

Diabetic Neuropathy: Patients' Experiences and Perceptions: A Qualitative Study in Type 2 Diabetics

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Received: 07-Sep-2022, Manuscript No. jdm-22-19206; **Editor assigned:** 09-Sep-2022, PreQC No: jdm-22-19206(PQ); **Reviewed:** 23-Sep-2022, QC No. jdm-22-19206; **Revised:** 27-Sep-2022, Manuscript No. jdm-22-19206(R); **Published:** 04-Oct-2022, DOI: 10.35248/2155-6156.1000955

Abstract

Background: Diabetic neuropathy is a serious complication of diabetes mellitus, it is a result from micro vascular injury that involves small blood vessels supplying the nerves (Vasa Vasorum), while the prevalence of diabetes mellitus is increasing globally, it is will be accompanied with increase in the rates of diabetic neuropathy and its sequelae.

Objectives: To elucidate the experiences and perceptions of diabetic patients with neuropathic pain and their priorities and strategies to cope with this pain.

Design: It is qualitative study design using face to face interviews; the collected data were analyzed using inductive thematic analysis.

Participants: The study included 21 diabetic patients with complaint with diabetic neuropathy.

Results: 4 themes were emerged from the data obtained from the patients' interviews, hearing from diabetic patients seeking help and advice, approach to management, patients' perspectives and perceptions about physical activity and psychological coping strategies and patients' fear from future complications.

Conclusion: the majority of patients expressed difficulties in their daily activities and sleep, some have found treatment is beneficial and others reported no effect of treatment, some of patients were coping with pain by their own strategies, some reputed their need to psychological consultation and others see no benefits from psychological interventions.

Keywords: Diabetic neuropathy; Pain management; Qualitative studies; Type 2 diabetes mellitus

Introduction

Diabetic neuropathy is a frequent complication of type 1 and type 2 diabetes mellitus, this complication is thought to be a micro vascular injury that involves the small blood vessels that supply the human nerves (Vasa

vasorum), in addition to macro vascular complication that can culminate diabetic neuropathy [1]. upon examination of many patients with diabetes mellitus, they have signs of diabetic neuropathy such as reduced nerve conduction velocity, but there are no symptoms. If the proper clinical tests are not performed and the diabetic patient is still asymptomatic, diagnosis of neuropathy may be delayed for many years until the patients begins to experience of symptoms such as neuropathic pain, loss of sensations, paresthesia and in advanced cases foot ulceration ,gangrene and amputation. The most risk factors associated with diabetic neuropathy in type 2 diabetes mellitus are progressing in age, duration of diabetes mellitus and poor glycaemia control [2].

In Kuwait the incidence of diabetes in adult population is one of the top five countries in the world 18% of the total population as 424 000 persons were diagnosed as diabetic patients in 2019 and the number is in great progress in the last decade [3]. The prevalence of diabetic neuropathy in diabetic patients ranges from 30-66% in Western counties where in Kuwait, the prevalence of neuropathic pain in 2010 39% in diabetic patients [4]. Diabetic peripheral neuropathy (DPNP) affects the physical function of patients, levels of independence, quality of life and psycho-social well-being of affected persons [5].

DPNP is complicated by depressive symptoms in those patients, resulting from continues neuropathic pain that may be not managed by drugs, affection of the social life of patients, fear of patients about their future with this pain and its progress and patients decreased productivity in their work, so that they may be terminated from their work or early retirement due to this neuropathic pain [6, 7].

Patients and methods

This is an interview study designated to recruit people with confirmed DPNP in diabetes clinic in Farwanyiah hospital-Kuwait. The interview aimed to understand and describe the experiences of patients with DPNP in patients with type 2 diabetes mellitus

Data collection

Interviews took place in diabetes clinic in Farwaniya, each interview started by establishing informed consent, and the patients were allowed to give detailed descriptions of their experiences about this neuropathic pain that during the interview that was lasting 30-45 minutes. Questions are related to their experiences in this period and previous phase also. The interviews mainly were comprised of open questions to encourage patients to tell in details about their stories.

Data analysis

An inductive approach using a constant comparative methods .The data obtained through formed questions ere independently analyzed by a researcher using six-stage thematic approach designed by Braun and Clarke [8].

Patients and methods

This study was conducted between January 2022 and April 2022 in the diabetes mellitus clinic in Farwaniya hospital-Kuwait, the co-researcher who is specialist in diabetes mellitus has assessed and confirmed the diagnosis of DPNP and has given a discussion about the process and objective of this study.

Selection Criteria

- Adult patients with diabetes mellitus who are 18 years and older
- Has been diagnosed and confirmed as a case of DPNP, with at least a 6 months history of DPNP with symptoms of neuropathic pain and diagnosed as having diabetes mellitus since 1 year at least.
- Both hands and feet of the patients have neuropathic pain
- Patients may have difficulties in walking

Exclusion criteria

- History of severe psychiatric problems as Schizophrenia, psychotic disorders and bipolar disorder within the past 6 months or they have a recent episode of major depressive disorders
- A recent history of gangrene and amputation operation
- Diabetic patients who have diabetic foot ulcers
- Presence of symptoms of neuropathy related to other caused than diabetes mellitus

Data collection

Data were collected through face-to-face in the diabetes clinic, and the principal investigator asked 21 diabetic patients with type 2 diabetes mellitus with open questions about their experiences and perceptions about DPNP and the interviews were recorded with a voice recorder as patients have given their permission to use this procedure. Patients with DPMP were interviewed through the questionnaire sheet that contains questions about the socio demographic characteristics as age, gender, educational level, employment and marital status and five questions about description of the disease DPNP, nature of neuropathic pain, its site, duration of complaint and treatment given to alleviate pain. The interview conducted focusing on the experiences of diabetic patients about their feelings, affection of their social life, effects about their family and relatives, psychological aspects, this was conducted through nondirective questions could you explain what do you feel about this pain? What do you mean by this word? Could you say more about that? The interview was lasting from 30-45 minutes.

The interview began with request and initial invitation to the diabetic patients to tell their own story of their illness from the start to the present time, during the interview the responses and answers of diabetic patients to stimulate and encourage them for further explorations of the symptoms of neuropathic pain [9].

Aim of the work

The main objective was to obtain stories about the life of diabetic patients with PDPN, after 21 interviews data saturation was reached and then we go to the stage of data analysis.

Data analysis

The transcribed text was imported NVivo (NVivo 11 for Mac, QSR International) for management and analyzed using inductive thematic analysis approach [8].

Results

Sample socio-demographic characteristics:

We selected 21 diabetic patients who were attending the diabetes clinic diagnosed with neuropathic pain. (Table 1)

Thematic analysis

Theme 1: Neuropathic pain hearing from diabetic patients

Participants spoke about the challenge of living with PDN from two perspectives. They described the personal experience of PDN. When I went outdoors to buy something and do shopping with my children, the neuropathic starts as numbness and tingling and becomes terrible, I cannot tolerate. The pain involved my legs and feet, I stopped waking and this was the end of shopping and return back to home by my car (Halimah Participant 4) "I went to the general GP and said look I've got these burning, burning in my feet and he just said it'll be neuropathy..." Mohammed Participant 3. Others described

Table 1: Sample characteristics were presented in table (1).

Characteristics	Number
Participants	21
Gender	
Females	10
Males	11
Age years	
Mean±SD	50±12.8
Marital status	
Married	17
Single	2
Divorced	2
Duration of diabetes	15.8±8.7
Duration of PDN	10.5±8.3 years
Employment	
Retired	15
Full time	2
Part time	4
Current treatment	
For DPNP	
Yes	16
No	5

many consultations and test procedures over several years before a diagnosis was established and treatment initiated. "I believe the nerve damage that I have got has been caused because I had it for such a long time before my GP referred me to [secondary care specialist]." Latifah participant 11, Participants had a variety of experiences of clinical consultations. Some described being moved through clinic appointments, without feeling involved in the process: When describing their experience of clinical consultations participants described feeling that clinicians had set formats to their consultation that did not often include enquiry about pain.

"when I talk to doctor he asks me about how your kidneys are?, how your liver is?, how your blood is?, how your eyesight is?, you know, all these different categories, your blood sugars, your blood pressure, your cholesterol, your fine, goes through the whole, but there doesn't seem to be any, anything automatic for nerve pain." Eisa 13. Closely linked to this issue, was the feeling of not being heard by the clinician, even when they were able to talk about the problems they experienced related to PDN. "So you almost in a way give up and think nobody is listening to me I'll just be quiet I'll just almost shut up." Hamidah participant 5. When I was working in my home for cleaning purposes, I may stand for some time to get rest and continue my work, when I stand I feel jabbing pain so I complete my work and task by sitting, I am also cooking in the kitchen on sitting position (Nabilah Participant 5) The lack of being heard created a sense their problems were being dismissed or they were in the wrong place to raise them. Other participants however, described their problems were heard and acknowledged, and then some form of treatment was forthcoming. "He said there are tablets out there you know and he was really the first person I thought 'no, he's listened to me', he sounds like he understands how disabling it's become for me" Said 20. "The pain management people came up and they were very good, they listened to everything and they prescribed all the tablets." Barbara, Mona 17 these descriptions suggest that getting clinicians in the health service to attend to and understand the nature of the persons' problems could present a challenge. Patients described feeling disempowered from raising the key issues they wanted to discuss with clinicians.

Theme 2: Forming treatment plans

This theme contained two subthemes: Delays in Treatment and Starting treatment. Delays in Treatment (- participants described the process of reaching some form of treatment for PDN, this journey may have been delayed by clinical inertia or lack of diagnostic certainty. Starting treatment once treatment was started this was usually the prescription of medication, and advice to focus on overall diabetes management.

Subtheme: Delays in treatment Participants had experienced delays both in diagnosis or, once the diagnosis was confirmed, delays to starting any form

of treatment. For some this was due to seeing different GPs in primary care, which they reported had led to a lack of coordinated care planning. For others, they had no real explanation for why these delays occurred. "There was a big period of time between first it occurring and actually getting somebody to deal, properly deal with it." Salma 1. "We're talking from seven years from having the symptoms to only about three years ago, so it took a good four years to get to the point where actually some treatment was started and then it took another two years no three years to get to the point of seeing a professor that was interested in diabetic painful neuropath and diagnosed my case (Safawat 1).

I cannot walk properly and I want to practice exercise to adjust my blood glucose levels but when I start prickling sensations in my feet and I stop walking (Hamed 3) "when I go to bed for sleep ,I wake up after 2 hours from neuropathic pain ,it jabbing pain, I hurry up to get my medicine (pain killers and analgesic cream),many nights my sleep is disturbed when I got my medicine I feel well (Saber 5).

Theme 3: Managing the experience of PDN

This includes all the strategies of participants explored to reduce pain experience of Painful Diabetic Neuropathy (PDN) as PDN were often described by participants as burning sensation so the application of cold to affected body part was a common approach .also participants found that short-term benefits from tropical application of menthol gel ,cold water baths or cold fomentations and drafts across the feet: I had to have the fan on my feet all the night for blowing cold .cool air on my feet to feel relief of pain(Kareem2) Some participants have tried warm water baths or hot water bottles. Again ,they found benefits were of short duration I have do hot fomentation to my feet ,but you cannot put your feet in warm water for 8 hours per day .if pain is severe this hot drafts are useless (Ahmed 4) Getting some rest may be so difficult PDN is often associated with affection of the quality of sleep and rest this consequently led to tiredness and reduced concentrations When the night time approach ,I feel afraid when I lying down ,as pain may disturb my sleeping ,which make me more sad and have a big impact on my life (Sakinah 5).

Theme 4: Fear from future complications

The majority of participants have expressed their fear about the future complications after the incidence of DPN like development of foot ulcers or chronic kidney disease or to perform their daily work I am afraid of future about other complications of diabetes and I have diabetes more than 22 years, so I may get problems with my kidney after I got DPN (Jamal 6)

Most of participants were worried and uncomfortable with the different symptoms DPN like affections of sleep so that most of participants may take tablets for sleeping and avoid caffeine and some get relaxation to pass the difficult days or develop new strategies to overcome anxiety developing from getting PDN I concentrate to take deep breathing many times and this takes my mind off other things that are happening in my body like the terrible neuropathic pain (Samir 7).

Patients' perceptions about management of neuropathic pain

Perspectives of physical activity

The majority of the study expressed their fair and anxiety of falling down on the ground while walking due to pain ,and numbness in their feet Some of those patients were using wheel -chairs and some refused these aids as it is a sign of disability "I miss using my feet to walk on the shore of the sea ,because I always to use wheel-chair ,but sometimes I try to walk but I cannot ,I am sad about that" (Rahmah 19) Most of the diabetic patients and were concerned about their physical fitness, and described simple exercises to preserve their physical health. The purpose of these exercises to maintain the fitness .strength of their muscles ,and increase the ability to stand "I am always trying to some exercises of my feet ,try to keep my muscles strong ,but I am doubt about that, I am not sure about their benefits for me but I should continue to do them, I do not know what else I can do(Salem 7)".

Perspectives on psychological coping strategies

The majority of the included diabetic patients in the study expressed their sadness about they did not find adequate psychological support of any health professionals "I suffer from pain every day, it is disturbing pain, I cannot see

any one to help me to relieve this pain, I had it for 4 years and I am coping with it with the way I can(Hani 8) Some of diabetic patients expressed about their feeling of depression and change in their mood due to this neuropathic pain "I think I should get medicine to improve my mood that will help me to cope with this pain and improve my activity in the life(Sameh 9)

Some of diabetic patients have stated that life stresses are aggravating their condition on glycemic control and the severity of pain, and the patients are able to talk about attitudes of family members towards them esp. partners as they were the best ones to listen and understanding about this terrible pain. Other patients did not want to be a burden on their partner's. Some of them described the potential benefits in talking with others who have the same problem PDN "no one understand my complaint about my pain ,which is burning in my back and legs ,however I tried to know another person with diabetes suffering from neuropathy as we have the same complaint so that we can help each other". On the other hand ,the idea of nerve damage was very clear in many patients and their mood was not affected at all and could not see any benefit from any psychological consultation or interventions this will not help them to get rid if this pain.

Discussion

The main findings in the present study were the daily experiences of diabetic patients with the terrible diabetic neuropathy, numbness and tingling most of them described the neuropathic pain as tingling and numbness in their feet, hands and toes with limited physical activity an mobility, they expressed their fear about their future and development of nephropathy ,heart disease or amputation.

Diabetic patients expressed their coping mechanisms to deal with this pain, like increasing physical activity and using emotional strategies to adapt and accept this pain. Bennet et al. 2007 [9], identified significant restrictions in movement and physical activity of old patients .Also these findings were reported in the study of Bord et al. 2015 [10], where the diabetic patients with type 2 diabetes mellitus talked deeply about this painful neuropathic pain and their experiences about it but they expressed few strategies and proposals to cope with this pain. Also may studies have reported that there was a limitation in mobility and physical activity and discomfort [11, 12].

The participants in this study expressed that they face 2 big problems continuous awareness of their glycaemia control and the management of their neuropathic pain, and moreover they reflected about the anxiety and fear from progression to more diabetes complications like hypoglycemia and so they demonstrated their distress in how to manage DPN symptoms, also the slow progression of DPN could contribute to the feeling that they are about losing control of their lives.

The participants in this study expressed their great need to know more knowledge about this DPN, causes and how to treat such condition this was described by Hansen et al. 2012 [13], where the included diabetic patients in this study declared lack of knowledge about the increased risk of symptoms related to peripheral neuropathic pain and the bad side effects of immunosuppressant drugs after organ transplantation, these results coincide with the complaint of our participants as they have a shortage of knowledge about the most common complications of diabetes and even no appropriate diagnosis of DPN by the treating doctor [14].

On the other hand, adults living with type 1 diabetes mellitus are fully aware of this illness and are successful in managing these symptoms and they consider it as a minor burden compared with difficult management of their glycemic control [15].

In our study, the informants have expressed fear of developing another complications of diabetes mellitus, this finding is also encountered in a study included adults with type 1 diabetes mellitus [16].On the other hand the potential development of foot ulcers was not considered as a serious complication of diabetes mellitus, most of patients considered kidney failure and amputation as additional complications of DM.

This study demonstrated strategies of diabetic patients to cope with this terrible pain like putting cold and hot packs on their feet ,some of them practiced physical exercise to alleviate pain. Medication strategies to treat neuropathic pain are of clinical challenge with common side effects of analgesics and may

be some times are not effective to relief pain. I was reported that there is general skepticism of diabetic patients towards the internet advice about the disease and how to control. Many approaches to evaluate the value of internet in health advices to patients have been published [17], however the critical appraisal and evaluation may not be an important issue for diabetic patients suffering from neuropathic pain in our study.

Some participants showed beneficial effect of physical activity on their pain however van Laake-Geelen et al.2019 [18], have reported that physical activity did not improve the quality of life and its secondary outcomes in diabetic neuropathic pain. However physical activity has its beneficial effects on other long term diseases like oncology, spinal cord injury, fibromyalgia and spondyloarthropathy [19, 20].

Conclusion

Diabetic patients explained their experiences and feelings about their neuropathic pain in the form of tingling ,numbness , stabbing or jolt and reported their own strategies to cope with this pain either by physical activity or drugs, it was apparent that there is a shortage of knowledge about DPN .So it is important to improve the knowledge of patients about diabetes neuropathy and its serious sequelae and it is advisable to open a dialogue between diabetic patients in one side and doctors and nurses in the other side to express their feelings and their own experiences and discuss strategies to cope with this neuropathic pain.

Future research

As we reported wide range of the impact of DPN on daily activities, so that it's important to adopt new strategies in pain management and psychological approaches to mitigate these impact ,so it is advisable to use the clinical model used by the evidence base for Acceptance and Commitment Therapy (ACT) that would appear an offer of reducing the psychological burden of the disease.

Conflict of Interest

The Professor Dr Ibrahim El Bayoumy has no conflict of interest to declare.

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