

Empowering people with diabetic nephropathy

Rachel Hawley

ARTICLE POINTS

1 Working with a quality circle group was invaluable in helping to develop services in a patient-centred way.

2 Research has enabled development based on actual rather than perceived need.

3 Information is known to be the best basis for making appropriate choices in health care.

4 The study group emphasised the importance of their needs being recognised from their own perspective.

5 It is appropriate to develop information with a strong involvement of patients.

KEY WORDS

- Nephropathy
- Empowerment
- Focus groups
- Quality circles
- Action research

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Introduction

A two-part study was commenced in 1995 as part of developing a service for patients with diabetic nephropathy. The aim was to establish whether patients' perceived needs for information were being met. This article describes the development of the service and how the initial findings were used to extend the study. An action research methodology was used with the aim of developing patient information material. A quality circle group of patients was recruited as part of the process. The study culminated in the production of a booklet for people with diabetic nephropathy entitled 'Helping Hand'.

A joint renal diabetes clinic was established in 1992 as part of the development of combined specialist services for people with diabetes. The impact and implications of the St Vincent Declaration (Diabetes Care and Research in Europe, 1990) subsequently led to great changes in the planning of diabetes care. Subgroups and working parties were established within the various specialties of diabetes to focus on improving care and health outcomes in a patient-centred way.

Working in this clinic highlighted the multitude of problems faced by patients. These raise many issues, concerning not only patients' physical wellbeing but also their psychological needs. The impact on the family as a unit was very apparent: roles become subject to change as a result of the patient's renal disease, particularly for relatives and other carers who are actively involved in providing day-to-day care.

Sheffield is a regional centre for renal care. At the time of the study the total number of patients receiving care for diabetic nephropathy was 191 (Table 1).

A small audit performed in the clinic emphasised gaps in patient knowledge about the practical aspects of diabetes care. The audit tool used was a short questionnaire with an interview format to establish patients' level of access to practical equipment and associated services for diabetes care.

The audit highlighted the need to explore

further how patients manage to live with diabetes when also faced with renal complications. A two-phase study was designed with the following objectives.

Study objectives: phase one

Phase one of the study aimed to:

- Assess the level of knowledge about current treatment and practical aspects of care for diabetes of patients attending the renal diabetes clinic.
- Establish whether the information provided met their needs.

While it was recognised that long-term health outcomes may not be altered once end-stage renal failure is established, it was hoped that an exploratory study would help to ensure that the service was providing the kind of information and support that is valued by this patient group.

Table 1. Total number of patients with diabetic nephropathy receiving care in Sheffield (April 1995)*

Pre-dialysis	105
Peritoneal dialysis	30
Haemodialysis	24
Transplant	32
Total	191

* Sheffield Kidney Institute, Northern General Hospital, Sheffield

Methodology and design

An action research methodology using a qualitative approach was used. This consisted of a structured exploratory questionnaire, followed by a focus group.

As this was a small study, a group of patients receiving the same treatment for both diabetes and renal care was selected to enhance the credibility of findings by limiting the number of confounding variables. The group, who were selected at random, were all treated with insulin therapy for their diabetes care and with continuous ambulatory peritoneal dialysis (CAPD) for their renal care. The aim was to include patients of working age who would be dealing with the impact of diabetic and renal care.

A wide selection of existing questionnaires were considered, but none met the needs of the study which aimed to consider practical aspects of patients' diabetic treatment and care. Bradley (1993a) presents a valid argument for using existing scales in research, i.e. ones that have been well validated and have recognised scoring systems, wherever possible. However, the researcher felt it important to address issues that had not previously been explored in this specialty.

The researcher perceived a significant need to explore practical aspects in order to determine the implications for patients' quality of life and independence.

A structured exploratory questionnaire was therefore designed specifically for this purpose, using relevant guidelines (Bradley, 1993b). The questionnaire was validated by a pilot study on a random group of four patients at a clinic. An interview process was chosen in view of the fact that many patients attending this clinic have visual impairments. The mean age of the 10 patients (five male, five female) interviewed was 41 years (range 33–59).

The structured exploratory questionnaire was designed to assess patients' knowledge of diabetes and practical aspects of self-care, including awareness of 'gadgets' for diabetes care which may enhance independence and, for some, quality of life.

Results

Structured exploratory questionnaire:

Data from all of the interviews were collated prior to analysis of each section.

The data included:

- Demographic data
- Knowledge about treatment
- Awareness of practical 'gadgets'.

A 10-point Likert-type scale was used to gather information about knowledge and self-care (0 = low level of knowledge and 10 = high level of knowledge). This highlighted important aspects of patients' requirements for information (Figures 1–4 and Table 2).

While it is assumed that more information leads to improved quality of life, some people feel better knowing less. However, it is essential to ensure that appropriate information is available to enable informed choices. Individuals find their own coping

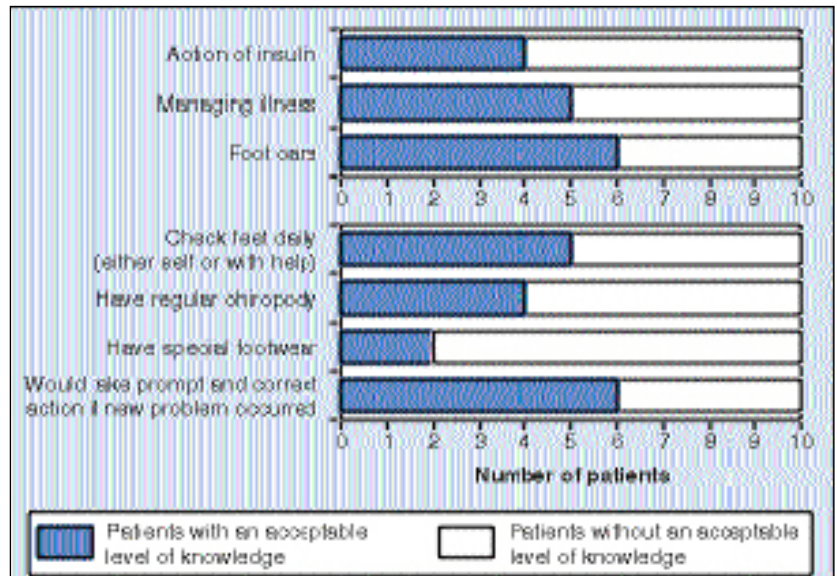


Figure 1 (top) Patients' level of general knowledge regarding diabetes care (n = 10).
Figure 2 (bottom) Patients' level of knowledge regarding foot care (n = 10).

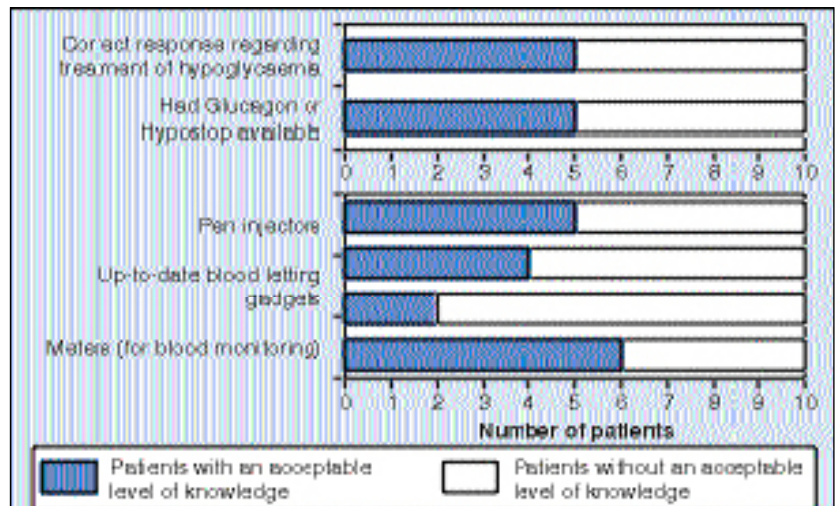


Figure 3 (top) Patients' level of knowledge regarding hypoglycaemia (n = 10).
Figure 4 (bottom). Patients' level of knowledge regarding diabetes-related 'gadgets' (n = 10).

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Table 2. Level of patient contact with the DSN and patient knowledge regarding action of insulin and practical 'gadgets'.

Diabetes nurse contact			
No, never			2
Yes, but not for years			3
Just since joint clinic			2
Ongoing, active			3
	DSN contact	No DSN contact	Total
Knowledge regarding accurate action of insulin	3	1	4
Pen	2	0	2
Modern finger-pricking device	4	0	4
Meter	2	0	2

strategies and do not necessarily want to change (Henley and Hill, 1990; Burzstajin et al, 1990).

Focus group

All of the patients who had participated in the structured exploratory questionnaire were invited to attend a focus group, which the researcher facilitated. The focus group, which was held in the Diabetes Centre, was a productive and interactive discussion which covered a wide range of issues. In the limited time available, some common themes were highlighted. Seven of the initial study group (four females and three males) attended. Three people declined to participate: two through illness and one because of problems with travel.

Following an introduction, participants were reminded of the presence of a tape recorder, to which they consented, and were assured that the tapes would be destroyed following analysis, to ensure confidentiality.

Themes for discussion had been prepared and included:

- How does diabetes impact on life now and where does it fit in among other problems and sexual issues?
- Diabetes control and what it means
- When the news of renal complication was broken.

The discussion guide consisted of topics in key areas to be covered during the discussion. Not only does this act as a memory aid, but it also provides a general framework for this exploratory discussion (Miller and Crabtree, 1992).

Information relating to the three themes was collected with respect to:

- Information
 - Emotional responses
 - Organisation of care
- Information was a particularly important theme for focus group participants and a number of issues were raised, including:
- Availability or lack of information
 - Quality and consistency of information
 - Honesty and trust regarding the exchange of information.

The focus group discussions emphasised the importance of practical information, but over much broader issues than diabetes which seemed, for this group, to be a secondary consideration to their renal care and associated problems.

In order to utilise the findings from phase one of the study, discussions were held with the renal and diabetes team; in particular, organisational issues were discussed and reviewed to address the issue of information need. A proposal to extend the study has developed from these discussions.

Study aims: phase two

Phase two of the study aimed to:

- Design and develop materials for information to meet the specific needs of people with diabetic nephropathy.

Phase one of the study highlighted the importance to individuals that their needs are recognised from their own perspective and that appropriate information is available and accessible to help them make informed decisions regarding care. It therefore seemed appropriate to develop information material with the strong involvement of the patients.

Methodology

Ten people with diabetic nephropathy were invited to take part in the consultation process. Stebbing (1990) described a quality circle as 'a small group of 3–12 people with the same interests who meet voluntarily on a regular basis with a trained facilitator to identify and analyse problems and recommend solutions'.

Forming a quality circle group with patients who have diabetic nephropathy provided further opportunity to explore their perceived needs and to reflect on previous experiences, which were shared by members within the circle group.

PAGE POINTS

1 Practical aspects were explored to determine implications for patients' quality of life and independence.

2 Individuals find their own coping strategies and do not necessarily want to change.

3 The study emphasised the importance of practical information over much broader issues than diabetes.

4 Consultation with patients enables a better understanding of what it means to be a patient.

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Figure 5. Members of the quality circle.

It is appropriate to ask patients what concerns them, in an effort to enhance care. Consultation with patients enables a better understanding of what it means to be a patient. In this way, qualitative approaches to improving nursing care can complement existing quality assurance strategies (Koch, 1992).

Patients who were eligible to participate in the quality circle were people on a range of treatments for renal failure, e.g. pre-dialysis, CAPD, haemodialysis and post-transplant. It was important to include representation of all these treatments in order to obtain as broad a perspective as possible in addressing information needs. The size of the group was also important, as too large a group makes it difficult for everyone to participate (Hutchins, 1990; Stebbing, 1990).

The quality circle met on four occasions in the Diabetes Centre, as planned for the purpose of the study. *Figure 5* shows a photograph of the group, which group members asked to be included as they felt it would personalise their contribution and offer support to other patients with diabetic nephropathy who use the resources.

The group acknowledged that individuals have varying needs for information, but all agreed that information should be friendly and non-medical in its approach. They also felt that the reader should be given additional sources of material/support which they could access by choice as needed.

They felt that the emphasis should be on practical information, ensuring that the reasons for decisions are given. Family and carers should also be included.

Many of the group members who had been faced with making decisions about their health care felt inadequately prepared. Information is known to be the best basis for making appropriate choices in health care (Bradley and McGee, 1994). The quality circle group worked with the researcher to develop a booklet called 'Helping Hand' which was published in 1998.

Results

'Helping Hand' (*Figures 6 and 7*) contains information to help people living with diabetic kidney problems. It addresses the key areas:

- Common feelings for families
- Practical information
- Contact information for further help if needed
- Families and friends, to help them gain confidence and a greater feeling of control.

Practical difficulties were encountered throughout the development of the booklet, but with support and planning were overcome. Group meetings, for example, were planned around the demands of treatments and multiple appointments, and included episodes of illness among some group members.

Between group meetings, the researcher

PAGE POINTS

1 Individuals have varying needs for information.

2 Appropriate information needs to be made available and accessible to facilitate informed decisions regarding care.

3 The quality circle agreed that information should be friendly and non-medical.

4 Emphasis should be on practical information and family and carers should be included.

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Figure 6. Cover of the 'Helping Hand' booklet.

liaised with colleagues from diabetes and renal teams in addition to the patient group. Contact was maintained by telephone and writing. An audiotape of drafts of the booklet was also used for one member of the group who is blind.

It was important to consider the readability of the booklet and acknowledge the help obtained from the guidelines suggested by Albert and Chadwick (1992), who recommend that writers of information for patients should aim for a Gunning Fog Index of 12 maximum. Involving the quality circle group ensured that the level of readability and style of materials ultimately produced accorded with their wishes and judgement. Since accurate and consistent information is required, it seems appropriate that such resources are not produced simply for people with diabetic nephropathy but with them.

Informal evaluation of the draft material was ongoing during the development of the content, and patients and staff contributed to the final production. The consultative process helped to ensure that the finished product met the needs of the target group.

This work was presented at the conference 'Demonstrating the Power of Practice' held in Harrogate in 1998 which enabled further evaluation of the booklet. It confirmed that there was a gap in existing information for patients in this specialised area of care, and therefore a need for such a resource.

Conclusion

Working with the quality circle has been invaluable in helping to ensure that services were developed in a patient-centred way.

'Nurses can learn so much from patients and their families, including a range of responses, meanings and coping options. Understanding these meanings without rendering them meaningless through de-contextualised analysis can provide a base for systematic study and the further development of practice and theory' (Benner, 1984).

Initiation of this research with patients who have diabetic nephropathy in Sheffield has enabled further service development and led to an enhanced patient service based on actual rather than perceived need. ■

The researcher wishes to acknowledge Novo Nordisk who supported the research and production of the 'Helping Hand' booklet. Special thanks to all the patients and their families who were involved in the writing and illustration of 'Helping Hands'. Sadly, some of the patients are no longer with us, but they will always be remembered.

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Contents

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- Aims of this booklet

Part 1

Thoughts and feelings

- How do you feel?
- Your family and friends
- Personal experiences

Part 2

Practical information

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- Food
- Hypoglycaemia

- Eyes

- Practical devices
- Feet
- Appointment diary
- Useful telephone numbers

Part 3

How to get more information

- Useful information (National)
- Helpful books
- Computer and internet resources

Figure 7. Contents of the 'Helping Hand' booklet.