been a focus of research. Previous qualitative work in diabetes education has identified the importance of ongoing support from healthcare professionals in patients' ability to self-manage along the lines taught on the course.²⁷⁻²⁹ However, these studies focus on the relationship between the specialist and patient rather than interactions with generalist healthcare professionals. In our study we found specific problems with interactions in primary and hospital care. This suggests that the power held by GP prescribers should not be overlooked when considering patients' ability to self-manage successfully.

Implications and future research

Although patient education is recommended for those with chronic conditions in general,^{1 30} the implications for the education of healthcare professionals are not currently considered in parallel. While modern medical and nursing education focuses on patient-centred care,^{31 32} it does not prepare healthcare students for situations in which their patients have more biomedical and practical knowledge than they do about a specific treatment regime or illness.³³ When the role of the patient in a healthcare interaction is ambiguous and contested, problems arise on both sides, and extra work is required by both patient and professional. Although courses like DAFNE could include sessions preparing students for post-course interactions, there are limits to the extent to which patient education can mitigate these problems. In the districts where this study took place, work was already being done to help support DAFNE graduates who needed to go into hospital, and to ensure they got letters to enhance their authority when asking for supplies from primary care. Findings from this study would suggest that this work is very much needed. However, even when this support was in place, graduates continued to encounter disempowering practices from healthcare staff who were not DAFNE-aware. When healthcare practitioners do not understand the patient's self-management

requirements or trust their ability, they may put up obstacles to improved health outcomes by limiting medical supplies or insisting on unnecessary hospitalisation. As more chronic illness care is put into the hands of generalists, such situations are likely to arise more and more often; the importance of teaching strategies to cope with patient expertise, rather than see it as a threat, is of increasing relevance.

Although this study has provided an insight into the kinds of issues encountered by people after formal education, further research with both patients and healthcare professionals is needed to establish how widespread these problems are on a national level, and whether similar issues are faced by patients with other kinds of chronic conditions following other styles of Expert Patient Programme.

Conclusions

Healthcare professionals cannot become experts in the detailed management of every complex condition; gathering specialist input from others has long been an important part of treatment decision-making. Doctors, nurses and others whose attitudes impact on patient care must be supported to extend that model of shared expertise to work with those who have chronic illnesses, seeing the patient as part of the healthcare team, and the patient's condition-specific biomedical knowledge as a valuable resource, not a threat.

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RS designed and carried out the research, and drafted the paper. She is guarantor. JS and CH supervised research, reviewed and edited the paper.

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Data Sharing:

The presented data are anonymised and risk of identification is low. Extra data is available by emailing RS.

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WHAT HAPPENS WHEN PATIENTS KNOW MORE THAN THEIR DOCTORS?

Diabetics' experiences of health interactions after patient education: a qualitative patient-led study

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Abstract

Objective

To explore the impact of patient education on the lives of people with diabetes, including the effect on interactions with doctors and other healthcare professionals.

Design

Qualitative user-led study using longitudinal interviews and 146 hours of participant observation. Data were analysed using a narrative approach.

Participants

21 patients with Type 1 diabetes, those either about to attend a patient education course or those who had completed the course in the previous 10 years.

Setting

Established patient education centres in three UK teaching hospitals teaching the DAFNE course (Dose Adjustment for Normal Eating).

Results

Both post-course and several years later, most participants spoke of the experience of taking part in education as life-changingly positive. It helped them understand how to gain control over a very complex disease and freed them from dependence on medical advice and restrictive regimes. However, interactions within the health system following patient education could be fraught. Participants emerged from the course with greater condition-specific knowledge than many of the healthcare professionals they encountered. When these professionals did not understand what their patients were trying to do and were uncomfortable trusting their expertise, there could be serious consequences for these patients' ability to continue effective self-management.

Conclusions

Patients who have in-depth knowledge of their condition encounter problems when their expertise is seen as inappropriate in standard healthcare interactions, and expertise taught to patients in one branch of medicine can be considered non-compliant by those who are not specialists in that field.

Although patient education can give people confidence in their own self-management skills, it cannot solve the power imbalance that remains when a generalist healthcare professional, however well-meaning, blocks access to medication and supplies needed to manage chronic disease successfully. There is a role for those involved in primary and hospital care, including those supporting and training healthcare professionals, to recognise these problems and find ways to acknowledge and respect chronic patients' biomedical and practical expertise.

Article Summary

Article focus

1. To explore the impact of patient education on the lives of people with chronic disease, including the post-intervention effect on interactions with healthcare professionals.

Key Messages

1. Patients who have taken part in intensive education courses are given practical condition-specific biomedical knowledge that exceeds that taught to all but the most specialist healthcare professionals.
2. The knowledgeable, self-managing patient created by such education can encounter obstacles in a health system that is not always prepared for them to take such an independent role. This can obstruct patients' efforts to manage their own condition, and can impair health outcomes.
3. Patient education alone cannot solve problems rooted in healthcare power structures and attitudes towards patient expertise. There is a role for those supporting and training healthcare professionals to recognise generic issues that arise when a population becomes self-efficacious and health literate, and ensure patient self-management is not undermined.

Strengths and Limitations

- Studies of patient education have been dominated by medical perspectives, resulting in an emphasis on questions about compliance and biomedical markers, with less attention paid to the impact on other parts of patients' lives. A strength of this study was its user-led focus, with a researcher from the diabetic community supported and advised by others from that community.
- The project fits the NIHR INVOLVE definition of research for patient benefit: "research 'with' or 'by' people who use services rather than 'to', 'about' or 'for' them."
- This qualitative study allowed a rich in-depth exploration of a particular education intervention, but this approach has inherent limitations; we cannot assume some of the condition-specific details are necessarily representative of other populations and other conditions.
- However, the broader findings of the study are applicable across the board: it has offered a new insight into the potential difficulties faced by highly health-literate patients, and suggests a need for serious reflection on existing practices, power hierarchies and training paradigms within healthcare.

What is already known and what this study adds

Research on patient education has looked mainly at cost-effectiveness and clinically defined outcomes. In diabetes, for example, structured education has been shown to improve quantitative scores for average blood glucose and quality of life. These outcomes, while important, have to date been researched and interpreted entirely by healthcare personnel within a medical perspective. This study, driven and carried out by people with Type 1 diabetes, is the first to explore several unaddressed areas, including the impact patient education has on people’s overall life stories, and consequences for their healthcare interactions in the longer term.

Patients who have taken part in intensive education courses are given practical condition-specific biomedical knowledge that exceeds that taught to all but the most specialist healthcare professionals. Our findings suggest that the knowledgeable, self-managing patient created by such education can encounter obstacles in a health system that is not always prepared for patients to take such an independent role. This power imbalance can obstruct patients’ efforts to manage their own condition, and can impair health outcomes.

Keywords:

Diabetes mellitus, Type 1; Health education; Professional-patient relations; Delivery of health care; Disease management

Introduction

For more than two decades the UK has been developing and refining effective patient education programmes in order to help those with long-term conditions to take responsibility for their own self-management and avoid unnecessary hospitalisation.^{1 2} Diabetes care has a particularly strong track record, with over 70 regional courses in England alone, and national programmes now being adopted abroad, such as DAFNE (Dose Adjustment for Normal Eating) and DESMOND (Diabetes Education and Self-Management for Ongoing and Newly Diagnosed).^{3 4} Randomised controlled trials have shown improvements in specific health outcomes and condition-related quality of life measurements, and NICE recommends that all people with diabetes should have access to this kind of structured education.^{5 6 7}

For the patients themselves, however, these clinical outcomes are only one part of living with a chronic condition. Our study, the first entirely patient-led research undertaken in this field, explores several unaddressed areas: the role created for the patient during education, what it means to take part, and consequences for patients' lives long-term. This paper draws on that research, looking specifically at the experience of attending DAFNE and how it affects post-course interactions with the health system.

Methods

Influence of service users

Service users with Type 1 diabetes were involved at every stage of the project, including choice of topic, formulation of research question, design, development and conducting of the investigation, as well as analysis and writing up. The James Lind Alliance (<http://www.lindalliance.org/>), INVOLVE (<http://www.involve.org.uk/>), and the entirely patient-led Diabetes.co.uk Forum (<http://www.diabetes.co.uk>) advised on the development of and recruitment to an Advisory Group for the study. The final membership comprised 15 people who, between them, had more than 400 years of living with diabetes, and experience of a variety of treatment regimes and patient education initiatives. Some had never attended patient education, some were DAFNE trained and some had had experience of non-DAFNE programmes. The Advisory Group shared experiences to help inform the kinds of interview topics of relevance to diabetics, gave feedback on patient information sheets, and three members participated in pilot interviews, on which they gave feedback. RS, herself a user-researcher with Type 1 diabetes, had overall responsibility for the research design and implementation, including data collection, analysis, and writing up.

Design

The study took an interpretive, qualitative approach. Those attending or teaching DAFNE courses acted as respondents or informants for the study, and a range of methods – interviewing, observations, and course participation – were used. Semi-structured interviews were conducted in order to allow these respondents' stories to emerge and give insight into the impact of the course on

their overall lives, including their health-related interactions with others. Open-ended questions (such as “tell me how you have learnt to manage diabetes”) allowed interviewees to direct large parts of the interview to follow the narrative they wished to tell.⁸⁻¹¹ If that initial narrative did not already include stories of interactions with others, they were prompted to think about times when they had had to discuss diabetes with friends, family, work colleagues, and healthcare professionals of all kinds. Post-DAFNE, participants were asked to reflect on their initial answers and consider how (and whether) they would fit DAFNE into the story of how they learnt to self-manage. They were also asked to consider any changes to the way they interacted with others about diabetes following the course.

The study aimed to look at changes in people’s perceptions of their situation and their own and others’ levels of expertise, so interviews with new DAFNE students before and after the course, observations and course documentation were included as part of the data making up the narratives in the study.¹²⁻¹⁴ This meant that changes connected with course attendance could be observed as they happened, and the immediate impact on participants’ overall life narrative noted. Roughly half the participants fell into this “new student” group. However, in order to explore how patients’ narratives might change over a longer time-frame, the rest of the participants were recruited from DAFNE “graduates” (those who had completed the course several years previously), who were asked for retrospective narratives in a single interview. Although the majority of interview data were collected in formal, recorded sessions with a topic guide, less formal discussion and exploration of ideas with students and educators also took place during observations.

Participant selection and setting

DAFNE centres are externally audited to ensure that students get the same quality of education wherever they attend the course.¹⁵ This consistency, along with DAFNE’s national reach, was one of the reasons behind the choice of this programme for the research study over other patient education projects with more localised or internal variation. Several different study sites were included to increase the diversity of participants and venues, rather than specifically to compare and contrast different experiences from one DAFNE centre to another. Each site ran the course over 5 consecutive days, with specially trained teams of two healthcare professionals, a Diabetes Specialist Nurse (DSN) and a dietitian, doing the teaching.

Participants were recruited from established DAFNE centres in three UK hospitals. All three were teaching hospitals with specialist Diabetes Clinics that continued to support patients along DAFNE principles post-course. The study thus looked at the journey taken by a group of perhaps the country’s most expert patients – those with one of the most complex conditions to manage, taught in one of the most comprehensive education programmes, administered by some of the most experienced programme leaders.

Patient education is open to everyone with established Type 1 diabetes, and is recommended for all.⁶ For this study, potential participants for the “new student” group were considered to be anyone accepted onto a DAFNE course at the chosen study sites during the study period (September 2011 to January 2012); 11 were interviewed. DAFNE graduates were recruited from course follow-up

sessions (n=4), ordinary clinic appointments (n=4), and field contacts (n=2), with the aim of recruiting a purposive sample, as heterogeneous as possible in terms of diagnosis era, stage of life at diagnosis, current age, educational level, type of work, ethnicity and gender. Participants in the “graduate” group had taken part in DAFNE between three and eleven years previously, with a mean and median of seven years since completing the course. Nobody who was approached to take part declined, although two people had to cancel the arranged interviews because of health or family problems and so were not in the end included in the study.

A breakdown of the participants’ demographics can be found in Table 1.

Table 1: Demographics of participants

Decade of diagnosis	
<i>Pre 1970</i>	5 participants
<i>1970s</i>	3 participants
<i>1980s</i>	4 participants
<i>1990s</i>	2 participants
<i>Post 2000</i>	7 participants
Stage of life at diagnosis	
<i>Child</i>	8 participants
<i>Teenager</i>	2 participants
<i>Young adult (under 25)</i>	3 participants
<i>Adult (25 and over)</i>	8 participants
Age at time of first interview	
<i>20s</i>	3 participants
<i>30s</i>	3 participants
<i>40s</i>	7 participants
<i>50s</i>	4 participants
<i>60s</i>	4 participants

Employment situation

<i>Full time (standard hours)</i>	10 participants
<i>Full time (shift work)</i>	2 participants
<i>Part time</i>	3 participants
<i>Student</i>	2 participants
<i>Unemployed/ on sick leave</i>	2 participants
<i>Retired</i>	2 participants

Last educational qualification taken

<i>None</i>	2 participants
<i>GCSE or equivalent</i>	3 participants
<i>A level or equivalent</i>	8 participants
<i>Degree level or equivalent</i>	5 participants
<i>Postgraduate level</i>	3 participants

Gender

<i>Male</i>	9 participants
<i>Female</i>	12 participants

Ethnicity		White Other	1 participant
White British	17 participants	Black Caribbean	3 participants

In summary, longitudinal narrative interviews were conducted with 11 new students before their course; they were observed during education, and re-interviewed three months post-course. Retrospective narratives were collected from ten former students of DAFNE, and additional information gathered from seven teaching staff. In all, data were gathered from 32 interviews with patients and 146 hours of observations, including five days of complete participation in DAFNE by a user-researcher with Type 1 diabetes, RS.

Analysis

Transcripts and field notes were coded using NVivo 9, using a mixture of thematic and structural narrative analysis.^{16 17} The ideal patient role and narrative being taught on DAFNE was compared with students' personal life stories, and with their stories of others' expectations of them once the course was over. The DAFNE curriculum document, patient-facing course booklet, and field notes from observations and participant observation were analysed along with transcribed interviews and notes of classroom discussions. Following a thematic narrative approach, whole stories rather than fragments of data were coded by theme, using *in vivo* codes derived directly from the actual words used in observations or documentation. This allowed story themes, woven through several days or even across observations, to be collected and compared. For students' individual narratives, interview transcripts were used as one set of data; for the new student group, this was supplemented by sections in observations where they had told personal stories. Each participant was coded separately, and a précis document created for each to summarise the elements important to their story. This final version could then be compared, not only with each other but with the roles and themes taught on the DAFNE course (the DAFNE narrative). Participants' post-course stories of diabetes-related interactions were examined to gain an insight into the metanarratives they were encountering and the cultural expectations with which they had to live; in other words, to discover the ways healthcare professionals and laypeople responded to graduates' status and knowledge in their new, post-DAFNE patient role.

Reflexivity

Of potential concern in this study is the issue of the reification of one user-researcher's experience at the expense of other people's stories.²³ Several steps were taken to mitigate this potential problem. Although the project was designed and conducted by a single user-researcher, RS, the Advisory Group described above provided a wider range of perspectives on living with diabetes, acted as a sounding-board for ideas, and helped to develop, refine and pilot the interview schedule and topic guide. Practical help was also enlisted from others in order to mitigate issues associated with RS being the only investigator conducting interviews. JS and CH checked transcripts, advised with analysis, and confirmed the extent to which respondents were allowed to tell their own stories. In

addition, the opportunity to observe students on DAFNE and then conduct follow-up interviews meant that a rapport was built up over time, and it was possible to return to previous stories and statements for clarification or expansion if necessary.

Some researchers recommend the use of respondent validation or “member checking”, where participants are asked to comment on findings and the conclusions made from those findings, although the benefit of this as proof of a study’s validity is contested.²⁴ A limited form of this practice was used in this study. Although there was no formal process for gathering feedback on the findings from every participant, general concepts and emerging theories were discussed post-interview with those participants who expressed interest in the turns the study was taking, and the insights gained in these discussions were invaluable.

Results

Expectations: the role of the expert patient

Consistently across all observed courses, students were encouraged by tutors to adopt certain ideals. Among these were concepts of empowerment, expertise, and independence. These principles are keystones of much patient education in the last couple of decades.^{1 25} As can be seen in the extract below, when students made statements suggesting blind compliance or dependence on doctors, they were gently challenged to think of themselves differently; as an empowered and expert patient, no longer dependent on doctors for decisions, but able to talk about their treatment requirements with healthcare professionals as an equal:

Student: “My consultant told me to [take insulin at a certain time].”

Tutor: “You’ll all be DAFNE trained by the end of the week, you will be having a discussion with your doctors about your insulins!”

Observation field notes

The structure and complexity of DAFNE course content has been written about in depth elsewhere, including the benefits for patients in terms of blood glucose control; but the amount of knowledge imparted, and the quantity of self-management work, is not always emphasised.^{5 18} Students in this study were expected to learn how to take control of their own treatment regime at a very high level, interpreting complex patterns of blood glucose results over time in order to make constant alterations to insulin dose and timing. This included understanding not only how to count carbohydrates, but also the action and interaction of different kinds of insulin, the interaction of foods to create an overall glycaemic index of a meal, the impact of hormones, stress, alcohol, different kinds of exercise, travelling across time zones, managing pregnancy and breast-feeding, and how to self-manage specific problems such as dawn phenomenon, rising blood glucose during various severities of illness, and hypoglycaemia unawareness.

In the DAFNE narrative, the patient is not a passive victim of circumstance. In the following extract, a student’s summary of previous experience as an inpatient is listened to, then a more active, independent role is suggested for the future:

Student: "Whenever I've gone to hospital, because I'm diabetic, they put me on a drip, everything."

Tutor replies that the Sick Day Rules [specific self-management guidelines] are there "to help you avoid that situation".

Observation field notes

In summary, the DAFNE graduate is taught not only key information, but also to accept a new role for him- or herself in the health system and the wider world: as empowered, knowledgeable and independent.

Experience – taking on the new role

Participating in the kind of detailed, comprehensive self-management education offered by DAFNE had a very positive impact on the personal lives of nearly everyone in the study. Participants from all groups talked of "life-changing" experiences on the course, and of having been freed from the "shackles" of a confusing or restrictive treatment regime by being given "the tools of the trade" to manage a central aspect of their own lives.

"I mean I really have nothing but praise for [DAFNE], it has been properly transformative in ... in a *fundamental* way, I've got a fundamentally better understanding of what it is that's actually wrong with me. Um... and that, yeah, that just allows me to be a lot freer."

Harry, new student, speaking in post-DAFNE interview

Those who had already built up self-management expertise pre-course talked about "fine-tuning" or solving a specific problem that had been causing them difficulty; nobody was entirely negative about attending DAFNE.

In short, students were largely comfortable with the new patient role being offered them via DAFNE. Knowledge, and independence from doctors and restrictive regimes, were mostly valued, although support from DAFNE specialists post-course was very much appreciated by some. The relationship of students to "empowerment" was slightly less clear cut; although power and control over diabetes was hugely enhanced by DAFNE, empowerment within the health system was more problematic, as we describe below.

Consequences – a clash of roles

Post-course, participants were often cast into ambiguous roles in healthcare interactions. Both the new student and the graduate groups had similar experiences; frequently, the condition-specific biomedical and practical information they had learnt was far greater than that of their doctors or nurses.

This was not necessarily a problem for everyone. Jane, below, described a positive experience with a primary care doctor who was keen to learn more and trusted her expertise:

I had an insect, I had a mozzie bite that closed my eye, bit me on the eye just here, the soft bit above the eye. And my eye swelled up, and I went to a walk-in clinic. And they wanted to give me steroids, which obviously push your blood sugar up, and I said 'well I

1
2
3 *know* that's going to happen, I can manage my blood sugar if it does shoot up, I can
4 increase my insulin and I use the DAFNE, do you have DAFNE?' and I had to go step
5 by step through with [this doctor] how it worked. And he wrote *loads of notes*; it was
6 really interesting, he wrote *loads and loads* of notes.

7
8 *Jane, DAFNE graduate, talking six years post-course*

9
10 Some participants simply avoided less specialist healthcare professionals if they could, relying instead
11 on advice from their DAFNE tutors. However, this was not always possible, and in many health
12 interactions, patients and healthcare professionals struggled to manage the tensions that arose from
13 the partial role-reversal of expertise after self-management education. In some cases basic or even
14 inaccurate information was imposed on patients, who on the whole swallowed their annoyance in
15 silence:
16

17
18 I went to a nurse [...] for like, I can't remember what even for, a flu jab or something, um
19 ... and, um [...] she started giving me advice about my blood sugars and it *really*, it
20 really got on my nerves, because they were just completely, completely counter to
21 everything that I'd just been taught. And, and obviously not *right*?
22

23 *Interviewer: What did you say?*

24 I, I didn't, I didn't say anything. I just left it.

25 *Interviewer: So she didn't know that you... what you were thinking?*

26 No. There's no point getting into an argument.

27
28 *James, new student, speaking in post-DAFNE interview*
29

30
31 Where this tension became more serious was in situations where a less knowledgeable doctor had
32 considerable power over the expert patient. This was most often seen in interactions with GPs, who
33 restricted prescriptions, sometimes surreptitiously, when they did not understand the importance of
34 blood testing to the patient's self-management regime. Using DAFNE principles, students learn how
35 to achieve tighter, smoother blood glucose control by performing blood tests at least four times a day,
36 using the results to make decisions about insulin dosage as well as ensuring that dangerously high or
37 low blood sugars could be avoided. For some, this meant a considerable increase in test strip
38 requirements as they took on the extra work to improve blood glucose control. Although course tutors
39 provided letters for GPs explaining the necessity for these adjustments, interviewees reported having
40 to be "quite tough" to successfully negotiate with primary care teams who were reluctant to absorb the
41 rise in short-term costs. Even when changes had apparently been agreed, they were sometimes
42 reversed by healthcare staff without explanation or warning.
43
44

45
46
47 Julia's story, below, is an example of the kind of interaction that could arise in these circumstances.
48 Although her GP did not refuse the prescription request outright, the dispensary simply reduced the
49 amount asked for without explanation:
50

51
52 "So I went to pick up my prescription, I'd asked for four boxes, so I went to pick up my
53 prescription when they were ready to go and pick it up, my husband got it and there
54 were only two.

55 So I rang them up. I said: 'There are only two boxes.'

56
57 '- That's all you need.'
58
59
60

So I said: 'Oh right. Why's that?'

So she said, um: 'Well you only do two tests a day, and that will last you for months.'

[..]

So I said: 'So, as you can see on {the letter from the diabetes specialist tutors} they're asking for me to have adequate supplies to do x number of blood tests a week.'

'- Well I think it's quite ridiculous, you don't need that many.'

Julia, diabetic 50 years, new student speaking post-DAFNE.

Phil, mentioned earlier, was another typical example. He recontacted RS six months after data collection ended, with an update: his GP, who had originally agreed to prescribe blood test strips, had subsequently taken the strips off repeat prescription and insisted on Phil taking time off work every month to come into the surgery and justify the next month's supply. Since this was not always possible to do, he had had to reduce his testing and his blood glucose had begun to rise again. As Phil put it, his doctor did not "win the battle" because of superior medical knowledge; the GP simply had more power, and chose to exercise it.

Healthcare professionals who were reluctant to trust patients' expertise in daily management could also cause difficulties. For example, one participant told of being sent to hospital when her blood glucose happened to be high because of an infection (something she had been taught to self-manage at home using DAFNE principles):

I don't go to my GP for *anything* to do with my diabetes, because they mainly deal with Type 2 diabetics. [...My GP] sent me to hospital when I had my blood sugar... I went in to see him about something and my blood sugar was 18, which was not unusual. And he called an ambulance and I *said* to him he was being O.T.T., because not many Type 2 diabetics would go to A&E.

Interviewer: Did he listen or did he still call the ambulance?

"He listened, but he still called the ambulance."

Interviewer: And then what happened?

Well I was in hospital for two days! [...] And then I had trouble getting out of hospital, because I didn't meet the criteria and I'm saying to them 'please, just let me go home, this is unnatural, you know, I'm stuck in bed, my blood sugars aren't coming down because I'm stressed, I've got an infection, it's no good putting me on...' you know, because I was on a sliding scale, I said 'you don't understand, you don't understand, you don't understand...'

Mary, DAFNE graduate, talking nine years post-course

Although the GP and hospital staff meant well, they had failed to appreciate not just the emotional but also the physical impact on the patient of their actions. Mary gave her account with great emphasis. She described her unnecessary hospitalisation and subsequent events as "frightening" because of the lack of power she was allowed over her own body; she could only watch her blood sugar rise needlessly without being able to use her own skills and expertise to keep herself safe. During the experience of being put on a "sliding scale" (intravenous insulin and glucose administered in hospital), the patient completely loses control over his or her diabetes, surrendering management to hospital

staff who are unlikely to be diabetes specialists. The National Diabetes Inpatient Audit has shown that in more than a third of cases this results in medication errors, which can lead to coma and occasionally death.¹⁹

Discussion

Principal findings

People graduating from intensive patient education courses such as DAFNE emerge with disease-specific biomedical, experiential and practical knowledge that exceeds that of many healthcare professionals. From the stories told by participants in this study, it was clear that serious obstacles to self-management arose when generalist and even specialist doctors and nurses were not comfortable with patients who had a high level of expertise. While this has been noted elsewhere in more general terms,^{20 21} this is the first study to confirm these findings in terms of healthcare professionals' reactions to formally trained Expert Patients. Although some healthcare teams were happy to support course graduates and even learn from them, this attitude could not be counted on, particularly when patients made budgetary demands that the budget-holders did not fully understand, such as requests for home blood testing equipment. Expertise taught to patients in one branch of medicine can be considered non-compliant by those who are not specialists in that field, and in some circumstances, such as inpatient care, self-management may be greatly discouraged or even forbidden by hospital policy.

Patient education has the potential to change people's lives for the better in a way that is perhaps not fully captured by standard clinical and quality of life outcome assessments. As well as offering practical information, DAFNE teaches people with diabetes to consider a new role as expert, independent, and empowered patients. Participants in this study found that hugely helpful, not only in terms of biomedical improvements, but also in terms of taking control over their own lives with chronic disease. However, there is evidence that having learnt how to self-manage successfully, patients find it frustrating, at best, and frightening, at worst, to have access to self-management resources denied them; in some cases problems with post-course interactions may be hindering patients' ability to hit biomedical targets and stay healthy.

Strengths and limitations

Traditionally, studies of patient education have been dominated by medical perspectives, with very little formal research conducted by patients themselves. This has resulted in emphasis on questions about compliance and biomedical markers, with less attention paid to the impact of educational interventions on other parts of patients' lives. A strength of this study was its user-led focus, with a researcher from the diabetic community supported and advised by others from that community. The project fits wholly within the NIHR and INVOLVE definition of research for patient benefit: "research 'with' or 'by' people who use services rather than 'to', 'about' or 'for' them."²²

The choice of a narrative methodology and semi-structured topic guide allowed patients to choose what to emphasise in stories they told about themselves, but this approach had its inherent limitations too, as did the decision to restrict the research to a single chronic illness and just one patient education course. The small sample size allowed in-depth qualitative analysis to take place, but both sample size and the particular challenges involved in managing Type 1 diabetes mean that we cannot assume disease-specific findings are representative of other populations and other conditions. However, the broader findings of the study are applicable across the board: it has offered a new insight into the potential difficulties faced by newly educated patients, and suggests a need for serious reflection on existing practices, power hierarchies and training paradigms within healthcare. There may be local differences in different populations, but the paradox remains: patients are being given expertise and confidence to self-manage, but there remains no pathway to having these skills recognised or valued more generally by those with power and access to resources. At best, this leaves patients vulnerable; at worst, it can undermine their hard work and health status.

Studies of post-education health interactions have been rather limited to date. Some evaluations have hinted at potential conflicts between knowledgeable patients and less knowledgeable health professionals, and the potential for this conflict to erode health outcomes over time,^{5 26} but this has rarely been a focus of research. Previous qualitative work in diabetes education has identified the importance of ongoing support from healthcare professionals in patients' ability to self-manage along the lines taught on the course.²⁷⁻²⁹ However, these studies focus on the relationship between the specialist and patient rather than interactions with generalist healthcare professionals. In our study we found specific problems with interactions in primary and hospital care. This suggests that the power held by GP prescribers should not be overlooked when considering patients' ability to self-manage successfully.

Implications and future research

Although patient education is recommended for those with chronic conditions in general,^{1 30} the implications for the education of healthcare professionals are not currently considered in parallel. While modern medical and nursing education focuses on patient-centred care,^{31 32} it does not prepare healthcare students for situations in which their patients have more biomedical and practical knowledge than they do about a specific treatment regime or illness.³³ When the role of the patient in a healthcare interaction is ambiguous and contested, problems arise on both sides, and extra work is required by both patient and professional. Although courses like DAFNE could include sessions preparing students for post-course interactions, there are limits to the extent to which patient education can mitigate these problems. In the districts where this study took place, work was already being done to help support DAFNE graduates who needed to go into hospital, and to ensure they got letters to enhance their authority when asking for supplies from primary care. Findings from this study would suggest that this work is very much needed. However, even when this support was in place, graduates continued to encounter disempowering practices from healthcare staff who were not DAFNE-aware. When healthcare practitioners do not understand the patient's self-management

requirements or trust their ability, they may put up obstacles to improved health outcomes by limiting medical supplies or insisting on unnecessary hospitalisation. As more chronic illness care is put into the hands of generalists, such situations are likely to arise more and more often; the importance of teaching strategies to cope with patient expertise, rather than see it as a threat, is of increasing relevance.

Although this study has provided an insight into the kinds of issues encountered by people after formal education, further research with both patients and healthcare professionals is needed to establish how widespread these problems are on a national level, and whether similar issues are faced by patients with other kinds of chronic conditions following other styles of Expert Patient Programme.

Conclusions

Healthcare professionals cannot become experts in the detailed management of every complex condition; gathering specialist input from others has long been an important part of treatment decision-making. Doctors, nurses and others whose attitudes impact on patient care must be supported to extend that model of shared expertise to work with those who have chronic illnesses, seeing the patient as part of the healthcare team, and the patient's condition-specific biomedical knowledge as a valuable resource, not a threat.

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RS designed and carried out the research, and drafted the paper. She is guarantor. JS and CH supervised research, reviewed and edited the paper.

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Data Sharing:

The presented data are anonymised and risk of identification is low. Extra data is available by emailing RS.

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