

Group education for painful peripheral diabetic neuropathy

Emma Holland, Hanna Bryan, Chas Skinner, Kate Robinson

ARTICLE POINTS

1 Painful peripheral diabetic neuropathy (PPDN) can dominate people's lives.

2 People suffering from PPDN often shared the same feelings of frustration and isolation, and were unaware of who or where to turn to for help.

3 This article describes how a diabetes centre organised a 2-hour patient focus group in order to identify issues surrounding PPDN from the patient's perspective and to guide future service development.

4 If healthcare professionals can target education regarding foot care and foot wear, and offer support in the treatment of PPDN then maybe they can have a greater impact on patient quality of life and reduce the likelihood of the development of future problems including limb amputation.

KEY WORDS

- Painful peripheral diabetic neuropathy
- Group sessions
- Education

Emma Holland is a Clinical Nurse Specialist in Diabetes and Kate Robinson is a Diabetes Nurse Specialist at Queen Alexandra Hospital, Portsmouth. Hanna Bryan is a Health Psychology Student and Chas Skinner is a Senior Lecturer in Psychology at the University of Southampton.

Introduction

Painful peripheral diabetic neuropathy (PPDN) can dominate people's lives. In 1990 the St Vincent Declaration admirably aimed to halve amputation rates due to diabetic gangrene (World Health Organization [Europe] and International Diabetes Federation [Europe], 1990). The incidence of lower limb amputations in people with diabetes has been reported as 248 per 100 000 patient years, compared with 20 per 100 000 patient years for those without diabetes (Morris et al, 1998). It is well known that the downward slide towards amputation often begins with peripheral neuropathy (Boulton et al, 2000). This article discusses group education sessions used to inform both the person with PPDN and the healthcare professional.

In the lead author's one-to-one clinic visits it became apparent that people with painful peripheral diabetic neuropathy (PPDN) often shared the same feelings of frustration and isolation, and were unaware of who or where to turn to for help. They also had a lack of knowledge regarding the causes, treatments and self-management of the condition as well as misconceptions of future risks involved with PPDN. Kumar et al (1994) reported that PPDN is often associated with sleep deprivation, depression and a significant decrease in quality of life.

Focus groups

The lead author's diabetes centre organised a 2-hour patient focus group in order to identify issues surrounding PPDN from the patient's perspective and to guide future service development (Holland et al, 2004). Sixteen patients with PPDN were invited to participate, 13 agreed and 11 attended. The group was facilitated by two senior diabetes specialist nurses (DSNs) and a health psychologist, and two podiatrists were also in attendance. The participants were asked about their thoughts on effective treatments for PPDN, frustrations with the existing service and recommendations for improvement. Frustrations included:

- a perceived lack of knowledge and

interest about PPDN from healthcare professionals

- limited information and advice about treatments and prognosis
 - poor symptom control
 - poor communication between healthcare professionals
 - limited practical assistance.
- Recommendations included:
- increased availability of information about PPDN
 - earlier diagnosis
 - increased support from healthcare professionals
 - contact with other sufferers.

Comments received during the focus group confirmed suspicions of those running the groups regarding current service development needs:

'Nobody has ever really explained what it [PPDN] is, or seems to know.'

'My GP told me I had peripheral neuropathy and that was that!'

'Nobody seems to understand or know how to treat it [PPDN].'

'They are just concerned about my HbA_{1c}, but this [PPDN] is ruining my life!'

In response to these clear emotional and

information needs those delivering diabetes services in Portsmouth and South East Hampshire felt that there was a definite need for patient education groups for those suffering from PPDN.

Theories regarding behaviour change are well documented (Glasgow et al, 2001). It was felt that group workshops would be best suited to addressing the identified issues. A 'group set-up' also offered inherent support by helping to address the feelings of isolation that are often reported.

Developing patient education groups

Aims

The groups were set up to enable people with PPDN to gain a greater understanding of their condition, its causes, treatment options and support services available, in order to help them make informed decisions about how to cope with the condition. Ultimately, this aimed to minimise the risks in order to prevent future problems.

Objectives

By the end of the group session patients should:

- have an understanding of PPDN
- be aware of the causes, symptoms and treatments available
- have knowledge of potential risks to their feet and what they need to do in order to minimise these risks and prevent the formation of a diabetic foot ulcer or amputation
- know what action to take and who to contact should a diabetic foot ulcer develop
- be able to share self-management techniques, develop their own support network and be aware of other local and national organisations which are able to offer support.

Logistics of setting up the groups

Groups are co-ordinated by reception staff at the diabetes centre. They are facilitated by a DSN with a special interest in the diabetic foot. The sessions are held within the patient's locality, as the health district spans three primary care trusts, on a 1- to 2-month basis depending on demand. Attendance is currently limited to those

being cared for by the secondary care specialist service.

A poster advertising the groups is displayed in the reception area within the diabetes centre. Patients wishing to attend can refer themselves or be referred by a member of the multidisciplinary diabetes team who enters their contact details onto a register. The aim is for six to ten patients (and their partners) to attend the 2-hour session, in which refreshments are provided. Group attendance is a one-off appointment so nurses, podiatrists and GPs provide follow-up support.

Session outline

A welcome and introduction by the facilitator is followed by group introductions. Questions are asked to facilitate discussion; examples include the following.

- How long have you suffered from PPDN?
- What treatment do you currently take?
- What do you want to know and hope to achieve by the end of the session?

Responses are then entered onto flip charts under the following headings.

- Name and specific question.
- What is PPDN?
- What do you understand are the causes?
- What are your symptoms?
- What treatments have you tried and what are available?
- What can you do to help yourself?
- Where to get more support/information.

Asking group members to discuss their own knowledge and experience ensures that each specific issue can be discussed. Any points not brought up by the group, but felt to be important by the healthcare professionals, are added onto the flip charts by the facilitator and discussed, thus ensuring that all aspects are covered. Specific discussions are held regarding the relationship of other diabetes risk factors with PPDN such as glycaemic control, lipid management, other medications and smoking.

Attendees are asked whether they would be willing to talk to people newly diagnosed with PPDN and the centre has started to create a database of local support networks for people with the condition. Information discussed is backed up by providing attendees an educational booklet (titled

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2 Evaluation of the groups verified that the key messages, such as foot care and foot wear, optimising glycaemic control and who to contact if they have a foot problem, were taken on board.

3 Due to the small number of participants it was beneficial to also conduct semi-structured telephone interviews to help provide an in-depth exploration of the issues. These provided first-hand feedback on potential behavioural changes.

4 Although at present these groups are run by a DSN, there is no reason why a podiatrist or foot health technician cannot be trained to facilitate future groups.

5 The lead author's diabetes centre is currently developing district-wide management pathways for the care of people with PPDN.

Painful peripheral diabetic neuropathy – What would you like to know? [Portsmouth and South East Hampshire Diabetes Centre, 2004]) which reinforces all aspects covered during the session.

Evaluation

Evaluation of the groups verified that the key messages, such as foot care and foot wear, optimising glycaemic control and who to contact if they have a foot problem, were taken on board. However, the centre also wanted to discover whether the groups helped to allay fears and assist people to develop coping mechanisms in order improve their quality of life.

Questionnaire

Individuals attending the first three groups were asked to complete a questionnaire booklet before the group sessions and 2 weeks after the groups, the questionnaire booklet was sent in the for a post-group evaluation. The booklet contained several validated measures assessing participants' beliefs about their PPDN (Moss-Morris et al, 2002), coping (Carver, 1997), quality of life and pain (Melzack, 1975) and an individualised measure of quality of life (Griffiths et al, 2000).

In hindsight, the author would not use so many questionnaires for the evaluation of group education sessions. Patients found them difficult to complete and it added an extra 30 minutes to the educational session due to explanation and assistance required in answering queries. A more simplified version should suffice in the future.

Telephone interviews

Due to the small number of participants it was beneficial to also conduct semi-structured telephone interviews, which were held a few weeks after the education sessions, in order to help provide an in-depth exploration of the issues. These provided first-hand feedback on potential behavioural changes although it could be argued that the interviewees could have been saying what they thought staff wanted to hear.

Feedback from the telephone interviews was very positive. Interviewees reported they were beginning to understand their PPDN. The comments received included

the following.

'It actually helps by realising you're not the only one, you know that you're not solo in this.'

'You always hear something you've never heard before from somebody else – that's interesting, you know.'

'You hear about the different drugs people take and the different effects and stuff like that.'

'People should be given the answers they need sooner, not just a tablet with no real explanation; people ought to be told about this condition when they are told they have diabetes, to help prepare themselves if it happens.'

Furthermore, this understanding seemed to result in changes in foot care behaviour – a couple of examples include the following.

'Every night I spend half an hour checking them [feet] and everything.'

'Yeah, I mean, I try and wear shoes now wherever I go, slippers round the house and that.'

The telephone interviews were extremely helpful and will be used for future reviews.

Future development plans

Although at present these groups are run by a DSN, there is no reason why a podiatrist or foot health technician cannot be trained to facilitate future groups. The group sessions also offer an education service to those new to diabetes care in learning about this condition. All relevant healthcare professionals are invited to attend these sessions for their own learning and development. From this, areas of future need were identified for PPDN management, including increased education of healthcare professionals and increased availability of information for patients. The lead author's diabetes centre is currently developing district-wide management pathways for the care of people with PPDN.

Conclusion

People with PPDN often develop their

own management and treatment plans which assist in the acceptance of the condition by having set goals and action plans to alleviate their pain and minimise their foot health risks. If healthcare professionals can target education regarding foot care and foot wear, and offer support in the treatment of PPDN, then maybe they can have a greater impact on patient quality of life and reduce the likelihood of the development of future problems, including limb amputation. ■

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