

Service provision for type 2 diabetes in the community: a qualitative study

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ARTICLE POINTS

1 The care of people with type 2 diabetes is accepted as a core activity in primary care.

2 Educating patients will not necessarily lead to the required lifestyle change.

3 Empowerment does not equate to motivating.

4 Central to providing quality care are the attributes and skills of the care providers and patients.

5 Visual mapping of a service structure and its relationships and dynamics can be a useful aid to care provision.

KEY WORDS

- Type 2 diabetes
- Service provision
- Empowerment
- Motivation
- Key participants in care

Introduction

With the increasing prevalence of type 2 diabetes, the Department of Health has recognised the need for diabetes services to be delivered in primary care settings wherever possible. The NSF for Diabetes: Delivery Strategy prioritises the need for more research into service organisation and delivery. This paper explores the views of key participants in diabetes care on how care is currently provided and how it might be improved.

The *National Service Framework for Diabetes: Delivery Strategy*, published in 2003 (DoH), sees the establishment of local diabetes networks as a key element in the delivery of good quality care:

'Experience has shown that networks, which are inclusive and bring together all necessary stakeholders, are most effective.'

Shifting the Balance of Power Within the NHS (DoH, 2001) outlines how the devolvement of power to frontline staff means that service provision can become more patient-centred. There has recently been a shift in emphasis from hospital care to community care for people with type 2 diabetes, as a result of limited hospital resources, increasing patient numbers and the recognition that people with type 2 diabetes, on the whole, do not have to be under hospital care (Fitzsimons et al, 2002).

Current and Future Research on Diabetes (DoH and the Medical Research Council, 2002) emphasises that the new commissioning and gate-keeping roles of primary care can 'ensure the timely and appropriate use of specialist resources'. The report recommends that future research needs to determine how best 'to facilitate organisational development around delivery of care at the whole systems and smaller unit level'.

Much of the previous research, which has sought to elicit the opinions of

stakeholders of care, has tended to concentrate on individual groups of care providers (Peters et al, 2001). There is a lack of evidence that addresses care provision by exploring the views of multidisciplinary team workers and service users.

Study aims

The aims of this study were to explore the views of major stakeholders in relation to the management and structure of type 2 diabetes care, to inform the provision of diabetes care and to describe the attributes of care providers and users that are felt to have an impact on service delivery.

Methods

This qualitative study was undertaken in one primary care trust in the northwest of England. Initial pilot interviews were used to inform the structure of the interviews.

A series of face-to-face interviews took place between the researchers, healthcare workers and service users. The interviews were audio-taped and transcribed verbatim in full, and field-notes were recorded throughout. Deliberate sampling was used to obtain a maximum variety sample reflecting age, sex, interests, qualifications, practice type and location.

A total of 17 interviews were undertaken involving two pilot interviews, nine GPs, two practice nurses, one diabetes specialist nurse (DSN), one district nurse and two expert patients.

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- 1 Thematic analysis of the interviews provided rich data.
- 2 Validation of the data was achieved through the use of triangulation.
- 3 Themes were mapped visually using 'metro-analysis'.
- 4 Routine day-to-day care should be community based.
- 5 More complex cases should be seen in hospital.

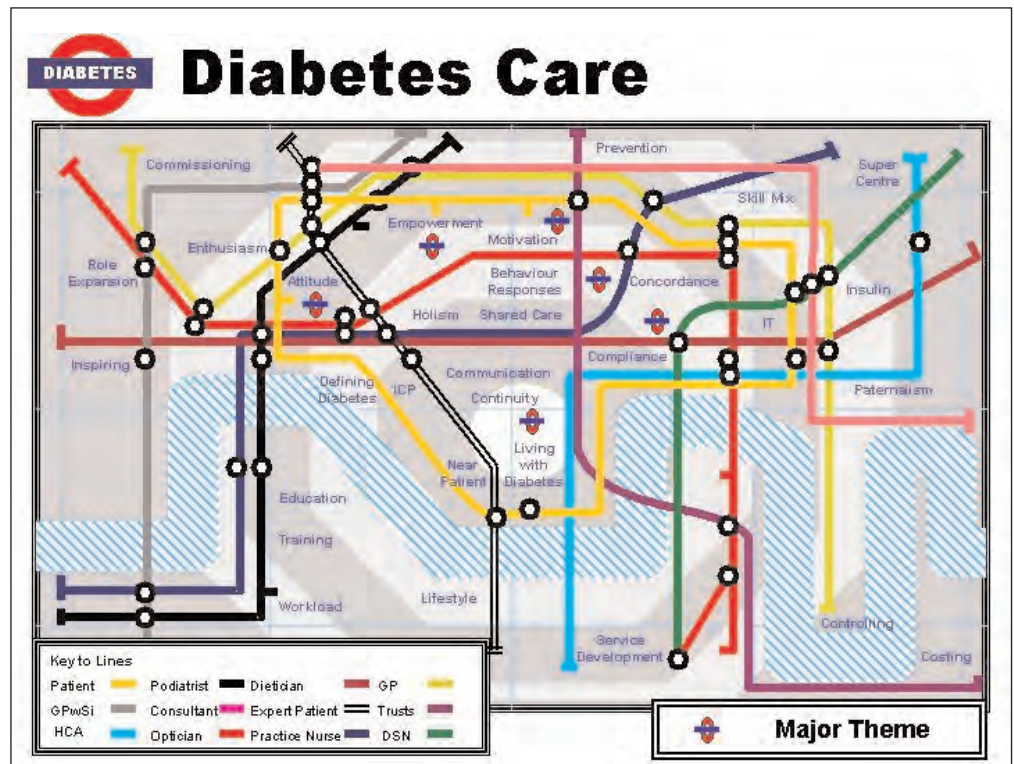


Figure 1. The 'metro-analysis'. GPwSi = GPs with a special interest; HCA = healthcare assistant.

Analysis

A qualitative software programme (NUD*IST QSR, version 4) was used to examine the collected data. Data were subjected to thematic analysis. Drawing on the techniques of framework analysis (Ritchie and Spencer, 1994), the researchers initially familiarised themselves with the data. The interviews were coded and emergent themes recorded. Any disagreements were resolved through discussion, and eventually the results of the thematic analysis were organised into four major themes:

- Attitude
- Service structure
- Empowerment
- Living with diabetes.

Validation

Triangulation was achieved by respondent verification. Triangulation involves the comparison of results from 2+ different methods. In this case we used respondent verification, whereby the analysis is fed back to the participants and their reactions are incorporated into the study findings. A summary of the initial analysis was sent to all participants for validation. The results

were incorporated into the final analysis.

Complex relationships between themes and stakeholders of care were visually mapped. The technique used was developed de novo and termed 'metro-analysis' (Figure 1).

A key principle behind this is complexity theory, which recognises the fluid and dynamic relationships that contribute to an organisational structure (Senge, 1990). This synthesised the relationship between identified themes and the participants in care. In the metro-analysis, the patient is central to the care structure, as are the major themes. Themes are mapped so as to visually correspond with their relationship to participants. The map is zoned into decreasing areas of importance in a radial fashion. The further out something is on the map, the less important it is at present to the overall structure.

Mapping an organisation in such a way lets us see pictorially what is important to that service at a given moment. In keeping with complexity theory, that which is important is not static but fluid. Relationships within the organisation are similarly dynamic. The map can be altered at any given point in time to account for this.

The researchers propose that this is a novel and useful way of explaining and illustrating the make-up of services within the NHS.

Results and discussion

Themes were identified and grouped under four major headings as described above.

Service structure

It was felt that routine day-to-day care should be almost entirely community based. Some participants believed that insulin initiation and maintenance should be carried out in a hospital setting. The development of complex medical problems such as renal failure was also deemed to warrant a hospital referral.

The actual setting for care provision in the community came under scrutiny. Most people favoured a practice-based system. There was no bias towards any participant group on this matter. Concerns were raised regarding fragmentation of care, the de-skilling of team members (particularly among GPs) and accessibility for patients if services were transferred to a locality-based setting.

'I mean what is general practice? If everything gets fragmented into various subspecialties what do I do all day? Because dermatology is going to disappear, diabetes is going to disappear, headache, rheumatology. What do I do? Do I just see sad people who are miserable? Coughs and colds can be dealt with by nurse practitioners. What do I do?' (Interviewee 3)

Predominantly, there was agreement that the service should be nurse led. Reasons cited for favouring a nurse-led service differed between doctors and nurses. GPs considered nurses to be more adept at adhering to guidelines and protocols. However, nurses felt that, in addition to being better at following protocols, their people skills were an important determinant of quality of care. People skills comprised an ability to listen, empathy and a holistic approach to care.

In terms of shared care there was a dichotomy of views. Nurses favoured an approach whereby patients were managed

jointly by doctors and nurses. GPs felt that their input should only be required on an occasional basis for an opinion on diabetes complications or changing medication.

The idea of GPs with a special interest (GPSIs) in diabetes working in primary care received mixed views. However, these were mostly negative. GPSIs were not felt to be of any additional benefit to the range of services already provided. It was felt to be unnecessary to install a two-tier service between primary and secondary care. Similarly, the views on commissioning of diabetes services by other practices were mostly negative. This is in contrast to the recommendations of the *NSF for Diabetes: Delivery Strategy* (DoH, 2003). Many felt that GPSIs could have a detrimental effect on patient care. GPs believed that GPSIs could contribute to a de-skilling of their profession.

The use of healthcare assistants was not consistent among the group. Many favoured an extension of their role, but for varying reasons. There were concerns regarding the training and knowledge of healthcare assistants. Many cited a blurring of the distinction between healthcare assistants and nurses. Some participants suggested that healthcare assistants could be used as tools for shifting the balance of power to the patient.

DSNs were considered integral to service provision. The need for more DSNs and a community base rather than a hospital was felt to be important. DSNs were thought to be most useful for education, complex cases and issues surrounding insulin.

Optician services were described as excellent. Many held the view that they were underused as a resource and their expertise was such that they should have the right of direct hospital referral of all ophthalmic cases.

The chiropody and dietetic services were believed to be under-resourced. Many participants commented that they had trouble accessing a dietitian for their patients with diabetes. There was uncertainty regarding the dietitians' role and localities.

Some believed that the pharmacists' role could be extended. It was felt that

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- 1 Participants were concerned about fragmentation of services.
- 2 Community diabetes care provision should be nurse led.
- 3 The idea of GPs with a special interest in diabetes care is often viewed negatively.
- 4 DSNs are seen as integral to service provision.
- 5 Primary care staff are a more important resource than the infrastructure.

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1 Information technology needs to be improved.

2 Ambiguity exists regarding attitudes towards traditional paternalistic modes of working.

3 Different skills and attitudes are attributed to specific professional groups.

4 The benefits of a holistic approach to care is explored.

5 The concept of empowerment is problematic.

Defining empowerment

- Rebound effect against paternalism
- Increasing knowledge
- Increasing power
- Increasing motivation
- Patient taking a holistic view of their condition incorporating lifestyle factors
- Passing control
- Actively playing a role in management
- Inspiring patients
- Management speak

Figure 2. Participants' definitions of empowerment.

pharmacists could be used for checking blood pressure and blood glucose levels. Little was known about the future role of expert patients. Many felt that the idea of having expert patients was potentially beneficial. Whether the expert patient programme was a useful tool in terms of the individual's care or could be useful in improving the care of other patients with diabetes was uncertain. Responses from expert patients revealed uncertainty regarding their role.

Several respondents raised the issue that trusts tended to take a short-term view on service planning whereas healthcare workers tended to take a long-term view on service planning. Continuity emerged as an important theme in terms of service planning.

There was an overall view that people were a more important resource than the infrastructure.

**'What about resources?'
(Interviewer 1)**

**'Well, that is the problem. I do not think buildings have anything to do with it. You need dedication.'
(Interviewee 8)**

An integrated information technology system, understood and used by all, was seen as central to improving communication within the service.

Behaviour responses

- Denial
- Acceptance
- Depression
- Minimisation
- Trivialisation
- Normalisation
- Externalisation

Figure 3. Behaviour responses of patients.

Attitude

Taking into consideration the increasing prevalence of type 2 diabetes, participants felt that there was a need for a shift of responsibility for management to patients. A less paternalistic approach was favoured.

However, there was ambiguity in the attitude of participants on the key issue of moving away from medical paternalism. From the interviews it was clear that many GPs were currently openly paternalistic in their dealings with patients, claiming that this approach was by and large justified by the patients' own wishes and for expediency.

**'I feel a lot of people really want to be told what to do. They are not very comfortable controlling their own disease.'
(Interviewee 7)**

Even some expert patients indicated a willing acceptance of the traditional order.

**'Because if you do what they tell you to do and you just look after yourself, you have no problems.'
(Interviewee 15)**

Nurses felt that they were more empathic and holistic than doctors. Nurses stressed that an empathic and holistic approach was central to good quality care and achieving the best outcome. Doctors tended to feel that their own role was to provide expertise and to deal with complications.

**'Qualitatively they [nurses] tend not to just concentrate on pure medicine the way that doctors do.'
(Interviewee 3)**

Defining diabetes

- A complex multisystem disease
- A chronic disease
- An illness requiring a multidisciplinary approach
- A vascular syndrome as opposed to an endocrine disease
- An illness requiring regular follow-up (about four times a year)
- A condition that requires lifestyle change
- An illness that rots organs
- An illness that grinds you down

Figure 4. Interviewees' definitions of diabetes.

'I am not sure you can just separate the diabetes from the rest of somebody's life...it is not a very holistic approach to caring for somebody. Developing relationships with people is important ...that gives them confidence.'
(Interviewee 10)

'If you come across as not particularly interested in them, if diabetes is just another thing, then I am sure that the patient picks that up. If they feel that you are interested in them they are much more likely to come back next time.'
(Interviewee 11)

Empowerment

According to the Department of Health, the idea behind empowerment is:

'To ensure that people with diabetes are empowered to enhance their personal control over the day-to-day management of their diabetes in a way that enables them to experience the best possible quality of life.'
(DoH, 2003).

All participants were aware of the term 'empowerment'. However, views on what empowerment actually meant and how it could possibly be achieved differed greatly (Figure 2). No-one was able to clearly explain the relationship between motivation and empowerment, or describe a motivational strategy.

Key points of care

- Focus on people not structures
- Understand the patient
- Consider the views of stakeholders of care
- Focusing merely on achieving targets is unlikely to be a successful strategy
- Concentrate on what might empower and motivate patients. Consider strategies and tools that might aid this process, such as motivational interviewing.
- Behavioural response developed to live with diabetes need to be considered to optimise management.

Figure 5. Key points of care.

'What do you understand by the term "empowerment"?' (Interviewer 1)

'It is about giving individuals the knowledge and tools to manage themselves.' (Interviewee 4)

'Do you think it works with people with diabetes?' (Interviewer 1)

'Sometimes, but not very often.'
(Interviewee 4)

Educating patients was viewed as very important. Whether or not it brought about lifestyle changes and improved care was not clear.

Living with diabetes

One interviewee described her view of living with diabetes.

'Diabetes is just overwhelming and how we sit here in judgement half the time. How many of us could go through life having diabetes, checking blood glucose, taking tablets at the right time, not having a piece of birthday cake? I think it is hard.' (Interviewee 12)

Transcription and analysis revealed several important behavioural responses ascribed to diabetes (Figure 3).

'To me...I know it is an illness...but it is more of a nuisance than an illness.'
(Interviewee 15)

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1 Important behavioural responses were ascribed to diabetes.

2 Definitions of diabetes were extracted from the interviews.

3 Understanding the patient perspective is vital for good care provision.

4 Improvements on the existing models of care are universally welcome.

5 Relationships within the service are complex, fluid and dynamic.

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- 1 Patient lifestyle modification is fundamental to providing effective diabetes care.
- 2 There is a need to increase patient self-management.
- 3 There was no understanding of how to motivate patients.
- 4 Existing patient education programmes are failing.
- 5 Motivational strategies and techniques could be more widely used in diabetes care.

Ideas about what it actually means to have diabetes varied among interviewees. No-one defined diabetes using biochemical parameters. Respondents repeatedly cited the practical points about diabetes (Figure 4).

Conclusion

Key participants in diabetes care are in agreement. Type 2 diabetes can and should be dealt with at a primary care level. Healthcare workers recognise that different skills, knowledge and attitudes can influence care.

Improved communication systems are vital to good teamworking. Developing and improving on the already existing model of care was favoured by participants. This will also prove to be a more cost-effective model and will have major implications for NHS resource management.

Relationships within the service structure are complex, fluid and dynamic. Relationship mapping that also considers which attributes are important to the structure can aid our understanding of the service. Relationship mapping and thematic analysis enabled a list of key points to aid service development to be drawn up (Figure 5). This can help us provide the most effective health care for a particular locality. Metro-analysis is a useful tool for carrying out this objective.

Although everyone, including government bodies, recognises the need for increased patient involvement in care and cites empowerment as one means of achieving this, it does not automatically equate to motivating people to change their lifestyle. There is no clear method for achieving this aim in clinical practice.

Patient lifestyle modification is fundamental to providing effective diabetes care. Motivational strategies and techniques are rarely taught to medical personnel, either at undergraduate or postgraduate level. This needs to be addressed since these techniques can be effectively taught and implemented (Maria et al, 2004). Such strategies are satisfactory and acceptable to patients with type 2 diabetes (Clark et al, 2001). They can be useful in a wide variety of lifestyle modifications including diet, weight control, alcohol, smoking, drug misuse and gambling (Colby et al, 1998;

Baker et al, 2002; Handmaker et al, 1999; Hodgins et al, 2001). In the UK, much emphasis has instead been focused on providing patient education, but there is little evidence to suggest that this is an effective strategy and it can be costly (Loveman et al, 2003). ■

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