

Consulting stakeholders in high-risk foot care services development

Susan Nancarrow and Nicole Devlin

Introduction

This paper reports the results of stakeholder consultation in the development of high-risk foot services in the Australian Capital Territory. Three consultation approaches were used, including a survey of service users, two workshops with a range of stakeholders, and in-depth interviews with 13 people with diabetes and a previous history of a lower extremity ulcer or amputation. The consultation phase identified a number of issues for improving lower limb services: the need to improve communication between health service providers; the need for services to be accessible; and the barriers when accessing appropriate footwear. The consultation led to an integrated, virtual approach to the delivery of foot care services.

The impact of the lower limb complications associated with diabetes is now well documented (Campbell et al, 2000; Caputo et al, 1997; Payne, 2000). Foot care programmes for people with diabetes have been shown to be effective in improving knowledge and altering behaviour, and in preventing ulceration and limb loss in a high-risk population (Barth et al, 1991).

Bild et al (1989) summarise the requirements of programmes designed to reduce lower extremity amputation as follows:

'Programmes to reduce amputations among people with diabetes in primary care should identify those at high risk; clinically evaluate individuals to determine specific risk status; ensure appropriate preventive therapy, treatment for foot problems, and follow-up; provide patient education; and, when necessary, refer patients to specialists, including healthcare professionals for diagnostic and therapeutic interventions and shoe fitters for proper footwear.'

The management of lower limb risk factors calls for an integrated approach. Health service providers should be aware of risk factors so they can facilitate effective screening and intervention strategies. By managing risk factors such as hyperglycaemia, cigarette smoking and high blood pressure and initiating effective treatment for patients at high risk of lower extremity amputations, decreases in amputation rates of 50–70% are possible (Jacot et al, 1990; Levin, 1997; Levy, 1993).

The need for service improvements and development in the area of diabetic foot disease was originally proposed in the

Australian Capital Territory (ACT) following the successful implementation of a three-tiered wound management system. The existing services for the management of lower limb complications were diverse, and included input from different disciplines and organisations from the public and private sector and primary, secondary and tertiary settings. The range of approaches created a number of potential boundaries to the development of truly integrated services.

Widespread consultation was undertaken to address the diverse needs of the stakeholders, including service users and providers. Stakeholder involvement in service development has great rhetorical appeal. However, there are limited published examples of the involvement of service users and other stakeholders in the development of services for the management of diabetic foot complications.

The consultation process

Following recognition of the need for a more clearly defined foot care system, a steering committee was formed and a project officer was appointed. The project officer was a registered nurse and diabetes educator who undertook the following tasks:

- A needs assessment to ascertain the extent of lower limb complications in the ACT.
- An assessment of consumer views regarding foot care in the ACT.
- Mapping of existing foot care services within the ACT.
- Research into existing service delivery

ARTICLE POINTS

1 The diversity of providers involved in the provision of foot care services in the Australian capital territory limited the provision of an integrated approach.

2 Stakeholders did not want a traditional, specialised, high-risk foot clinic model.

3 The quality of information provided to services users was poor.

4 Service users want better communication between stakeholders, accessible services and access to appropriate footwear.

5 The study led to a change in practice: an integrated, virtual approach to the delivery of foot care services was developed.

KEY WORDS

- Stakeholders
- Models
- Communication
- Accessible services

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PAGE POINTS

1 The views of the users of foot care services within the ACT were elicited through a questionnaire survey.

2 Service user and provider views were elicited through workshops and the development of subcommittees to represent particular interests within the group.

3 In-depth interviews were undertaken with 13 participants who had experienced ulceration or amputation.

models.

- Research into the development of care pathways for the management of lower limb complications.
- Consultation with major stakeholders and consumer representatives through the establishment of a steering committee, individual meetings with local experts and service users and workshops with stakeholders.

In order to obtain the breadth and the depth of stakeholder input, three different approaches were used. First, the views of the users of foot care services within the ACT were elicited through a questionnaire survey. Second, service user and provider views were elicited through a series of workshops and, subsequently, through the development of subcommittees to represent particular interests within the group. Third, in-depth interviews were undertaken with 13 participants who had experienced ulceration or amputation as a result of diabetes or other conditions. While it was

acknowledged that diabetes is the major risk factor for lower extremity complications, the service development was not limited to diabetes alone and was designed to include any condition with the potential to lead to lower extremity ulceration or amputation.

The stakeholders were identified as ACT Community Care (CC), The Canberra Hospital, ACT Division of General Practice, Diabetes Australia (DA) ACT and public and private sector podiatrists within the ACT. Additionally, footwear retailers were involved through a project called the Supportive Footwear Strategy (Nancarrow, 2001).

Consumer survey

A survey was administered to participants, who were sampled from representative consumer groups, to determine the rates of foot assessment, receipt of education and client satisfaction associated with foot care provided by healthcare providers in the Canberra region. The sample was selected to be representative of the wider population who may be at risk of developing foot complications. The results were used to provide information to help develop the at-risk foot service. The sample was drawn from a range of organisations that were perceived to have an interest in the at-risk foot including Diabetes Australia, health consumers of the ACT, private podiatry practices, the Arthritis Foundation, the Division of General Practice, and the Council on the Aging. The demographic and service use profile of the participants is summarised in *Table 1*.

A total of 52 people completed the survey. All regions of the ACT and surrounding areas were represented by the group. Of the sample, 83% (43) reported having had their feet assessed by a healthcare professional in the previous 12 months. Professionals involved in the assessment were GPs (17%), nurses (25%), podiatrists (71%) and specialists (10%). Several people had had their feet assessed by more than one healthcare professional.

Over two-thirds (70%) of the sample said that they were ‘very satisfied’ or ‘extremely satisfied’ with the foot care services they received. The remainder (23%) reported that they were either ‘occasionally satisfied’ or ‘not satisfied’ with current foot care services. Areas of general dissatisfaction

Table 1. Details of survey respondents

| | | |
|-------------------------------------|---------------------------------|----------|
| Total no. of respondents | | 52 |
| Age (years) | <65 | 21 (40%) |
| | 66–80 | 28 (54%) |
| | <80 | 3 (6%) |
| Medical conditions | Diabetes | 22 (42%) |
| | Arthritis | 24 (46%) |
| | Vascular disease | 18 (35%) |
| | Heart disease | 16 (31%) |
| | Hypertension | 21 (40%) |
| | Cerebrovascular accident | 15 (29%) |
| | Foot callus/ulcer/infection | 13 (25%) |
| | Foot deformity | 5 (10%) |
| | Thick toenails | 18 (35%) |
| | Peripheral neuropathy | 7 (13%) |
| Previous amputation | 2 (4%) | |
| Health service utilisation | Feet assessed in last 12 months | 43 (83%) |
| Assessed by | GP | 7 (17%) |
| | Nurse | 11 (25%) |
| | Podiatrist | 31 (71%) |
| | Specialist | 4 (10%) |
| Frequency of podiatry visits | Annual visit | 3 |
| | Twice yearly | 2 |
| | 3–4 times a year | 21 |
| | >4 times a year | 5 |

Table 2. Suggestions for a high-risk foot care system

Service accessibility

- Easy access, close to bus line
- Home visits
- Available parking with easy access from car to clinic
- Inexpensive service
- Short waiting time
- Fast access for urgent problems
- A recall system for assessment
- Good referral system to healthcare professionals

Footwear

- Clinic to sell footwear
- More information on footwear – cost/availability
- Consultation with orthotist

Education

- More frequent education
- Foot care education to use clear literature and videos
- Seminars for education
- Communication services available for education, i.e. interpreter

Other

- GP needs to know more about diabetes
- People providing foot care treatment should be sensitive
- Limited paperwork for patients

included inconsistent care from healthcare providers, treatment not being clearly explained, and poor communication between healthcare providers.

Twelve people reported previous hospitalisation for a foot problem. Three were dissatisfied with the care they received in hospital resulting from inconsistent nursing care, poor communication between GPs and specialists, and the treatment not being explained clearly.

Most participants (62%) stated that they had been provided with education or information about foot care from a healthcare professional. Footwear was an important issue for the group. Eight people reported that their shoes did not fit adequately (causing blisters, pain and/or rubbing), 25 stated that they had difficulty buying shoes and 12 had their shoes specially made or altered.

Participants were asked an open-ended question in which they could make suggestions for an at-risk foot care system. These are recorded in *Table 2*. Three broad themes emerged from the qualitative feedback. The most commonly raised issue involved the accessibility of services, which included physical access such as transport and car parking, as well as the prioritisation of services for urgent problems. The importance of footwear was reflected in the

qualitative feedback, with requests for services to integrate the provision of footwear (or at least provide information about footwear). The quality and accessibility of education was raised as the third theme.

Workshops with stakeholders

Two workshops were undertaken with key stakeholders, including diabetes educators, podiatrists, GPs, people with diabetes, arthritis and stroke, an endocrinologist, a general surgeon, a vascular surgeon, an ACT Community Care manager, the project officer and pharmacists. The goal of the first workshop was to determine the structure of the at-risk service. The model that was developed as a result of the initial consultation was presented to the same stakeholders at the second workshop.

The main issues that arose from the first workshop were:

- The need for a central coordinator of care.
- The need to improve communication between all stakeholders.
- The need for the service to be accessible to all service users.
- The rejection of the traditional model of care, consisting of a co-located group of specialists in a tertiary setting.
- The need to raise community awareness of at-risk foot issues.
- The current fragmentation of care and variations in practice quality.

The concept of a centrally located at-risk foot clinic was rejected by all parties, due to the perception that they were run by specialist practitioners, giving the impression that those who do not work at the high-risk clinic lack the skills required to manage serious foot complications. The group believed that having these specialists would create a certain level of dependency for care on a particular person or group of people. It was acknowledged that there are a number of providers in the community with adequate skills to treat lower limb complications. This model was also perceived to reduce the accessibility of the service to people who were unable to travel to the central location.

Podiatrists in private practice were concerned about their capacity to manage chronic ulcers for a long period of time, owing to resource requirements (particularly the high cost of dressings).

PAGE POINTS

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1 To ensure that minimum standards were met by each practitioner, health service providers agreed to adhere to guidelines in their practice, enforced through the use of clinical pathways.

2 The interviews were used to identify the pathways that led to amputation or ulceration and the consequences of the foot complication on the individual and his/her carers.

3 Lower limb complications adversely influenced the income and employment of five of the participants.

4 In an extreme case, a man with a long history of diabetes estimated that he had spent \$20 000 trying to buy appropriate footwear.

5 A general mistrust of the medical profession as a result of contradictory information being provided to service users was apparent.

This issue was addressed by enabling podiatrists to refer these people to the publicly funded ACT Wound Clinic.

To ensure that minimum standards were met by each practitioner, health service providers agreed to adhere to guidelines in their practice, enforced through the use of clinical pathways. Podiatrists and diabetes educators from the public and private sector met to develop care pathways that would direct the service user through their lower limb and diabetes care. A great deal of discussion surrounded the need for a care coordinator and who that person should be. Consensus was reached on the GP as the central manager of patient care.

A second workshop was held 4 months later, to which the same stakeholders were invited to view the proposed model for the footpath and discuss evaluation strategies. There was general agreement on the model from the stakeholders and a variety of evaluation strategies were proposed.

In-depth interviews with service users

In-depth interviews were undertaken with 13 people with diabetes who had had an ulcer or amputation in the previous 6 months, who were current podiatry service users in the ACT. When available, the carers were also interviewed. The interviews identified the pathways that led to amputation or ulceration and the consequences of the foot complication on the individual and the carer. Interviews were tape recorded and transcribed. The interviews highlighted the fragmentation of existing foot care services, in terms of poor accessibility to services, inconsistency of information at every level of foot care (from podiatry to specialist inpatient), the lack of coordination of diabetes services and enormous variations in the quality of the care delivered. Several common themes emerged:

- Loss of income and employment.
- Cost of purchasing dressings and appropriate footwear.
- Health care service quality.
- Lack of knowledge of available services and access.
- The burden on partners and carers.
- The importance of footwear as a pathway to amputation.
- Difficulty in recognising the signs and symptoms of diabetes.

Loss of income and employment

Lower limb complications adversely influenced the income and employment of five of the participants. Two of the participants had to change their employment due to their lower limb problems. One, a 39-year-old plumber with diabetes, developed osteomyelitis from an interdigital corn. The infection spread to the adjacent tissues and he eventually had his fifth toe amputated. The lesion did not heal and he was readmitted to hospital for another amputation. This pattern was repeated four times over 2 years, resulting in 49 weeks of hospitalisation, loss of employment and a career change, as well as a substantial burden on both his family and the local health services.

Other participants reported a similar burden as a result of their diabetes-related lower limb complications:

'It knocked a year out of my life and a year's salary. I work as a contract engineer and I only get paid for what I do and if I can't do anything, then I don't get paid.'

'Oh 100 grand... lost income. The wife works and I had a few bob stashed away, financially these episodes cost you... Keeping a house running costs money and I have nothing coming in and everything going out.'

Cost of dressings and footwear

The cost of wound dressings to patients varied greatly. One participant estimated that he spent \$3000–4000 on dressings over a 2-year period. Some participants received government benefits and said that without them they would not be able to afford the costs of dressings and footwear.

'They were \$607, these shoes. The government gave me \$500 and Trace (carer) paid \$100 and they didn't get the \$7.'

Participants reported difficulties in accessing appropriate, affordable footwear. One man with a long history of diabetes estimated that he had spent \$20 000 trying to buy appropriate footwear. Similar issues around the cost and availability of appropriate footwear were reported in a focus group of people with diabetes and their carers at the same time as this consultation.

Healthcare service quality

A general mistrust of the medical profession as a result of contradictory information being provided to service users was apparent. One

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2 The majority of interviewees said that they had not known about the availability of foot care services until they had developed a serious foot complication and started attending a clinic for their wound management, or until they had been hospitalised.

3 Partners and carers play an important role in the help and support of people who have diabetic foot complications.

4 Little formal support was provided for partners or carers in the management of diabetes lower limb complications.

interviewee had recently undergone a transmetatarsal amputation and was told by the surgical resident that he could start walking in 4–5 days. The wound opened, with saw-tooth tearing around the sutures, and was unable to be restitched because of local tissue damage. When the specialist saw the patient, he asked why he had been walking.

'This situation made me lose all faith in doctors.'

The same patient also felt that his recovery was hindered from a lack of continuity of staff which resulted in different approaches every time. This inconsistency came from all levels and he felt that a single, consistent approach would have made a difference. The carer of one interviewee thought the community nurses did not have sufficient time or knowledge for what was needed by people with diabetes.

'Pat had seen a nurse that morning who had said, "Oh it looks like you have an infection". Pat stayed home alone all day. The nurse didn't say, "I'll ring the doctor" or "you must ring the doctor" or "you need help". The phone must have rung 10 times that day; I was at work and didn't know and Pat couldn't get up from the chair. By the time we found her she had a raging temperature and was terribly sick. It was distressing that the nurse didn't realise Pat needed help.' (Carer)

Difficulties in recognising diabetes signs and symptoms

Three participants reported delays in the initial diagnosis of diabetes, reducing their confidence in the medical system. One lady complained of common symptoms of diabetes, such as fatigue and excess fluid intake, for nearly 15 months to her GP. It was not until she suggested that she may have diabetes that the GP ordered the appropriate medical tests. Other participants reported similar delays in diagnosis, despite symptoms of polyuria, excessive thirst and fatigue.

Knowledge of services

The majority of the interviewees said that they had not known about the availability of foot care services until they had developed a serious foot complication and started attending a clinic for their wound management or until they had been hospitalised. Only one participant had been referred to a podiatrist for routine care before his foot complication

arose. Two had attended hospital diabetes services intermittently.

Participants were asked about their main sources of diabetes information. One person relied on her husband to access all of her information. Other sources included information from GPs, pamphlets from dietitians, and diabetes educators. One participant went to the university library to access reference books himself.

The burden on partners and carers

Partners and carers play an important role in the help and support of people who have diabetic foot complications. The impact on partners and carers varied greatly. The wife of a man with diabetes, with four children, had to take time off work to provide transport and groceries for her husband.

'When you say did it affect our lifestyle, we had to drop everything.' (Carer)

One participant reported that his wife used to be a nurse, but he refused to let her nurse him. Long hospital stays also impose extra stress and burden on the partners and carers.

'It's a long drive from where we live to the hospital and it was getting dark early. So it was affecting our relationship; she was tired.'

Little formal support was provided for partners or carers in the management of diabetes lower limb complications. Only one participant utilised community nursing for help with showering and bathing, even though community nurses had to attend regularly to change dressings. Three participants reported that family members changed wound dressings. Carers were also required to provide transport for the participants when they had foot complications.

Footwear as a pathway to amputation

A number of pathways to amputation were described by the interviewees; all but one were caused by inappropriate footwear. The only non-footwear-related pathway was precipitated by a spider bite. One client reported he had been advised on appropriate footwear by a podiatrist, but 'they wore a hole in my toe'. A lady who was admitted to hospital with bipolar disorder said that staff neglected to manage her diabetes. Her carer told us:

'One of the doctors had said that she should wear sneakers to support her feet.'

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Because she didn't sleep she was walking and pacing and that's when the sneakers actually rubbed and caused the ulcer.'

It was revealed that this patient had a Charcot neuroarthropathy which remained undetected during her hospitalisation. Other footwear that caused complications included shoes rubbing bunions and sandals rubbing on the inside of one participant's heel.

Discussion

The questionnaires and interviews with service users highlighted common themes around the existing provision of foot care services in the ACT region. There were strong messages about the need for services to be accessible and integrated and for health service providers to communicate with one another. The difficulties in accessing appropriate footwear and the consequences of inappropriate shoes are powerful messages for health service providers. Finally, the quality and consistency of the information provided to people at risk of developing lower limb complications requires radical improvement.

The interviews identified the impact of lower limb complications on the family and carers of people with diabetes, an issue that is poorly addressed by current service delivery.

This consultation process provided insight into the needs and desires of service users and service providers which differed from the existing models of high-risk foot care. The feedback led to a model that was different from the one that was originally envisaged and to the traditional, tertiary approach to care. The removal of the centrally, co-located team of professionals meant that a 'virtual' integrated model was developed instead. This required agreement on care pathways from a range of stakeholders from different settings. For instance, public and private sector podiatrists met regularly to develop a care pathway for podiatry. The diabetes educators from Diabetes Australia ACT and ACT CC also developed similar pathways. There were a number of benefits to this approach, including:

- Identifying the issues that are important to all of the stakeholders in management and prevention of the at-risk foot.
- Creating a community-based focus for an issue that was previously managed in the tertiary sector.
- Gaining agreement within disciplines from

across a range of sectors (including the public and private sector) about the use of a standardised approach to care through the use of a clinical pathway. Ensuring that practitioners have the skills and instruments required to implement this approach.

- Gaining consensus on an approach to the management of the at-risk foot across different disciplines.
- Community ownership of the project.
- Creating networks between a range of stakeholders, including service users and service providers.

The approach helped to break down traditional boundaries between the public and private sectors and hospital and community sectors. Representatives from these sectors developed a common focus on the needs of service users and acknowledged their own strengths and weaknesses in the delivery of high-risk foot care. This approach should ultimately improve the quality of services provided to the people that most need them.

The only limitation of this approach was potentially the cost of the consultation phase. The exact cost of the consultation phase is difficult to quantify, owing to the amount of time given by many of the stakeholders to participate in workshops and subcommittees. Similarly, the benefits obtained by each participant individually were difficult to quantify. Anecdotal feedback suggested that the involvement of clinicians has led to better practice outcomes, increased referrals from other workshop participants and a reduced sense of practice isolation.

Conclusion

The use of a mix of approaches to consult with service users and providers gave a valuable insight into the potential barriers to effective service delivery and ways in which to overcome these barriers. Services need to recognise that the impact of diabetic foot disease extends well beyond the lower limb to include social, financial and emotional costs to the patient, their family and carers. The different approaches to the organisation of health services and health systems mean that the findings from this study may not be applicable in other settings. However, the use of widespread stakeholder consultation is replicable and may identify ways in which existing foot care services can be improved.■