An exploration of patients' experiences, coping strategies and management of peripheral neuropathy in Kuwait

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Dedication

I dedicate this academic venture to my parents, Ibrahim and Badriyah, who have always been the fuel in my pursuit of personal and academic development. I am indebted to them for their limitless patience, endless guidance, prayers, and above all their true love. I also dedicate this thesis to my supervisors - Kath Ryan, Amelia Hollywood, and Becky Green - who have provided me with the necessary support, education, and academic guidance during the entire period of my PhD journey. To my lovely children - Aisha, Ahmed, Ibrahim, and Abdullah - who always bring a smile to my face. Finally, I dedicate this to my colleague, Hamad Alhasan, for his never-ending motivation and support throughout my PhD journey.

Abstract

Background: Peripheral neuropathy is a neurological disorder characterised by pain, numbness, or tingling due to nerve damage. It can be caused by a number of conditions, including vitamin deficiency, immune system diseases, viral infections and diabetes. Peripheral neuropathy is one of the main health issues in Kuwait, which affects a large proportion of people therefore their treatment journey needs to be explored.

Aim: The thesis aims to explore the experiences of people living with peripheral neuropathy. The systematic review study aimed to explore the experiences of people living with peripheral neuropathy by carrying out qualitative research on the existing literature. The aim of the process map study was to examine the patient journey of people living with peripheral neuropathy in Kuwait. Finally, the interview study aimed to explore the experiences of people living with peripheral neuropathy in Kuwait concerning both coping and management strategies.

Methodology: The methodology of this study was based on foundational elements of sociological research: the epistemological means employed was theoretical constructionism, and hence the methodology selected was phenomenology, the theoretical perspective governing which was based on interpretivism. Constructionism was chosen as it describes the knowledge gained or "constructed" through individual perceptions and social awareness which was very relevant to the perceptions of people living with peripheral neuropathy. Phenomenology was selected as the qualitative approach because it highlights the essence of individual experiences, which is the main focus of the present study. Interpretivism, an approach that seeks to define meanings for each situation was apt as this thesis was culturally derived from residents of Kuwait living with peripheral neuropathy.

Methods: The thesis consisted of three studies exploring people's experience living with peripheral neuropathy. The first study was a systematic review which involved searching through three electronic databases for qualitative studies exploring the experiences of people living with peripheral neuropathy. The quality of studies was appraised using the Critical Appraisal Skills Programme (CASP), and then thematic synthesis was conducted to identify themes in the findings. The second study was a process map study. The study involved the participation of 25 individuals living with peripheral neuropathy in an exploratory study in Kuwait using semi-structured interviews that were approximately 45min to an hour in duration. Following the completion of the interviews, all were transcribed, translated into English and coded using NVivo 12 software. Four of the 25 patient journeys were comprehensively mapped out, and the four journeys were then compared and condensed into a single process map. Finally, the remaining 21 interviews were also reviewed against the single process map to ensure the final map signified all patient journeys and helped to discover various themes in the data. The final study involved the use of the same dataset included in the process map study and generated from the semi-structured interviews with the 25 participants selected from a Kuwaiti neurology hospital. The data was used to gain an in-depth insight into the experiences of people living with peripheral neuropathy in Kuwait. The transcripts were analysed using thematic analysis to identify themes and subthemes.

Results: For the first study in the thesis, twenty-three studies were selected for the systematic literature review. Qualitative methods were employed for each study and included the use of focus groups and interviews. The use of qualitative methods allowed the examination of the various experiences of individuals living with peripheral neuropathy. Moreover, all of the 23 studies were assessed for the quality of their data. The main themes identified were: is the body sick or the mind; the relationship between the patient and the healthcare professional; and positive aspects of living with peripheral neuropathy "Is the body sick or the mind?" and "the relationship between the patient and the healthcare professional" were the first two themes, which supported previous themes reported in the literature. The final theme; positive aspects of peripheral neuropathy, emerged as a new theme following the systematic analysis of the data collated in the thesis. The second study which generated the process map found that individual patients reported similar healthcare pathways and faced numerous difficulties concerning their condition. These difficulties included lack of psychological support, administrative issues and inadequate medical care. The process map identified similarities between Kuwait and the UK regarding the pharmacological treatment of the condition, with the exception of the availability of some medications. The final study in the thesis identified three major themes from interviews with people living with peripheral neuropathy in Kuwait. The themes identified included: treatment beliefs such as the efficacy of treatments and searching for alternate treatments. Additional themes also covered barriers to the management of pain, such as side effects of the medication, the individual’s relationship with healthcare professionals and lack of information and access to healthcare. The third theme was the impact on the quality of life, which refers to the effect it, has on an individual’s work, their social standing, psychological consequences and physical consequences.

Conclusion: The first study was a systematic review, which highlighted a connection between the body and mind, which has an impact on people’s lives, along with the potential positive aspects that emerge. There is a need for healthcare professionals to support people living with peripheral neuropathy to improve their quality of life. Such support could include encouraging self-management as well as pharmacological treatment. For the second study in the thesis, the process map study was conceived and conducted to understand the healthcare journey of people living with peripheral neuropathy in Kuwait, as this was identified as a gap in the literature. The process map highlighted a need for an integrated referral approach, the use of technology for electronic medical recording and report transmission, alongside education on self-management, coping mechanisms and treatment options for people living with peripheral neuropathy. Since the process map identified that the patient journey of people living with peripheral neuropathy in Kuwait was different to that in Western countries, there was a need to explore the patient experience in this cultural context and tailor recommendations relevant to Kuwait. The final study was identified treatment beliefs, barriers to pain management and the impact on the quality of life as necessary to people living with peripheral neuropathy in Kuwait. To improve quality of life; information and support on the condition to promote coping strategies should be adopted. Overall, the thesis concluded that there is scope to improve the current management of peripheral neuropathy in Kuwait, with a focus on patient-centred care.

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Declaration

I, Maryam AL-Kandari, certify that:

This is my own work and the use of all material from other sources has been acknowledged.

This thesis has not been submitted, either in full or in part, for the award of any other degree in my name, at this University or any other institution.

This thesis contains published work and work prepared for publication, contributed by other co-authors.

Signature: [Maryam Ibrahim AL-Kandari]
Date: November 2019

Publications & Presentations

Publications

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Presentations

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Ethical Approval

Ethical approval, sought before commencing work on this thesis, was obtained from the following committees:

- University of Reading Ethics Committee (UREC – 16/46).
- Standing Committee for Health and Medical Research Coordination in the Ministry of Health in Kuwait (Ref no: 194/2014)**.**

See Appendices 1and 2 for approval letters.

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Abbreviations

IASP	International Association for the Study of Pain
NICE	National Institute for Health and Care Excellence
FDA	Food and Drug Administration
WHO	World Health Organization
EMR	Electronic Medical Records
CASP	Critical Appraisal Skills Programme
ENTREQ	ENhancing Transparency in REporting the synthesis of Qualitative research checklist
NHP	Nottingham Health Profile
ACP	The American College of Physicians'
QoL	Quality of Life
DN4	Douleur Neuropathique 4
PDQ	Pain DETECT
NPQ	Neuropathic Pain Questionnaire
EMG	Electromyography
NCV	Nerve Conduction Study
QST	Quantitative Sensory Testing
CT	Computerised Tomography
MRI	Magnetic Resonance Imaging
NeuPSIG	Neuropathic Pain SIG
BMI	Body Mass Index
ACPA	American Chronic Pain Association
NHANES	National Health and Nutrition Examination Survey
MOH	Ministry of Health – Kuwait
GPRD	General Practice Research Database
MNSI	Michigan Neuropathy Screening Instrument
NINDS	National Institute of Neurological Disorders and Stroke

GBS	Guillain-Barré syndrome
US	United States
UK	United Kingdom
ISH	Ibn Sina Hospital
PNP	Peripheral Neuropathic Pain
PN	Peripheral Neuropathy
UREC	University of Reading Ethics Committee
REC	Research Ethics Committee
GP	General Practitioner
NP	Neuropathic pain
PDPN	Painful Diabetic Neuropathy
NHS	National Health Service
BPS	British Psychological Society
PIS	Patient Information Sheet

CHAPTER ONE

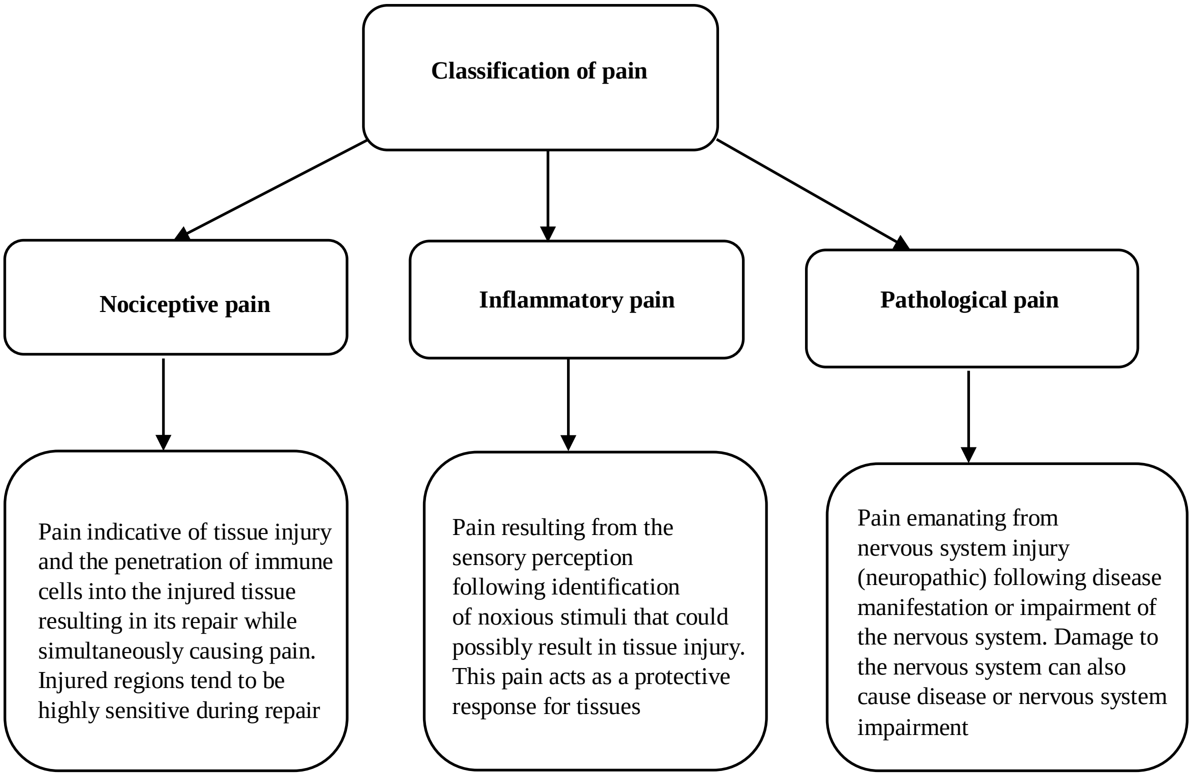
1 Introduction

Neuropathic pain (NP) and peripheral neuropathy (PN) are topics that have been widely discussed in the literature. This chapter will provide a background of pain in general, followed by a background on neuropathic pain. The chapter will also discuss neuropathic pain's aetiology, diagnostics and means of management that are currently available for the condition. Peripheral neuropathy's distribution, variation and prevalence in Western nations and Kuwait will be discussed. Different aspects of peripheral neuropathy will be discussed, including the symptoms, causes, associated factors, prognosis, psychological impact and treatments, as well as pharmacological and non-pharmacological management options for people living with the condition. Previous studies exploring peripheral neuropathy through the patients' experiences will be highlighted, thereby, revealing the critical impact of this condition on their lives. The present study is unprecedented in investigating peripheral neuropathy through the experiences of patients living with the condition, specifically in Kuwait. The research questions, the aims of the research, the individual objectives and the significance of this research study will be presented in this chapter.

The research presented here is an assessment of the patients' experiences and coping strategies. It is also an assessment of how individuals living with peripheral neuropathy are managed in Kuwait. This study also explores perceptions within Kuwait of the use of international guidelines for the treatment of the condition. Consideration is given for whether the implementation of these recognised guidelines would improve Kuwait's existing treatment regime for peripheral neuropathy. There is a need to shed light on the nature and treatment of this pain to enhance understanding of the neuropathic pain experienced by individuals living with peripheral neuropathy Accordingly, for this study this will be carried out in the context of the development and the use of medication for the condition in Kuwait.

1.1 General definition of pain

The term pain is described as a localised or generalised uncomfortable bodily sensation or group of sensations and an emotional experience that may be associated with the potential of actual injury of the body tissue (Vadivelu, Urman, & Hines, 2011). Pain can be categorised into three types (Woolf, 2010). Generally, *nociceptive* pain tends to be associated with the recognition of a stimulus that could be a threat for tissues, and thus, is protective in nature. *Inflammatory* pain is linked to tissue damage. *Pathological* pain is the state of disease in which damage has been done to the nervous system and has resulted in a dysfunctional pain system. Figure 1 provides an outline of each group.



Pain indicative of tissue injury and the penetration of immune cells into the injured tissue resulting in its repair while simultaneously causing pain. Injured regions tend to be highly sensitive during repair

Pain resulting from the sensory perception following identification of noxious stimuli that could possibly result in tissue injury. This pain acts as a protective response for tissues

Pain emanating from nervous system injury (neuropathic) following disease manifestation or impairment of the nervous system. Damage to the nervous system can also cause disease or nervous system impairment

Figure 1. Illustration of pain classification (Woolf, 2010).

The traditional concept of pain, thought to have been initially defined by Descartes, was initially described as the result of tissue damage in the periphery (Baliki & Apkarian, 2015). However, recent studies have confirmed that clinical pain is only very loosely linked to peripheral tissue damage. Today, clinical pain is considered a problem that threatens the overall functioning of an individual, rather than being confined to a specific part of the body.

There are four primary theories of pain. First is the specificity theory which is founded on the development of the perception of pain through the transmission of stimuli from specific pain receptors to the brain's pain centre, resulting in the ultimate perception of this pain. Essentially, "*each somatosensory modality has a specific receptor and associated sensory fibre that is sensitive to one specific stimulus*" (Moayedi & Davis, 2013). Historically, it is clear the theory is derived from the previous perception of pain as emanating from a particular physical position on an individual's body or the surrounding area. Thus, treatment of pain tended to be addressed through surgery and amputation as a means of fixing the damaged nerves of the periphery. Since then, the focus has been on the role of the brain and the central nervous system (CNS), and this gave birth to the 'specificity theory'. Descartes considered pain as a brain perception, differentiating between pain and nociception and describing how pulling nerve fibres results in a sensation. Moreover, Descartes (as detailed by Moayedi & Davis, 2013) considered the pain to be the result of a fibre breaking after experiencing significant pulling tension. Thus, the majority of medical concepts were governed by the specificity theory, with pain thought of as a straight path travelling from the peripheral nerves to the brain. It was not until well into the 19th century that the role of the central nervous system was considered.

Second, the intensity of pain which is described as an emotional response to a stimulus, one that is more powerful than normal. In the fourth century, Plato (1998) was the first to note that pain had a degree of intensivity. Plato did not consider the experience to involve senses. "Sensory spots" was a term used by Goldschieder in the 1890s. The term described how particular skin regions were sensitive to different sensations e.g. pressures, hot, cold, or even pain. They were the first to describe the involvement of the spinal column (the dorsal horn region) in receiving stimuli from the peripheral nerves. They established that the intensity of pain was the result of too much (not a single) stimulation. Thus, the greater the degree of pain, the more intense the pain experienced. Therefore, it was the intensity theory that directed medical personnel to considering the central nervous system and not simply treating the peripheral nerves. By coining the term ‘nociceptor’, Charles Sherrington combined the specificity and intensity theories, stating that “ *the main function of the receptor is to lower excitability threshold of the reflex arc for one kind of stimulus and heighten all others*” (Moayedi & Davis, 2013).

Third, the pattern theory, which is founded on the brain receiving various pain signals that are combined, resulting in a specific pattern or combination of the pain. Here the brain is a site for receiving and combining signals and not a site for managing the perception of pain. Thus, this was described by Melzack and Wall (1965) as the nerve impulse pattern for pain which is produced by intense stimulation of nonspecific receptors since “there are no specific fibres and no specific endings.” Moayedi and Davis (2013) thus stated that, “*any somaesthetic sensation occurred by a specific and particular pattern of neural firing and that the spatial and temporal profile of firing of the peripheral nerves encoded the stimulus type and intensity*”.

Finally, there is the gate control theory of pain. The beliefs held about pain, and the experience of pain is complex, being managed by several factors including physical, emotional and psychological. This led to the gate control theory, which allows comprehension of the pain experienced by considering changes impacting the body. The term ‘gate’ refers to points on the spinal cord where stimuli are received from any site on the body, thus indicating that the spinal cord is the initial point where the various paths of the nervous system meet. The significant changes to our thoughts on pain occurred in 1965. It was that year when Melzack and Wall (1965) challenged our perceptions of pain by hypothesising that the transmission of pain from the peripheral nerves to the central nervous system was modifiable and that this was governed by intrinsic neurones and by the brain controlling this pain perception. Melzack and Wall (1965) extended the theory by including the variations in pain caused by the different afferents, by times of central excitability and changes to both these processes following nerve injury. Thus, gate control was no longer considered simply a measure of excitability; instead, it was delicately controlled. They also introduced the concept of pain signal modulation, depending on the particular situation and actioned through afferent nerves that can be turned on and off. A description of the gate control theory and its association with people living with peripheral neuropathy is provided. As previously mentioned, the gate control theory indicates that one’s pain experience is associated with ‘the gate’s’ condition. Here, Melzack theorises that particular factors lead to the opening of the gate. The physical factors include stimulation or damage of large fibres, whereas, the emotional factors include depression, tension, anxiety or fear. Boredom or concentrating on the pain is behavioural factors. Equally, certain factors also close the gate. The physical factors include stimulation of small fibres and drugs, whereas, the emotional factors include feeling happy, relaxed or optimistic. Distraction from the pain and concentration are behavioural factors. Thus, this proposes that how open the gates are is controlled by our thoughts, our feelings and what we are doing.

1.2 Neuropathic pain

One definition of pain describes it as an uncomfortable and localised body sensation. Other definitions describe the generalisability of pain such as that experienced through fibromyalgia, or a complex uncomfortable sensation targeting a regional area of the body. The majority of definitions describe it as associated with tissue injury or as a sharp sensation (‘piercing’, ‘fiery’, ‘twisting’, ‘wrenching’, ‘pressing’), or as an emotional or physical response (‘scary’, ‘queasy’, ‘stomach-turning’) (Belmote & Cevero, 1996). In 1994, the IASP or the International Association for the Study of Pain, defined pain as *“initiated or caused by a primary lesion or dysfunction in the nervous system”* (Merskey & Bogduk, 1997).

Recent researchers have highlighted the ambiguity and lack of precision in this definition that is required to describe such a challenging condition. Since that time, the IASP has renewed the way it defines neuropathic pain to that which is “caused by a lesion or disease of the somatosensory nervous system” (IASP, 2011). While this definition does offer a greater degree of precision, it does not provide healthcare professionals with clinically relevant guidance likely to be helpful in diagnosis. Nevertheless, the IASP has acknowledged that all pains derived from the impairment of the central nervous system, the peripheral nervous system or from injury to these regions, and causing damage to the path of impulse transmission, as neuropathic pain. These characteristics sadly make neuropathic pain an irreversible and long-term condition in many individuals (IASP, 2011). Table 1. Shows the definition of neuropathic types.

Table 1. Types of neuropathic pain.

Type of pain	Definition
Central neuropathic pain	**Location:** Damage to the central regions (spinal cord, brain and brainstem) of the somatosensory nervous system **Cause:** Spinal cord injury, multiple sclerosis or stroke (referred to as central post stroke pain).
Peripheral neuropathic pain	**Location:** Damage to the peripheral (external) regions of the somatosensory nervous system. In such situations the peripheral nerves are damaged. **Cause:** Diabetic neuropathy, post-herpetic neuralgia infections/autoimmune conditions (Guillain-Barré syndrome), trauma (chronic low back pain and carpal tunnel syndrome)

The nociceptive system is presently noted to contribute to pain, as pain is considered a general outcome of nociception. Nociception, specifically, describes the programming and processing of harmful stimuli in the central nervous system. Their levels can be quantified using electrophysiological methods. This system involves the activation of nociceptors (C, Aδ and Aβ fibres) of the peripheral nerves by harmful stimuli. The endings of these sensory neurons are termed free nerve endings (Baliki & Apkarian, 2015). The majority of nociceptors respond to various modalities (polymodal). They would respond to chemical stimulants and harmful external stimulants such as hot or cold. Moreover, they would also respond to harmful mechanical stimulants, including tissue injury through a cut, or causing pain through pressing or squashing (Belmonte & Cevero, 1996).

Pain is a grave and enduring condition, no matter its cause or the form it takes. Estimations indicate that the condition is experienced by one percent to five percent of a population (Jongen *et al.*, 2014). As this condition can be managed but not completely cured, the majority of healthcare professionals focus on addressing the aetiology of pain, rather than the actual pain.

Neuropathic pain is diagnosed through a combination of techniques that include a neurological examination and a detailed medical history. Over the years, many effective questionnaires have been designed to distinguish neuropathic pain from other problems with similar symptoms, such as nociceptive pain. Example questionnaires include DN4 or the Douleur Neuropathique 4, NPQ, which stands for Neuropathic Pain Questionnaire and PDQ or Pain DETECT (PDQ). Although these can be used as tools for screening, they are insufficient for confirming a confirm diagnosis and have varying levels of predictability and specificity. Clinical neuropathic pain is identifiable from altered sensitivity of the patient's body, which causes short episodes of evoked pain. Allodynia, hyperalgesia and hypoalgesia are terms used to describe this condition depending on a person's specific response to stimuli that induce pain (Jongen *et al.*, 2014).

Another tool used in cases of pain is the sensory examination, which helps to establish the reliability of diagnosis (Mulla *et al.*, 2014). However, the success of this examination is highly dependent on the person's ability to cooperate. Other important tests to confirm the diagnosis include testing reflexes, muscular strength, coordination, and the ability to utilise basic skills. Poor test results and a suspicious medical history necessitate additional examinations prior to having the diagnosis confirmed. Examinations that could be conducted include computerised tomography (CT), electromyography (EMG), nerve conduction study (NCV), quantitative sensory testing (QST) and magnetic resonance imaging (MRI) (Cole, 2010).

Numerous guidelines were released throughout the past few decades on neuropathic pain treatments. Most of these treatments are the outcomes of evidence-based research. However, these guidelines tend to be adjusted by each country according to its particular needs, local practice, cultural preference, as well as drug and resource availability. In the present study, three treatment guidelines for neuropathic pain have been selected. The National Institute for Health and Care Excellence (NICE), the

National Health Service (NHS) and Neuropathic Pain SIG (NeuPSIG) has similar guidelines. According to Dworkin *et al*. (2010), Neuropathic Pain SIG (NeuPSIG) is one of the best sets of guidelines on the condition. This guideline originates from the International Association for the Study of Pain (IASP) and form a set of well-defined standards that are employed globally. As these standards were implemented by the Ibn Sina Hospital in Kuwait as part of their treatment of individuals living with peripheral neuropathy, therefore, this International Association for the Study of Pain standards were also chosen for this thesis. Neuropathic Pain SIG proposes that the first-line treatment for neuropathic pain should be anti-epileptic drugs, tricyclic antidepressants and serotonin–norepinephrine reuptake inhibitors, opioid analgesics such as tramadol are considered as suitable agents but are not recommended as first-line treatments. It should be noted that any of these treatments may be used as the first-, second-, or third-line treatments and that this should be determined by a person's history, their symptoms and their reaction to the medication.

Neuropathic pain continues to lack a gold standard treatment; one that is both highly efficacious and suitable for all patients. As a result, most researchers have advocated the use of a combination of medications (Chaparro *et al*., 2012). Most of the guidelines published on the treatment of neuropathic pain agree that the final management strategy for a patient experiencing neuropathic pain must be made with the underlying mechanisms, the patient's symptoms and their history in mind. This is extremely vital to ensuring the optimum patient outcome, to enhance the efficacy of treatment, and avoid unnecessary costs to the patient and healthcare service involved. This means that, in most cases, healthcare professionals will have to design a bespoke treatment plan for each patient, often adjusting it in light of trial and error (Jongen *et al*., 2014).

1.3 Peripheral neuropathy

1.3.1 Definition

Peripheral neuropathy or PN is one of the frequently diagnosed neurological conditions. It is often disturbing, disabling, and can even be fatal (NINDS, 2015). Peripheral neuropathy refers to pain affecting the peripheral nervous system caused by injury or disease. Several disorders are linked to peripheral neuropathy. These include post-herpetic neuralgia, AIDS, diabetic neuropathy ischaemic neuropathy and cranial neuralgias (e.g. trigeminal neuralgia) (NINDS, 2015). Moreover, peripheral neuropathy may also be from iatrogenic causes such as chemotherapy and limb amputation, or from infectious causes such as Guillain-Barré syndrome (GBS). Nerve trauma and entrapment, such as in cervical radiculopathy and carpal tunnel syndrome, can also cause peripheral neuropathy (NINDS, 2015).

A variety of symptoms are associated with peripheral neuropathy ranging from a dull pain in the feet to fragile or tingling sensations. It can also involve a numbing or penetrating pain that initiates in the feet or hands of an individual. This pain can be continuous, unprompted, induced or spasmodic. Neuropathic pain is not only a physical feeling of unease, but can also lead to emotional and mental distress, thereby adversely affecting one’s quality of life. An individual’s health and quality of life can be adversely impacted by a range of feelings such as worry, stress, tension and anxious feelings.

1.3.2 Causes of peripheral neuropathy

Peripheral neuropathy can be attributed to a range of disorders. The most notable of these is diabetes mellitus, where peripheral neuropathy arises as a consequence of hyperglycaemia and microangiopathy. Distal symmetric sensorimetric polyneuropathy is the form of peripheral neuropathy that is frequently diagnosed in diabetics (Martin *et al.*, 2014).

Approximately half of all individuals with diabetes experience peripheral neuropathy during their lifetime (Young *et al.*, 1993). One study performed in the USA; the San Luis Valley Diabetes Study, had estimated that 25.8% of patients with diabetes had peripheral neuropathy , compared to 11.2% of patients who had an impaired glucose tolerance, and 3.9% of the control group (Franklin *et al.*, 1990). Moreover, research performed on a Spanish cohort determined that 21% of people lived with diabetes in primary healthcare facilities compared to 27% of hospital inpatients who lived with diabetic peripheral neuropathy (Dyck *et al.*, 1993).

People with diabetic peripheral neuropathy can experience pain and discomfort in the lower extremities. In such cases, the patient's protective sensations also fail. These changes mean patients are more likely to live with foot ulcerations, and therefore, a poor quality of life (Wu *et al.*, 2015). Other common causes of peripheral neuropathy include alcoholism, post-herpetic neuralgia, AIDS, cranial neuralgia, acute inflammatory polyneuropathy, trauma, carpal tunnel syndrome, and chronic low back pain (NINDS, 2015). Nutritional causes include thiamine and vitamin B_{12} deficiency, while malignancies such as renal cell carcinoma and lymphoma can also cause peripheral neuropathy. Furthermore, peripheral neuropathy can also be the result of autoimmune disorders including rheumatoid arthritis and systemic lupus erythematosus (George & Twomemey, 1986).

Peripheral neuropathy from infections and inflammatory conditions can also occur. The most common infection that causes peripheral neuropathy is HIV, but it is also seen in patients infected with herpes simplex virus, hepatitis C, the cytomegalovirus, West Nile and Epstein-Barr virus and the rabies virus. Bacterial infections that cause peripheral neuropathies include *Borrellia burgdoferi*, diphtheria, *Campylobacter jejuni*, *Mycobacterium tuberculosis*, *Mycobacterium leprae, Brucella*, and *Clostridium botulinum* (Brizzi & Lyons, 2014).

Guillain-Barré syndrome (GBS) results from inflammatory causes of neuropathy and the most frequently diagnosed form of GBS is acute inflammatory demyelinating polyneuropathy. One disorder closely associated to GBS is Miller-Fisher syndrome

(MFS), a rare disorder that continues to acute motor axonal neuropathy. MFS causes ocular muscle palsies and ataxia, with one or two persons per 100,000 affected by it per annum (Sejvar *et al.*, 2011).

1.3.3 Factors associated with peripheral neuropathy

1.3.3.1 Pain

When diagnosing chronic pain, the most frequent clinical symptom is the feeling of pain. Chronic bodily pain is more likely to manifest as a result of severe, acute pain that is present in multiple sites (Talbot *et al.*, 1991). Efficacious management of this pain through treatments would result in the resolution of the neurological changes in the brain. Thus, this suggests that the prompt management of pain should be pursued, with added importance on preventative measures to avoid such pain (Ahmad & Abdul Aziz, 2014).

1.3.3.2 Mental health

Depression and anxiety are the mental disorders that are most commonly linked with chronic pain. Both conditions result from extremely adverse concepts and perceptions of pain. Clinical knowledge shows that this leads to poor prognosis in the control of chronic pain (Marazziti *et al.*, 2006).

There is a temporal association between health and the sensation of chronic pain. This relationship is still not fully understood. Gurej *et al.* (2008) described these causes of pain as a ‘bi-directional aetiology’. These results in one’s mental health being adversely affected and the opposite are also true. In patients with depressive illness, neuroimaging studies have revealed a dysfunction in regulation, with marked frontal lobe brain activity observed during experimental pain stimulation (Drevets, Price, & Furey, 2008).

Depression and anxiety are two elements that contribute to chronic pain, as they are linked to the reinforcement of chronic pain. These mental illnesses accentuate the perception of chronic pain. Trials that treat the depressive symptoms of such patients using only monotherapy will lead to less amenable improvements in the patient. Nevertheless, a doctor with exceptional skills will treat both the pain and the depressive symptoms together to improve their patient's outcomes (Gerrits *et al.*, 2012).

1.3.3.3 Multimorbidity

Several long-term conditions including cancer, ischaemic heart disease, asthma and diabetes mellitus are characterised by an increased presence of chronic pain. Such chronic pain not only increases the burden of the disease, but any associated co morbidities could lead to disability and failure to manage multiple conditions simultaneously. Severe chronic pain is also known to lead to disability and low levels of physical exercise. Chronic pain can therefore lead to a three-fold increase in the mortality of people living with chronic obstructive pulmonary disease or ischaemic heart disease (Booth, Roberts, & Laye, 2012).

The occurrence of chronic pain is more likely to occur as a result of numerous physical conditions. Consequently, these conditions could act directly by increasing the nociception of peripheral nerves, leading to peripheral or central pathophysiological changes, and finally to chronic pain (Booth *et al.*, 2012). Such conditions could also act indirectly through the long-term stimulation of systems for stress regulation. Therefore, these systems can result in bone, muscle or nervous tissue injury, subsequently resulting in further pain. Moreover, other co morbidities not linked to chronic pain, will most likely exacerbate the level of complaints from patients of chronic pain and lead to its increased reporting as they cannot be managed in isolation. A joint evaluation and management strategy are, therefore, necessary for patients with co morbidities.

1.3.3.4 Alcohol

Centuries ago, cheap wine was used as pain relief for those in extreme pain or condemned to crucifixion. Despite its use as medication by the public, alcohol’s analgesic impact is only temporary (Riley & King, 2009). Numerous hazardous are effects associated with mixing alcohol with other treatments. The most significant impact regarding the control of pain can be derived from the intake of safe quantities of alcohol every day. However, consuming alcohol in such a manner will result in the build-up of an individual’s tolerance to the alcohol’s analgesic impact. During alcohol withdrawal, the pain sensation is increased, and this increased feeling of pain may cause patients to drink more to reverse this withdrawal-related pain (Brennan, Schutte, & Moos, 2005). One study conducted by Ekholm (2009) on a cohort of the general Danish population indicated that alcohol chronic pain patients were not expected to consume alcohol, particularly compared to those on opioid treatment (Ekholm, 2009).

1.3.3.5 Obesity

There is an established relationship between obesity and pain sensation. This has been ascribed to the direct effect of increased body weight on joints, as well as decreased exercise and reconditioning. Nevertheless, the association between obesity and pain is more complex merely its relationship to mechanical burdens. Genetic and environmental elements were significantly implicated in this relationship as demonstrated through several twin studies in the community. Increased body mass index (BMI) also affects the way the body functions and one’s quality of life with respect to their health (Okifuji & Hare, 2015). Obese patients have a greater chance of scoring badly on the pain health subscales when examined using quality of life instruments, however, the direct impact of an individual’s weight on such measurements has yet to be determined (Janke, Collins, & Kozak, 2007).

According to Janke *et al.* (2007), chronic pain is more likely to manifest in people living with central obesity and not from other factors including metabolic disorders, anxiety, depressive illness and other co morbidities. A greater prevalence of pain and an increase in incidence were linked to a higher BMI (body mass index) in older patients (Janke *et al.*, 2007).

Numerous research studies have proposed a link between weight loss in patients and decreased feelings of pain. However, the strength of this association varies between studies. The benefits of weight loss are linked only to obese patients with conditions such as osteoarthritis in which the mechanical load on body joints is a significant factor. Studies have indicated that losing weight can significantly indicate improvements in pain and this was also seen in cases where depression was managed (Okifuji & Hare, 2015). These findings were thought to be due to better levels of self-assurance and of an awareness of pain.

Muehlbacher *et al.* (2006) researched the impact of losing weight through use of topiramate in individuals living with pain in their lower back. The study demonstrated a significant decrease in symptoms associated with pain symptoms and a marked improvement in the quality of life of these patients. Controlling factors, including management of body weight, that are associated with diabetes mellitus and hypertension are just as vital as controlling blood pressure and diabetes in minimising cardiovascular risks (Andersson, 2009; Tesfaye *et al.*, 2005). It may be more vital to implement this secondary measure to decrease its general effect, more so than just addressing the gravity of the pain.

1.3.3.6 Exercise

Data supporting the advantages of physical exercise in decreasing pain are poor. This has been attributed to variations in studies; differing in their quality and the type of pain examined. Furthermore, these studies also tend to lack information about the form of exercise employed. In patients experiencing fibromyalgia, strength training and performance of aerobic exercises under supervision were shown to improve a patient's level of pain. Walking (including on a treadmill) did not produce positive results when indicated as a treatment for lower back pain patients (Booth *et al.*, 2012). In patients living with chronic arthritis, tai chi, an ancient Chinese form of exercise, was found to slightly contribute to decreasing pain and lessening a patient's disability (Han *et al.*, 2004). Studies of other forms of exercise, such as pilates, have had moderate patient outcomes. The precise nature of the components of this exercise is discussed in the study reported by (Kloubec, 2011). Exercise is an important part of secondary and tertiary pain inhibition, and in the control of co morbidities (Booth *et al.*, 2012).

1.3.4 Management of peripheral neuropathy

Generally, peripheral neuropathy is managed using pharmacological or non-pharmacological options (IASP, 2011).

1.3.4.1 Common pharmacological agents

Pharmacological treatments in peripheral neuropathy are effective for most people with the condition. Medications prescribed include antidepressants such as selective serotonin reuptake inhibitors, tricyclic antidepressants and serotonin–norepinephrine reuptake inhibitors. Moreover, alternative pharmacological interventions are also available including topical treatments, antiepileptic or anticonvulsant drugs and opioid analgesics (IASP, 2011).

Pharmacological therapies are employed as the first course of treatment for peripheral neuropathy in developing countries such as Kuwait. These medications can achieve the desired results with few observable side effects. Indeed, pharmacological treatment is often more long-lasting for treating long-term peripheral neuropathy compared to other management options. However, before using a pharmacological treatment, healthcare professionals in Kuwait should ensure the suitability of the respective medication for the patient with the condition. The need to define the suitability is necessary because the effectiveness of the medication often depends on the recipient's psychological attitude and preparedness. Perhaps most importantly, healthcare professionals in Kuwait should assess the commitment of those with the condition to trying pharmacological treatment to establish whether they are willing to adhere to the prescribed treatment.

Pharmacological treatment is considered medically safe for both young and old people of both sexes (Matthews *et al.*, 2013). There is, however, a shortage of pharmacological treatment services in many areas of Kuwait, and prescribing drugs is considerably more expensive than other methods of treatment (Weerdt *et al.*, 2015).

Different analgesics can be employed for the treatment of peripheral neuropathy. These may include anti-inflammatories that are non-steroidal or simple analgesic drugs such as paracetamol. Choice of analgesic is dependent on the history of a patient and their reaction to treatments, and the action duration of a treatment and any adverse effects resulting from its use (Carlisle, Kroon, & Koda-Kimble, 2005).

In situations where such analgesic treatments do not resolve the painful neuropathy, tricyclic antidepressants can be employed as the next course of action. Tricyclic antidepressants are extensively researched, more so than other drugs and they are known to be highly efficacious treatments. Imipramine and amitriptyline are frequently prescribed and perform well in the management of peripheral neuropathy. The medications are taken daily with prescribed doses ranging from 25 mg to 150 mg. Analgesia manifests following 1 week to 4 weeks. Carlisle *et al.* (2005) had reported that sufficient levels of pain relief are experienced using the higher dose range from 75 mg to 150mg.

Carlisle *et al.* (2005) also described the employment of anticonvulsant drugs such as carbamazepine for control of peripheral neuropathy. However, these drugs are seldom used owing to the resulting adverse effects . One anticonvulsant that is hardly ever refused is gabapentin. Despite adverse effects such as somnolence and dizziness being associated with this drug, patients tend to accept it because of the significant improvements in pain, particularly compared to a placebo. Gabapentin, however, is not as taxing on patients as other anticonvulsants owing to its low numbers of interactions with other medications. Novel anticonvulsants that are employed in the control of peripheral neuropathy include pregabalin, topiramate and lamotrigine which have been shown as efficacious in managing peripheral neuropathy (Carlisle *et al.*, 2005).

1.3.4.2 Other agents

Numerous drugs have been shown to be efficient in controlling peripheral neuropathy. One drug described by Vinik and Mehrabyan (2004) is tramadol. This drug functions by associating with the μ-opioid receptors. This binding results in the weak inhibition of norepinephrine and in the uptake of serotonin. Painful diabetic neuropathy is one of the conditions that are effectively managed using tramadol.

Jarvis and Coukell (1998) described the use of several medications including mexiletine, antiarrhythmics and lidocaine in the control of peripheral neuropathy. Resistant neuropathy is one condition that is successfully managed using these drugs. Despite these successes, these drugs are only employed in extreme cases after trialling other options because of their variable benefits and the higher chance of adverse effects. Clonidine is another drug that has been researched in the management of peripheral neuropathy. This is because neuronal ischaemia may be reduced through peripheral vasodilation. Laederach-Hofmann, Weidmann and Ferrari (1999) conducted a study on administration of clonidine through the skin and found that it efficiently relieved cases of peripheral neuropathy.

Capsaicin cream is frequently recommended by healthcare professionals. Rains and Bryson (1995) described the efficacy of capsaicin cream in the treatment of postherpetic neuralgia. The findings of this study recommended its use for people living with diabetic neuropathy.

1.3.4.3 Combination pharmacotherapy

The provision of symptomatic respite remains the core approach to treating peripheral neuropathy. Optimum impact is felt following use of tricyclic antidepressants or gabapentin. Nevertheless, alternative therapies and their occasional use as combination therapies can also result in control of peripheral neuropathy in patients where conventional therapies failed (Carlisle *et al.*, 2005). The restricted efficacy of present medications calls for their use in combination.

Using such drugs at reduced doses and in combination could potentially enhance their impact and reduce their individual adverse effects. Supporting evidence for this approach, however, is poor. Contrasting data was found following the analysis of several studies. For example, the use of gabapentin in combination with morphine was found to be highly effective. Moreover, combining gabapentin with venlafaxine was found to be more efficacious than using gabapentin as a single therapy (Simpson, 2001). However, combining amitriptyline with fluphenazine (a neuroleptic drug) did not result in any measurable benefits (Graff-Radford, Shaw, & Naliboff, 2000). Consequently, further research is required to establish the combinations of medications and to examine their compliance, safety and cost-efficiency (Sadosky *et al.*, 2008).

1.3.4.4 Non-pharmacological management

The pain of people living with peripheral neuropathy can also be managed using options that do not involve medications. These can take many forms, such as walking, swimming, acupuncture, transcutaneous electrical nerve stimulation and surgery. Walking and swimming can be helpful in treating pain in affected limb extremities. Simply creating a social environment where people with peripheral neuropathy are no longer neglected by others can help in easing their pain and enable them to cope better with their condition.

One of the frequently championed treatments for control of peripheral neuropathy is acupuncture. Although Chinese therapy-acupuncture is an alternative therapy, several studies have suggested that acupuncture helped in alleviating pain and contributed to the treatment of peripheral neuropathy (Dimitrova, 2017). One study on acupuncture and peripheral neuropathy reported that 77% of participants showed greater improvement in pain symptoms (Abuaisha, Constanzi, & Bulton, 1998). Only one adverse effect is linked to acupuncture use, and that is an increased chance of infections being spread through combined use of needles. Nevertheless, this issue is easily resolved through use of single use needles.

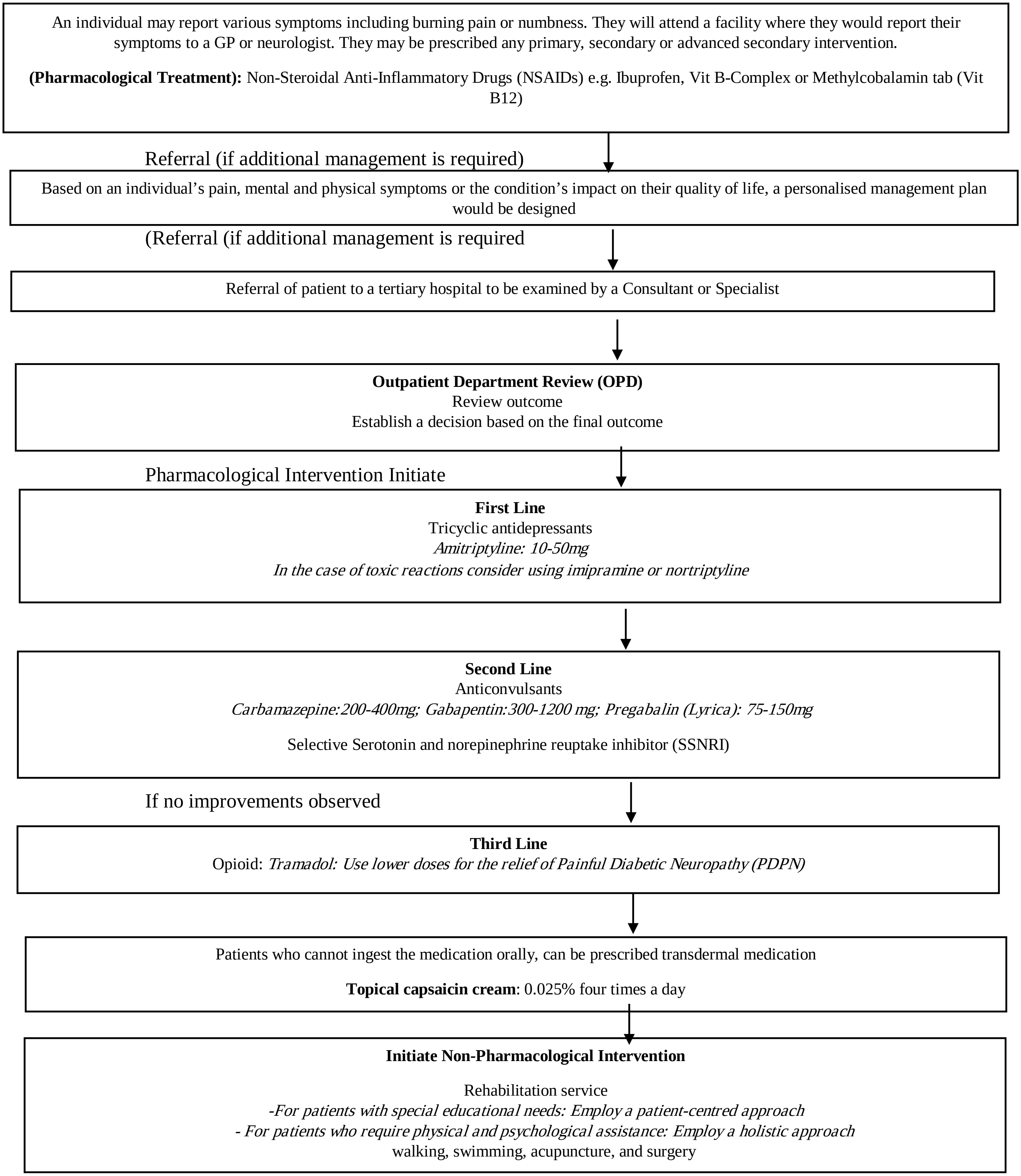
Alternative non-pharmacological treatments also exist. One such treatment involves the use of transcutaneous electrical nerve stimulation which works through the stimulation of an affected area with mild electric pulses generated using a surface electrode. To date, as described by Proctor *et al.* (2002), there have been no severe side effects documented for this technique. Nerve decompression surgery is another management option used in peripheral neuropathy, restoring sensory function and reducing pain (Cornblath *et al.*, 2007).

Lonnstedt, Stahl, and Rydholm (2011) also reported the benefits of an optimistic outlook in aiding people with peripheral neuropathy. A positive attitude allows patients to more effectively control the pain experienced, thereby improving their lives. Healthcare professionals (and psychologists in particular) are vital in helping people with peripheral neuropathy accept their condition, learning to control it and to continuously think positively (Taverner, Closs, & Briggs, 2014). Moreover, individuals living with peripheral neuropathy can be educated on distraction mechanisms, including the immersing of themselves in favoured activities they are able to perform, such as simple exercises and chores (Lonnstedt *et al.*, 2011). An appreciation of a patient's strong and weak points is necessary when healthcare workers work with their patients. It is also vital that they have an understanding of their capabilities and preferences, to help establish which activities they can perform without causing pain. Once this has been done, those with the condition should be given further guidance on how they can improve their productivity. This could include, for example, making use of help from others or managing periods of rest between activities (Taverner *et al.*, 2014). This will help construct a routine and enable these people to feel in control and thus more confident in performing other activities.

At present, less effective guidelines of non-pharmacological treatment exist in Kuwait, despite peripheral neuropathy being as prevalent in the country as anywhere else in the Arab world. Accordingly, this project seeks to understand and examine the experiences of peripheral neuropathy patients in Kuwait. Moreover, this project will also explore why healthcare professionals in Kuwait rely solely on drugs, rather than using non-pharmacological treatment where appropriate, to ease the pain experienced daily by people living with this chronic condition.

1.3.4.5 Treatment guidelines of the National Institute for Health and Care Excellence (NICE)

Guidelines outlined by NICE for the management of peripheral neuropathy are employed globally (NICE, 2013). The NICE guidelines' focal point is the employment of both pharmacological and non-pharmacological therapies in the care of patients at both the primary and secondary level. The treatment of peripheral neuropathy in Kuwait is performed by following the NICE guidelines. Figure 2 is a schematic diagram demonstrating the steps to follow for the treatment of peripheral neuropathy.



An individual may report various symptoms including burning pain or numbness. They will attend a facility where they would report their symptoms to a GP or neurologist. They may be prescribed any primary, secondary or advanced secondary intervention.

(Pharmacological Treatment): Non-Steroidal Anti-Inflammatory Drugs (NSAIDs) e.g. Ibuprofen, Vit B-Complex or Methylcobalamin tab (Vit B12)

Referral (if additional management is required)

Based on an individual's pain, mental and physical symptoms or the condition's impact on their quality of life, a personalised management plan would be designed

(Referral (if additional management is required

Referral of patient to a tertiary hospital to be examined by a Consultant or Specialist

Outpatient Department Review (OPD)
Review outcome
Establish a decision based on the final outcome

Pharmacological Intervention Initiate

First Line
Tricyclic antidepressants
Amitriptyline: 10-50mg
In the case of toxic reactions consider using imipramine or nortriptyline

Second Line
Anticonvulsants
Carbamazepine:200-400mg; Gabapentin:300-1200 mg; Pregabalin (Lyrica): 75-150mg

Selective Serotonin and norepinephrine reuptake inhibitor (SSNRI)

If no improvements observed

Third Line
Opioid: *Tramadol: Use lower doses for the relief of Painful Diabetic Neuropathy (PDPN)*

Patients who cannot ingest the medication orally, can be prescribed transdermal medication

Topical capsaicin cream: 0.025% four times a day

Initiate Non-Pharmacological Intervention

Rehabilitation service
-For patients with special educational needs: Employ a patient-centred approach
- For patients who require physical and psychological assistance: Employ a holistic approach
walking, swimming, acupuncture, and surgery

Figure 2. A schematic illustration of the NICE guidelines for the management of peripheral neuropathy (NICE, 2013).

1.4 Regional variation and cultural context

Although this thesis is focused on Kuwait, the following offers a comparison to Western countries. Thus, this comparison will help highlight underlying similarities and differences between both countries on their approach to tackling the condition.

1.4.1 Distribution and variation of peripheral neuropathy in Western countries

Peripheral neuropathy's prevalence in Western nations is increasing at an alarming rate (Azhary *et al.*, 2010). A retrospective analysis reported that peripheral neuropathy is experienced by approximately 20 million individuals in the United States of America (NINDS, 2015). The American Chronic Pain Association (ACPA) estimates that the incidence of peripheral neuropathy has risen to eight in every 100 people aged 55 or older (Azhary *et al.*, 2010).

An estimated four in every ten patients attending primary care settings were associated with experiencing pain (Mantyselka *et al.*, 2001). Diagnosing such patients is difficult for healthcare staff due to the complexity and the varying aetiology of pain. Nevertheless, regardless of this difficulty, starting the treatment of pain in a timely manner is vital for improving pain experienced. The causes underlying peripheral neuropathy can vary according to social setting and the geographical location linked to the development of the condition. In developing nations, peripheral neuropathy is most commonly associated with trauma or conditions such as AIDS, however, peripheral neuropathy is linked more to diabetes in developed nations (Daousi *et al.*, 2004).

Approximations made by NHANES or the USA National Health and Nutrition Examination Survey, indicated that, on testing both feet using a monofilament, of a group of people living with diabetes, 28.5% would experience peripheral neuropathy in a minimum of a single insensate region (Gregg *et al.*, 2004). A study conducted by NHANES indicated that just over one in 10 (10.9%) of people with diabetes lived with symptomatic peripheral neuropathy, while a study by the Mayo Clinic indicated that one-fifth of patients had symptoms of peripheral neuropathy. Symptoms were defined as experiencing pain, a lack of sensation or a numb or tingling feeling in the feet for a minimum of three months (Gregg *et al.*, 2004).

Hall, Carroll, and McQuay (2008) reported that the prevalence of neuropathic pain in the UK between 1992 and 2002 was approximately 15.3 individuals per 100,000 of the population. The ratio has since increased every year. Approximately three million individuals were diagnosed as people living with diabetes in 2011, and this was equated to less than one per 100 of the population experiencing diabetic neuropathy (Abbott *et al.*, 2011). The diagnosis and management of the treatment of peripheral neuropathy is, therefore, vital in being linked to both the diagnosis and management of treatment of the underlying condition. According to a study by Hall *et al.* (2006) and following an examination of the UK's Clinical Practice Research Datalink (CPRD), cases of painful peripheral neuropathy have risen significantly in the past few years.

Another study based in the UK examined how many cases of chronic painful peripheral neuropathy had been diagnosed in a single year and had approximated that it was experienced by 16.2% of people living with diabetes in the researched communities (Daousi *et al.*, 2004). Improvements in the management and help of individuals with and those likely to live with the condition in the future are vitally needed.

1.4.2 Prevalence of peripheral neuropathy in the Arab region

Before exploring the situation in Kuwait in more detail, it is worth looking at other neighbouring countries in the Arab world. Globally, Saudi Arabia is classified as having the seventh-highest number of diabetes cases (24%), and cases of painful diabetic neuropathy accounting for one-fifth of people living with diabetes (Wang *et al.*, 2014). While in Jordan, 39.5% of people with type 2 diabetes were living with peripheral neuropathy. The most frequently diagnosed signs were determined by the MNSI or the Michigan Neuropathy Screening Instrument. The identified signs included numbness in 32.3%, as well as pain while walking in 29.7%. The least frequently diagnosed signs include the diagnosis of 3.8% with the loss of feelings in their legs and feet when walking and 1.3% having an amputation. Statistical evaluations using multivariate logistic regression showed that diabetic retinopathy, unemployment, dyslipidaemia, cardiovascular disease, and a long history of diabetes mellitus (≥ 5 years) were significantly associated with diabetic peripheral neuropathy (Khawaja *et al.*, 2018).

Recent research has irrefutably indicated that proper management of type 2 diabetes postpones the manifestation of complications associated with the disorder. Thus, proper management enhances the patient's general quality of life. Evidence of this nature is welcome since, on a global scale, type 2 diabetes is presently considered an epidemic and a primary issue for health systems, not least in the Arab world. Reporting produced by the IDF or the International Diabetes Federation, indicated that the prevalence of people live with diabetes mellitus in 20 Arab nations is almost 20.5 million people (Boutayeb & Serghin, 2006). Of those, 13.7 million were found to be in the pre-diabetes stage and with dysfunctional glucose tolerance (Boutayeb & Serghin, 2006). The highest prevalence of diabetes in these nations was 21.1% in Kuwait, 20.2% in Qatar, 20.2% in Lebanon, 20% in the Kingdom of Saudi Arabia, 19.9% in Bahrain and 19.2% in the United Arab Emirates. The Gulf region is clearly facing a diabetes epidemic of its own.

The majority of individuals living with diabetes mellitus in developed nations are over the retirement age. Contrastingly, approximately 66% of people with diabetes in the Arab region are aged below 60 years; their productive years (Mandil, 2009). Consequently, such individuals are worsening the disability load of this condition that is facing these nations. Abu El-Asrar *et al.* (1999) indicated that complications from diabetes are also increasing. For example, just under one-third (31%) of people living with type 2 diabetes in the Kingdom of Saudi Arabia, living with the condition for a decade, are also inflicted with diabetic retinopathy (Abu El-Asrar *et al.*, 1999). Complications experienced were more severe in the western region of the Kingdom of Saudi Arabia who have been with 82% of people living with diabetes affected by neuropathy (Abu El-Asrar et al., 1999).

1.4.3 Prevalence of peripheral neuropathy in Kuwait

Before examining the prevalence of peripheral neuropathy in Kuwait, it is worth exploring the cultural context of the existing healthcare system. In the north-western region of the Arabian Gulf is Kuwait; a Middle Eastern nation. The culture of Kuwait is an extension of Islamic and Arab culture. The geographical location of Kuwait has made society in Kuwait open to accepting surrounding cultures. One of the most prominent features of local Kuwaiti culture is the *Diwaniya*, a gathering room that is isolated specifically for men to sit and socialise.

The strong purchasing power of the Kuwaiti citizen has resulted in a culture of consumerism. The economic boom in the seventies and eighties after the emergence of oil, as well as legislation on financial increases on all items of monthly income of the Kuwaiti citizen, strengthened the Kuwaiti citizen's concept of consumption, including that of unhealthy foods and products.

The healthcare system in Kuwait is state-funded, providing treatment for every Kuwaiti national. The World Health Organization (WHO) describes health as being a complete state of spiritual, physical and mental wellbeing. Health is therefore not only the absence of disease or disability. Health anywhere around the world is based on three main axes: human factors (labour force), buildings, and equipment. As reported by the World Health Organization in 2011, the mean life expectancy for males was 77 years and 82 years for females; with an overall mean expectancy of 80 years. This places Kuwait in seventh place in worldwide rankings of life expectancy (WHO, 2017).

The health sector in Kuwait faces several challenges, including a lack of hospitals and the emigration of highly qualified doctors. The Ministry of Health (MOH) is required to work with other ministries to address these challenges in the health sector. Furthermore, the centralisation of medical equipment acquisition has exacerbated the difficulty of service provision difficult to provide when required in a short time (Ministry of Health State of Kuwait in AL-Jarida newspaper, 2008).

Perhaps one of the most important reasons for the decline of the healthcare system and the lack of confidence of many citizens (and indeed people living with peripheral neuropathy) is that healthcare services still use an old and traditional system for the provision of healthcare, without seeking to adopt improvements. Kuwaiti health institutions function with poor healthcare services that are fragmented among departments. Awareness programmes on diseases such as diabetes and peripheral neuropathy are also poorly planned and executed nationwide.

In 2017, 54% of the people living with diabetes in Kuwait were living with painful diabetic peripheral neuropathy. (Ahmed *et al.*, 2017). The current study centres on the aetiology of peripheral neuropathy. Of these, diabetes is highly prevalent in Kuwait compared to Western nations where prevalence is at 28.5% only. This study aims to provide further information on diabetes as a cause of peripheral neuropathy, as the prevalence in Kuwait is almost double than that of Western nations. This is exemplified in Table 2.

Table 2. Comparison of the prevalence of peripheral neuropathy in Kuwait, the West, and the Arab region.

Conditions frequently identified with neuropathic pain	**Western countries**	**Arab World**	**Kuwait**
Diabetic neuropathy	USA National Health and Nutrition Examination Survey (NHANES) (Gregg *et al*., 2004): -*A Symptomatic:* 28.5% of people living with diabetes are found to have a peripheral neuropathy in at least one insensate area. -*Symptomatic:* Peripheral neuropathy was identified in 10.9% of adult living with diabetes. Symptoms included pain, numbness, loss of feeling and tingling in the feet for a minimum of three months. UK (Daousi *et al.*, 2004): - The prevalence of chronic painful peripheral neuropathy was approximately 16.2% of the people living with diabetes in the communities studied.	The Kingdom of Saudi Arabia (KSA) (Wang *et al.*, 2014): - One-fifth of people living with diabetes live with painful diabetic neuropathy. In comparison, more people living with diabetes in Jordan live with peripheral neuropathy (39.5%).	Kuwait (Ahmed *et al.*, 2017): -Of the people living with diabetes in Kuwait, 54% lived with painful diabetic neuropathy.

Income in Kuwait is one of the highest, resulting in Kuwaiti citizens enjoying a high quality of life regarding their wellbeing and social services. The standards and health parameters used in Kuwait are equal to parameters employed in developed nations (WHO, 2014a). Diabetes and pain of the lower back are frequently indicated as the causes of peripheral neuropathy in Kuwait (WHO, 2014a). An evaluation of the Kuwaiti adult population finds that Kuwait is ranked within the highest five countries for diabetes incidences. The past ten years has seen the prevalence of diabetes double and in 2014, 18% of the population lived with diabetes with 424,000 cases being diagnosed in 2019 alone (Harvard T.H. Chan School of Public Health, 2014). Shahab *et al.* (2012) reported that by 2010, approximately 39% of people with diabetes mellitus in Kuwait were impacted by peripheral neuropathy. Moreover, the older the age group in Kuwait, the greater both the prevalence and the incidence of diabetes and this has been associated with an increase in peripheral neuropathy cases (Ministry of Health State of Kuwait, 2012).

A recent study conducted in Kuwait examining diabetic patients in five clinics located across the country, established that there was a prevalence of 54% of painful diabetic neuropathy (Ahmad *et al.*, 2017). Diagnosis of painful diabetic peripheral neuropathy in these patients was determined by neurological testing of the patient and by evaluating the patient's pain history in the upper and lower limbs. Compared to patients without peripheral neuropathy, patients living with painful diabetic neuropathy had a BMI over 30, a raised fasting blood glucose level and were older. The authors of this study concluded that patient education, as well as optimisation of treatment and management, is decisive factors contributing to the raised prevalence of cases of peripheral diabetic neuropathy in Kuwait. The aims of this research study are the evaluation of the patient experience and their coping and management strategies for living with peripheral neuropathy in Kuwait.

Although not examining the prevalence of diabetes, Al-Dahi (2019) indicated that complications of diabetes affect more than half of the patients, pointing out that peripheral neuropathy affects 20 to 30% of patients. He indicated that this disease is a state of neurological damage that in the majority of cases impacts the legs and feet prior to the arms and the hands. Moreover, it was also noted that Kuwait was ranked in the ten highest nations with the greatest diabetes rates and that the majority of people lived with type 2 diabetes.

Alongside diabetes, low back pain is another common cause of peripheral neuropathy found in 40−60% of Kuwaitis people living with the condition (Al-Shubaili & Sharfuddin, 2010). In the 10 to 18-year-old group in Kuwait, this condition affects 58% of individuals with 65% and 51% of females and males affected, respectively (Shahab *et al.*, 2004). This figure has been rising with age in both sexes (Shahab *et al.*, 2004). It must be noted that the limitations in analysing these prevalence studies has been identified and is caused by the variation in methods used to diagnose neuropathic pain.

1.5 Experiences of people living with peripheral neuropathy

Peripheral neuropathy results in several physical, financial, and psychological problems for people living with the condition. These problems include severe depression and disturbance of sleep patterns (Norrbrink Budh, Kowalski, & Lundeberg, 2006). The quality of life of individuals living with peripheral neuropathy is impacted and so too is that of their immediate families and care givers. Besides affecting their quality of life, the condition entails costs that many find themselves unable to bear (McDermott *et al.*, 2006). These costs include those associated with healthcare visits, diagnostics, medications, and surgical procedures undertaken to alleviate the pain.

In keeping with publications on chronic pain, data exists supporting the part played by psychological elements in adjusting to peripheral neuropathy. These elements include mood, pain-coping strategies, social support, and psychosocial dysfunction. Peripheral neuropathy can be divided into at least four categories: diabetic neuropathy, post-herpetic neuralgia, post-amputation pain, and AIDS-related pain.

Of individuals with herpes zoster, the new cases of post-herpetic neuralgia were established as falling between 10–34% (Dworkin & Portenoy, 1996). The progression of post-herpetic neuralgia was found to be linked to age and the baseline for pain severity (Dworkin & Portenoy, 1996). One year following an infection, approximately 63% to 70% of people still report feeling pain (Watson *et al.*, 1988). During the acute stage of the herpes zoster rash, the patient's quality of life diminishes, but this rises again once the rash is treated (Lydick *et al.*, 1995). Although the psychosocial impact of post-herpetic neuralgia has been frequently discussed in the literature, it has, nevertheless, received very little empirical attention (Dworkin & Portenoy, 1996). Rowbotham *et al.*'s (1998) study was one of only a handful of research studies that investigated the psychosocial effect of the condition. The study findings concluded that depression, anxiety, and psychosocial disability and dysfunction are significant when the pain from the condition becomes chronic. Recent placebo-controlled pharmacological trials using gabapentin on patients with post-herpetic neuralgia have shown an enhancement in certain aspects of quality of life, such as vitality, mental wellbeing and their physical function (Benbow, Cossins & MacFarlane, 1999). Other pharmacological trials have also highlighted the need to focus and resolve the effect of post-herpetic neuralgia on both psychosocial and physical performance.

Although people living with diabetic neuropathy have been shown to exhibit a high prevalence of pain, only a few studies examined the effect of this pain on an individual's performance and their quality of life (Benbow, Wallymahmed, & MacFarlane, 1998). Numerous daily tasks are thought to be impacted by painful neuropathies, including social pursuits, leisure activities and work (Benbow *et al.*, 1998; Galer, Gianas, & Jensen, 2000).

Data on the raised prevalence of pain in individuals with HIV has been reported (Breitbart *et al.*, 1996). Despite the variation in pain with the stage of the disease, as well as with study methodology and healthcare setting, persistent pain of moderate intensity occurs in 40–60% of patients with HIV. Many HIV/AIDS patients complain of pain in several places, and research has shown that as the disease develops, so too does the prevalence of pain. Painful peripheral neuropathy is frequently diagnosed as a pain disorder in individuals living with HIV, with approximately 30% of HIV patients experiencing it (Kieburtz *et al.*, 1998). Pain in the abdomen is another disorder usually experienced by HIV patients, as well as headaches and painful rheumatologic conditions (Hewitt *et al.*, 1997). Pain related to HIV is linked with more people living with psychological and functional impairment, both cross-sectionally (Breitbart *et al.*, 1996) and longitudinally (Singer *et al.*, 1993). Compared to HIV patients not living with pain, HIV patients who simultaneously live with pain complain of reduced quality of life with regards to their relationships (both social and family) (Evans *et al.*, 1998).

The chance to evaluate psychosocial factors that contribute to increases in pain in short prospective periods, is afforded by using daily diary research studies. These diaries determine whether factors such as mood, coping, and social responses to pain exacerbate or alleviate pain. In a study on amputees, daily diaries established extensive variation in the daily associations between stress and pain (Arena *et al.*, 1990). An increase in stress on one day led to an increase in pain the next day, followed by an expected increase in stress in response to an increase in pain. Using time-lagged analyses, a diary study of individuals living with reflex sympathetic dystrophy, demonstrated that a low mood on one day contributed to pain the next day; this effect was not seen with anxiety or anger on the first day (Feldman, Downey, & Schaffer-Neitz, 1999). In the same study, however, the pain on the first day contributed to an increase in the next day's depression, annoyance and anxiety. Both research studies provide data supporting the fact that adverse affective states add to the development of neuropathic pain.

Compared to young adults and teenagers, peripheral neuropathy in the older generation is a frequent occurrence (Volpato *et al.*, 2003). Presently, more studies seek to understand peripheral neuropathy from the viewpoint of individuals living with the disorder. Sofaer-Bennett *et al.* (2007a) concluded that peripheral neuropathy has the potential to significantly disrupt the life of anyone living with the condition, but especially those of older age. The study surveyed 16 people with peripheral neuropathy, with all participants being older than 60 years. The research study's outcomes indicated several factors that restricted the participants' lives including an increased chance of developing depression or of adopting a negative outlook on life.

Peripheral neuropathy also has a significant impact on the mental state and the quality of life of the patient's spouse. Relationships between couples are more vulnerable to break down due to the worsened condition of the person living with peripheral neuropathy, which seeks isolation and withdraws from numerous daily activities. The findings of a study demonstrated how pain caused elderly individuals living with peripheral neuropathy to avoid their grandchildren as they found themselves incapable of joining them in play as normal (Sofaer-Bennett *et al.*, 2007a). By limiting the degree of physical interactions they had, they could manage the pain they experienced.

Older people with peripheral neuropathy reported that the condition limited their interaction with society. The condition curtailed their ability to freely move about and take part in activities such as walking, using public transport, or even driving. They could no longer socialise with other people as they might have done in the past. These restrictions distanced them from their loved ones, thus negatively affecting the quality of their lives. The pain experienced also resulted in unemployment for many people with peripheral neuropathy. Such individuals found difficulty in controlling their pain in the work setting. Besides the physical restrictions, other factors such as the uncertainties surrounding the condition affect the socialisation of people with peripheral neuropathy. All of these limitations in combination gradually increase the risk of depression and sleep deprivation, resulting in a vicious cycle (Sofaer-Bennett *et al.*, 2007b).

With regard to the extent of the citizens' confidence in the healthcare system, the issue of treatment abroad is the biggest evidence of a defect in this aspect. The challenge of keeping the Kuwaiti citizen in the country for treatment requires more concerted efforts through a collaborative approach. Such an approach would include ministries in Kuwait including the Ministry of Information, the Ministry of Health and the Council of

Nation. Enhancing and developing the citizens' confidence in the Kuwaiti healthcare system requires the contribution of more than a single establishment (Ministry of Health State of Kuwait in AL-Jarida newspaper, 2008).

Pain resulting from peripheral neuropathy is considered a widespread chronic condition in Kuwait, requiring a tremendous effort to treat alongside other diseases. Initially, pain influencing the lives of individuals living with peripheral neuropathy is light in nature; possibly manifesting as numbness or a sense of tingling. For example, it was similar to being pierced by a pin, walking on a sponge or a feeling of heat from within the arm. Unfortunately, some do not pay attention to them, and may not tell the doctor, believing that they are not related to diabetes, but these symptoms are only the beginning (Al-Dahi, 2019).

Only a few research studies on the impact of peripheral neuropathy on patients in Kuwait have been conducted. Moreover, there is a paucity of supporting evidence on the use of tactical strategies, including an organisational process, non-pharmacological assistance and medical care in improving an individual's sleep, social associations and mood. The lack of peripheral neuropathy specialists, combined with the endless problems faced by those living with the condition, has created a dire need to construct a map outlining the process a patient experiences as the condition progresses in this nation. Thus, the process map generated of the patient journey in Kuwait is part of a study that the researcher has published in a journal, and it will be discussed further in Chapter 3.

1.6 Significance of the research

The current research addresses the issue of peripheral neuropathy in Kuwait. Several research studies have detailed the prevalence in the Arab region of peripheral neuropathy in the Arab world (El Sissi *et al.*, 2010; Jambart *et al.*, 2011). However, no significant studies have been published on the experiences of people with the condition in the Middle East and the Arabian Gulf. In Western countries, there have been tremendous efforts to aid patients experiencing the impact of peripheral neuropathy to cope with their pain and any other experiences that result from the condition. When caring for patients with peripheral neuropathy, such support is usually fostered through multidisciplinary teams (Norrbrink Budh *et al.*, 2006). The perceiving of greater levels of support enhances the coping strategies of patients (Norrbrink Budh *et al.*, 2006).

This research study reflects the reality experienced by individuals living with the impact of peripheral neuropathy in Kuwait. The research covered in this study specifically focuses on the paucity of care for the psychosocial impacts experienced by individuals affected by peripheral neuropathy. It highlights the burden of living with the condition, and all the referrals, administrative procedures, and treatments involved on a daily, weekly and monthly basis. Moreover, this study also examines other issues related to peripheral neuropathy, such as the psychological effect of the condition and medications used, and the nature of the relationship between healthcare professionals and people living with the condition.

Studies have, until now, only focused on the medical nature of the treatments used, ignoring the people themselves and their experiences. Notably, no studies of this kind have been conducted in Kuwait. Indeed, the lack of psychosocial support for people with this condition, and the lack of multidisciplinary care in Kuwait, has created a dire need for this study. The gap in psychosocial care is observed in a number of ways. For example, healthcare professionals focus solely on the physical treatment and ignore mental health issues. Moreover, communication between individuals experiencing peripheral neuropathy and their healthcare workers is lacking. Furthermore, the time spent with each individual patient is limited. Anecdotal evidence suggests that patients are having difficulties in coping with and accepting their condition in Kuwait (Ministry of Health State of Kuwait, 2012). Crucially, one of the primary contributions of this study is data on the gap between Kuwait and Western countries in the provision of healthcare for individuals impacted by peripheral neuropathy. The findings of this research will enhance the knowledge and comprehension of the impact of psychosocial treatment on individuals living with peripheral neuropathy.

The study described in this thesis is a much needed call to action for all healthcare professionals who care for people with peripheral neuropathy to consider the patient's condition and its management from multiple angles. The significance of this matter is evident against the background of the medical and administrative issues surrounding the management of the condition. This study is vital in the creation of a framework of procedures in which people living with peripheral neuropathy are given medical and psychological support equally. It is also crucial in the future development of an automated referral system that eases the journey of the patient living with the condition.

The impact of this study could be seen in the development of better services at Kuwaiti healthcare centres. These measures of improvement to the patient's journey could include raising the standard of services, reducing waiting times for referral to a service, and improving the lives of people with the condition by providing access to the latest and best medical breakthroughs, equipment, and healthcare professionals.

1.7 Research aims and objectives

1.7.1 The aim of the study

The underlying objective of the study is to examine the experiences of individuals impacted by peripheral neuropathy in Kuwait, including coping and management strategies, and the use of different medications. The question we are therefore asking is what are patients' experiences, coping and management strategies of peripheral neuropathy in Kuwait?

Alongside this central question, the following supplementary questions will be addressed:

A) Reviewing the existing literatures that explores the experiences of people living with peripheral neuropathy.

B) What are the experiences of people living with peripheral neuropathy in Kuwait? A process map of the patient journey.

C) Exploring the experiences of people living with peripheral neuropathy in Kuwait including the coping strategies and pharmacological and non-pharmacological treatments.

1.7.2 Study objectives

The individual objectives outlined for this research study are as follows:

A) Provide background data about peripheral neuropathy and its management, both globally and in Kuwait.

B) Explore patients' experiences of peripheral neuropathy in Kuwait to:

i. Establish the effect of symptoms on the quality of life of people living with peripheral neuropathy.

ii. Document their coping and management strategies, including their experiences with medication.

iii. Explore the various forms of practical, social and emotional assistance received by people living with peripheral neuropathy.

C) Draw appropriate conclusions and make recommendations to enhance the general management of individuals impacted by peripheral neuropathy in Kuwait.

1.8 Structure of the thesis

This study consists of five chapters investigating the experiences, coping strategies, and management of individuals living with the impacts of peripheral neuropathy in Kuwait. Several chapters have been adapted into publications, as is detailed below. The aim of the thesis is to gather participants' experiences to aid the development of current practices and procedures used by the healthcare professionals in the country that treat people living with the condition.

Chapter 1 presents background information about peripheral neuropathy and its treatment, before setting out the study's research aim, its key research questions, how these are addressed, their significance, and the structure of the study. Moreover, this chapter also reviews and compares the nature of treatment procedures between Western countries and Kuwait, revealing the differences in practice and difficulties faced by individuals influenced by the effects of peripheral neuropathy in the respective countries. Responding as this study does to the gap identified following a review of the literature with respect to the management and treatment of peripheral neuropathy in Kuwait (rather than being a systematic academic survey), the literature review provides an argument for the rationale of the research. Chapter 2 introduces the appropriate backgrounds related to the research approaches necessary to accomplish the study's objectives and other key parts of the methodological approach. The methodology chapter details the thesis objectives that were defined to help examine the different research topics. Specifically, the chapter encompasses the research methodology, philosophical world views, a summary of the researcher's three studies along with other central components to each study; namely, the consistency and reliability. The chapter also provides a detailed discussion of each study's analysis methods, sampling technique and the reflexivity of the study. Furthermore, the chapter fore grounded a profound examination of each topic with an emphasis on the thesis's objectives. Crucially, the chapter explains the rationale for adopting certain methodologies in preference to other methods. Essentially, a clear overview of the researcher's three studies and their objectives was introduced. Chapter 3 presents the first paper, titled *Is the body sick or the mind? A systematic review of people's experiences of peripheral neuropathy*. This paper examines the impacts of peripheral neuropathy on individuals living with the condition; specifically their psychological and social experience, as well as self-management techniques. This manuscript, still under review, was submitted to the journal *Health Expectations* in November 2019.

Chapter 4 presents the second paper, titled *The Experiences of People Living with Peripheral Neuropathy in Kuwait: A Process Map of the Patient Journey*. This paper explores the pathway employed in the management of the impacts of peripheral neuropathy experienced by individuals in Kuwait and resulting in the creation of a schematic map of the process, outlining the patient's life through their experiences of peripheral neuropathy. The guidelines outlined by the International Association for the Study of Pain guidelines, National Institute for Health and Care Excellence (NICE), and the UK guidelines are then compared to the process map generated through this process. In July of 2019, the journal *Pharmacy* published this paper. Chapter 5 presents the third paper, titled *People's experiences living with peripheral neuropathy in Kuwait: A qualitative study*. The aims of this study were the examination of peripheral neuropathy in Kuwait through the experiences of patients. The study employed a semi-structured interview schedule consisting of open-ended questions. The use of this particular study design was necessary to elicit answers from the participants and aimed to identify the coping mechanisms they employed with peripheral neuropathy. Further to this, the interview included an examination of the influence of the condition on the psychological health of the participants. This manuscript which is still under review, was submitted to the journal Chronic Illness in November 2019. Finally, Chapter 6 discusses the findings of the study, noting the study strengths and any limitations, and providing conclusions based on these findings.

CHAPTER TWO

Research Philosophy, Theoretical Approach and Methods

2 Introduction

The primary aim of this study was to explore the experiences of individuals living with peripheral neuropathy. The prevalence of peripheral neuropathy in Kuwait and the exacerbation of risk factors such as diabetes mellitus were both contributing reasons for the study. Moreover, the researcher's direct observation of the adverse and devastating effect peripheral neuropathy has on the lives of participants and their relatives, was a key factor in undertaking this research. In seeking the optimum research methods, the researcher reflected on the efficacy of implementing different approaches which are described in this methodology chapter. This methodology chapter discusses the thesis in terms of the research methodology, reliability and consistency in general and specific to the objectives of the thesis, along with philosophical world views.

2.1 Philosophical world views

The use of epistemology aids a researcher in understanding a range of philosophical world views. This, in turn, enables the formulation of a robust methodology. Epistemology is the term used to describe the theory of knowledge and defines the processes used to acquire knowledge (Cote & Levine, 2002). Epistemology and methodology are similar in that they both assess the processes used (Cote & Levine, 2002). However, distinction is drawn between the two in that methodology defines workable characteristics and focuses on the *practices* that can be used to improve our comprehension of the world (Cote & Levine, 2002). Unlike, methodology, epistemology enhances our understanding of the world using *philosophical* means. The theories of positivism, post-positivism and constructivism are three global philosophical concepts that are extensively used in understanding the world. The theory of positivism is a philosophical concept describing how natural phenomena, their characteristics and associations are the basis of accurate ("positive") knowledge. Therefore, sensory experiences lead to the generation of information that can subsequently be interpreted using both logic and reason and which leads to the formation of positive knowledge (Larrain, 1979). Positivism was coined by Auguste Comte (1798–1857), in supporting a new field, sociology. Comte was inspired to do this following his observation of Newton's law of gravity which he took as an example. The positivism theory aims to describe the reasons for events, thus, allowing the identification of the laws that govern them. Consequently, the discovery of such laws enables the prediction and, therefore, the control of similar future events as stated:

> Based on these predictions it becomes possible, by manipulating a set of variables, to control events so that desirable goals are achieved, and undesirable consequences eliminated (Carr & Kemmis 1986).

The verified (positive) information that is acquired from the senses is referred to as empirical evidence; and it is because of this that positivism is described as based on empiricism (Macionis & Gerber, 2015). Another philosophical concept, which originated from positivism, is the theory of post-positivism (also termed post- empiricism). The crucial difference between the two theories lies in the emphasis of autonomy between the researcher and the object (or researched individual) in positivism and the appreciation of the impacts of bias in post-positivism. The latter theory highlights the impact of hypotheses, theories, values and background knowledge of the researcher on their observation (Robson, 2002) . Accordingly, post-positivists are considered to pursue an objective approach owing to their appreciation of bias (Miller, 2007). Additionally, second vital differences between the two philosophies are the methodologies they employ. Whilst positivists rely on quantitative methods, post-positivists prefer the use of mixed (qualitative and quantitative) methods (Taylor & Lindlof, 2011) .

The third concept is that of constructivism which specifies that all knowledge is derived from individual experiences and not the result of identified and verified knowledge (Richardson, 2003). Constructivism is further divided into three forms; epistemological, social and psychological constructivism. The former; epistemological constructivism, describes the knowledge we have gained or ‘constructed’ through individual perceptions and social awareness (Richardson, 2003). It is also reliant on agreement. The second, social constructivism or social constructionism, forms part of the sociology and learning theory. Social constructivism dictates that knowledge and sets of reality are actively constructed as a result of the social associations and exchanges between individuals (Richardson, 2003). Lastly, psychological constructivism, involves the development of hypotheses. Specifically, psychological constructivism examines how systems are formed by humans to allow their implicit comprehension of events and the world around them (Richardson, 2003). Psychological constructivism relates to one of the psychology theories that was coined in the 1950’s by George Kelly; namely, the theory of personality. Kelly, a psychologist, noted that one’s individual mental attributes are guided by how they foresee situations (Benjafield, 2008).

The views governing constructivism range from post-positivism perspectives to relativism. Accordingly, this infers that retained knowledge is not a mirror image of inspirational or external realities. Supporters of constructivism consider it a substitute for empiricism classic rationalism. As constructivist perspectives are both realistic and relativistic, they tend to negate scientism and positivism. They stipulate that science is not knowledge that is created by scientists nor is it discerned through employment of stringent scientific techniques, but rather it is produced by the scientists. Moreover, it maintains that no one methodology is individually compelling and that in the case of social science, the employment of other methodologies may be most suitable.

The various types of constructivism are related in that they each do not centre on an ontological actuality ("reality-as-it-is-in-itself", is deemed by constructivists to be incomprehensible and doubtful), rather they are built on reality. Therefore, any statements on realism, factual truth or universalism are immediately discounted by constructivists. Although constructivists will acknowledge that their take is simply a perspective, nevertheless, they consider this a perspective that works towards comprehending matters and that has so far been employed by constructivists as a representation of this world (Phillips, 2000).

Constructionism was the epistemological means employed in this thesis. Thus, the knowledge acquired was described as knowledge that is constructed and not identified. By implementing constructionism, there was an appreciation that an indistinguishable association existed between the research subject (the researcher) and the research object (the researched topic; the participants' pain experiences). Each object constituted part of the human world; however, it was only through interaction with these objects could the subject derive meaning. Consequently, definitive realities or precise explanations could not exist as everyone's explanation or understanding of the object would differ. Nonetheless, one also recognised that as all communications were held in places that consist of socially created definitions, then an array of agreeable meanings existed; each followed by numerous individuals or groups. It stood to reason, therefore, that interpretations were deemed more acceptable, more likely to occur or aid individuals. Constructionism did not refer to either objectivity or subjectivity, instead it centred between these two extremes and centred more on benefitting from an object's assets. Constructionism accentuated the need to consider an object without prior impartiality, thereby allowed one to derive novel meanings from it.

Given that the epistemology of this thesis was based on constructionism, then the methodology employed was phenomenology. The theoretical perspective governing phenomenology was interpretivism; an approach that seeks to define meanings for each situation. The basis of interpretivism centres on the idea that theories and outcomes are reliant on an event. The basis of interpretivism, therefore, directly opposes the idea that a single strategy can define many occurrences. Thus, interpretivism 'looks for culturally derived and historically situated interpretations of the social life-world (Crotty, 1998). Accordingly, the findings of this thesis could only be associated with a single culture; specifically, residents of Kuwait who were living with the condition of peripheral neuropathy. Furthermore, such an association meant the thesis findings cannot be generalised to other population groups. Such a task can only be completed by performing future studies on such population groups. Nevertheless, the findings are still significant as an example and as a standard. The following sections will describe the process which led to the development of each subcategory in this thesis.

2.2 Research Methods

There are three principal research methods generally employed in the analysis of research including; qualitative, quantitative, and mixed methods approach. A quantitative study “describes, infers, and resolves problems using numbers. Emphasis is placed on the collection of numerical data, the summary of those data and the drawing of inferences from the data” (Ritchie *et al*., 2013). Conversely, qualitative research focuses on unquantifiable elements that are not based on numbers. These include one’s emotions, feelings, the words they use, the sound they make and other elements that are not quantifiable. It is worth noting that:

> Information is considered qualitative in nature if it cannot be analysed by means of mathematical techniques. This characteristic may also mean that an incident does not take place often enough to allow reliable data to be collected (Herbst & Coldwell, 2004).

Both quantitative and qualitative methodologies were clearly described by Anderson (2006). Anderson defined the quantitative approach as an objective strategy. This is a strategy that employs a definite scientific approach used to assess a hypothesis. The quantitative approach tends to initially involve a literature review. A research question is then posed that seeks to establish quantities. Moreover, a thesis aim is established which follows a single reality and is both specific and focussed. The facts generated are free from bias, a feat attributed to the use of a control, to setting limitations and establishing accuracy. All findings are noted as numbers. Moreover, this methodology is performed in extensively controlled settings using instruments. Additionally, this strategy does not include the researcher who views individuals as subjects. Consequently, such a methodology is highly quantifiable. In contrast, qualitative methods are subjective. Such a methodology allows the development of a hypothesis using a soft scientific approach. Additionally, the literature is not reviewed just at the start, rather, the literature is reviewed continuously. Moreover, instead of following a single reality, the research question seeks to identify what occurred and why. In doing so, the research question examines more than one reality using a comprehensive and clear perspective. The aim, however, is specific and well-defined. The quality of the facts determines whether they are considered findings. Furthermore, researchers must be novel in their approach and should be able to define and interpret the findings that consist of phrases and words. The approach involves observations and extensive communication and is performed in a flexible and natural setting. The researcher is involved in the process and the individuals studied are considered participants. Unlike quantitative strategies, qualitative strategies are interpretive.

The mixed methods approach describes a combination of both qualitative (interviews, focus groups) and quantitative (surveys, experiments) techniques. Precisely, the mixed method is considered a mixed method as the data collection and analysis are mixed together. Thus, using this approach, both qualitative and quantitative methods are employed in the collation, analysis and interpretation of data. However, the mixed method is of benefit when research requires validation or corroboration and where one method is used to inform a second method. It is also used to examine a research question from various angles, where the researcher is constantly reviewing the research question. Such an approach helps the researcher to clarify unexpected findings and any possible contradictions. Furthermore, the continuous re-examination of the research question aids the researcher in developing a hypothesis about the phenomenon being investigated, followed by the testing of the hypothesis and the generalisation of the findings to other similar groups. It should be noted here that these features of the mixed methods approach were not in keeping with the aims or the objectives of this thesis. Furthermore, the greatest disadvantage of the mixed method approach was the complexity of its research design. Not only was such a complex design time consuming and cumbersome to plan and apply, but also such complexity was likely to generate discrepancies in the findings that would be challenging to resolve and therefore to interpret.

2.2.1 The rationale for employing a qualitative design, sampling and data saturation

2.2.1.1 Design

The design of this thesis was based on an exploratory methodology to add to previously derived data employing qualitative methodology. Thus, this thesis explores the individual’s feelings, their experiences and the language they employ in defining these. The style used was, therefore, *“an inductive style, a focus on individual meaning, and the importance of rendering the complexity of a situation”* (Creswell, 2007).

In the past, scientists have preferentially opted to quantify and compare various data sets by assuming a defined reality and employing statistical methods; thereby opting for quantitative rather than qualitative methods (Long, 2014). Conversely, this thesis aimed to comprehend the bases of each one’s experiences and so it followed a cognitive course that eliminated the need for statistics. The absence of quantifiable outcomes is considered by some researchers reason enough to oppose qualitative methodologies as they deem them to be of minimal benefit. The aim of this thesis, however, was not to obtain outcomes that could be applied to the whole population, but to comprehend the feelings, viewpoints and experiences of individuals living with peripheral neuropathy in Kuwait. The thesis therefore, represents this group of individuals, while also enhancing research into healthcare.

Given the qualitative nature of this thesis, communication between the researcher and the participants was vital. Interviews were transcribed verbatim using the participant’s mother tongue instead of employing technical terms to aid the researcher’s understanding of the participant’s journey. Holloway (2005) described qualitative strategies as person-centred, and therefore the use of such strategies is not guided by a theory which, in turn, allows comprehension of the experience. However, such an approach can result in greater challenges for proficient healthcare experts such as the researcher. These challenges are attributed to the possession of prior opinions by researchers; opinions that they may seek to introduce to the research. Accordingly, the researcher tried to remain impartial though not at the expense of forgoing the expert’s experience. Before initiating every interview, the researcher introduced herself to the participants explaining her prior experience as both a pharmacist and an administrator at Kuwait’s Drug and Food Control Administration (Ministry of Health). The researcher then went on to detail her own research experience in the hope of gaining the participants’ trust as such an impact was expected to increase the participant’s desire to collaborate with the researcher. The interview specifics were also outlined. Therefore, the participants were informed of the nature of the research; which was described as a study of peripheral neuropathy and not a diagnostic or advisory process. The latter detail was added as a preventative measure to diminish the chance of participants seeking advice on peripheral neuropathy or their personal lives from the researcher. In case a participant sought advice, or detailed personal facts that were unrelated to the research, the researcher was sympathetic to their cause but also worked to return their focus back to the research while simultaneously directing them towards sources that could help them if they were in difficulty, including counselling.

Holloway (2005) described the inquiry procedure of qualitative studies as flexible. As previously noted, the researcher maintained an open tone with participants to encourage their contribution of meaningful responses. The researcher was also prepared for handling atypical or confusing occurrences. From a psychological perspective, the researcher observed everyone's experience resulting in the derivation of an infinite array of possibilities. Accordingly, the likelihood that unanticipated occurrences would transpire remained a possibility. Qualitative research does not offer the seclusion of quantitative studies given that the researcher is in direct contact with the participants. As previously noted, the researcher was equipped to handle unexpected occurrences such as any emotional reactions the participants may experience following relaying of a story in an interview, whether they experienced a personal impact of such situations or were disturbed by them. Consequently, pre-arranged debriefing sessions with the Kuwaiti advisors and sessions with professional counsellors were arranged for such instances.

Despite authors describing how current understanding indicates *“there is now increasing awareness that both styles of research may have a contribution to make to a project”* (Wood & Welch, 2010) the researcher did not opt to implement such a mixed methods approach. Given the subjective and interpretive requirements of this research, the qualitative approach was selected as the optimum strategy. Moreover, this decision was further supported by the application of a phenomenological approach in this thesis without the need for any statistics and the participant-centred approach.

The qualitative method refers to the deferment of one’s judgement to allow a greater understanding of the individual experience. Thus, qualitative research also eliminates bias as it seeks to remove pre-conceptions to allow close examination of an individual’s personal experience. In qualitative research, facts that have a high degree of evidence are of greater quality. Thus, the findings and their quality are dictated by the quality of the facts used that are subsequently interpreted by the researcher. The interpretation involves examination of the fundamental causes as opposed to examining quantities and statistical outcomes such as in quantitative research. Consequently, any data can have a quality associated to it. Moreover, qualitative research is often associated with specific kinds of data, usually involving words or images, rather than numbers (Ritchie *et al.*, 2013). In this thesis, the findings were associated with cognitive realities, thus leading to the reporting of the findings as words, as numerical representation was not possible. The participants were closely observed by the researcher, requiring a setting for the interview such as an interview room with a recorder placed at the centre between the researcher and the participant. This one-to-one setting allowed the collation of data from a relatively minor group of participants. As the researcher was in communication with the participants; interviewing and questioning them on their emotions and the pain they experience, it stands to reason that the researcher could be described as involved in the research. In relaying their responses to the researcher, and by receiving this information, the researcher was instantly associated with the responses. Thus, the researcher could be considered to have deeply contributed to this process and can, therefore, impacted its path. This can be demonstrated by the fact that a single participant could have relayed two different responses to different researchers and in such situations no resolutions existed. Rather, the study must believe the researcher remained impartial. Consequently, this research moved further from science and closer to psychology and thus, the humanities.

It must be recognised that any author or researcher would inevitably possess personal partialities since:

> Participant observation is conducted by a biased human who serves as the instrument for data collection; the researcher must understand how their gender, sexuality, ethnicity, class, and theoretical approach may affect observation, analysis, and interpretation (Kawulich, 2005).

Although such partiality could not be eliminated it was, however, reduced to a minimum level. Moreover, the interview process is subject to continuous review owing to the verbatim transcription of all interviews. Additionally, the interpretive process was continuous and infinite and was supported by the repeated review of the transcriptions. Thus, this allowed the inclusion of a more inclusive thesis. However it is crucial to realise that *"transcripts are not copies or representations of some original reality, they are interpretative constructions that are useful tools for given purposes"* (Fink, 2000). Furthermore, the interpretive process does not indicate that an outcome is noted.

Pope and Mays (2006) reported an array of qualitative methodologies employed in addressing questions on human behaviour, treatment compliance and the undertaking of decisions by organisations, clinical establishments and healthcare sectors. Accordingly, following guidance from Pope and Mays (2006), this thesis employed the following methods: interviews consisted of semi-structured questions and were conducted face-to-face, thereby providing primary data. Following the collection of primary data, a phenomenological strategy was implemented. Finally, the data generated from the interviews were analysed using the QSR NVivo 12 software (QSR International, 2018).

2.2.1.2 Sampling

Polit and Beck (2017) describe sampling as a process involving the selection of participants, situations or a context for the provision of rich data on the phenomenon being investigated. Qualitative research does not involve random sampling, rather, it requires the use of direct sampling approaches such as purposive, criterion, theoretical, convenience and snowball sampling. Purposive sampling involves choosing participants based on the researcher's opinion of which participants would provide rich quality data. Criterion sampling is a technique where participants must meet inclusion criteria, while theoretical sampling describes a method that requires the selection of participants who represent the hypothetical ideas derived from emergent findings. Convenience sampling is a method that results in the selection of participants who are easily accessible, while snowball sampling results in the selection of participants who subsequently refer other participants and this pattern of referral continues, thereby increasing the sample size. Polit and Beck (2017) highlighted the need to carefully choose the key informants as they should be experts on the research phenomenon. Moreover, they should be individuals who are willing to share their expert knowledge with the researcher and they would also have access to participants, particularly following the examination of relevant patient groups. Furthermore, key informants should be capable of presenting the researcher with means of validating their concepts and perceptions.

The use of random sampling or the addition of samples that had not been deliberately selected can affect the credibility of a study. Accordingly, this thesis used both theoretical saturation and purposive sampling techniques. The use of purposive sampling in this thesis ensured that participants could present rich responses to the questions posed. Theoretical saturation is also referred to as theoretical analysis. It defines criteria that are used to establish when enough participants have been recruited for a category. Thus, saturation describes the researcher reaching capacity and not being able to identify additional data to improve the properties of a category (Beck, 2004). Polit and Beck (2004) note that one means of identifying the point of saturation is through observation of experiences. Moreover, the groups that are recognised by the researcher are those that exceed the data range, thus, ensuring data saturation are reached for an indicated category. Therefore, to ensure that categories are established and that they are investigated far beyond the data range derived from purposive sampling, this research used the theoretical saturation methodology (Devers & Frankel, 2000).

Evidently, the use of such sampling techniques means that the research would only require a small sample size as the participants are expected to detail experiences that are in keeping with those recorded in the earlier literature. Moreover, such an approach is suitable for performing small-scale qualitative research that requires in-depth data. Specifically, with respect to this thesis, the sample consisted of individuals living with peripheral neuropathy who were also receiving treatment at Ibn Sina Hospital, of which there was only a small number. Accordingly, the use of purposive sampling ensured that the researcher selected participants from this population. The participants were, therefore, able to provide comprehensive data but were also capable of eloquently and coherently conversing about their experiences with peripheral neuropathy. The study also involved others who could discuss their experiences clearly as a result of other earlier experiences that impacted them similarly. Overall, purposive sampling helped the researcher in gathering quality data which enhanced the researcher’s ability to form themes. Moreover, this process helped the researcher establish that the same sample could be used for both the interview study and the process map study.

2.2.1.3 Data saturation

By extending the recruitment process across several weeks, the researcher was able to avoid over recruitment. Moreover, this technique also allowed the researcher to reply to participants in appropriate time. Five invitation letters were provided to a duty nurse by the researcher on a weekly basis. The researcher then collected the responses at the end of the week, thereby allowing the researcher to efficiently record all participants who had a desire to participate. This also ensured the researcher could estimate the number of participants recruited each week, thereby allowing the researcher to adjust the number of invitation letters distributed in subsequent weeks. The researcher had determined that only 10 to 15 weeks were needed for completion of the recruitment and interview processes. This ensured two weeks were given per participant with enough time for transcribing of interviews and performing the initial analysis, before completing the remaining interviews. Weeks where uptake of participants was low was corrected by distributing more invitation numbers in the weeks that followed and vice versa.

2.3 Overview of the three studies and methods used in each study

Section 2.3 explains the thesis research question and the supplementary questions that followed. This explanation is significant to understanding the methodology of the thesis. The methodology, research question, and supplementary questions will be clarified to provide an understanding of the thesis. The main objective of the current thesis was to explore the experiences of people living with by peripheral neuropathy in Kuwait, their management and coping strategies, along with their use of various medications. Therefore, the main research question was: what are participants’ experiences with management and coping strategies for peripheral neuropathy in Kuwait? Together with this main question, the following supplementary questions were addressed:

A) Reviewing existing literature that explores the experiences of people living with peripheral neuropathy.

B) What are the experiences of people living with peripheral neuropathy in Kuwait? A process map of the patient journey.

C) Exploring the experiences of the people living with peripheral neuropathy in Kuwait including the coping strategies and pharmacological and non-pharmacological treatments.

One of the three themes discovered following the systematic review was: ‘Is the body sick or the mind?’ was the question asked of the initial study. This constituted a systematic review of the experiences of individuals living with peripheral neuropathy. Specifically, it sought to examine both social and psychological experiences of individuals living with peripheral neuropathy, together with their self-management styles. Accordingly, the methodology chosen involved qualitative constructivism. which describes reality as the outcome of the human mind and the experiences it goes through. Therefore, as this thesis sought to understand how the experiences impacted the responses of individuals living with peripheral neuropathy, the use of constructivism qualitatively by collating qualitative data through interviews helped in answering this point (Elliott *et al.*, 2000). Qualitative constructivism was founded on phenomenology and interpretivism. Phenomenology is a philosophical examination of individual experiences (Davidsen, 2012), while interpretivism is a theory that describes how individuals interpret their actions can base a means of furthering our understanding of the world around us. Collectively, the use of qualitative constructivism, phenomenology and interpretivism aided in the use of interviews to gain a philosophical understanding from the participant’s perspective of their experience (Ryan, 2018), together with an understanding of their interpretation of their coping mechanisms.

Themes identified in the 23 studies included peripheral neuropathy symptoms, the impact on quality of life and well-being of people living with peripheral neuropathy and the relationship between the healthcare professional and the individual living with the condition. The themes were then addressed and transformed using thematic synthesis. Thematic synthesis involved the use of participant quotes and any other text reported in the "results" or "findings", in the studies selected. Each article's full text was reviewed to guarantee that all material related to the participants' experiences of those living with peripheral neuropathy were included in the synthesis process. Each article's concepts were compared to each other, thereby allowing the researcher to note the similarities and differences between them with the focus being on extrapolating specific themes. These were detailed before the data from each study was classified including participant perspectives on themselves, the researcher and the two together and this was based on their individual themes (Critical Appraisal Skills Programme, 2018). To this end, most of the data included in this research was derived from the participant quotes identified in the 23 articles chosen. Accordingly, a list of present themes was extricated by employing this qualitative strategy, thus, constituting the initial analysis. Key data was highlighted and descriptions of them given by completion of line-by-line coding. Numerous reviews were conducted on each article to guarantee all relevant information on the subject being analysed was included in the coding. The outcomes from all included studies were first defined and then assessed to form the themes.

The application of thematic synthesis in the systematic review allowed the identification, analysis and establishing of the primary themes in the selected studies (Thaivalappil, Waddell, Greig, Meldrum, & Young, 2018). Although these themes mirrored those outlined in the indicated publications, the thematic synthesis also provided novel interpretations of the themes that transcends the interpretations provided by the primary studies. However, the novel themes generated did not challenge the original themes; rather, they resulted in the generation of a series of secondary concepts from each study regarding the positive features of peripheral neuropathy. Examples include the realisation that certain participants had higher levels of resilience which, in turn, allowed them to handle their experiences of peripheral neuropathy better. Moreover, individuals selected to direct their energy towards helping individuals undergoing the same experiences instead of directing their energy inwards. Thus, feelings of solidarity and empathy were generated.

Overall, the themes from each of the 23 studies were collated by the researcher to form a novel and powerful theme. The philosophical assumptions underlying the thematic synthesis must be considered by the researcher as a critical realist lens was employed as the philosophical strategy in thematic synthesis, where comprehension of the experiences was primarily initiated through the researcher's personal viewpoints and beliefs (Tong, Flemming, McInnes, Oliver, & Craig, 2012). Two out of the three themes identified were deductive and one was creative (novel or inductive strategy). The ENhancing Transparency in REporting the synthesis of Qualitative research (ENTREQ) checklist was employed as a reporting standard in this review and as a synthesis guide for qualitative research (Tong *et al.*, 2012). The ENTREQ checklist allowed the researcher to detail the elements that were most frequently associated with the synthesis of qualitative health studies; specifically, the investigation of and selection of qualitative research, quality appraisal and techniques for the synthesis of qualitative findings.

The first two themes confirmed themes identified previously in the literature; namely, is the body sick or the mind; the relationship between the patient and the healthcare professional. The third theme; positive aspects of peripheral neuropathy, was a novel theme that emerged through the systematic analysis in this thesis. Owing to the central concept of the healthcare journey and how participants interacted with their healthcare professionals, the researcher established a need for a detailed examination of the journey of people living with peripheral neuropathy . Consequently, this resulted in the second study entitled, 'The Experiences of People Living with Peripheral Neuropathy in Kuwait: A Process Map of the Patient Journey'. As this study required an exploratory, qualitative methodology, semi-structured interviews together with the phenomenology approach were applied. The study was conducted on the 25 participants, and data saturation was achieved with no new themes identified. A semi-structured interview guide was used to assess the experiences of participants. Initially, demographic-related questions were put to participants covering the participants' sex, age and nationality. Moreover, questions also assessed the duration of the peripheral neuropathy condition and any co morbidities experienced. The interviews consisted of open-ended questions which were initiated with general questions querying the pain felt. Subsequently, more specific questions were asked regarding the healthcare process including any medication, therapy and if they considered their care to be incomplete. The literature formed the basis for the interview questions, and this was developed together with consideration of the Kuwaiti healthcare process and the culture.

All transcripts were added to NVivo12 software for the purpose of data management and data analysis. Manual coding of the data was performed first. The data was then coded inductively following familiarisation. The next steps involved the undertaking of both text-based and coding queries before extracting data leading to the generation of a first report.

The researcher then identified the need to structure a flow chart, having to choose between the process mapping and the value stream mapping method. The former process mapping method targets only one process and only establishes any non-value that is added within a single process (Timothy *et al.*, 2010). Thus, it allowed deliberate planning in the short term which ensured the development of steps that are small but that are also applicable. On the other hand, value stream mapping accounts for the full value stream and determines the non-value added, while also accounting for the various system enhancements, and it was typically important but challenging to perform. Value stream mapping should be applied to reduce inconsistencies and create greater levels of standardisation across departments and the organisation.

Observation and capturing data “in situ” are necessary to introduce the above and eliminate non-value adding steps between the different processes (Grove *et al.*, 2010). Moreover, it allows the planning of long-term approaches. Overall, while value stream mapping centres on pushing forth changes in a process, the process mapping technique, together with mining and discovery instead, focuses on enhancing the efficacy of processes. Consequently, to ensure the individuals living with peripheral neuropathy experienced a more efficient journey, the process mapping method was selected.

The following well-designed strategy was used to generate the process map. Therefore, this guaranteed a detailed account of the participant experience and was subsequently implemented on the data. Four transcripts provided rich data, and this was attributed to the interview duration, interviewee’s articulacy and pain gravity. The richness of the data in these four transcripts meant they were selected for the outlining of four specific pathways. The pathways were then contrasted and compared to establish similarities (pharmacological therapies and referrals) and differences (including discrepancies in length of waiting times and in referral times). Collectively, these led to the production of an initial process map. Minor facts were mirrored in the maps, such as symptoms, signs, diagnostic outcomes and physical exams, as well as referral and follow-up pathways and the participant’s present condition. Next, a second version was produced following the addition of data from the additional 21 transcripts. This involved the inclusion of extra information which was clarified by combining it with the data in the initial process map. Following many reviews, an abridged and shortened process map was generated that was inclusive of the experiences of all individual's living with peripheral neuropathy in Kuwait.

First, four participant journeys were mapped out comprehensively. Subsequently, they were compared and summarised into one process map. The additional 21 participant interviews were then reviewed against the single process map. Overall, this research enhanced the need to assess the experiences of individuals living with peripheral neuropathy in Kuwait from the perspective of clinical management, in addition to their coping and management approaches.

Finally, the third study was entitled ‘People’s experiences living with peripheral neuropathy in Kuwait: A qualitative study’. This study utilised the same data set that was obtained using the semi-structured interviews in the previous study. The data was manually coded following familiarisation, then a combination of text search and coding queries were executed to extract preliminary nodes and themes. Expert peers were then debriefed on the extracted themes and discussions were held.

Thematic analysis technique was employed thereby allowing the identification of themes in the data. These themes were then analysed, and conclusions drawn, by applying the concept of interpretivism. Thematic analysis of the previously collected data was selected as it presented a structure for detailed comprehension of the experiences of individuals living with peripheral neuropathy, while also providing an explanation through study of the themes extracted. The application of this methodology in this thesis allowed the construction of a framework that enhanced comprehension of the experiences of individuals living with peripheral neuropathy while also presenting an opportunity to interpret the experiences using the themes.

2.4 Methodological approach

2.4.1 Qualitative research approaches

With qualitative research, there are several approaches that can be employed including grounded theory, phenomenology, the case study technique or ethnography. A comparison of the various theories will now be described.

2.4.1.1 Grounded Theory

First, Creswell (2007) describes the grounded theory as *"a qualitative stage of inquiry in which the researcher derives a general abstract theory of process, action or interaction grounded in the views of participants in a study"*. The grounded theory is typically employed in sociology and seeks to define a hypothesis by rationalising data findings, thereby allowing further understanding of the researched condition. Observations and interviews are used to collect data and are achieved by the researcher observing the daily occurrences in the world prior to analysing the data without showing bias through applying their own preconceptions. The data employs the constant comparison method due to the need to continuously compare data findings of one method of data collection against another. Common themes that emerge can be used to form a framework.

Thus, the investigation of interactions, processes or actions is conducted through a process of open coding, axial coding and ending in selective coding and an analytical strategy that leads to the inductive development of a hypothesis of the researched condition.

2.4.1.2 Phenomenology

Second is phenomenology, a method frequently employed in philosophical research and where the study seeks to understand the events and experiences of individuals. Once again, data is collected using interviews, observation and documentation methodologies, while also using analytical strategies to establish an individual's primary experiences of an occurrence. As a qualitative method, phenomenology seeks to describe the reality of a situation. The researcher aims to employ a precise definition of the phenomenon by keeping to the facts and without applying a pre-conceived structure. Thus, in the context of this thesis, the researcher seeks to understand both the psychological and social phenomena from the participant's perspective. The researcher would achieve this by centring on the association of individuals with the issue under study as well as their authentic experiences of it. Thus, the analysis is used to interpret and define experiences by describing major and sub themes. Through the interviews, the researcher will derive common themes, first from a control set of interviews and then by extending it to all the interviews. The overall finding of the phenomenological study is the provision of a comprehensive description of themes that define the real meaning of the participant's experience.

When used in healthcare, the actual significance of the experience together with its potential benefits and drawbacks and how they impact the individual, can be examined using phenomenology. However, this methodology does not identify the reasons for experiences and the overall aim is to clarify meanings of experiences. A clinical application of phenomenology is observed in mental health research; an area that was traditionally governed by quantitative methods. With the advent of qualitative research in mental health studies, more researchers have opted for this technique. The increasing use of this methodology is primarily attributed to such methods allowing participants to readily communicate their experiences and to deliberate them with others within a similar organisation or community. Such communities can be in the shape of forums where participants can maintain diaries of their experiences, thereby, ensuring all communication is clear and visible to all**.**

2.4.1.3 Case studies

The third methodology is case studies which are employed in numerous fields including psychology, sociology, science, law, medicine, business and education. By using simple questions such as how, why and when, the researcher can conduct an in-depth assessment of multiple events. Accordingly, case studies are identified as empirical research as they are founded on experience and knowledge. Moreover, small sample sizes can be employed to gather the data and, therefore, control events. Similar to phenomenology, data is collected using interviews, observation and documentation methods and the findings are reviewed using analytical strategies. The final outcome is usually a report of the study context, established trends and any challenges noted. In healthcare, case studies can be used to assess the impact of one event (such as the use of private healthcare establishments to employ care givers) in affecting another (such as the number of care givers recruited to National Health Service (NHS) posts). The employment of case study researcher in this manner means the research can examine the individuals in their natural setting ; therefore, allowing the assessment of the phenomena in context.

2.4.1.4 Ethnography

The final methodology is typically used in anthropology. Essentially, ethnography is concerned with describing the cultural characteristics of a group. In keeping with the grounded method, the data is typically collected using observations and interviews mainly. It also involves the investigation of a target group and its analysis. The findings generated would then be used to define trends in their culture. In contrast to the previous three methods, where face-to-face interviews are the norm, this method requires the researcher actively take part in each day of an individual's life over prolonged periods. The researcher will conduct observations throughout this period by asking questions and listening to exchanges and generally collating all data that would aid in explaining and clarifying the topic under investigation. Throughout the research they will converse with participants and such interactions will form part of the data collection together with listening and observing. Thus, collectively, these methods will allow the iterative development of answers to the research question posed.

To aid their research, the researcher will be continuously noting observations and interactions, while also commenting on events as they occur, thus aiding the iterative process. The notes collated will form the basis of their analysis and significant findings. Ethnography, however, centres on daily events and doesn't provide the researcher with an understanding of the broader context. Furthermore, ethnography is quite laborious as the observation stage may take several weeks or months. Ethnography is similar to case studies as the analysis involves identifying trends in participant behaviour and thought process. The comparison of the behaviours or thoughts of different participants and comparing trends against each other allows the development of flowcharts and maps leading to a narrative outlining a situation or other such event.

2.4.2 Suitability of methodologies

Given that this thesis did not seek to identify cultural characteristics of individuals living with peripheral neuropathy in Kuwait, it was clear from the comparison above that although ethnography could have been applied in this thesis, however, it was not the best method to employ considering the needs of this thesis. Furthermore, as this research did not require an in-depth recounting of various events, the case study methodology would also be inappropriate. Therefore, the grounded theory and phenomenology were the most suitable. To establish which was more suited to this thesis, the two methods are described in detail below.

In 1967, Glaser and Strauss required a means for conducting continuous comparative analysis, and so the grounded theory was developed. Through the systematic collection of data and its instant analysis, a theory is formed. The methods used in the theory can be divided into three:

A) Participation observation involving conducting fieldwork to record the participant's daily routines and personal experiences.

B) Interviewing involving the collation of data from a group of individuals using interviews that are either structured or semi-structured.

C) The collation of texts and artefacts by assessing comprehensive literature sets including charts and protocols.

The grounded theory has many benefits; however, the phenomenological strategy is more powerful regarding the evaluation of the experiences of participants and the way they impact their individual social health. The grounded theory is an inductive approach that details systematic standards for collecting, synthesising, analysing and conceptualising qualitative information with the aim of creating hypotheses. Phenomenology, however, centres on how common a real experience is with reference to a specific group. The primary aim of the phenomenological strategy is to define the reality of a specific concept (Creswell, 2013). Normally, the interviews are held with participants who have direct experience of an occurrence, condition or setting. Moustakas (1994), noted that the aim of the interviews in phenomenology is the gaining of responses to two general questions: What experiences do you possess regarding the occurrence? What circumstances or conditions have essentially impacted your experiences of the occurrence? Moreover, other types of information, including reports, observations and art materials, may also be employed. Findings generated are reviewed continuously ensuring the constant removal of duplicated data and themes to allow formation of meaningful clusters (Creswell, 2013). Ultimately, this cyclic process results in the researcher creating a universal definition of the occurrence, condition or setting, thereby resulting in them develop deep comprehension of the occurrence.

The aim of this thesis was not to define a theory nor was it to provide a definite answer to a specific question. Rather, this research was a general investigation of individuals living with peripheral neuropathy. As described by Glaser and Holton (2007), the grounded theory aims to examine a concept. However, the objective of this thesis was to research a trend through the study of individuals. The thesis centred on researching the emotions of individuals and formed a prime example of the contrast between examining individuals rather than matter. The grounded theory seeks to address ideas which exist, whilst phenomenological strategies centre on individuals. Moreover, this research did not employ means used in the grounded theory such as the use of observation-fieldwork that aims at studying the daily habits of participants. Rather, it employed phenomenology which seeks to investigate how certain subject matter impacts an individual's reality. Accordingly, the target of this research is to acknowledge how the participants define their experiences by using their individual words to describe the matter and their version of it.

Had the researcher only conducted an observation of the participants, the data generated would not have been beneficial enough to address the thesis objectives as it would only establish the personal opinions of the researcher. Additionally, the thesis employed a semi-structured interview methodology in two of the studies that is common to both the grounded theory and phenomenology. However, the studies did not involve the collation of words, protocols, charts or artefacts. Hence, the researcher selected phenomenology as the qualitative approach employed in this thesis. The selection of this strategy was attributed to phenomenology allowing the emphasising of the essential features of the participant's experiences. In doing so, phenomenology fulfilled this thesis's primary aim. Prior to detailing the methodological strategy, it is worth noting the three studies that were performed as described in the next section.

2.4.3 Use of Phenomenology in this thesis

Implementation of phenomenology and interpretivism was adopted in the first study and aided the elucidation of the three primary themes in the systematic literature review. Specifically the themes identified were, the association between clinical professionals and the patient, establishing whether the condition affected one's physical or mental health and the possible benefits of a life living with peripheral neuropathy. It is worth noting, however, that all these themes were established following research performed in the Western world. The literature review highlighted a gap in the literature regarding the need to investigate the experiences of people living with peripheral neuropathy in Kuwait. No such studies were identified through the review of the literature. As the patient's healthcare experience and their association with clinical professionals was indicated as a core concept. This established the necessity for comprehensive research of these subjects and the creation of a process map outlining the journey travelled by individual's living with peripheral neuropathy and residing in Kuwait. Accordingly, this led to the design of the interview study and the process map study. The study data was collated through semi-structured interviews which allowed the researcher to develop a comprehensive understanding of the experiences of individuals living with peripheral neuropathy in Kuwait.

Interviews constitute a systematic method and a rational means of collecting data from participants in a study. Kvale (1996) described interviews as a means of collating descriptive data linked to an individual and their experience of the specific event being researched. Nonetheless, opting to undertake interviews rather than applying a focused group approach was a difficult choice. The latter method is also a qualitative methodology that involves a team of typically six to 12 individuals who are grouped together to conduct directed discourse on a specific subject. Such focus groups are beneficial in identifying normal occurrences in a group, gathering opinions about such normal occurrences and in identifying the range of characteristics in each population. Furthermore, they carry the advantage of collecting data within a short time frame while also forming group dynamics that encourage debate and discussions. These benefits, however, did not fit with the aim of this thesis. The researching of this study required the benefits of conducting interviews which are designed to collate the individual experiences of people, while also collating data on their emotions and opinions. Interviews have the added benefit of managing issues that are considered sensitive and the encouraging of participants to offer detailed answers. Moreover, they encourage nuances and result in ambiguity which allows the formation of interpretive views. As the interview technique carried benefits that were considered in keeping with this thesis's aims, the researcher took the decision to incorporate this methodology and to conduct 25 semi-structured interviews to address the aim of gaining deeper understanding of the journey of individuals living with peripheral neuropathy in Kuwait.

The availability of various forms of interview styles is noted; including non-directive, semi-structured, structured and unstructured interviews. However, the researcher's choice of the semi-structured interview is attributed to the need to modify questions in accordance with how each interview is progressing and to ensure the interview flows well (Saunders *et al*., 2007).

Semi-structured interviews have several benefits including enabling the use of complex questions which can be further explained by the researcher as required when interviewing. Moreover, these questions are similar to open-ended questions as they don't restrict the response generated from the interviewee. Rather, they enable the researcher to direct various questions at the interviewee while directing the questions to the core research subject. Additionally, as noted by Chadwick *et al*. (2008), non-verbal cues can aid the interviewer and allow them to manage the interview as required.

In addition to aiding the researcher in studying the experiences of individuals living with peripheral neuropathy, interviews also allow the understanding of the emotions that result from living with neuropathic pain and the experiences the participants had with current forms of management. Moreover, the data generated from interviews will be unrestricted and comprehensive compared to other available methods (for example, questionnaires).

The researcher primarily centred on ensuring efficacious collation of data which would subsequently allow the data analysis steps to be consistent. Inclusion criteria indicated that the participants must have had a diagnosis of peripheral neuropathy for a minimum of six months and that they must have undertaken treatment for it. Confidentiality was maintained and assured for all participants; noting that both their personal data and answers would not be disclosed through this thesis. In keeping with the Instructional Assessment Resources (IAR) (2012) standards, the duration of interviews would be kept to an appropriate length to ensure participants were always comfortable and to maintain suitable response rates. A few days prior to the interview scheduled, participants were sent reminders that required their confirmation of attendance. Moreover, all participants were debriefed on the thesis aim immediately before the interviews were initiated. The researcher ensured that the language employed, and the questions asked were easily understood and followed by all participants.

The questions included in this thesis followed the styles of Craig (2012) and of Lönnstedt *et al.* (2011). Earlier research such as Hensing, Sverker, and Leijon (2007) and Sofaer-Bennett *et al.* (2007a) was used in this thesis to establish the interview structure. Accordingly, the interviews questions consisted of a clear background of the participants in the studies and their experiences of the pain resultant from the peripheral neuropathy. The responses generated sought to describe what living with peripheral neuropathy meant which required the employment of open questions. For example, one question asked was, ‘Tell me about a situation when peripheral neuropathy was a hindrance and a restriction’.

The questions employed were designed for the collection of the maximum amount of data regarding an individual’s experience of living with peripheral neuropathy. All questions were formulated to address the research aims and objectives on all the matters being investigated. The open-ended questions used were impartial, sensitive and comprehensible (Chadwick *et al.*, 2008). The interview was opened using simple questions which ensured the participants relaxed into the interview process. These questions were followed by more challenging, sensitive questions, once the researcher noticed the participants relax into the process and their confidence was enhanced.

As this thesis is not aiming to prove a specific hypothesis, this allows the researcher to be entirely open with the participants. The researcher sought to relate to the participant’s experience as much as possible. ‘Leading’ the participants is a potential risk of such a methodology as the researcher may identify a matter relating to the participant from which the researcher may try to extricate a particular response. The aim is to prevent such an occurrence. Despite the desire to relate to the participant's experience, the researcher must ensure they are impartial and straightforward. Throughout the interview process, the researcher ensured the participants could detail their experiences, which the researcher subsequently detailed in the thesis findings, thereby promoting the impartiality of the researcher.

To allow the interview schedule to be set and to ensure it was appropriate, a pilot study was performed on five individuals who were randomly chosen. This allowed the researcher to determine the suitability of the interview questions and the ability of participants to respond comfortably to the questions detailed. Any subsequent modifications were applied, thereby ensuring all questions were simple to understand and respond to and that the responses generated were the optimum responses. Interviews were one hour in length and no follow ups were scheduled.

2.5 Ethical considerations, dependability and confidentiality

The performance of primary research in healthcare settings and any studies that involve the collection of participant data can be challenging ethically. Similarly, studies such as this research can require researchers to ask participants challenging questions or may lead to the identification of information that participants may be uncomfortable sharing. All these reasons are why the consent process is considered a vital part of research and why it must also be done correctly, thereby ensuring that participants are fully aware of the research aims and the aims of the interview. Participants must also be notified that their data would be secure and that neither their personal identifiers nor their answers would be accessible by the public. Researchers can be assisted by various international bodies on the correct ethical standards such as those used by the National Health Services (NHS) in the UK and British Psychological Society (BPS). Such establishments greatly benefitted this thesis. Following a review of their guidelines, the researcher designed the consent form and specified this thesis's ethical guidelines. In keeping with Olsen (2003), the following four criteria were noted as crucial for a paper to accurately and efficaciously meet the required ethical standards, including:

A. Specifying the research purpose.

B. Detailing research conditions, which necessitate the research and ensure that it is in keeping with ethical and moral standards.

C. Ensures a detailed examination of the thesis topic.

D. Cautiously examines the thesis methodology.

The researcher employed these criteria to conduct detailed examinations of all ethical matters linked to the thesis subject and including the methods employed. Moreover, the researcher ensured that none of the ethical standards were broken. A participant information sheet was distributed by the nursing staff (outpatient clinic and ward staff), after having obtained permission from the neurology specialist and the head of the neurology department. A patient information sheet (PIS) was also included in the invitation pack and it served two specific purposes. First, it aimed to provide patients with ample information on the study and how it would be conducted, and second it detailed what the individual would undergo if they chose to participate. The researcher required all participants to provide written consent to the research by signing the supplied consent forms. The forms also explained the participants' rights with respect to upkeep of all ethical standards. Consequently, this data included their rights to being informed of the research aims and objectives, that the participants would not be used in any manner if they did not consent nor would they be deceived. Furthermore, that the participant had the right to discontinue their participation as and when they deemed it necessary. Participants were informed that their data would be anonymised and securely stored, that they would not be placed in a position of danger and that they could follow the research developments whenever they so desired.

Given the sensitive nature of the thesis topic, ethical approval was obtained from the University of Reading Ethics Committee, from Kuwait's Ministry of Health, specifically from the Standing Committee for Health and Medical Research Coordination and from the Human Ethics Committee (at the Kuwait Institute for Medical Specialisation). The research was designed and outlined, thereby ensuring that participants were always kept safe and that ethical rules were always followed. Moreover, all participants were informed of the research procedures.

All participant data and their responses together with any communication with the researchers were kept under the strictest levels of confidentiality. Participants were also given the time to consider the research and its requirements, thereby ensuring they were fully informed prior to deciding whether they wanted to participate. This ensured they were given the freedom to choose and avoided bias. The consent form aided the ethical process as it not only outlined the thesis requirements, aims and objectives, but also detailed the measures of confidentiality and the anonymisation of participant data. This gave participants the confidence in knowing that their anonymity would not be compromised, and their data would not be passed to external bodies. Given that certain participants may not speak English, the consent form was also translated into Arabic. Thus, this ensured the maintenance of effective communication between the researcher and the participants and that the data collected was both reliable and valid. Overall, this ensured that participants were able to receive enhanced knowledge, that all their questions were answered with regards to their expectations of the research and that the participants developed a trustful and honest relationship with the researcher. The research process and participant confidentiality was further enhanced by assigning a code to each participant to anonymise their data.

2.5.1 Data protection and confidentiality

All the interviews were recorded on an audio-recorder, and the recordings were downloaded and stored on a secure device immediately after the interview. All recordings were then transcribed into a Word document that was password protected to ensure all data was kept secure. To ensure further participant confidentiality all transcripts were only labelled with codes and no participant details were noted on any transcripts. Transcript files were also password protected for added security. Once the data collection was complete, all data was stored in a secure filing cabinet that was stored in a secure office situated at the University of Reading’s School of Pharmacy.

The filing cabinet could only be accessed by the researcher and their supervisor. The data will be maintained for the duration of six years as specified by the policies of the University of Reading.

2.6 Trustworthiness, transferability, rigour and reflexivity

The researcher had various reasons for selecting this topic. Not only is the researcher acquainted with those who live with peripheral neuropathy but also, the researcher has a personal connection to an individual living with peripheral neuropathy; their mother. Consequently, the researcher has directly observed the impacts of this condition. Owing to the researcher having observed their mother living with peripheral neuropathy, the researcher's level of empathy for the participants is understandable. The researcher also grew up in Kuwait making them highly informed of both the lifestyle and the culture of the participants.

2.6.1 Trustworthiness, transferability and rigour

The research can be applied to other populations of individuals living with peripheral neuropathy and nations owing to the transferability of the methods employed. Moreover, given that the thesis focused on the participant experience, and despite the small sample size, the findings of the thesis are considered valid. Additionally, detailed responses were given to all questions put to participants during the interview process. Questions could be modified as required by the researcher, for instance, in situations where participants were not happy to give a complete answer. By modifying the questions, the researcher helped the participant relate to the question (Appendix 3). The thesis's reliability was further increased by noting the exact context it was set in (Kuwait). This also demonstrated that the examination of different sample groups could lead to different findings. The thesis was not limited by the inclusion of only one hospital in the research nor by the small sample size. As previously noted, this was due to the detailed responses provided by the participants for all interview questions. The reason for only including one hospital, Ibn Sina Hospital, in this research, because this is the only hospital in Kuwait with a Neurology Department. The generalisability of the thesis was also not impacted by the sample size, especially as specific criteria determined the participants selected for assessment. Thus, ensuring that the context and the interview location was the same for all participants.

The supervisors continuously reviewed all interview transcripts, the findings identified by the researcher and any recommendations made, thereby helping to develop the thesis. The studies validity was strengthened through the review of the initial four transcripts that were used to form the initial process map by both the researcher's supervisor and the Kuwaiti advisory board. The advisory board was made up of Dr Jasem Al-Hashel who is the Head of Neurology at Ibn Sina and a senior neurologist. Dr Samar Farouk was also an advisor and a senior neurologist. Dr Al-Hashel and Dr Farouk have both used thematic analysis and have deep experience in qualitative interviews as well as several publications in the field. Both the advisory board and the supervisors also helped the researcher in applying an agreed system for coding.

The outcomes of this thesis were presented locally at Ibn Sina Hospital, and at both the national level and the international stage. The thesis was also reported and submitted to peer reviewed journals for publication. The thesis findings are also being implemented in various ways. For example, at Ibn Sina Hospital, the proposals derived from the thesis findings are being reviewed with a view of their inclusion in the hospital's standards on how neurological disorders should be managed. Moreover, the thesis proposals are being altered to allow their distribution and to make them available to different professional groups including clinicians, neurology consultants, general practitioners, psychologists, mental health staff and nursing groups. The groups also include counsellors, policymakers and family members. Finally, the thesis recommendations are also being reviewed for a webpage on the website of the Ibn Sina Hospital and on the website of the Ministry of Health in Kuwait.

To ensure the studies rigour was maintained, the researcher made their experience known to all participants, including their experience as a pharmacist, researcher and administrator at the Kuwait Drug and Food Control Administration (Ministry of

Health). Providing participants with their personal background before each interview enhanced the participant’s trust in the researcher and increased their desire to contribute to the research. Furthermore, the researcher ensured all participants understood that the process was only for research and was not a diagnostic process. Nor was it for the purposes of advising the participants on their condition. In doing so the researcher attempted to avoid diagnostic or advisory questions from the participants that could lead to unrelated discussions of a personal nature. Such situations could have been time consuming. When such a situation arose, the researcher showed empathy towards the participant but also directed the participant back to the research topic. They would also aid them by directing them to available help such as that provided by counsellors. The researcher made participants aware that they did not have to answer any questions that impacted them emotionally, nor did the researcher delve further into matters that were considered sensitive.

2.6.2 Reflexivity

Ensuring the practice of reflexivity, the researcher recorded their thoughts in a personal diary in relation to the research. In doing so, the researcher noted their personal experiences and the reasons for each step they took in the research process. The term reflexivity can be defined as *"an effort to reflect on how the researcher is located in a particular social, political, cultural and linguistic context"* (Alvesson, 2002). This is in opposition to the way clinicians are trained as they are required to eliminate all of themselves except a little of their self from a consultation. This ensures that they can work in a patient-centred way. However, when the researcher focuses on themselves, they are then able to establish any assumptions or values they may hold at a subconscious level that may also be directing the interview. Reflexivity is therefore a process that is required to ensure that only the knowledge derived from the participants is included in the data collection and in the interpretation of the findings (Alvesson & Skoldberg, 2000). Reflexivity also helps the researcher to understand the potential impact of their existing knowledge on the condition, the assumptions noted and the finding interpretations.

2.7 Conclusion

This chapter discussed the optimal research approaches required in order to achieve the objectives of the thesis. The appropriate methodological approach was also outlined in this chapter, which included a description of the research methodology, philosophical worldview, a summary of the three studies conducted, as well as a discussion on the reliability and consistency of each of the three studies. The decision to adopt a certain methodology over another was rationally justified. This chapter also discussed the present thesis’s reflexivity, sampling techniques, and methods of analysis. This chapter presented a clear examination of each topic in the thesis by first providing a general perspective before focussing a specific lens on the objectives of each of the three studies conducted. The following chapters will discuss the studies included in the thesis in detail.

CHAPTER THREE

Study 1: Is the body sick or the mind? A systematic review of people's experiences of peripheral neuropathy.

3.1 Publication relevance to thesis

This chapter presents the first paper in this PhD thesis. The paper was submitted to the peer-reviewed journal Health Expectations in November 2019. Although the aetiology of peripheral neuropathy has been studied in-depth by many, a comprehensive review of the studies exploring the experiences of people living with peripheral neuropathy was lacking. Hence this qualitative study was aimed at reviewing existing literature that explored the experiences of people living with peripheral neuropathy. The methodology adopted included systematically searching electronic databases (Scopus, PubMed, and Web of Science) using key terms, appraising the quality of studies (using the Critical Appraisal Skills Programme), and conducting thematic synthesis to identify themes in the data. Supplementary materials, consisting of all relevant tables and figures, can be found at the end of this chapter.

3.2 Title of publication (submitted to *Health Expectations*)

Is the body sick or the mind? A systematic review of people's experiences of peripheral neuropathy.

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Key words: Systematic review, patient experience, behaviour change, qualitative methods, pain, quality of life, peripheral neuropathic pain.

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Conflict of Interest

MA, AH and KR declare that they have no competing interests.

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Is the body sick or the mind? A systematic review of people's experiences of peripheral neuropathy

Abstract

Background: Peripheral neuropathy is a neurological disease characterised by pain and caused by conditions such as diabetes. Although the aetiology of the condition has been studied in-depth, a review of studies exploring the experiences of people living with peripheral neuropathy is lacking.

Objective: The aim of this systematic review was to explore the experiences of people living with peripheral neuropathy, using a qualitative research.

Methods: Key terms were used to search electronic databases, with studies further identified manually from the reference lists of selected full text studies. The quality of the studies selected was appraised using the Critical Appraisal Skills Programme (CASP) checklist for qualitative studies. Thematic synthesis was used to draw conclusions from the studies selected.

Results: Twenty-three studies were selected. Three main themes were identified including: is the body sick or the mind; the relationship between the patient and the healthcare professional; and positive aspects of living with peripheral neuropathy. This last theme is novel and was discerned during the synthesis of the published studies.

Conclusion: This paper reviews existing qualitative studies that explore the experiences of people living with peripheral neuropathy. The key finding shows that there is a connection between the body and the mind, which has an impact on the condition of people's lives, and the potential positive aspects that emerge. The need for healthcare professionals to support people living with the condition is highlighted, which includes motivational techniques alongside pharmacological treatment to improve quality of life. Further research is required on the themes that are reported in this paper, particularly in non-Western countries.

Key words: Systematic review, patient experience, behaviour change, qualitative methods, pain, quality of life, peripheral neuropathic pain.

1. Introduction

Neuropathic pain is a medical condition that is a result of damage to the nervous system. Its causes are usually idiopathic but it is often a manifestation of an underlying systemic condition.[1] There are two types of neuropathic pain: central and peripheral. [1,2] Central neuropathic pain presents in the central nervous system due to lesions in the spinal cord from conditions such as multiple sclerosis and spinal cord injury. Peripheral neuropathic pain presents in hands and feet due to lesions in the peripheral nerve. The present review focuses on peripheral neuropathy, which is characterised by pain, numbness, tingling, swelling or muscle weakness. Peripheral neuropathy can be secondary to conditions such as diabetes, or due to side effects of certain medications such as gabapentin, which has been known to cause dizziness and somnolence. [3] It might seem ironical, that the same gabapentin is included as a treatment for peripheral neuropathy. [3]

The main symptom experienced in peripheral neuropathy is pain, but other neurological symptoms such as sensory loss, motor weakness and autonomic disturbances are also observed during the course of the disease. [1,4] The pain experienced could be a dull, stabbing, sharp, or burning sensation combined with or without sensory and motor loss or dysfunction. The severity and extent of these symptoms depend on both the causative disease and the geographical distribution of the affected neural fibres. Peripheral neuropathy is not only psychologically disturbing for the individual, but also often functionally disabling especially due to complications like gangrene or infected wounds. [5] Diagnosing peripheral neuropathy is difficult as it is a complex condition with several underlying causes. In developing countries, these causes are mostly associated with HIV and trauma, whereas in developed countries, diabetes is the leading cause of the condition.[1,6,7]

Peripheral neuropathy is experienced worldwide, and the prevalence increases with age. The importance of addressing this disease can be better understood by taking a look at the international statistics regarding prevalence of peripheral neuropathy. An estimated 20 million people in the USA live with the condition. [8]The prevalence of peripheral neuropathy in people over 55 years old is 2.4% in India and 8% in Italy. [9] A study conducted in Rwanda, which included 507 cases of peripheral neuropathy, showed that the average age of individuals with the condition is 42 years old.[10] In Kuwait, peripheral neuropathy in people with diabetes has been reported to affect 3.9% of people aged over 57 years old.[11]

A number of pharmacological treatments are used in the management of peripheral neuropathy. The most commonly used medications are antidepressants, which include tricyclic antidepressants (for example, amitriptyline), selective serotonin reuptake inhibitors and serotonin–norepinephrine reuptake inhibitors. Antiepileptic drugs are also used, together with topical treatments (creams, foams, gels) and opioid analgesics. Pain from peripheral neuropathy is also managed using neuromodulators such as gabapentin. Although these medications are available at a low cost, they have not been shown to be effective. A number of side effects have also been associated with these drugs, so individuals often choose to rest to relieve their pain, a safer option, rather than taking these medications.[12,13]

The experiences of living with peripheral neuropathy vary. Some people require only minimal pharmacological intervention to permanently relieve their symptoms, while others experience chronic pain due to concurrent major health or psychological issues.[4,14] Most report the geographical distribution of their symptoms as being symmetrical and involving the distal parts of their upper and lower limbs (the so-called 'glove and stocking' distribution). Pain in peripheral neuropathy usually increases as the disease progresses, until small nerve fibres are destroyed and become non-functional. The pain experienced can be spontaneous, induced, constant, or intermittent.[4,15] In addition to causing physical discomfort, peripheral neuropathy can have a negative impact on the quality of personal, social and psychological life of people living with the condition through psychological and emotional consequences such as stress, fear and anxiety.

Although many accept the pain of peripheral neuropathy as part of living with the condition, most do not, leading to emotional withdrawal or depression[13]. The result of this psychological state is that people living with the condition often give up on treatments and isolate themselves from society to deal with the pain in their own way.[13] The aim of this systematic review is to explore the experiences of people living with peripheral neuropathy worldwide. Previous reviews have focused on the treatment methods used in peripheral neuropathy and the effectiveness of different management options. However, there has not yet been a systematic review of studies that explore the experiences of people living with the condition using qualitative research. Accordingly, this gap in the literature provided the rationale for the review. Therefore, the aim of this paper was to explore the experiences of people living with peripheral neuropathy, using a qualitative research methodology.

2. Methods

This systematic review will employ thematic synthesis to identify, analyse and draw conclusions from the main themes in the studies included.[16] While these themes will reflect those presented in the current literature, thematic synthesis will offer a new interpretation of these themes that goes beyond the primary studies. The philosophical assumptions that underpin the thematic synthesis must be taken into consideration. A critical realist lens was the philosophical approach utilised in thematic synthesis, where understanding of reality is mainly initiated by the researcher's own perspectives and beliefs. [17] In total of the three themes, two were deductive and one was creative (novel approach or inductive). The ENhancing Transparency in REporting the synthesis of Qualitative research (ENTREQ) checklist was used in this review as a reporting guide and standard for synthesis of the qualitative research.[17] The ENTREQ checklist allows researchers to report the most commonly associated elements related to the synthesis of qualitative health research, namely, searching and selecting qualitative research, quality appraisal and methods for synthesising qualitative findings.

Search strategy

A comprehensive search of three electronic databases (PubMed, Scopus and Web of Science) was conducted for studies published from January 2000 to December 2018.

No studies had been conducted on peripheral neuropathy before January 2000 and the review was conducted at the beginning of 2019. Two independent reviewers (the researcher and librarian) carried out these searches. Any relevant empirical research that utilised qualitative techniques, such as interviews and focus groups, was searched for as part of this first stage. Through the application of the ENTREQ checklist, keywords were selected based on the appropriate health or clinical topic (peripheral neuropathy), the experiential phenomenon (terms relating to patients' experience), in combination with terms for the qualitative methodology (the qualitative method). The following keywords were used to search the databases: (patient* experien* OR patient* attitud* OR patient* percep* OR patient* perceiv*) AND (medic* OR therap* or treat*) AND (qualitative) AND (peripheral neuropathy OR peripheral neuropathic pain). The reference lists of the studies found were also manually scanned for further studies. A total of 486 studies were identified (479 from the database search and seven from the manual search). Of note, the full databases also were searched using three filters; specifically, the free full text, publication date and species. After title and abstract screening, the texts of 42 studies were deemed potentially relevant for inclusion. After full text screening, 23 studies were selected for critical appraisal by all authors. Figure 1 outlines the literature search strategy and identification of studies included in this review.

<Insert Figure 1>

Selection criteria

Inclusion and exclusion criteria were primarily related to the study methodology and were determined in accordance with the ENTREQ checklist. Those included within the criteria were adult participants living with clinically diagnosed peripheral neuropathy defined as any condition involving damage to the peripheral nerves.[18] Qualitative methods were used, all empirical research was relevant to the search terms, and published in English. Excluded criteria were any studies involving central neuropathic pain, abstracts or posters from meetings or conferences and grey literature, studies relating to trials involving placebo (including randomised controlled trials), quantitative studies, papers published in languages other than English, and no full text available. Age was not included in the exclusion or inclusion criteria as selecting a specific age group would decrease the comprehensiveness of this review. Moreover, specifying age may be considered a bias factor. Nevertheless, it would be much more difficult to interview children. Those over 18 will have more life experience, greater self-awareness and are more likely to be able to articulate their experiences of pain better than children and adolescents. Including children would potentially complicate the data.

Quality appraisal

The full text of the studies that fit the selection criteria were retrieved and reviewed for the quality appraisal. The Critical Appraisal Skills Programme (CASP) checklist was then used as a guide to assess the relevance of the studies included.[19] In total, 23 studies were assessed using this tool, which consists of a ten-question checklist to test the reliability and relevance of the qualitative studies systematically. Based on the 10 question checklist, for each article, the title and abstract, introduction and aims, method and data, data analysis, ethics and bias and results were all individually assessed by producing a "yes", "no " or "can't tell" response if the criterion was met or not, or could not be conclusively determined. All papers met the majority of the quality appraisal criteria and, therefore, a threshold or cut-off point was not required.

Data extraction

After screening the studies for relevance and quality, data extraction was conducted by one of the authors and then reviewed by a co-author. Any discrepancies were discussed to achieve consensus. Four types of data were extracted from each study: publication date, participant characteristics, country of the study and research design.

Synthesis

Existing themes in the 23 studies included peripheral neuropathy symptoms, the impact on quality of life, the well-being of people living with peripheral neuropathy and the relationship between the healthcare professional and the individual living with the condition. The themes were then reviewed and transformed using thematic synthesis. For the thematic synthesis the quotes from participants, and other text reported in the “results” or “findings", in the studies selected were included. The analysis process was performed on the full text of each study to ensure that relevant material related to the experiences of people living with peripheral neuropathy was integrated into the synthesis. The similarities and differences between the studies, in terms of the study aims and themes, were extrapolated. The data in this study was therefore primarily drawn from quotes of participants who were interviewed in the 23 studies selected. This qualitative approach provided a list of themes that were generally derived from the 23 studies which further formed the preliminary analysis. Line-by-line coding, which involved highlighting and providing descriptors of key information, was conducted and each study was read through several times to ensure that all text on the topic was integrated into the coding.[20] Findings from each study were initially described and then analysed to create the themes.

3. Results

The aim of this study was to explore the experiences of people living with peripheral neuropathy. The study focussed on qualitative research which included in-depth interviews with the respondents in order to highlight participants' experiences in rich detail. Data generated were then analysed qualitatively rather than quantitatively as quantitative data primarily involves the comparison of different data groups using specific measurements. Therefore, quantitative data works towards a fixed reality and employs statistical methods for analysis. In contrast, data examined in this thesis is generated from the individual experiences of people living with peripheral neuropathy. Thus, the data is produced as a set of words describing the thoughts, senses and experiences of participants. Such data is mathematically unquantifiable. Rather it is qualitative in nature and is, therefore, more suited to qualitative analyses which examine images or words.[21]

As described in the methods, quality appraisal, data extraction and synthesis were conducted.

Quality appraisal was conducted for the 23 included studies. The aims and objectives of most of the studies were stated and used an appropriate method for data analysis. Three studies did not publish details of ethical approval, but may have been required to provide evidence of this for publication in the peer-reviewed journals which was inferred from the journal impact factor. Table 1 reflects the appraisal rating system used and the rating of each paper.

<Insert Table 1>

The 23 studies included in this review involved a cumulative total of 850 participants, with an age range of 20 to 83 years. Nine studies were conducted in the United Kingdom, four in Sweden, two in the USA, one in USA and Japan combined, one each in Norway, Austria, Canada, Hong Kong, Turkey and the Netherlands and one international study that included participants from Brazil, China, Finland, Spain, Japan and the USA. These studies are summarised in Table 2.

<Insert Table 2>

All studies used qualitative methods, such as interviews and focus groups, to explore the different experiences of living with peripheral neuropathy. Among the twenty-three studies, six provided an insight into the different experiences of those with PNP physically, and with regard to mental and emotional well-being (problems with sleep, stress, anxiety, fright, depression, and relationships with other people) .[22, ,23,24,25,26,27] One study, which included the experiences of patients in several countries, focussed on the influence of different climates and cultures on a person's experience of pain. For example, Hispanic individuals described their pain as 'heart stabbing' and as a 'needle through the heart'. The word 'heart' was used to figuratively indicate the severity of their pain rather than to describe the anatomical area on their chests.[28]

Three major themes were identified through the thematic synthesis of the published studies that reflect patients' experiences of peripheral neuropathy in different countries, and that was mainly carried out based on the patients' quoting in the inductive theme. However, the other two deductive themes were in keeping with many previously published studies. These themes include, is the body sick or the mind; the relationship between the individual living with the condition and the healthcare professional; and positive aspects of living with peripheral neuropathy. Figure 2 illustrates the themes and subthemes that emerged from the analysis of the published literature.

<Insert Figure 2 >

Table 3 outlines a comparison of the different themes emergent from the studies selected for this review by detailing the theme, a description of it together with a description of the sub-themes and then noting the number of studies identifying each theme. The table has to be read using the concept that if a dot is present in the corresponding intersecting cell, it means that the article in that row contributed to the theme mentioned in the corresponding column.

The first theme is, ‘is the body sick or the mind’. The sub-themes identified include the physical symptoms experienced together with their consequences; psychological consequences and the coping mechanisms employed. Most studies identified the first theme as it emerged in 19 studies. The second theme specified ‘the relationship between the patient and the healthcare professional’. The sub-themes identified included the therapeutic strategies; understanding and empathy with a total of five studies identifying this theme. Finally, the third theme specified ‘the positive aspects of living with peripheral neuropathy. The subthemes indicated were the unintended consequences of pain and resilience. This theme was emergent in a total of six studies.

<Insert Table 3>

Is the body sick or the mind?

The relationship and connection between the body and the mind was a crucial part of individuals' experiences of peripheral neuropathy. Many neuropathic diseases involve both physical and mental symptoms. However, pain can be perceived differently and there were individual differences with regards to the experience of pain. The mind has the capacity to either amplify or minimise the level of pain experienced by individuals.[23] Healthcare professionals cannot predict or dictate the level of this pain, so this presents a challenge when caring for people living with peripheral neuropathy. This theme provided a significant insight into the nature of peripheral neuropathy, with the subthemes identified examining the relationship between body and mind in peripheral neuropathy. These subthemes include physical symptoms and their consequences; psychological consequences and coping strategies.

Physical symptoms and their consequences

The physical symptoms of peripheral neuropathy range from twinges to sharp electric shocks. People living with peripheral neuropathy commonly share similar experiences of physical discomfort, such as stabbing, burning, pins and needles and extreme sensitivity to touch. The latter symptom is the most common, with one individual with the condition describing the touch of a nightdress, a very gentle stimulus, precipitating a massive response of pain.

> *The nightdress just touches my leg and I'm immediately reminded of my pain*. (Female, 60 years old)[29]

The consequences of these physical symptoms include lack of sleep and memory loss. Lack of sleep arises due to the pain of peripheral neuropathy impacting every aspect of the person's life. The inability to properly rest is a common complaint of people living with peripheral neuropathy. Sleep disturbances impact cognitive function, neurophysiological organisation and immune system function. People living with peripheral neuropathy experience disturbed sleep as well as reduced sleep efficiency.

> *I cannot decide where I will put my hands and feet when I feel severe pain in the evenings. If there's numbness, my sleep is disturbed. I cannot sleep. Sleep, wake up, sleep again, and wake up, until the morning. I wake up tired.* (Female, 53 years old) [30]

Memory loss is another consequence of peripheral neuropathy. People living with the condition can forget several things on a daily basis, leading them to believe that they are no longer living a normal and healthy life.

> *My attention is distracted very easily. I have extreme forgetfulness. I forget everything. I forget what I'm talking about and what I am doing. I've never burned a meal until now. Things like that are starting to happen. I forget names, things that I will make. This situation causes a big challenge for my life.* (Female, 53 years old) [30]

Psychological consequences

A number of psychological consequences were highlighted by people living with peripheral neuropathy, including depression, isolation and fear. Depression is a common psychiatric disorder but is particularly associated with peripheral neuropathy. The greatest risk of depression and developing a negative attitude towards life was found in older people living with peripheral neuropathy, as indicated by the following quote .

> *Sometimes I panic and think, is this how my life is going to be? That's how I feel*. (Female, 65 years old) [31]

Peripheral neuropathy impacts the psychological state of not only the individual but also their loved ones and particularly their spouse. Relationships between couples where one spouse is experiencing peripheral neuropathy become strained and disintegrate due to the progression of the condition and their subsequent social isolation. People living with peripheral neuropathy often avoid any involvement in social activities due to the pain they experience.

> *Well basically it sends me into fits of depression and sometimes my depression is quite severe … and I feel sometimes I'm ready for the little wooden box.* (Male, 74 years old) [25]

Depression and lack of sleep brought up certain fears. Individuals feared social isolation, a failing marriage, or being alone while in pain. People living with peripheral neuropathy reported few signs of positive feelings or energy owing to the range of limitations placed on their lives due to their condition. Several people described how fear hindered them participating in their usual daily activities.

> *I can't run … I'd go on a nice little run, but I dare not because I'm scared now. You know I'm very scared that I could do some injury to myself … The only thing I do is just walking, you know, as much as I possibly can. As soon as I start feeling tired, I just take a bus.* (Male, 45 years old) [32]

Coping strategies

People living with peripheral neuropathy that took a positive outlook tended to cope better and more effectively manage their pain. Individuals who made sense of their pain found that this could be a helpful coping strategy in managing to live with it. One person suggested that they tried to control some aspect of the pain with the will of their mind.

> *With me, it's just determination to try and override the pain when I'm doing things. I mean I make myself.* (Female, 64 years) [33]

Another tactic in coping with the pain was for people living with the condition to engage in manageable activities such as simple physical exercise and talking to friends, which gave them hope that their condition would improve.

> *And then when I started to exercise and discovered that I could stand up, everything [improvement in their condition] went very fast.* (Male, 50 years old) [34]

The relationship between the patient and the healthcare professional

While the first theme revolved around the people living with the condition and their relationship with their own bodies, this second theme pertains to the relationship that these people have with their healthcare professionals. Healthcare professionals work with people living with peripheral neuropathy to treat and support them with their condition.

Therapeutic approach

Regarding treatments offered by healthcare professionals, some people reported dissatisfaction with what they were offered as they felt it was not effective and they had not been given a cure.

> *And all that time those people have seen me I feel like if it was a car with something wrong with it, they would have found out how to fix it you know.* (Male, age unknown) [35]

Some people living with the condition were happy with the treatment they were provided, along with the conduct and rapport of their healthcare professionals. Therapists in particular enabled people living with peripheral neuropathy to view their condition from a different angle. Individuals reported learning about themselves and how to deal with their pain.

> *The cognitive behavioural therapist has taught me to look at myself in a different way* (Female, 51 years old)[31]

Understanding and empathy

There was some evidence that healthcare professionals could show a lack of understanding of the symptoms of people living with peripheral neuropathy. This had a negative effect on the emotional state of these individuals, with some becoming frustrated with their healthcare professionals.

> *But as I say it's awkward to explain. As I said, you could go one day and it's so bad that you virtually crawl over to the doctor's and then you get a 'what do expect me to do for you' sort of thing.* (Male, age unknown)[35]

Several individuals living with the condition wanted their healthcare professionals to deal with them with empathy and compassion to reduce the feeling of helplessness and distress. When describing their symptoms to their doctors, for example, these individuals felt they were not believed.

> *Sometimes it feels like they don't really believe me … I have a life and I take care of my children and our home and all those things and I try to be happy. You can't see when someone is in pain and I think that they are questioning my pain … it's a feeling you get … and then you get the comments, Are you really in pain? You seem so happy.* (Female, 42 years old)[31]

Positive aspects of peripheral neuropathy

Few published studies have explored the theme of the advantages of peripheral neuropathy. The present review presents the novel idea that there are positive aspects to living with peripheral neuropathy. Many examples of people living with peripheral neuropathy have shown that living with this condition has made them mentally stronger and more resilient [33,36] (so the fact that peripheral neuropathy had a positive impact on quality of their life might be considered as a positive aspect).

Unintended consequences of the pain

The pain that some people living with peripheral neuropathy experienced caused them to stop thinking about themselves and instead focus on helping others, thereby helping these individuals feel less isolated.

> *Helping others with the same condition helps you because, for one thing, you stop thinking about your pain.* (Female, 79 years old) [33]

One person living with peripheral neuropathy highlighted an element of camaraderie and how she empathised with others with the same condition.

> *I think it is very nice to be among people, who are in similar circumstances, and everybody has their own* problems, *but nobody seems to grumble about them.* (Female, 63 years old) [33]

Resilience

Some people were naturally resilient and described it as the new norm, which enabled them to cope with the difficulties of living with the condition.

> *Now, when I am sitting here talking to you, being interviewed, I don't feel the pain as much as when I am not busy. The remarkable thing is that you get used to the pain. I have got used to it.* (Female, 65 years old) [31]

Several participants described developing a more positive outlook on life despite the persistent pain they lived with.

> *The pain remained, but I have become more positive.* (Male, 72 years old) [36]

Some took ownership of their own condition and felt more empowered in taking control of their reaction to their circumstances.

> *It's a battle between me and the pain and the pain won't win*. (Female, 44 years old) [31]

Many individuals underwent various stages of emotional stress from initial diagnosis, but this developed into acceptance of their condition and satisfaction from achieving daily tasks over time.

> *I do not let the pain ruin my life. I just do what I think I have to, and often, I go too far. It destroys me, but I benefit from it. I get a feeling of satisfaction. Yes, I still can do this!* (Male, 51 years old) [36]

The importance of continuing daily activities despite the pain was also highlighted by some as giving them purpose in their lives.

> *A little bit of housekeeping, preparing a meal, yes, it costs a lot of effort and pain. But I want to do that. That is the only purpose I have in my life: caring for my husband and daughter as good as I can.* (Female, 61 years old) [36]

4. Discussion

The findings of this review highlight the experiences of people living with peripheral neuropathy and the impact of the condition on their daily lives. Three main themes were identified in this review: is the body sick or the mind; the relationship between the individual living with the condition and their healthcare professional; and positive aspects of living with peripheral neuropathy. These three themes encompassed the experiences of people living with peripheral neuropathy worldwide, from papers published in English.

The first theme identified in the systematic review highlights the concept of whether it is the body that is sick or the mind. The thematic synthesis revealed three aspects of living with peripheral neuropathy; including the physical and psychological causes and consequences; as well as coping strategies. The physical symptoms of peripheral neuropathy are wide-ranging, but the most commonly experienced symptom is extreme sensitivity to touch. The consequences of these symptoms were a negative impact on sleep and memory, thereby affecting daily activities.

Pain from peripheral neuropathy also led some individuals to feel depressed, isolated and fearful, which negatively affected their relationships with family members and friends. The latter point demonstrates the connection between the mind and the body; the mind became affected by psychological illness when the body was enduring with a physical condition. In comparison the literature also identified that individuals were able to cope with peripheral neuropathy by transforming their negative experiences into positive coping strategies to manage their pain. [33 ,24] The overall evidence from the studies in this review support the existence of a relationship between the mind and the body for people with peripheral neuropathy. New ways of coping with neurological conditions such as peripheral neuropathy could be developed if an integrated relationship between the body and the mind was explored. A conflicting relationship between the mind and the body results in people living with peripheral neuropathy feeling isolated and disconnected from their bodies.[27] However, those who were more knowledgeable about their illness, were motivated to adapt to and ease their daily pain. People living with peripheral neuropathy also found it important to focus their attention away from the pain and to accept living with the condition in a positive way.

The second theme that emerged from the thematic synthesis of the studies selected was the relationship between the individual living with the condition and their healthcare professional. From this theme, two subthemes were identified including the therapeutic approach, and understanding and empathy from healthcare professionals. A range of experiences were identified in the studies with the majority described as negative. [31, 35, 37] Some healthcare professionals seemed to misunderstand the symptoms presented by people living with peripheral neuropathy, which may be a result of their understanding of the condition. Communication between people affected by this condition and healthcare professionals should therefore be open and clear to avoid any misunderstanding during consultations. People living with peripheral neuropathy reported that healthcare professionals did not believe the symptoms of pain they experienced, which indicated a lack of empathy. When people were believed by their healthcare professionals, they felt less distressed and helpless. The best relationships between people living with peripheral neuropathy and their healthcare professionals were formed when the therapeutic approach to the management of the individual with peripheral neuropathy was patient centred. This approach would address both the physical and psychological aspects of their care. Physical treatment would include receiving appropriate medication to address the pain, while psychological treatment would include talking therapy to help people accept their condition and manage it by developing adaptive coping strategies. Such an approach will help people living with peripheral neuropathy plan out their routines, allowing them to feel in control and much more confident.

The final theme from the thematic synthesis examined the positive aspects of living with peripheral neuropathy. This theme is one that can make a considerable contribution to the current literature as it has not been previously considered. While some studies report that people discuss the positive impacts of living with peripheral neuropathy, this has not been addressed as a theme in its own right.[33,36] Resilience in relation to the pain was reported by some individuals, who accepted their condition and developed a positive outlook towards managing their pain. These individuals developed a more positive perspective as a result of the experience of living with the condition. They were forced to stop thinking about themselves and focus on helping others. It is possible that without the peripheral neuropathy they might not have made such an effort to help other people. The enduring sometimes brought out the strong nature in people, allowing them to demonstrate resilience. The level of pain that some people experienced often created strength in these individuals and brought them closer together with others experiencing the same type of pain. Some people living with peripheral neuropathy found comfort and purpose in offering help to other individuals with the same condition. This camaraderie allowed people living with peripheral neuropathy to help others in similar circumstances, leading to a greater feeling of satisfaction and self-worth.

Implications

This review presents several important implications and contributes to existing knowledge on the management of people living with peripheral neuropathy. It highlights the importance of improved communication between healthcare professionals and their patients. Healthcare professionals might benefit from training and support to improve their communication. This review suggests that the treatment of both the body and the mind together is important, and that therapeutic approaches used in managing peripheral neuropathy need to consider both aspects. Furthermore, people living with peripheral neuropathy need support to identify the potential positives from living with the condition. The traditional approach purely focuses on pharmaceutical remedies and often does not consider the ability of the mind to manage physical pain.[33] The present review recommends that the management of peripheral neuropathy should consider and incorporate the ability of the mind to deal with pain alongside the more traditional approach. Management strategies should also involve family members and friends, who are able to provide the patient with a support network. The role of support networks in improving the experience of living with peripheral neuropathy should be further explored in future studies. To be able to live a healthy life with the pain, the contribution of family and friends is extremely important and so they should also be included in such therapies. Such therapies may also include the alleviation of feelings of depression amongst such patients or the involvement of family members to help the patient cope with the condition.

Strengths and limitations

The main strength of the present review is the breadth of evidence used and the synthesis of these studies to identify commonalities in the findings. This review has also examined a number of minor themes in the studies identified, which were synthesised to present a new major theme on the positive aspects of living with peripheral neuropathy. Thus, this theme is not only novel, but it also confirms and agrees with the themes that emerged from the original studies. Another strength of this review is the use of the Critical Appraisal Skills Programme (CASP) checklist to assess each study before inclusion. Through the use of this rating system, all 23 studies selected in the search for this review met the quality criterion and were highly rated. Another important strength of this paper is the collaboration of the researcher with a second reviewer, who was a librarian, trained at validating literature searches. This study also excluded unpublished work that has not been subject to the peer-review process. However, a limitation of this study is that studies published in languages other than English were excluded. This may have resulted in the exclusion of studies that could have provided useful insights into the experiences of people in different cultures. This limitation is further highlighted by the 23 studies included in the study focusing on Western countries, thus missing out on the patient experience in the Middle East, for example. Further research should be conducted on these distinct populations, to further represent their patient population. The credibility of these findings was achieved by focusing on the perspectives of the participants themselves. The researcher assessed the quality of the 23 studies by examining the methodologies used and by establishing high-quality ratings for each study. Therefore, all the studies examined were robust studies that showed quality in the way they were reported and their level of rigour. The researcher intends to conduct further research to confirm the findings in this study and to further elaborate on them.

5. Conclusion

The present review summarised the current existing qualitative literature on the experiences of people living with peripheral neuropathy. A thematic synthesis was conducted. Thematic synthesis involved line by line coding of the findings of the studies, then the descriptive and analytic themes were developed and finalised. Three main themes emerged from this review: is the body sick or the mind; the relationship between the patient and the healthcare professional; and positive aspects of living with peripheral neuropathy. There is a connection between how the body and mind interpret pain. Healthcare professionals should provide people living with peripheral neuropathy with comprehensive information on existing treatments and on living with the condition. Such information should include promotion of a healthier lifestyle, which can have a major impact on the physical and psychological well-being of people living with peripheral neuropathy. This in turn will improve the patient experience. Patient engagement can inform patients and provide education and policies, as well as enhance service delivery and governance. Furthermore, the existing literature is dominated by studies conducted in Western countries, so these themes should be explored further in non-Western populations.

Data Availability Statement: Data sharing is not applicable to this article as no new data were created or analysed in this study.

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Table 1. Critical Appraisal Skills Programme (CASP) results for the 23 studies selected

Reference	**Was there a clear statement of the aims of the research?**	**Is a qualitative methodology appropriate?**	**Was the research design appropriate to address the aims of the research?**	**Was the recruitment strategy appropriate to the aims of the research?**	**Was the data collected in a way that addressed the research issue?**	**Has the relationship between researcher and participants been adequately considered?**	**Have ethical issues been taken into consideration?**	**Was the data analysis sufficiently rigorous?**	**Is there a clear statement of findings?**	**How valuable is the research?**
Krohne and Ihlebaek [23]	N	N	Y	Y	Y	Y	Y	Y	Y	Y
Paton *et al.* [24]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Closs *et al.* [22]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Crawford *et al.* [28]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Sofaer-Bennett, Walker *et al.* [25]	Y	Y	N	Y	Y	Y	Y	Y	Y	Y
Lonnstedt *et al.* [31]	Y	Y	N	Y	Y	Y	Y	Y	Y	Y
Gustorff *et al.* [34]	Y	Y	Y	N	Y	Y	Y	Y	Y	Y
Ownby and Dune [26]	Y	Y	Y	Y	N	Y	Y	Y	Y	Y
Osborn and Smith [27]	Y	Y	N	Y	Y	Y	Y	Y	Y	Y
Sofaer-Bennett, Holloway *et al.* [33]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Hensing *et al.* [29]	Y	Y	Y	N	N	Y	Y	Y	Y	Y
Hwang *et a*l. [40]	Y	Y	Y	Y	N	Y	Y	Y	Y	Y
Brod *et al.* [41]	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Morley *et al.* [38]	Y	Y	Y	Y	Y	N	CT	Y	Y	Y
Taverner *et al.* [37]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Snelgrove and Liossi [35]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Forsberg *et al.* [34]	Y	Y	Y	Y	Y	Y	CT	Y	Y	Y
Svensson *et al.* [42]	Y	Y	N	Y	Y	Y	CT	Y	Y	Y
Khu *et al.* [43]	Y	Y	N	Y	Y	Y	Y	Y	Y	Y
De Souza and Frank [32]	Y	Y	N	N	Y	Y	Y	Y	Y	Y
Metin, and Arslan [30]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Chan *et al.*[44]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Kanera *et al.* [36]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Y Criteria was met, N Criteria not met, CT Cannot tell if criteria was met

Table 2. Summaries of studies included in the review of people's experiences of peripheral neuropathy

Author(s)	Country	Study design and participant characteristics
1. Brod *et al.* [41] Brod M1, Pohlman B, Blum SI, Ramasamy A, Carson R. Burden of Illness of Diabetic Peripheral Neuropathic Pain: A Qualitative Study. *Patient*. 2015; 8: 339-48.	United States	Semi-structured interviews 70 respondents (63 respondents had type 2 diabetes, with only seven having type 1 diabetes.)
2. Chan *et al.* [44] Chan CW, Cheng H, Au SK, Leung KT , Li YC , Wong KH , Molassiotis A. Living with chemotherapy-induced peripheral neuropathy: Uncovering the symptom experience and self-management of neuropathic symptoms among cancer survivors. *Europ J OncoNurs*.2018; 36 :135–141	Hong Kong	Semi-structured interviews Purposive sample 12- Chinese female
3. Closs *et al.* [22] Closs SJ, Staples V, Reid I, Bennett MI, Briggs M. The impact of neuropathic pain on relationships. *J Adv Nurs*. 2009 b; 65: 402-11.	United Kingdom	Focus groups 10 participants joined in three focus groups. Because of the low response rate of 20% from the initial sample, a second sample of 16 patients was invited to participate.
4. Crawford *et al.* [28] Crawford B, Bouhassira D, Wong A, Dukes E. Conceptual adequacy of the neuropathic pain symptom inventory in six countries. *Health Qual Life Outcomes*. 2008; 6: 62.	United States, Brazil, China, Finland, Spain, Japan	Semi-structured discussion, guide-conducted focus groups 132 participants spread throughout six countries **(U.S. (50), Brazil (16), China (18), Finland (17), Spain (16), Japan (13))**
5. Forsberg *et al.* [34] Forsberg A, Ahlstrom G, Holmqvist LW. Falling ill with Guillain-Barré syndrome: Patients' experiences during the initial phase. *Scand J Caring Sci*. 2008; 22: 220–6.	Sweden	Interviews 35 individuals, interviewed 2 years after the onset of Guillain-Barre Syndrome

6.Gustorff *et al.* [39] Gustorff B, Dorner T, Likar R, Grisold W, Lawrence K, Schwarz F, Rieder A. Prevalence of self-reported neuropathic pain and impact on quality of life: Aprospective representative survey. *Acta Anaesthesiol Scand.* 2008; 52: 132–6.	Austria	Interviews performed via internet inquiry 260 participants
7. Hwang *et al.* [40] Hwang S, van Nooten F, Wells T, Ryan A, Crawford B, Evans C, English M4.Neuropathic pain: A patient-centred approach to measuring outcomes. *Health Expect.* 2018; 21: 774-786.	United States, Japan	In-person interviews 30 subjects with painful diabetic neuropathy or post-herpetic neuralgia
8. Hensing *et al.* [29] Hensing G, Sverker A, Leijon G. Experienced dilemmas of everyday life in chronic neuropathic pain patients - Results from a critical incident study. *Scand J Caring Sci*. 2007; 21: 147–54.	Sweden	Interviews 39 participants (23 female and 16 male) living with neuropathic pain
9. Kanera *et al.* [36] Kanera M, van Laake-Geelen M, Ruijgrok M, Goossens E, Jong R, Verbunt A, Geerts M , Smeets J, Kindermans P. Living with painful diabetic neuropathy: insights from focus groups into fears and coping strategies. *Psychology & Health*. 2018; 36: 1-22.	Netherlands	Semi-structured focus group interviews Three semi-structured focus group interviews were conducted with a representative sample of persons with painful diabetic neuropathy (N=12)
10. Khu *et al.* [43] Khu K, Bernstein M, Midha R. Patients' perceptions of carpal tunnel and ulnar nerve decompression surgery. *Can J Neurol Sci*. 2011; 38: 268–73.	Canada	Semi-structured, open-ended interviews 30 adult patients who had experienced carpal tunnel syndrome (CTS) or ulnar nerve decompression
11. Krohne and Ihlebaek [23] Krohne K, Ihlebæk C. Maintaining a balance: A focus group study on living and coping with chronic whiplash-associated disorder. *BMC Musculoskelet Disord.* 2010; 11: 158.	Norway	Focus groups interviews 14 Norwegian men and women with Whiplash-Associated Disorder (I or II)

12. Lonnstedt *et al.* [31] Lonnstedt M, Hackter Stahl C, Hedman A. Living with long-lasting pain – patients' experiences of neuropathic pain. *J Nurs Healthc Chronic Illn*. 2011 ; 14; 3: 469–75.	Sweden	Interviews 11 people lived with neuropathic pain (seven female and four male)
13. Metin and Arslan [30] Metin Z, Arslan I. Diabetic Peripheral Neuropathic Pain From the Perspective of Turkish Patients: A Qualitative Study. *J Trans Nurs*.2018; 29: 514–522.	Turkey	Face –to-face interviews 14 Turkish people lived with neuropathic pain
14. Morley *et al*. [38] Morley G, Briggs E, Chumbley G. Nurses' Experiences of Patients with Substance-Use Disorder in Pain: A Phenomenological Study. *Pain Manag Nurs.* 2015; 16 : 701–11.	United Kingdom	Semi-structured interviews Convenience sample of 5 registered nurses
15. Osborn and Smith [27] Osborn M, Smith J. Living with a body separate from the self. The experience of the body in chronic benign low back pain: An interpretative phenomenological analysis. *Scand J Caring Sci*. 2006; 20: 216–22.	United Kingdom	Semi-structured interviews 6 participants with chronic back pain
16. Ownby and Dune [26] Ownby K, Dune L. The Processes by Which Persons with HIV-Related Peripheral Neuropathy Manage Their Symptoms: A Qualitative Study. *J Pain Symptom Manage.* 2007; 34: 48–59.	United States	Interviews 19 persons with AIDS
17. Paton *et al.* [24] Paton J, Roberts A, Bruce G, Marsden J. Patients' Experience of therapeutic footwear whilst living at risk of neuropathic diabetic foot ulceration: An interpretative phenomenological analysis (IPA). *J Foot Ankle Res.* 2014; 7: 16.	United Kingdom	Semi-structured Interviews 4 people with Diabetic neuropathy

18. Snelgrove and Liossi [35] Snelgrove S, Liossi C. An interpretative phenomenological analysis of living with chronic low back pain. *Br J Health Psychol*. 2009; 14: 735–49.	United Kingdom	Semi-structured Interviews 10 respondents living with chronic lower back pain (three males and seven females)
19. Sofaer Bennett, Holloway *et al.* [33] Sofaer-Bennett B, Holloway I, Moore A, Lamberty J, Thorp T, O'Dwyer J. Perseverance by older people in their management of chronic pain: A qualitative study. *Pain Med*. 2007; 8: 271–80.	United Kingdom	Unstructured, in-depth interviews 63 participants with neuropathic pain
20. Sofaer-Bennett,Walker *et al.* [25] Sofaer-Bennett B, Walker J, Moore A, Lamberty J, Thorp T, O'dwyer J. The social consequences for older people of neuropathic pain: A qualitative study. *Pain Med*. 2007; 8: 263–70.	United Kingdom	Interviews 16 participants with neuropathic pain
21. De Souza and Frank [32] De Souza L, Frank A. Experiences of living with chronic back pain: The physical disabilities. *Disabil Rehabil*. 2007; 29: 587–96.	United Kingdom	Unstructured interviews 11 subjects (5 male, 6 female) with chronic back pain
22. Svensson *et al.* [42] Svensson G, Wendt G, Thomee R, Danielson E. Patients' experience of health three years after structured physiotherapy or surgery for lumbar disc herniation. *J Rehabil Med*. 2013; 45: 293–9.	Sweden	Open-ended interviews 20 people lived with peripheral neuropathy
23. Taverner *et al.* [37] Taverner T, Closs S, Briggs M. The journey to chronic pain: A grounded theory of older adults' experiences of pain associated with leg ulceration. *Pain Manag Nurs*. 2014; 15: 186–98.	United Kingdom	Semi structured Interviews 11 people lived with neuropathic pain

Table 3. Comparison of the different themes generated by the studies selected for this review.

Reference	**Theme 1** Is the body sick, or is it the mind?	**Theme 2** The relationship between the patient and healthcare professional	**Theme 3** Positive aspects of living with peripheral neuropathy
Krohne and Ihlebaek [23]	●		
Paton *et al.* [24]	●		●
Closs *et al.* [22]		●	
Crawford *et al.* [28]	●		
Sofaer-Bennett ,Walker *et al.* [25]	●		
Lonnstedt *et al.* [31]	●	●	●
Gustorff *et al.* [39]	●		
Osborn and Smith [27]	●		
Snelgrove and Liossi [35]	●	●	
Hwang *et al.* [36]	●		
Ownby and Dune [26]	●		
Taverner *et al.* [37]	●	●	
Morley *et al.* [38]		●	
Hensing *et al.* [29]	●		
De Souza and Frank [32]	●		
Forsberg *et al.* [34]	●		
Brod *et al.* [41]	●		
Svensson *et al.* [42]	●		
Khu *et al.* [43]	●		●
Sofaer-Bennett, Holloway *et al.* [33]	●		●
Metin and Arslan [30]	●		
Chan *et al.* [44]			●
Kanera *et al.* [36]			●

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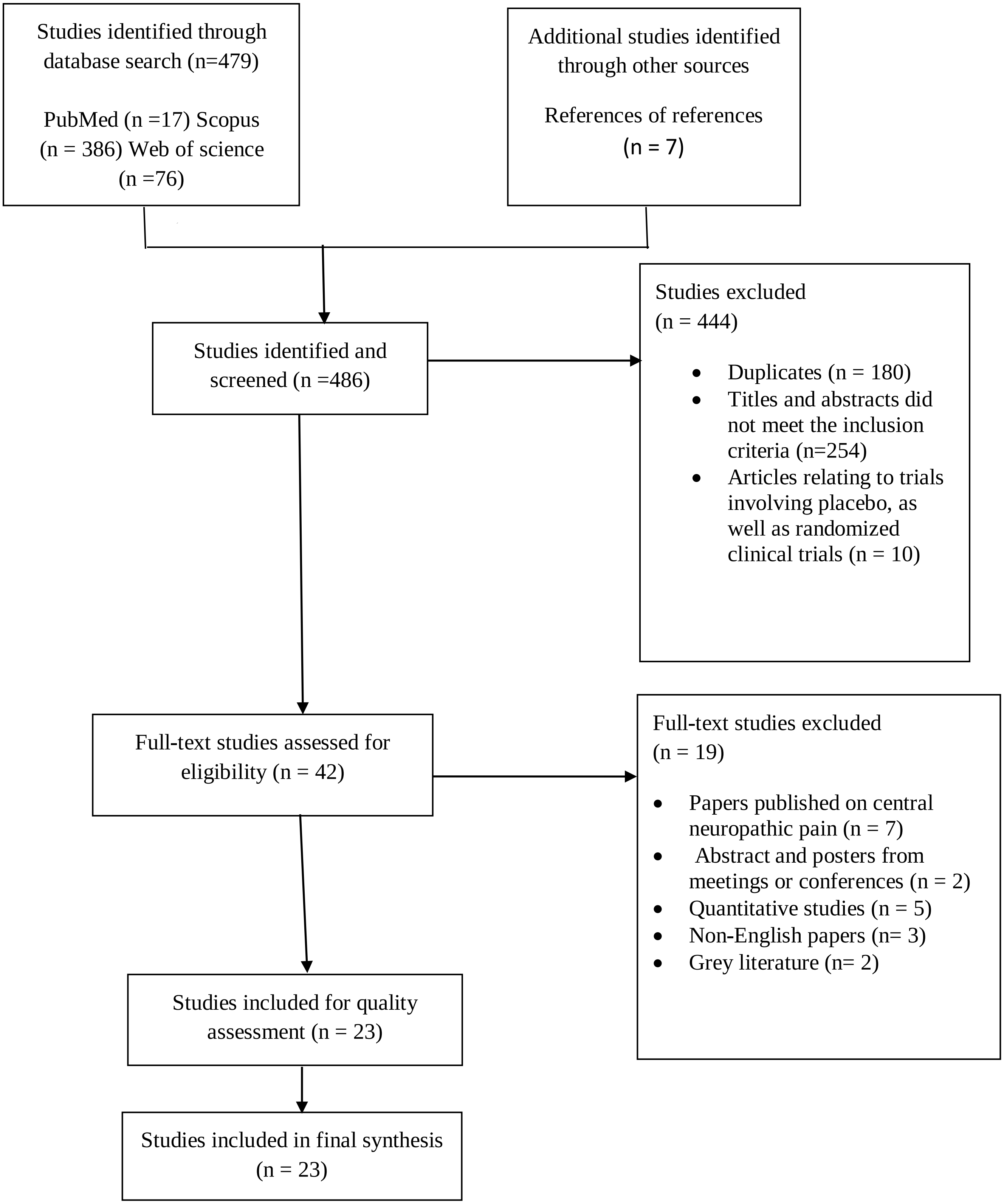

Figure 1. The literature search strategy and identification of publications included in this review

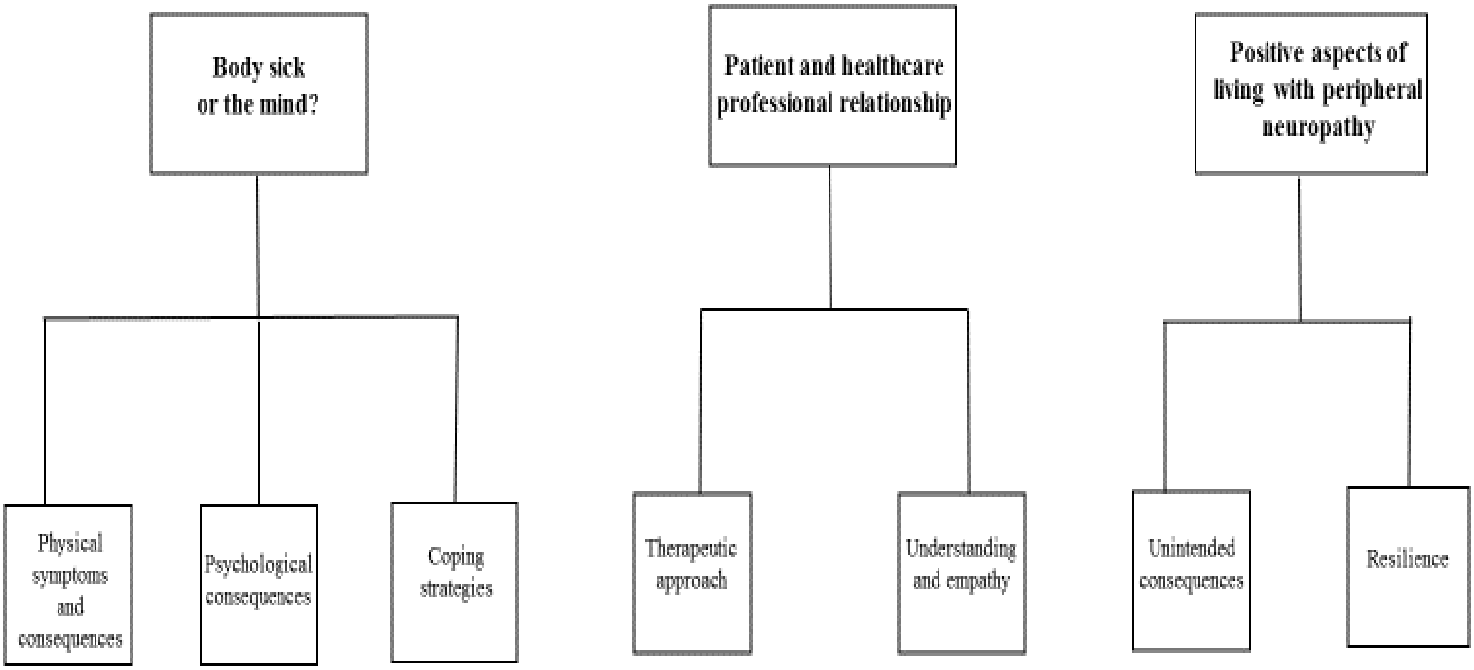

Figure 2. Illustration of the themes and subthemes identified during the analysis of the published studies

3.3 Conclusion

This chapter, which reviewed and extracted themes from studies on people's experiences of living with peripheral neuropathy, helped identify the three main themes. The three main themes were; is the body sick or the mind, the relationship between the patient and the healthcare professional and potential advantages of living with peripheral neuropathy. However, this was all based on studies conducted in the West. This review highlighted a need for research into the experiences of people living with peripheral neuropathy in Kuwait as no studies were found. Since the healthcare journey and interaction with healthcare professional seemed a pivotal concept, there was a need to explore the patient journey in-depth, which will be addressed in chapter 4.

CHAPTER FOUR

Study 2: The Experiences of People Living with Peripheral Neuropathy in Kuwait: A Process Map of the Patient Journey.

4.1 Publication relevance to thesis

This chapter presents the second paper in this PhD thesis. The paper was published by the peer-reviewed journal Pharmacy in August 2019. Chapter 3 had provided an insight into the psychological and social experiences of people living with peripheral neuropathy in the West. Most research conducted in the Arab region had only reported the prevalence of peripheral neuropathy and research focusing on patients' experiences in the Middle East was lacking. In order to specifically understand the experience of people living with peripheral neuropathy, the first step would be to observe the patient journey. To allow the observation of the various steps in the patient’s journey, one of two methods may be applied; either a process map or value stream mapping (VSM). Timothy *et al.* (2010) described process mapping as a technique that focuses on one process, also defining non-value that is included in the one process. Accordingly, it enables the use of minor steps, that are easily implemented, that not only allows short-term planning but also enables improvements in the effectiveness of the process (when employed with mining and discovery). Conversely, value stream mapping assesses many steps. Accordingly, it is employed in long term planning, thus, the steps required are not easily implemented. Nevertheless, due to the greater detail required and due to its consideration of non-value that is included between these different steps, value stream mapping aids in decreasing discrepancies (Grove *et al.*, 2010). Thus, value stream mapping is typically used to for long-term projects and to aid modifications in a process. Therefore, given that this thesis sought to enhance the efficacy of the patient journey, the process mapping technique was employed. Thus, an initial process map was developed from the detailed mapping of the journeys of four participants. Next, the process map was used to review the additional 21 interviews of the other participants resulting in the production of a final map that provided a comprehensive description of the experiences of individuals in Kuwait who were living with peripheral neuropathy. Specifically, it presented the views of these individuals with regards their management by clinical teams and the strategies the participants employed in coping and managing peripheral neuropathy.

In addition, the concept of a process map seemed one of the most effective ways of identifying existing problems and improving the patient journey (NHS, 2018). This qualitative study was designed to examine the patient journey of people living with peripheral neuropathy in Kuwait. The purpose of the study was to create a process map and compare it to the UK guidelines, thus enabling the identification of areas for improvement. The UK guidelines used are termed the National Institute for Health Care Excellence (NICE) guidelines. These guidelines address the various conditions by describing the care and any services that serve them. Moreover, these guidelines are one of the well-established international guidelines. Concerning the treatment of individuals with peripheral neuropathy, Kuwait currently follows the UK guidelines to ensure the prevention of compromised health. Furthermore, by applying these guidelines, Kuwait ensures it will enhance, safeguard and promote better health, quality of health and of the care services provided. Finally, these guidelines also allow the adapting and supply of health care and social care services. The methodology adopted was conducting of 25 semi-structured interviews in Arabic or English, transcribing, translating into English, and coding. Then four individual patient journeys were mapped out in detail, compared and condensed into a single process map. A final review of the remaining 21 interviews was conducted to ensure the final map represented all patient journeys. Theoretical saturation was conducted and involves establishing criteria for defining the point at which no further benefit could be derived from recruiting additional participants for a category (Beck, 2004). Concerning this study, the recruitment of 25 participants established that no additional new themes could be generated following the review of their interview transcripts, thus indicating that data saturation had been met. When the Kuwaiti system was compared to that implemented in the UK as indicated by the UK guidelines, it was clear that there were three areas that required a highly planned strategy. Specifically, these were medical care, non-pharmacological support and the organisational procedures followed. In Kuwait, the management of peripheral neuropathy was manged from the pharmacological angle and lacked provisions for psychological support including information and counselling sessions that is also provided in UK settings. Furthermore, the extended waiting lists were deemed the result of inappropriate communication, structure and organisation between the various clinical arms which also resulted in the loss of clinical documentation. This was further exacerbated by the absence of a central and electronic medical records system and the unavailability of experienced staff in sufficient numbers. Moreover, a self-referral system was evident in Kuwait that led to certain individuals by-passing the normal processes and resulted in the delay of others.

Nevertheless, the comparison between the Kuwaiti and UK systems highlighted similarities in the pharmacological medication used as noted by both the National Institute for Health Care Excellence (NICE) and the International Association for the Study of Pain (IASP). This was detailed in Table 3. Certain management streams were incomplete; for example capsaicin, a topical medication, could not be accessed in Kuwait. Moreover, the use of gabapentin (300–1200 mg) or carbamazepine (200–400 mg) as a first line medication for treatment of diabetics was not implemented, nor was the prescribing of tramadol for peripheral neuropathy pain experienced by diabetics. The study underlined the need for effective clinical management, adherence to medication and an understanding of coping and management mechanisms the individuals were also using. Moreover, access to treatments prescribed in the UK but not in Kuwait would enhance medical management, together with ensuring staff are suitably trained and that patients are examined and reviewed at the correct time periods. This would allow an understanding and the implementation of proper escalation from first to second or third line treatments which would, in turn, enhance the efficacy of patient care in Kuwait.

This study has been published and can be found in Appendix 4. The reference for the paper is: Alkandari, M., Ryan, K., & Hollywood, A. (2019). The Experiences of People Living with Peripheral Neuropathy in Kuwait: A Process Map of the Patient Journey. *Pharmacy*, 7 (3), 1-14. The following chapter has additional information on the study.

4.2 Title of publication (Published paper)

The Experiences of People Living with Peripheral Neuropathy in Kuwait: A Process Map of the Patient Journey

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Abstract

Peripheral neuropathy is a neurological disease characterised by pain, numbness, tingling, swelling, or muscle weakness due to nerve damage, caused by multiple factors such as trauma, infections and metabolic diseases such as diabetes. In Kuwait 54% of the diabetic population, has peripheral neuropathy. In this exploratory, qualitative study conducted in Kuwait, 25 subjects with peripheral neuropathy took part in one-on-one, semi-structured interviews lasting 45-60 minutes. Interviews were transcribed, translated into English and coded using NVivo 12. Four individual patient journeys were mapped out in detail, then compared and condensed into a single process map. The remaining 21 interviews were then reviewed to ensure the final map represented all patient journeys. Participants reported similar healthcare pathways for their peripheral neuropathy and faced various difficulties including lack of psychological support, administrative issues(long waiting referral periods, loss of medical documents, shortage of specialists and lack of centralized electronic medical records) and inadequate medical care (shortage of new treatments and deficient follow-ups).Mapping the patient journey in Kuwait showed similar pharmacological treatment to UK guidelines, except that some medicines were unavailable. The map also indicated the need for an integrated referral approach, the use of technology for electronic medical recording and report transmission, alongside education on self-management, coping mechanisms and treatment options for people living with peripheral neuropathy.

Keywords: Peripheral neuropathic pain; diabetes, patient experiences; process map; Kuwait healthcare

1. Introduction

Peripheral neuropathy is a common neurological disorder affecting people from both developed and developing countries. It can be caused by various conditions such as vitamin deficiency, traumatic injury, alcoholism, immune system diseases, viral infections, or most commonly diabetes [1,2,3]. In 74-82% of people, the cause can be determined by a combined approach of patient medication history, examinations and ancillary testing [4]. Symptoms of peripheral neuropathy include sensory symptoms (e.g. numbness and tingling), weakness, autonomic symptoms (e.g. impotence, orthostatic hypotension and sweating abnormalities), or neuropathic pain (burning, stabbing, electrical) [5]. Kuwait is a high-income country providing a high standard of health and social services to its citizens with health indicators similar to those of highly developed countries [6]. The most common causes of peripheral neuropathy in Kuwait are diabetes and lower back pain as discussed below [7,18] . Furthermore, the incidence of diabetes in the adult population in Kuwait is one of the top five in the world, with 18% of the population (424,000 in 2019) diagnosed as diabetic. This number has increased dramatically in the last decade [8]. This number includes all diabetics and are not confined to the diabetics living with peripheral neuropathy alone. The prevalence of peripheral neuropathy in the general population (worldwide) is 2.4% and increases to an estimated 8% in those older than 55 years [9,10]. In Western societies, the most common cause is diabetes mellitus, with a prevalence of peripheral pain in diabetics ranging from 30-66% [11-14]. In a population-based study in the Netherlands diabetes was found to be the third main cause of peripheral neuropathy[15]. Hall *et al*. [16] found that there were approximately 15.3 cases of neuropathic pain for every 100,000 individuals in the United Kingdom between 1992 and 2002, and since then this ratio has been increasing every year. In Kuwait, in 2010, peripheral neuropathic pain was estimated to affect around 39% of the diabetic population [17]. In 2017 54% of the people living with diabetes in Kuwait were living with painful diabetic peripheral neuropathy [18]. Like elsewhere in the world, the incidence and prevalence of diabetes also increases dramatically with age in Kuwait, which indicates a rise in the number of people who will have to live with peripheral neuropathy[19].In addition, lower back pain is prevalent among Kuwaitis, which leads to peripheral neuropathy. In Kuwait, the prevalence of lower back pain among 10-18 year-olds was found to be 58% (51% in males and 65% in females),increasing with age in both males and females, thus increasing the risk for developing peripheral neuropathy[20].

In western countries, multidisciplinary care for people living with peripheral neuropathy is encouraged, and receiving a wide range of additional support allows people to manage their own condition[21].Most research conducted in the Arab region has only reported the prevalence of peripheral neuropathy[22,23]and research focusing on patients' experiences in the Middle East is lacking. The main purpose of this research was to explore the experiences of people living with peripheral neuropathy by examining the healthcare pathway in Kuwait from the patient perspective. This paper uses the technique of process mapping to chart the journey experienced by people living with peripheral neuropathy in Kuwait, and to compare that journey with standards existing in peripheral neuropathy care in Western countries. Process mapping allowed us to see and understand the patient's experience [24] by separating the management of peripheral neuropathy and its treatment into a series of consecutive events or steps (for example, activities, interventions or interactions with healthcare professionals).

2. Materials and Methods

2.1. Study Design

This qualitative study aimed to explore the pathway of standard care for the management of people living with peripheral neuropathy in Kuwait and to develop a schematic process map of the patient journey based on their experiences. The process map was then compared with existing guidelines in the UK, where the National Institute for Health and Care Excellence (NICE) and the International Association for the Study of Pain (IASP) guidelines are used.

2.2. Study Setting

The study was conducted at Ibn Sina Neurology and Neurosurgery Hospital, the tertiary center to which neurology patients are referred by neurology specialists in general hospitals. The principal investigator informally observed people living with peripheral neuropathy and attending the outpatient clinic of Ibn Sina Hospital, from different locations, namely reception, neurology clinic, triage room, waiting lounge, and pharmacy.

2.3. Recruitment Strategy

A study summary was provided to the neurologists attending the outpatient clinics to identify potential participants meeting the eligibility criteria (aged over 18 years, diagnosed with peripheral neuropathy, resident in the State of Kuwait, speaking Arabic or English). The nursing staff distributed an information pack (consisting of an invitation letter, patient information sheet and pamphlet with further contact details) to potential participants. Interested people contacted the principal investigator via phone or email.

Recruitment started in February 2017 and was completed within two weeks. Of ninety-five potential participants, twenty-seven contacted the principal investigator (28% response rate). After obtaining consent, the principal investigator undertook an in-depth review of the medical records of these outpatients to confirm that they met all the inclusion criteria. Two people were excluded because one did not meet the age criteria (was under 18 years old), and the other was excluded on the grounds of having neurological problems other than peripheral neuropathic pain. Therefore, twenty-five people (20 Kuwaiti and 5 Non-Kuwaiti) were deemed eligible for inclusion in the study. The concept of purposive sampling was used to ensure that participants provided rich quality data.

2.4 Data Collection

A semi-structured interview guide with open-ended questions (see Table 1) was developed from the literature, taking into consideration the culture and healthcare system in Kuwait. Interviews began in March 2017 and were conducted over a period of a year. Participants were assigned study specific numbers and initials to anonymize their identity. Each participant was interviewed individually in a private room in the hospital, in the language of their choice (English or Arabic). Out of the five non-Kuwaiti participants, three preferred English. All Kuwaiti participants preferred Arabic. Interviews lasted 45-60 minutes and were audio-recorded. The English interviews were fully transcribed in English; the Arabic interviews were transcribed in Arabic and later translated into English. From the twenty-five transcripts, six were selected for review to ensure that the transcriptions and translations were accurate. Four transcripts were reviewed by an academic lecturer in the Languages Center at the University of Jordan, who was proficient in both Arabic and English; and two by a bilingual physician at the Department of Community Medicine and Behavioural Sciences, Kuwait University.

2.5. Data Analysis

To collate sufficient data for analysis and to establish the process map, the 25 semi-structured interviews that were conducted in either Arabic or English were transcribed. The Arabic interviews were also then translated into English following the transcription process as this ensured increased accuracy by the translation of accurately transcribed data. All the data was coded once an English transcription or translation was available. Next, four of the patient journeys were comprehensively mapped out into one process map. To ensure that the process map was representative of all journeys, the remaining 21 interviews were then assessed against the initial process map and any additional data included. Thus, the final process map was a representation of the data derived from all 25 interviews and, therefore, all 25 patient journeys.

The transcripts were transferred to NVivo12 software for data management and analysis. Theoretical saturation was achieved in less than the 25 interviews, which ensured the appropriateness of sample size selected. The data was initially manually coded inductively after familiarization and then by a combination of text search queries and coding queries, and then extracted to generate a preliminary report which helped to plot the patient journey process map, which in turn aided in identifying the weaknesses in the existing patient care pathway. It also helped to formulate suggestions for improvement, propelled by the implicit and explicit deductions made by the researchers. Validation was ensured not only by prolonged engagement, but also by peer debriefing.

Four transcripts were chosen based on their rich data (eloquence of interviewee, length of interview, severity of pain) to plot four individual pathways. These pathways were compared to identify similarities (such as referrals and pharmacological treatments) and differences (such as disparities in referral time and waiting periods). These were combined to make a preliminary process map which reflected even the minutest details for example, signs, symptoms, investigation results, physical examinations, referral systems, follow-ups and their current situation. This was expanded into a second version by layering on details from the twenty-one remaining transcripts. This involved the inclusion of extra information which was clarified by combining it with the data in the initial process map. After multiple iterations, a simplified and condensed process map (see Figure 1) was produced that captured the journey for all people living with peripheral neuropathy in Kuwait.

2.6. Ethical Consideration

Ethical approval was obtained from the University of Reading Ethics Committee (UREC – 16/46) as well as the Standing Committee for Health and Medical Research Coordination (SCHMRC) in the Ministry of Health (MoH) in the State of Kuwait (Ref no: 194/2014).

3. Results

The primary focus of this paper is to explore people's experiences with peripheral neuropathy and identify the care pathway in Kuwait. The results were derived from the interviews and the observations.The main symptoms experienced by people living with peripheral neuropathy were neuromuscular; and their most frequent complaints were physical pain in the feet, hands, extremities, back, leg and knees, as well as numbness and tingling. Demographic and other data of the study participants are presented in Table 1.

<Insert Table1>

Close analysis of the interviews showed that subjects experienced similar treatment and care pathways despite differences in the presentation of their complaints. Some attended their primary clinic when they were experiencing a slight degree of pain and obtained a medical certificate for absence from employment whereas others tolerated their pain until it became unbearable.

> *There are those who do not care and avoid their work as they are still young, trying to attain more medical leave. For me, I have no problem. I love the job even if there is pressure at work—Male, 35 years old, living with peripheral neuropathy for 15 years.*

> *I only come to the doctor when I am tired and feel bad—Female, 56 years old, living with peripheral neuropathy for 30 years.*

The process map of the outpatient journey, as described by patients in Kuwait and as depicted in Figure 1, shows a referral from a local primary clinic to the general hospital, where people living with peripheral neuropathy would see a general doctor and a neurologist, then on to a specialist/consultant at the national neurology hospital.

<Insert Figure 1 >

3.1. Primary care clinic - the journey starts

Administrative issues at the primary clinic were strongly evident to most of the people living with peripheral neuropathy. There were usually only a few members of staff (doctors or nurses) on duty at the clinic, and this led to a long queue of people and long waiting times.

> *Some people living with peripheral neuropathy feel more pain while sitting on cold seats, awaiting their turn to see the doctor—Female, 82 years old, living with peripheral neuropathy for 20 years.*

Some people were able to bypass the long waiting time by using their social influence (connections) in healthcare. Kuwait also has a green card system that is intended to function as a waiver of such waiting periods, to ensure that old people, for example, have shorter even no waiting times, and can complete their hospital visits quickly. For some participants, however, this card did not seem to fulfil its function.

> *Once, I entered the staff room to tell them that they must let me enter and see the doctor fast, as I had a green card and the right to see the doctor fast…One of them replied that I should wait, as there is someone preceding me in the queue and there are others who suffer from rheumatism too—Female, 82 years old, living with peripheral neuropathy for 20 years.*

To also cut the waiting time, some people relied on other bypass methods, such as giving bribes to the porters.

> *I had to wait a month and a half, and I also needed Wasta (a gift or bribe) to get the magnetic resonance image—Male, 35 years old, living with peripheral neuropathy for 15 years.*

> *The Bengali porter, who knows everyone inside the clinic, is given two or five Kuwaiti Dinars to help in getting a faster service, some others call their doctor friends and other acquaintances to help them avoid these queue systems—Male, 62 years old, living with peripheral neuropathy for 10 years.*

Furthermore, participants thought that the care given by some doctors, inside the consultation rooms, did not meet their expectations.

> *There was a doctor who keeps speaking on the phone and does not care about my sick condition, or doesn't tell me to sit or not—Female, 82 years old, living with peripheral neuropathy for 20 years.*

This participant commented that her Kuwaiti senior friends would rather use their health insurance to go to a private hospital. The Kuwaiti government levies around two percent of a public servant's salary in taxes and retirees receive a health-card entitling them to free care in all private hospitals.

At the primary clinic, the doctor was engaged with the patient for less than five minutes, during which time their medical history was quickly assessed; a judgement was made about which laboratory tests to conduct, such as blood glucose (see Table2), and the doctor reviewed the current treatment of symptoms. A variety of problems were reported from the patients' perspective, including various areas of patient care and prescription difficulties.

<Insert Table 2>

Prescriptions usually included general pain management using basic analgesics (see Table 3).

> *Unfortunately, the doctors here are not very familiar with this matter, but only give the painkillers, do not treat the disease and pain, do not tell me what this pain is and do not treat the inflammation—Female, 45 years, living with peripheral neuropathy for 9 years.*

<Insert Table 3>

Depending on the duration of their symptoms, intensity of pain, and response to the prescribed medication, the patient will obtain a standard or an emergency referral from their primary care general practitioner to the general hospital.

> *They give a medical appointment for three months or two or two and a half months and if you missed your medical appointment, it is a big problem—Female, 56 years old, living with peripheral neuropathy for 30 years.*

Due to the long waiting periods, and sometimes feeling a lack of care from doctors, some patients exited mainstream care to try alternative therapies such as acupuncture, massage, sujok (a Korean method of reflexology), and herbal medicine.

3.2. General hospital – multiple referrals

3.2.1. Referral to doctors in a general hospital

Administrative problems during referral mean it can take anywhere between 2 and 8 weeks to get an appointment at the general hospital depending on the waiting list in the local area. Since Kuwait does not have a centralized electronic medical record system, the paper medical files or referral documents play an essential role in the care of patients. These documents might get lost or go missing from the clinic, or the patient might lose their referral letter. In such cases, there are detrimental consequences. The patient may have no option but to repeat the whole process of opening a file and getting a referral letter, thus increasing the waiting period to as much as 12 weeks. This long waiting time usually tests the patience of the individual or causes them to seek alternative therapies.

> *My file was lost. When I went to the general hospital and showed them my referral paper, they said to go back to the clinic and reopen a new file and then come. It took me another three months to finally meet this doctor as I had to wait again—Male, 62 years old, living with peripheral neuropathy for 10 years.*

Doctors in the general hospital have to repeat the entire process by conducting basic laboratory tests, such as HbA1c, and other procedures, such as advanced neurological investigations, to ensure there is a full investigation. They then continue appropriate pharmacological treatment, often without adequate patient notes, and lack of proper communication and cooperation with their peers. Furthermore, there are time pressures and a heavy patient load. Table 3 presents the medication prescribed for general pain management.

> *If you see a doctor, you find him either on leave or travelling, and thus you have to go to another doctor who does not know anything about your condition. So, the two doctors are the same, but the second one prescribes the medication and the diagnosis. Days are passing in my life and I still feel pain and loss at the same time—Female, 55 years old, living with peripheral neuropathy for 30 years.*

Depending on factors such as their symptoms, response to medicine and social status people were prescribed medications and asked to return for follow-up after a few weeks or months. Some people did not visit the doctor for follow-up for various reasons, including the effort involved, enduring the waiting time, and the possibility of administrative problems, for example, their record not being available. Other people preferred to send their relatives or a representative to the pharmacy to get a repeat prescription without even seeing the doctor. Prescriptions could be repeated numerous times, without a requirement to reassess the patient’s condition.

> *In Kuwait, doctors pay no attention to the nature of the pain. They only give the patient painkillers and never know the cause—Female, 45 years old, living with peripheral neuropathy for 9 years.*

3.2.2. Referral to neurologist in general hospital

If deemed necessary, people may also be referred by the doctor in the general hospital to a neurologist in the same hospital. An appointment might take 3-6 months depending on the waiting list, and may even extend for a further two months due to the loss of medical documents in between. Some patients felt that their doctor did not give them their full attention.

> *The doctor should know the medical record of the patient before the patient enters. Here, doctors turn to the computer or read the medical record during meeting the patient, rather than giving us their full attention—Male, 47 years old, living with peripheral neuropathy for 3 years.*

The neurologist usually repeats the full investigations, as done by their predecessor, but also adds advanced investigations along with conducting further neurology-specific tests, such as the assessment of degree of loss of protective senses and reflexes, and continues appropriate pharmacological treatment as mentioned in Table 3. If the patient still shows no or minimal improvement, they will be referred to the national hospital for neurology treatment. People living with peripheral neuropathy also reported exiting at this point to try alternative medicine.

3.3. *National hospital for neurology – ultimate destination for peripheral neuropathy care*

The delay in getting an appointment for referral to the national hospital for neurology, including the waiting period and possible extension time of 3-6 months, plus another 2 months in case of loss of medical documents, inevitably added to the difficulties caused by administrative problems. This led to weariness and frustration for most patients, although some received quicker referrals due to their social influence or high economic status.

> *Long referrals of up to a year! And pain still continues… I think if the whole subject was based on money, they would pay more attention—Female, 63 years old, living with peripheral neuropathy for 24 years.*

The neurology specialist/consultant at the national hospital started from the beginning once again in terms of history taking, examinations and treatment. They conducted full laboratory investigations including HbA1c and a physical examination, placing specific emphasis on neurovascular examinations (see Table 2). Nerve conduction studies and advice on podiatry care for people with diabetic peripheral neuropathy were also provided here. Again, depending on the level of their symptoms, as well as the progress of their disease or their response to medication, people could be further referred to another experienced neurology specialist/consultant in the same hospital.

At this stage, patients received a structured pharmacological regimen, similar to the UK guidelines for peripheral neuropathy pain care, consisting of anticonvulsants as the first line of treatment. If there was an inadequate response, the patient received the second line of treatment, and if needed, there was an escalation to the third line of treatment, which included opioids. Table 3 reflects the pharmacological treatment options that were reported. Some patients also exited at this point hoping for better symptomatic management and care from alternative medicine.

> *Okay, I am always in pain …., I think Ginseng tablets are the best solution……… it takes less time to manage my pain levels…. I myself decided to take it, but I asked the doctor if I could keep using it; he said, "You know if you feel good about, no problem using it"—Female, 56 years old, living with peripheral neuropathy for 7 years.*

> *I massage my fingers, close my hands, and move my hand in warm water for some time... I move my fingers, put them in warm water and I massage them again so the pain goes —Male, 62 years old, living with peripheral neuropathy for 10 years.*

In general, participants who stayed within the national healthcare system continued the cycles of monitoring and repeat prescriptions for medication with very little improvement in their health. Furthermore, some patients were concerned that they knew very little about their disease or its progression, while others felt disappointed that they were not referred for psychological or dietary support, or given any information about alternative therapies.

> *If they (seminars) are available in the national hospital, it will be so helpful and should be given to patients—Male, 43 years old, living with peripheral neuropathy for 4 years.*

> *The doctor prescribed only the medication but never gave any psychological support or referral for psychological counselling—Female, 60 years, living with peripheral neuropathy for 4 years.*

Participants described various difficulties, caused by, in their opinion, not receiving satisfactory care. Patients reported a lack of awareness about their disease and the treatments available, which in turn caused anxiety regarding the progress of their disease. They reported staffing and management issues such as a shortage of healthcare professionals that was evidenced by the long waiting times, not only to see the doctor, but also the few very busy nursing staff. Participants also mentioned several administrative problems, such as long waiting time for referrals that were exacerbated by the unavailability or loss of medical records. The lack of universal electronic medical records also meant the unnecessary repetition of history taking, examinations and full investigations. Social practices, such as giving gifts and bribes to porters, helped a few people to bypass waiting lists, and receive more medical attention and a better quality of care.

Many patients chose to exit the traditional care pathway to try alternative therapies at different points during their patient journey, especially when they felt frustrated waiting for their appointments, or when they didn't get the expected care from the medical team or relief from symptoms by following the prescribed medications. Furthermore, because the pain influenced their mood, sleep, relationships and functional capacity, the need to seek alternative therapies became necessary. Many reported trying self-help options such as ignoring the pain, exercising, dietary change (by seeking out a dietician and educational sessions from private hospitals or Dasman Diabetes Centre in the public sector). Alternative therapies were obtained from the hospital for Islamic Medicine in the public sector, or private massage parlours functioning independently or as a part of well-known private hospitals such as Dar Al Shifa Hospital. Most people living with peripheral neuropathy wanted to receive further psychological support and education sessions to help them cope better with their condition.

4. Discussion

This patient journey map is the first of its kind in the Middle East for peripheral neuropathy, though there have been other patient journey exercises conducted in other therapeutic fields such as irritable bowel syndrome in Dubai, Qatar, Kuwait, and Saudi Arabia [25]. This process map depicts an overview of the journey experienced by patients from the primary clinics to the national hospital of neurology. Though the use of a process map reflecting a collective map from individualised interviews, might be deemed to have caused loss of key information, such as significant differences between the individuals, multiple steps were adapted in this study to ensure an accurate overview of the patient journey. First purposive sampling, which ensures that the individuals being studied can provide rich data to address the research question, was opted over random sampling, to ensure that the patient journey was comprehensive in the detail collated. Also theoretical saturation, a method that employs a range of criteria for determining the point of recruitment of sufficient participants for a particular category, was utilised to ensure credibility. The concept here was to achieve a point when no additional data could be discovered by the researcher, thus, having attained full capacity. The purposive sampling was ensured by identifying a sample of individuals who were living with peripheral neuropathy in Kuwait and who were being treated for this condition at the Ibn Sina Hospital in Kuwait, the only hospital dedicated for this in Kuwait. This selection confirmed that the target individuals could supply detailed information on the topic and discuss relevant experiences.

The process map was formed using a planned strategy which involved multiple steps of compilation and layering, whilst avoiding repeated or duplicate statements, through repeated iterations. The detailed map of the journey was created by providing an overview of the process, but without loss of relevant data, and ensuring credibility. A close analysis of the patient journey map and comparison with standard care in the UK [26] highlighted that a much more strategic approach is required in three main areas including non-pharmacological support, organisational systems and medical care.

4.1. Psychological support

There are three factors that play an important role in pain perception: namely psychological, psycho-behavioural and psychosocial components [27,28]. Many participants in this study reported that their pain had influenced their mood, sleep, relationships and functional capacity. This finding is similar to research reported by Hensing *et al.*[29] in 2007 that showed examples of exaggerated pain and consequences of chronic pain in neuropathic patients, where the touch of a nightdress triggered a massive stimulus, which in a healthy patient would be negligible.

In the UK people living with peripheral neuropathic pain and their families are given information regarding the causes of the disease, treatment, and prognosis alongside psychological support via counselling sessions guided by qualified psychologists [30]. Treatment in Kuwait, however, depends on the pharmacological management of symptoms alone. According to World Health Organization (WHO), effective management of patients' emotional distress has contributed to the success of primary healthcare, by utilizing the tool of reassurance [31], which places emphasis mainly on patient education and counselling. Improvement in this area to help people living with peripheral neuropathy in Kuwait is highly recommended.

4.2. Administrative problems

In Kuwait, waiting times for referrals from the general practitioner in the primary clinic to the doctor in the general hospital took anywhere between 2 and 8 weeks, to the neurologist in the general hospital another 3-6 months, and to the neurology specialist/consultant in the national hospital another 3-6 months. In case of loss of medical records, these times were extended to up to 12 weeks, 8 months and 8 months respectively. The above findings regarding long waiting times for referrals in Kuwait are similar to a study conducted in 2011-12 in rural areas of Iran that identified inadequacies in the government healthcare referral system [32]. The Iranian study highlighted specific issues with the referral system such as a lack of communication between different levels of the system itself. In addition, the study showed that people living with peripheral neuropathy possessed insufficient knowledge of the system, self-referred or bypassed it entirely. The referral system in Kuwait, from the patient's perspective, could be improved by coordination between different levels of the referral system, strengthening the public sector of the system, increasing public awareness about the referral system, and preventing self-referral, similar to those improvements implemented in Iran [32].

There is no centralized electronic medical record system in Kuwait, which leaves physicians with no choice but to hold bulky paper files, most of which are loosely arranged and often lost during referral. Consequently, succeeding specialists prefer to repeat all tests and treatments instead of spending time deciphering the patient history in the file or communicating with the previous physician. In conjunction, patients are asked to repeat their histories at every stage of the journey. This leads to an inability of the treating physician to visualize the treatment of a patient as a whole [33]. Electronic medical records could therefore potentially reduce delays and overall staff workload. Technological advancements and electronic medical records can have a significant impact on a referral system [34]. They can improve quality of care, patient outcomes, and safety through improved management, reduction in medication errors, and reduction in unnecessary investigations. Furthermore, they can improve communication by phone, email and face-to-face among primary care providers, patients, and other providers involved in care [35]. Electronic medical records have been demonstrated to improve efficiencies in workflow through reducing the time required to create charts [36], improving access to comprehensive patient data, helping to manage prescriptions, improving scheduling of patient appointments, and providing remote access to patients' charts. Electronic medical records capture point-of-care data that informs and improves practice through quality improvement projects, practice-level interventions, and informative research [35]. The suggestion of Aij *et al.* [37] in the Netherlands, for example, that hospitals and healthcare providers should source third party consultants to train management on how to manage and implement solutions, could be a useful recommendation based on the results of this current study. If this was implemented, the patient journey could be redesigned to avoid repetition, remove inconsistencies and create greater standardization across related departments and organizations [38].

4.3. Medical care

Table 3 shows that pharmacological treatment of peripheral neuropathic pain in Kuwait aligns with the UK NICE and IASP guidelines, except that many diabetics are not prescribed carbamezepine (200-400 mg) or gabapentin (300-1200 mg) tablets as first line treatment [26,39]. Furthermore, topical applications such as capsaicin cream, are not available. However, one participant had reported buying capsaicin cream from abroad and had attested to its efficacy which was in keeping with the findings of various studies. Tramadol was rarely used to treat people experiencing diabetic peripheral neuropathic pain. However, the availability of these other medications and training for personnel to use and prescribe them would help people manage their peripheral neuropathy more effectively. Guidelines regarding the intervals for assessment and reviewing changes in medication, for example, when to escalate from 1st to 2nd or 3rd line treatment, could improve the follow-up process. New treatments could then be introduced carefully and with the assessment of their efficacy in the Kuwaiti context.

4.4. Implications for research

The main strength of this study is the high level of patient involvement and the wide range of individuals interviewed. Patient perspectives are not routinely explored through research in Kuwait. There are several limitations, however, that have implications for how future research studies in this area are designed and implemented. This study was hampered by the unavailability of a centralized Electronic Medical Records (EMR) system to confirm the diagnosis and treatment being followed in locations or clinics other than the National Hospital for Neurology. Another limitation was the age range of participants which meant younger people, aged 18-34, were not represented so it was not possible to explore how similar their experiences are to those reported here. The recommendations outlined in this article could become the basis for further qualitative research in the area. For example, observational studies could assess the success of implementation of recommendations and procedures suggested in the treatment of people living with peripheral neuropathy in Kuwait. At the same time, in-depth interviews with individual family members and medical staff could be undertaken to fully explore their problems and issues. A mixed qualitative approach such as observation and in-depth interviews would provide deeper insights and therefore a broader perspective.

4.5. Implications for practice

The overall medical system could be enhanced by addressing the identified issues with communication and organization. With regard to communication, perceptions of treatment for peripheral neuropathy could be improved by focusing on the doctor/patient interaction, along with relationships within the multidisciplinary team. Medical professionals could create a culture of mutual respect and cooperation among both medical and administrative colleagues to view patient care as a collective and collaborative effort [40]. Furthermore, in regard to administrative issues, a way to address the current deficit would be to employ a more organized approach to the care pathway, in particular the use of electronic medical records.

5. Conclusion

This map of the patient journey of people living with peripheral neuropathy is a fresh representation that Kuwaiti health officials and medical personnel might find helpful in visualizing the process from the patient's perspective. The study and journey map provide evidence based on interviews that there are several shortcomings and weaknesses in the medical and administrative systems, at all levels (primary and secondary care) in Kuwait, which people living with peripheral neuropathy have to overcome. The process map indicates where changes can be made to improve patients' experiences and potentially their satisfaction with their healthcare and treatment. By addressing administration, medical care and psychological support issues highlighted in this study, people living with peripheral neuropathy could experience more positive treatment outcomes.

Author Contributions: We certify that we have participated sufficiently in the intellectual content, conception and design of this work or the analysis and interpretation of the data (when applicable), as well as the writing of the manuscript. We take public responsibility for the work and have agreed to have my/our name listed as a contributor to the work.

Intellectual content, conceptualization, methodology, formal analysis, writing- review and editing, MA, KR and AH. Investigation, writing- original draft preparation, MA.
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Characteristics		**Observations (n=25)**
Nationality	Kuwaiti	20
	Non-Kuwaiti	5
Sex	Male	12
	Female	13
Age	Range	35-82
(years)	Mean (Standard Deviation)	55 (SD=10)
Comorbidities	Type 2 Diabetes Mellitus	16
	Hypertension	10
	Dyslipidaemia	8
Duration of peripheral neuropathy	Range	3-30
(years)	Mean (Standard Deviation)	13.76 (SD=7.4)

Table 1. Characteristics of people living with peripheral neuropathy in Kuwait

Center	Investigational Procedures performed
Primary clinic-general practitioner	Blood routine, random blood sugar, fasting blood sugar and postprandial blood sugar for diabetics
General hospital- doctor	Blood routine and HbA1c (glycosylated haemoglobin)
General hospital- neurologist	Blood routine, HbA1c and other blood test, advanced neurological investigations: loss of protective Sense, +1 of reflex ankle-vibration- pin prick- gait
National hospital- neurology specialist/consultant	Physical examinations, full neurovascular examination, nerve conduction study, and foot care diabetic peripheral neuropathy. Investigation and examination: HbA1c and other blood tests

Table 2. Investigational procedures carried out for people living with peripheral neuropathy in Kuwait

Treatment option	Commonly prescribed drug	n=number of participants that were on the treatment therapy
General pain management	ketoprofen (Fastum2.5%) Gel	1
	etoricoxib (Arcoxia) 30 mg tablets	1
	ibuprofen (Ibuprofen)200-400 mg tablets	10
	acetaminophen (Acetaminophen) 500mg tablets	5
	alpha-lipoic acid (Thiotacid) 600mg tablets	2
	vitamin b complex (B complex) 500 mg tablets	7
First line treatment *	pregabalin (Lyrica) 75-150mg tablets	8
	Tricyclic antidepressants (TCAs): amitriptyline (Tryptizol) 25-150mg tablets	1
Second line treatment	Selective serotonin and norepinephrine reuptake inhibitor (SSNRI): duloxetine (Cymbalta 60-120 mg capsules, and Cymbatex 30 mg capsules)	1
Third line treatment	Opiods: tramadol (Tramol) 50 mg Tablets	1

Table 3. Treatment options provided for people living with peripheral neuropathy in Kuwait *The current study showed that people with peripheral neuropathy, who are mainly diabetics, were not using Carbamazepine 200-400mg tablets or Gabapentin 300-1200 mg tablets as first line medications.

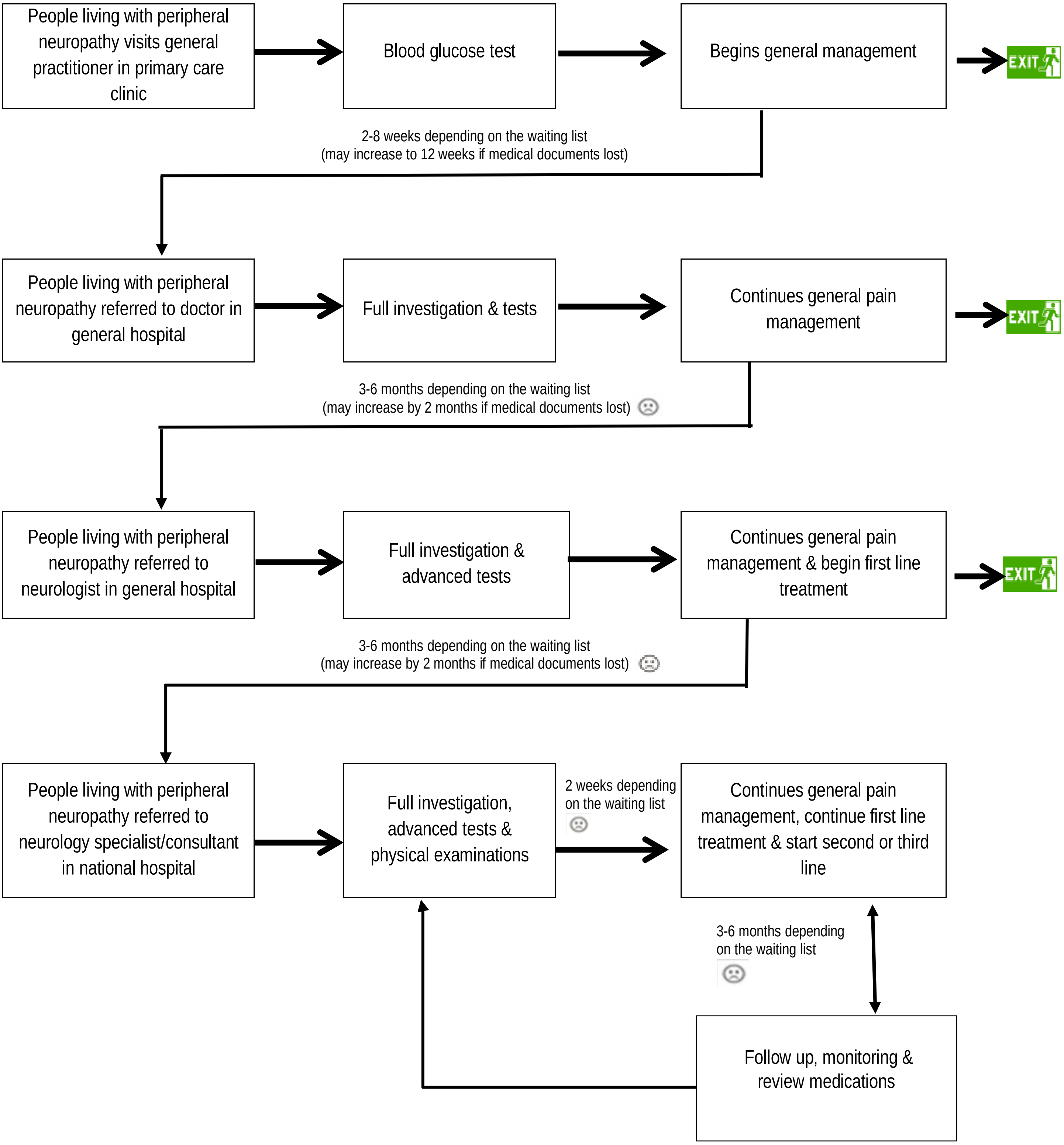

Figure 1. A Process Map of People Living with Peripheral Neuropathy in Kuwait

4.3 Conclusion

This chapter analysed the patient journey of people living with peripheral neuropathy in Kuwait, from primary clinic through to the national hospital of neurology. The study identified a few pertinent issues that related to medical and administrative systems. These issues included the lack of psychological support, administrative deficiencies such as long waiting referral periods, loss of medical documents, shortage of specialists and lack of a centralised electronic medical records. Moreover, issues were also born of inadequate medical care including the shortage of new treatments and lack of follow-ups.

Several important suggestions were presented to help improve their journey, as identified through the process map but there is a need for more in-depth research into the patients' difficulties. The process of simplifying the process map by generating a collective map from the individualised interviews had the potential for loss of crucial information, such as significant differences between the individuals. Nevertheless, collation of the data for this thesis and the development of the process map were both performed in a manner that sought to prevent the loss of such key information.

First, to ensure that patient journey was comprehensive in the detail collated the participants included were recruited using purposive sampling. Unlike random sampling, purposive sampling ensures that the individuals being studied can provide rich data through the questions delivered which, therefore, ensured the credibility of the data collated for analysis. The credibility of the data was further ensured through the use of the theoretical saturation technique together with purposive sampling. Theoretical saturation is a method that employs a range of criteria for determining the point of recruitment of sufficient participants for a particular category. Beck (2004) described it as the point when no additional data can be discovered by the researcher, thus, indicating the researcher having attained full capacity. This was further expanded by Polit and Beck (2004) who described this point as identifiable through experience observations that allow the identification of participants who go beyond the data range (Devers & Frankel, 2000). In this thesis, purposive sampling together with theoretical saturation identified a sample of individuals who were living with peripheral neuropathy in Kuwait and who were being treated at the Ibn Sina Hospital in Kuwait, the only hospital dedicated for this in Kuwait. Thus, this ensured that the participant group was made up of the target individuals who could supply detailed information in an articulate and rational manner. Moreover, it also included individuals who could present previous experiences that affected them in a similar way. Collectively, the data collated from all individuals in this group was of a high quality which enhanced the researcher's derivation of themes from this data, thus ensuring the findings of the study were highly credible. Moreover, these sampling methods ensured that the same data set from the same group of individuals could be employed for the generation of the process map. Once again, to ensure the credibility of the findings, the process map was formed by following a planned strategy. This involved the formation of an initial map from four interviews that demonstrated the greatest degree of rich data through their consistency, articulation and eloquence. Similarities and differences were noted in the four and included similarities in treatment and referrals and differences in waiting list times or referral times. The initial map was comprehensive which ensured that differences between individuals were not lost whether they related to symptoms, physical examinations, the referral process, follow up, results or their current status. To ensure even greater detail, the review of the initial map against the additional 21 interviews was carried out using a layering process. Thus, ensuring further detail was added that enhanced the clarity of the initial map. To avoid repeated or duplicate statements, repeated iterations were performed which simplified the data without loss of key information, thereby resulting in a detailed map of the journey experienced in Kuwait by individuals who lived with peripheral neuropathy.

One of the limitations of this study was that the process map focussed on the patients journey within the healthcare system in Kuwait, this meant that the map did not illustrate the support or care patients accessed outside of this. Psychological support was an additional resource that a few participants accessed outside the healthcare system and also a resource that a few had hoped they could receive within the process. The main outcome of this study was to highlight deficiencies in the patient journey and the lack of psychological support within the healthcare system was a key element. This process map study promoted the need to explore the patient experience in its entirety with a focus on medical management, coping and management strategies of people living with peripheral neuropathy in Kuwait, which will be discussed in Chapter 5.

CHAPTER FIVE

Study 3: People's experiences living with peripheral neuropathy in Kuwait: A qualitative study.

5.1 Publication relevance to thesis

This chapter presents the third paper in this PhD thesis. The paper was submitted to the peer-reviewed journal Chronic Illness in November 2019. After conducting the systematic review of the literature then exploring the patient journey through a process map, there was a need to explore the experiences of people living with peripheral neuropathy in Kuwait in more detail. Participants, who provided data to create the process map, also provided the data for this qualitative study. Thus, same data set used in previous study contributed to this study as well. Accordingly, this was a qualitative study designed to explore the experiences of people living with peripheral neuropathy in Kuwait in-depth, with a focus on coping and management strategies including medications. The methodology adopted was to conduct semi-structured interviews, transcribe to the NVivo 12 programme, then manually code to identify themes using thematic analysis. Supplementary materials consisting of all relevant tables, figures and declarations forms can be found at the end of this chapter.

5.2 Title of publication (submitted to *Chronic Illness*)

People's experiences living with peripheral neuropathy in Kuwait: A qualitative study.

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Abstract

Objectives: Incidents of peripheral neuropathy are a rising concern in Kuwait. This qualitative study explored the experiences of people living with peripheral neuropathy in Kuwait.

Methods: Semi-structured interviews were conducted with 25 participants recruited from the national hospital for neurology in Kuwait. Interviews were transcribed and translated into English then coded using NVivo 12. Thematic analysis was then conducted to identify themes in the data.

Results: Three major themes were identified including treatment beliefs (perceived effectiveness of treatment and seeking alternative treatments), the barriers to pain management (side effects of the medication, relationships with healthcare professionals and lack of information and access to healthcare), and the impact on quality of life (the impact on work and social/physical/psychological consequences). Self-efficacy was a key construct that was discussed in all the major themes.

Discussion: This paper presents the experiences of people living with peripheral neuropathy and reveals there is much scope for improvement of current treatments in Kuwait. Self-management strategies are recommended alongside prescribed medication and healthcare professionals are encouraged to use a patient-centered approach. To improve quality of life; information and support on the condition to promote coping strategies and self-efficacy, should be adopted.

Keyword: patient experience, self-efficacy, peripheral neuropathic pain, quality of life, qualitative research.

1. Introduction

Peripheral neuropathy (PN) is a condition that involves damage to the peripheral nervous system.[1] It is caused by a number of factors, including diabetes, trauma and drugs (e.g. cisplatin and taxanes).[2,3] Symptoms include pain, numbness, tingling, a burning sensation, and muscle cramps. [3] Peripheral neuropathy exists worldwide and affects more than 20 million individuals in the United States alone, thus it is rapidly becoming a public health concern. [3] Peripheral neuropathy is more common among the elderly compared to younger individuals. [4] According to one study , the prevalence of peripheral neuropathy among the general population is 1%, but increases to approximately 7% in adults over 65 years old. [5] In Western countries, such as the UK, pain presents in approximately two-thirds of people living with peripheral neuropathy. [6] Pain is the main disabling symptom of peripheral neuropathy and often has a detrimental effect on the mental health and quality of life of people living with the condition. [7] Peripheral neuropathy has been shown to cause a marked reduction in the physical, social and emotional functions. [8] One study reported that diabetic patients with peripheral neuropathy had a significantly reduced quality of life compared to diabetic patients without peripheral neuropathy. [9] Furthermore, another study showed that peripheral neuropathy had a negative effect on the sleep and work life of these individuals. [10]

There has recently been a growing interest in peripheral neuropathy from the individual’s perspective. Peripheral neuropathy has the potential to significantly disrupt the lives of people living with the condition, specifically the elderly. Vulnerability is found more in the elderly, who experience a loss of confidence in their ability to perform daily activities after experiencing the negative effects of peripheral neuropathy. [11] A better understanding of the perspectives of people living with peripheral neuropathy would need to include an exploration of the support these people receive from their family and friends.

Peripheral neuropathy is present in 54% of the diabetic population in Kuwait.[12] A significant rise in the incidence of diabetes mellitus is seen with age. [13] Furthermore, the increasing prevalence of peripheral neuropathy is also caused by a rise in the number of people suffering from lower back pain. [14] Studies on people living with peripheral neuropathy in Kuwait have reported that pain negatively affects mood, sleep, relationships, and functional capacity. [15]

Although the management guidelines for peripheral neuropathy are similar in Kuwait to those in the UK, there is no integrated referral system for consistent health care. Moreover, patient education on self-management and coping strategies is lacking in Kuwait. [15] Multidisciplinary cares for people living with peripheral neuropathy is encouraged in Western countries, with many receiving a wide range of additional support . [16] Part of this multidisciplinary care includes the promotion of self-efficacy, which is the confidence in one's ability to perform a particular behaviour.[17, 18] Self-efficacy has been shown to be useful in promoting behaviour change in relation to pain management, such as in foot self-care in the elderly diabetic population in Malaysia. [19]

A range of studies were conducted in the Western world examining the encounters of people living with peripheral neuropathy at various levels including the psychological (thinking optimistically) and emotional (such as conversing with family or friends) and physical (including basic exercise and performing simple tasks). [11, 20-24] All these methods function as coping strategies. The goal of this particular study was to examine the journey of peripheral neuropathy patients in Kuwait and it highly centred on their approaches to controlling and coping with the condition.

2. Methods

Design

This study used an exploratory qualitative study to explore the experiences of people living with peripheral neuropathy in Kuwait. A semi-structured interview schedule was used, which contained open-ended questions, with the aim of examining the impact of the condition on the participants.

Setting

The setting for this study was the neurology outpatient clinic of the Ibn Sina Hospital. This clinic is one of the main clinics that neurology patients are referred to in Kuwait, when presenting with peripheral neuropathy. Ethical approval was obtained for this study from the University of Reading Ethics Committee, as well as from the Standing Committee for Health and Medical Research Coordination in the Ministry of Health in Kuwait. The semi-structured interview schedule was developed following an extensive literature review.

Recruitment

Permission was obtained from the Dean of Medicine at the Ibn Sina Hospital to conduct the study on the premises and to collaborate with neurologists attached to the neurology outpatient clinic to identify eligible participants. The inclusion criteria consisted of participants being a resident of Kuwait, able to speak either Arabic or English, over 18 years old and diagnosed with peripheral neuropathy.

Potential participants identified by the neurologists were provided with an invitation pack by the nursing staff in the clinic. This invitation pack consisted of an invitation letter and a patient information sheet. Potential participants were asked to contact the study investigators if they were interested in the study. Completed consent forms were obtained from each participant and securely stored. Interviews were conducted between March 2017 and March 2018 in a private room at the Ibn Sina Hospital.

Procedure

The nursing staff approached 95 potential participants, of which 27 contacted the study investigators. Through screening two recruits were excluded: one recruit was under 18 years old and the other had a neurological condition that was not peripheral neuropathy. Twenty-five recruits were selected for the study (26% recruitment rate) and consent was obtained, with recruitment complete by February 2017. Interviews were conducted in either Arabic or English, depending on the language preference of the participant. Participants were asked about their pain including symptoms and treatments along with the impact on their daily lives. The interview also explored psychological issues as a consequence of the condition and coping strategies employed by the participants. Each interview lasted between 45 minutes and one hour (mean 51 minutes). Once informed consent had been obtained, demographic and medical information was collected through a review of the participants’ hospital records prior to each interview. Interviews were audio recorded and subsequently transcribed verbatim. Interviews conducted in Arabic were transcribed in Arabic then translated into English. Interviews conducted in English were transcribed directly into English. The accuracy of the transcriptions and translations were checked by sending six of the total 25 transcripts for review. Four of these transcripts were reviewed by a bilingual lecturer (proficient in both Arabic and English) and two by a similarly bilingual physician.

Data analysis

The verbatim transcripts were transferred to NVivo 12 software (QSR International, Melbourne) [25] for data management and analysis. For the purpose of this study, thematic analysis was used to identify recurring themes in the data, analyse these themes, and draw conclusions. [26] This methodology was chosen because it provides a framework to deepen the understanding of peoples' experiences of living with peripheral neuropathy and offers an interpretation through the extracted themes. The data was manually coded following familiarisation, then a combination of text search and coding queries were executed to extract preliminary nodes and themes. The latter was performed through the compilation of the themes obtained to extract more specific themes. The suitability of each theme was then reviewed by integrating the data to generate a final list of themes. An example of a preliminary node and theme is the side effect of prescribed medication (such as Lyrica) hindering the management of pain from peripheral neuropathy. This theme, which is a barrier to pain management, was then interpreted to highlight other barriers. The selected themes were then discussed with peers who were experts on neuropathic pain and in particular peripheral neuropathy. Table 1 depicts an example of how the initial codes were constructed from the quotes and how the themes emerged from the data.

< Insert Table 1>

3. Results

The focus of this study was to explore the experiences of people living with peripheral neuropathy in Kuwait. Participants in this study mainly experienced neuromuscular symptoms; including physical pain in the feet, hands, extremities, back, leg and knees, as well as complaining of numbness and tingling. Table 2 reflecting the characteristics of participants included in the study.

<Insert Table 2>

The analysis identified three major themes: treatment beliefs, barriers to pain management and the impact on quality of life. The overarching theme which was present throughout was self-efficacy. The themes identified through the interviews are illustrated in Figure 1.

<Insert Figure 1>

Treatment beliefs

Participants noted the importance of pain management and its role in improving their daily functioning. Different strategies were used to counteract pain including over-the-counter medication and complementary and alternative treatments.

Perceived effectiveness of treatments

Prescribed medication, such as Lyrica and over-the-counter pain relief, such as acetaminophen (Panadol) and ibuprofen tablets, were reported to be used by most participants. They identified over-the-counter pain relief to be most useful in tackling both physical and psychological symptoms.

> *I would not be able to sleep at night. I would be in a lot of pain and would have to wake up and take some Panadol. Thank God we have painkillers. (Female, 56 years old, PN- 30 years)*

Participants also reported the use of topical analgesics, such as ketoprofen (Fastum) 2.5% gel and capsaicin cream, to provide pain relief. Although these products are of limited clinical benefit in peripheral neuropathy, some participants still reported feeling relief by incorporating them into their treatment plans. One woman even mentioned that she was very resistant to changing her use of the topical analgesic, capsaicin cream, though she had to take extra efforts in procuring same during travel abroad, as capsaicin cream was not available locally in Kuwait.

> *The pain lessens when I use the capsaicin cream for my feet, thank God. I can stand up again when I use the cream. Frankly, I have been using it from a long time. This is my cream. I never changed it, although many women tell me that I have to change my pain medication, but I refuse it. I do not change my medication and will keep it until I die. (Female, 82 years old, PN- 20 years)*

Seeking alternative treatments

Some participants sought out complementary and alternative therapies such as Korean therapy-sujok, Chinese therapy-acupuncture and massage to manage their pain independently. These participants did not consult their healthcare professional before starting the treatments. Information was obtained from shared experiences by colleagues, family, and friends. In particular, Korean therapy-sujok was mentioned as providing remarkable immediate pain relief.

> *I practice the Korean therapy- sujok, which relieves the pain immediately within two minutes and its effects are immediately felt. As for painkillers, if you take them, they will need 10 to 20 minutes, but this sujok therapy takes only seconds. This is really unbelievable. (Male, 43 years old, PN- 4 years)*

In addition, several participants mentioned trying massage and acupuncture to alleviate their pain. The use of these alternative treatments allowed participants to feel in control of their symptoms.

> *I massage my fingers, close my hands and move my hand in warm water for some time. To reduce my pain, however, I regularly go for acupuncture sessions when I'm free. (Male, 62 years old, PN- 10 years)*

As a natural alternative to medications, herbal therapy (for example, ginseng tablets and cinnamon tea) was also used by a number of participants. Although many did not fully endorse the efficacy of herbal therapy initially, they continued with it as they believed it was unlikely to do any harm. Participants also felt that herbal therapy was worth pursuing without prior discussion with their healthcare professionals, who did not pay much attention to alternative treatments.

> *Well, whenever I feel pains, I take two tablets of ginseng per day, in the morning at breakfast and in the evening at dinner. It's a herbal treatment for my legs to reduce the pain and I decided to take it without asking my doctor and he never asked me about it. (Female, 56 years old, PN- 7 years)*

Barriers to pain management

Participants reported several barriers to pain management when discussing the experiences of living with peripheral neuropathy. The main barriers discussed included side effects of medications, the relationship with the healthcare professionals and a lack of information and access to healthcare.

Side effects of medications

Participants reported that the side effects of prescribed medication had a significant impact on their pain management. A key factor discussed by a number of participants for discontinuing the use of Lyrica tablets was the side effects of the medication. Participants held negative views of the medications they were prescribed and expressed concerns about continuing the entire course of their medications due to the side effects.

> *Due to the countless side effects from Lyrica, including weight gain, I no longer take the dose that the doctor prescribed for me. (Female, 45 years old, PN- 9 years)*

Relationship with the healthcare professionals

Participants discussed how their healthcare professionals would focus on the medical management of the disease rather than highlighting the importance of behaviour change and coping with the illness. Participants reported that this approach led to emotional consequences such as fear, anger and stress, which meant they did not adhere to the medication.

> *I am saddened by the doctors' apathy. This apathy and neglect led me to neglect myself. The stress coupled with the severe pain and neglect led to stop taking my own medication. I wish doctors considered our pains and feelings in order to examine us more carefully. (Female, 45 years old, PN- 9 years)*

Some participants reported that the limited duration of the consultation with their healthcare professional resulted in a lack of empathy. This led to a lack of information received by participants about their condition and its management, leaving them with uncertainty and feeling in a worse state than they were before the consultation.

> *They should give enough time and not rush even if they have a second patient. They need to examine and listen to me as it should be. They also should give me more than just treatments. (Female, 36 years old, PN- 10 years)*

Lack of information and access to healthcare

Several participants reported suffering their condition in silence. These participants highlighted that they did not have access to the necessary information about peripheral neuropathy and its management, with some noting a lack of motivation to join a support group for their condition.

> *There are no such seminars that educate patients. The doctor also did not speak about such seminars and did not give me brochures. (Female, 82 years old, PN- 20 years)*

Many participants felt unable to manage their condition due to long waiting times in receiving pain relief. Participants preferred immediate treatment rather than waiting many months.

> *As for the referrals, they are the same for the person who feels pain and the person who does not feel pain. In detail, they give a medical appointment for three months, and if you miss your medical appointment, it is a big problem.*

> *By the time I get to the doctor I am tired and feel bad. (Female, 56 years old, PN- 30 years)*

Impact on quality of life

Participants noted that their quality of life was negatively affected by their condition. The physical and psychological symptoms of peripheral neuropathy impacted their work, emotional and social lives.

Impact on work

The workplace was reported to be an unsupportive place by some. Mechanisms were not put in place to help participants manage their condition. A few participants recommended that receiving assistance from colleagues in completing certain tasks would help make the workplace more manageable.

> *In fact, the nature of my work obliges me not to sit at the office, where I should go and come back because I am responsible for the whole section. If I finished work and sat down, I will begin to feel pain, forcing me to rise again and move to press on my feet, then I go to my friend in the job so that she can go down with me to another division in order to move and press my feet because if I press them, the pain will decrease, but if I continued to sit, the pain will continue. (Female, 45 years old, PN- 9 years)*

Social consequences

Some participants noted that the misunderstanding of their condition by other people resulted in social isolation and loneliness.

> *Do you mean that I talk to anyone? No. Because of my pain, I now have a different routine from most men. Most men go from the house to the mosque to religious seminars to the Diwaniyah [men's gathering] once a week where they talk about themselves. I do not like talking about myself and my pain, which is why I do not go to the Diwaniyah. To be honest with you, I do not want to go to the Diwaniyah anymore because of the pain. (Male, 62 years old, PN- 25 years)*

Several participants reported that strong emotions such as anger had become a part of their life. Some reported their family roles had become impaired and the happiness of their children was affected.

> *I have become so nervous that I fight with the children a lot and I make a problem about something trivial. (Female, 45 years old, PN- 9 years)*

Most participants reported that their condition resulted in a loss of independence and weakened relationships with family and friends. Participants also felt that they were unable to fulfil their family roles.

> *Sometimes I want to change my clothes and put on trousers. I cannot, so I ask my wife for help and here I begin thinking that I have reached such a degree that I cannot change my trousers. (Male, 60 years old, PN- 15 years)*

This situation was further worsened when participants felt embarrassed and were unable to openly discuss their condition with their own family members.

> *I also do not consider it a subject of discussion even with my wife because my wife only feels my pain if we travel or walk together. (Male, 64 years old, PN- 18 years)*

Physical and psychological consequences

Participants who were left uninformed about their condition reported stress and discomfort in not knowing whether their condition was improving or getting worse. A number of participants described experiencing fear that resulted in mood swings and emotional outbursts.

> *I feel a sense of fear when I am at work. I am afraid of feeling pain while I am working. (Male, 62 years old, PN- 10 years)*

Other participants reported a lack of sleep and a sense of vulnerability due to physical symptoms such as tingling and stabbing.

> *Due to diabetes I had severe tingling in the extremities of my hands and feet. Not only that, I also felt a kind of burning in my hands and feet. It was a kind*

> *of heat that led to sense the tingling in my hands and feet, particularly when I am sleep. (Female, 60 years old, PN- 4 years)*

Over-arching theme of self-efficacy

The over-arching theme discerned throughout the data was self-efficacy, apparent in all subthemes. Self-efficacy refers to the way in which an individual believes in their ability to execute behaviours to achieve certain attainments. [17] Self-efficacy was reflected in the first theme, which was their beliefs about treatment, in relation to dealing with the pain associated with peripheral neuropathy by developing resilience and exhibiting a positive attitude towards over the counter treatments.

> *I also asked the doctor to refill my prescription of Panadol pills, which are the first thing I get refilled from the clinic. Later on, when I met the doctor, she told me that Panadol pills are excellent for me. Thank God! When I used it, I relaxed a lot. We must continue to fight the pain. (Female, 56 years old, PN- 30 years)*

The second theme, which was the barriers to pain management, had an impact on the perceived control people experienced in relation to their condition. Some reported low self-efficacy in that they did not feel capable of coping with and managing their pain. A number of participants highlighted their interactions with healthcare professionals and the healthcare system impacted on their ability to control their pain. Participants described the lack of empathy from their healthcare professionals lead them to stop taking their medication, which was a barrier to pain management.

> *I informed the doctor about the severe numbness and other pains. He said that he cannot do anything about it until the pain grows enough to do further tests. The fear of pain coupled with the doctor's neglect affected me and discouraged me from taking my medication. (Male, 43 years old, PN- 4 years)*

The third theme identified in this study was the impact of peripheral neuropathy on the quality of life of participants. Self-efficacy was apparent in this theme as participants reported feeling unable to complete tasks required as part of their working lives.

> *I feel tired and exhausted. I can't complete work, or I need to take a break and then go back to complete the work. (Male, 62 years old, PN- 10 years)*

4. Discussion

The findings of this study give insight into the experiences of people living with peripheral neuropathy in Kuwait, with a focus on coping and management strategies. Specifically, these included avoiding the prescribed medication (i.e. Lyrica), camaraderie in sharing experiences with others in a similar situation, and the use of alternative medicine (such as Sujok therapy and acupuncture). The first theme identified in the present study highlights the participants treatment beliefs and their perceptions of the effectiveness of treatments and alternative treatments that they explored. Patients were aware that pain management was a key factor in improving daily life. The 'instant relief', as well as physical and psychological comfort described by participants in relation to the use of over-the-counter remedies, supports current guidance used as standard practice in Europe, which suggests self-management through the use of over-the-counter analgesics for localised neuropathic pain. [27] A total reliance on over-the-counter pain medications should be noted with caution as a recent study regarding self-medication with over-the-counter analgesics reported that 40% of the sample showed substantial concern about the perceived need for pain medication and the perceived potential for harmful effects. [28] The use of alternative therapies and massage to counteract their pain and symptoms was usually an autonomous undertaking, conducted without consulting with their healthcare professional. This should be viewed as a means of contributing actively to their individual treatment and of gaining a sense of control over their health condition. The suggestion that basic self-help or alternative treatments such as massage and acupuncture helped in alleviating pain and stress is also supported by previous research. [29] Nevertheless the use of herbals, even if there are no apparent side-effects, should be viewed with caution and discussed with a healthcare provider in case of potential interactions.

The second theme identified was barriers to pain management which were attributed to the side effects of medications, their relationship with the healthcare professionals and a lack of information and access to healthcare. The fear of side effects has often been reported worldwide as a contributor to a lack of medication adherence. [30-32] Relationships with healthcare professionals was noted as strained by the participants, with a need for longer consultations and empathy from doctors. Robbins *et al.* (1993) found that the time physicians had spent on their health education, by keeping up to date on the effectiveness of treatments, had an important bearing on patient satisfaction. [33] Paying attention to the emotional needs of patients [34, 35] and using empathic statements [36] has been demonstrated to result in better healthcare outcomes. The lack of information about their disease and its prognosis, experienced by our participants, needs to be tackled as access to health information is a key determinant of health. Governments have a legal responsibility under international human rights law to provide access to healthcare information to citizens and health workers. [37] It is noted that longer waiting times are negatively associated with clinical provider scores of patient satisfaction and that every aspect of the patient experience, specifically confidence in the care provider and perceived quality of care, correlated negatively with longer waiting times. [38] Moreover, in our study, many participants felt unable to manage their condition due to long waiting times in receiving pain relief.

The final theme from the thematic analysis examined the impact on quality of life. The sub-themes identified were the impact on work, social consequences and physical and psychological consequences. Work environment was often reported as unsupportive, especially where mechanisms were not put in place to assist people living with peripheral neuropathy. The importance of workplace assessments as well as notifying employers and colleagues about the condition can help make the work environment a better place [39]. Social isolation and loneliness were reported by many participants in the current study. Parallels were found between the findings of this study and those made by Aloisi *et al.* (2016) [40] where patients developed a fear of becoming weak or disabled and of their increasing dependency on family and friends.[41] Closs *et al.* (2009) [20] suggested that health outcomes were primarily challenged by a reduction in the quality and/or number of personal relationships that the patient had, which was similar to those reported in this study. The physical and psychological consequences of living with peripheral neuropathy reported by our participants, such as lack of sleep, mood swings and anxiety, are coherent with the findings of the long-term effects of chemotherapy-induced peripheral neuropathy [42] and the mood disorders witnessed in neuropathic pain.[43]

The results of this study highlighted an overarching theme of self-efficacy. Through the treatment beliefs, barriers to pain management and the impact on quality of life; self-efficacy was apparent. Previous research has suggested that self-efficacy partially mediates the association and changes in pain and disability. [44] High self-efficacy has been associated with better functional outcomes, and variability in self-efficacy mediates the association between pain intensity and disability. [45] This has been observed in various other pain conditions such as arthritis, headaches [46, 47], fibromyalgia [47, 48] and paediatric pain conditions. [48, 49]

The themes identified in the current study find reflection in the protection motivation theory. This theory proposes that people protect themselves based on the perceived severity of a threatening event, the perceived probability of the occurrence or vulnerability, the efficacy of the recommended preventive behaviour (response-efficacy), and the perceived self- efficacy.[50] These findings provided support for self-efficacy expectancy as a fourth component of the protection motivation theory: Self-efficacy has a strong impact on intentions and it is connected with two other components of the protection motivation theory.[50] The theory stems from the concepts of threat-appraisal and coping-appraisal. Threat-appraisal incorporates severity and vulnerability along with the rewards of continuing the unhealthy behaviour or condition. Coping-appraisal includes the response-efficacy and self-efficacy. [50] In this study, the severity of pain and symptoms of peripheral neuropathy were discussed in relation to the fear of disease progression. Vulnerability due to physical symptoms, lack of sleep and the lack of health information, along with a lack of proper treatment for peripheral neuropathy, led to a threat-appraisal. An adaptive coping-appraisal was demonstrated in this study through the response efficacy of effective treatment and self-efficacy from the use of over-the-counter products or turning to alternative therapy. With a high threat and coping appraisal, people living with peripheral neuropathy were motivated to seek better care.

Implications for research

The main strength of this study is that it gives an in-depth insight into the experiences and beliefs of people living with peripheral neuropathy in Kuwait. The method employed, which was a semi-structured interview, enhanced the flexibility, sensitivity, reliability and depth of the data collected. Furthermore, the analysis enabled the identification of key themes surrounding the views of people living with peripheral neuropathy in Kuwait and their attitudes towards the treatment and practices of their healthcare professionals. The study also highlighted the relevance of the protection motivation theory in the field of peripheral neuropathy management which can provide the theoretical underpinnings for future research.

Some limitations of this study include the sample size, where it was found adequate for the methodology used. Data saturation was reached during analysis of the themes extracted, and this was appropriate for the sample size. However, since the study was qualitative and employed a homogenous sample, its results cannot be generalised to everyone with peripheral neuropathy. Due to data saturation and no new themes emerging it could be suggested that the findings are representative and may apply to people living with peripheral neuropathy in Kuwait. Further studies should explore novel methods to improve the lives of people living with peripheral neuropathy in Kuwait. Based on the findings of this study, potential areas of future research could include the impact of non-pharmacological treatments to improve physical and psychological well-being , this could involve a trial exploring the effectiveness of Sujok and acupuncture to improve pain management, which was a strategy used by participants in this study.

Furthermore the impact of a multidisciplinary intervention, where medical doctors/specialists work in combination with complementary medicine to facilitate adaptive coping in individuals living with peripheral neuropathy, is also possible. [52]

Implications for practice

The findings of this study offer potential implications for clinical practice. As participants identified the benefits of alternative treatments, such as acupuncture. Therefore, healthcare professionals should offer advice and support by recommending them as self-management strategies. Furthermore, as participants identified concerns relating to the perceived effectiveness of prescribed treatments, healthcare professionals should assist patients to understand how and when they should use over-the-counter medication and when to consult a physician. Recommendations should be made to promote beneficial self- management strategies and to prevent contraindications from some alternative treatments. All initiatives should be directed towards promoting self-efficacy in people living with peripheral neuropathy.

To achieve a patient-centred approach and to overcome potential barriers in pain management, healthcare professionals should practice compassion, trust and good communication. With respect to Kuwait, there is a need for an organised counselling network to aid patients and families, which could be supported by a 24-hour hotline to respond to patient queries and concerns regarding side-effects, as other research has shown this has beneficial effects on patient outcomes. [51] Furthermore, access to healthcare including appropriate treatments and medical appointments, especially duration, should be sufficient to address all aspects of patient care. Healthcare professionals should also consider a holistic approach to the consultation. A holistic approach takes into account all aspects of an individual’s well-being that includes physical, emotional and mental perspectives. Several studies have demonstrated improvements in functional performance, quality of life and the alleviation of neuropathic symptoms following endurance training, balance training, and cognitive behavioural therapy. Therefore, healthcare professionals should consider offering behaviour change advice as part of the consultation or referring patients to appropriate therapists. This study highlights the importance of the workplace on the quality of life for people living with peripheral neuropathy. Workplace policies should promote the use of workplace assessments and managers should encourage a supportive environment to help people living with peripheral neuropathy remain in employment. Occupational therapists could be involved in multidisciplinary care to help people develop strategies to help them continue to perform activities that are important in their day-to-day life.

Patient-centred care is a pillar of most Western healthcare systems. Patient-centred care ensures the patient’s voice is heard, that patients contribute to their own management plan and that they are made fully knowledgeable of all aspects of their care. [53] Overall, the healthcare system in Kuwait needs to develop patient-centred care and welfare services further, including setting up peripheral neuropathy support groups where patients can connect with others. New services could be co-produced by patients and healthcare professional working together to develop a new approach that ensures the patient needs are met. Collaboration between people living with peripheral neuropathy and healthcare professionals can include the implementation of different practical approaches, such as educating people living with peripheral neuropathy about their condition, as well as supporting patient and family engagement with the new services. These approaches will involve people in their own care and improve overall patient outcomes.

5. Conclusion

This study provides insight into the experiences of people living with peripheral neuropathy in Kuwait, with a focus on the coping mechanisms and management strategies. This study contributes to the literature by identifying relevant themes to improve patient care. The treatment beliefs, barriers to pain management and impact on quality of life were key areas identified. The results reflect the extensive scope for improvement of current treatments and the management of peripheral neuropathy in Kuwait to improve people’s quality of life. These can be achieved by individual behaviour change and by developing improved practice for healthcare professionals providing support to people living with peripheral neuropathy.

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7. Supplementary material

Table 1. An example of the transformation of data through thematic analysis.

Quotes	**Codes**	**Theme**
“ I get nervous and feel that everything angers me, and my body as a whole hurts me” (Female, 56 years old, PN- 30 years). *“ this pain affects me and makes me always nervous”(Male, 47 years old, PN- 3 years).* *“ I feel numbness in my hand… I was crying, crying and getting nervous”(Female, 36 years old, PN- 10 years).*	Emotional and Psychological effects	**Impact on quality of life**
“ …it affects me as I have to do everything slowly or sit down because when I feel the pain, I may drop the child or something like that…. of my friends told me that lately, I rapidly and suddenly get angry…” (Female, 62 years old, PN- 17 years). *“… before having these pains, I had several friends… As for now… social activities are no longer more”(Female, 56 years old, PN- 7 years).*	Environmental & Social (Family, friends)	**Impact on quality of life**
“ I work with students with special needs who need normal person to help them and I can’t continue as most of the time I was standing, bending, walking and moving…”(Female, 62 years old, PN- 17 years). *“pain of my foot increases my nervousness and co-workers feel that there is something inside me boiling, which causes me to explode by talking to the staff and colleagues”(Female, 45 years old, PN- 9 years).*	Tension and Embarrassment at Work	**Impact on quality of life**

Table 2. Reflecting the characteristics of participants included in the study.

Characteristics		**Observations (n=25)**
Nationality	Kuwaiti	n=20
	Non-Kuwaiti	n=5
Sex	Male	n=12
	Female	n=13
Age	Mean (SD)	55 (10) years
	Range	35-82 years
Comorbidities	Type 2 diabetes mellitus	n=16
	Hypertension	n=10
	Dyslipidaemia	n=8
Duration of peripheral neuropathy	Mean (SD)	13.76 (7.40)
	Range	3-30 years
Over-the-counter treatments	Nonsteroidal anti-inflammatory drugs: ibuprofen (Ibuprofen) 200-400 mg tablets	n=10
	Analgesics: acetaminophen (Panadol) 500 mg tablets	n=5
	Topical Analgesics: ketoprofen (Fastum 2.5%) gel	n=1
	capsaicin cream	n=1

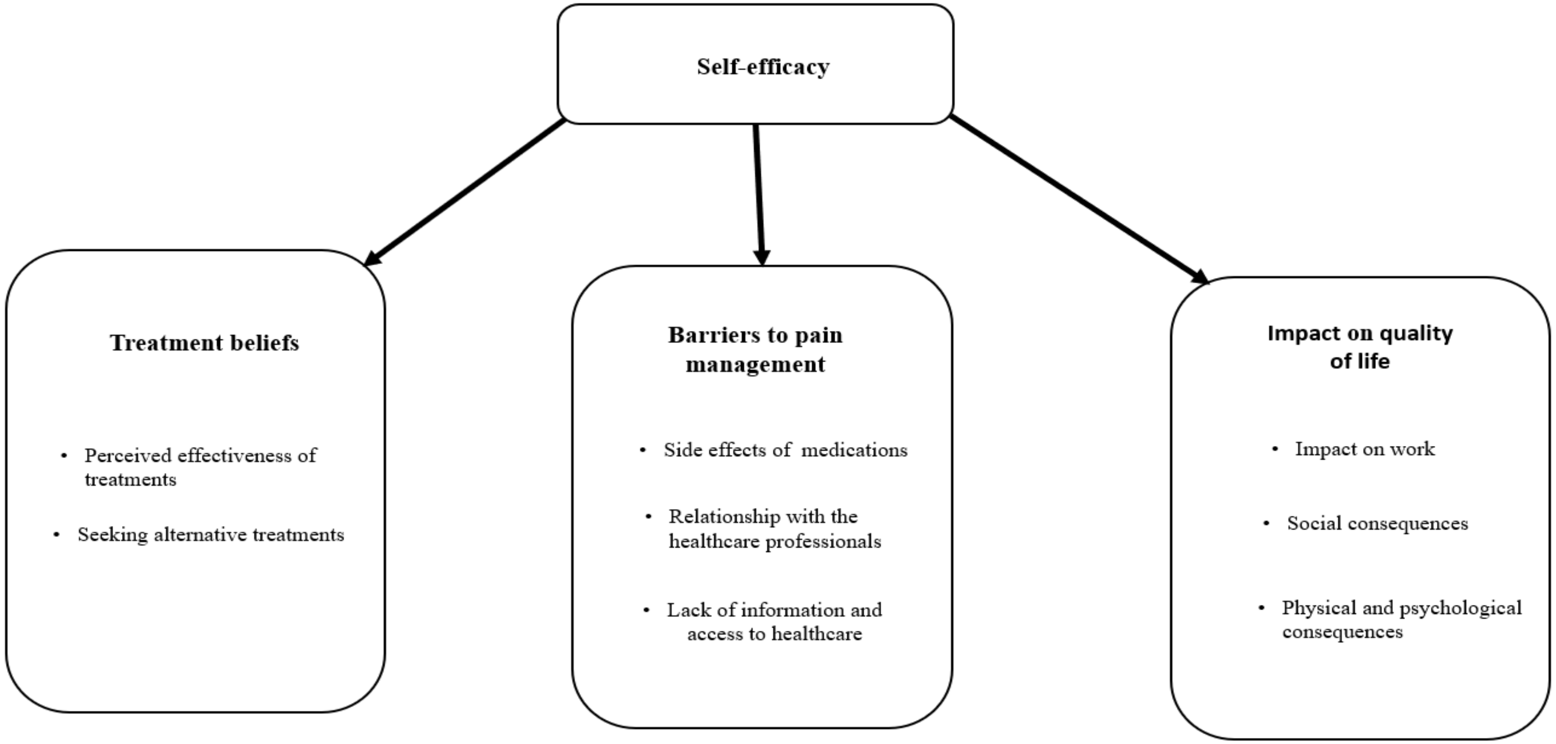

Figure 1. An illustration of the themes that were identified from people living with peripheral neuropathy

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Title of Manuscript: People's experiences living with peripheral neuropathy in Kuwait: A qualitative study.

Declaration of Conflicting Interest: The Authors declare that there is no conflict of interest.

Funding: This work was supported by a full-time scholarship for MA provided by the State of Kuwait Cultural Bureau in London and Ministry of Health in Kuwait.

Ethical approval *(include full name of committee approving the research and if available mention reference number of that approval)***:** Ethical approval for this study was obtained from the University of Reading Ethics Committee (UREC 16/46) and the Standing Committee for Health and Medical Research in the Ministry of Health (MoH) in the State of Kuwait (Research no.: 194/2014).

Informed Consent: Written informed consent was obtained from all subjects before the study.

Trial Registration *(where applicable)*: N/A

Guarantor: * AH

Contributorship: MA, AH, and KR contributed to the study concept and design. MA conducted the interviews in Kuwait and supervision was provided by AH and KR. All authors contributed to the data analysis and MA wrote the first draft of the manuscript.

All authors reviewed and edited the manuscript and approved the final version of the manuscript.

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5.3 Conclusion

This chapter sought to examine the experiences of people living with peripheral neuropathy in Kuwait. The study identified three main themes, namely treatment beliefs, barriers to pain management and impact on quality of life in people living with peripheral neuropathy. The treatment beliefs included perceived effectiveness of treatments and seeking alternative treatments. The barriers to pain management included side effects of medications, the relationship with the healthcare professionals and a lack of information and access to healthcare. The impact on quality of life was reflected as the impact on work, social consequences and physical and psychological consequences. The observations made clear that there is greater scope for improvement for helping treat, care and inspire people living with peripheral neuropathy from a healthcare and social perspective. This chapter precedes the final discussion chapter, where the main findings, study strengths and limitations, links with existing literature, implications for theories and implications for practice and research will be discussed further.

CHAPTER SIX

6 Discussion

Chapter six will initially provide a brief summary of the results in the context of the original underlying aim. The chapter will then progress to a discussion of each chapter overall summary by providing links to existing literature, proposing the implications for theory, practice and for research. Finally, the chapter will close by presenting an overall conclusion of the analysis of this thesis. The overall general aim of this work was to explore the experiences together with the coping and management strategies of individuals living with peripheral neuropathy in Kuwait. Table 1 lists the overview of papers contained in this research project; Is the body sick or the mind? A systematic review of people's experiences of peripheral neuropathy; The Experiences of People Living with Peripheral Neuropathy in Kuwait—A Process Map of the Patient Journey, and People's experiences living with peripheral neuropathy in Kuwait: A qualitative study. These shall be referenced as a systematic review study, process map study and interview study. All these were conducted following the award of approval by the ethics committee from the University of Reading and Ministry of Health, Kuwait (Appendices 1 and 2).

The systematic review study aimed at exploring the experiences of people living with peripheral neuropathy worldwide, and to review the impact of peripheral neuropathy on the psychological and social experiences of this target group, especially in Western countries. Likewise, the process map study sought to examine the patient journey followed by people living with peripheral neuropathy in Kuwait, with the eventual plotting of a process map. Finally, the interview study was a qualitative analysis conducted with the aim of exploring the experiences of people living with peripheral neuropathy in Kuwait, with an emphasis on coping and management strategies, and their experiences using different medications.

Table 1. Overview of papers contained in this research project.

Article citation	Research aim	Methods	Key findings
1. Alkandari, M, Ryan, K, & Hollywood A. (2019). Is the body sick or the mind? A systematic review of people's experiences of peripheral neuropathy. *Health Expectations*. (submitted November 2019)	To conduct a systematic review of psychological and social experiences of people living with peripheral neuropathy worldwide, and to examine the self-management techniques used by people living with the condition	-Three electronic databases (Scopus, PubMed, and Web of Science) were systematically searched -The quality of the studies was appraised using the Critical Appraisal Skills Programme (CASP) -Thematic synthesis was then used to identify the themes and subthemes in the selected studies	The three main themes and subthemes identified: **-Is the body sick or the mind** *Physical symptoms and consequence* *psychological consequences* *coping strategies* **-The relationship between the person living with the condition and the healthcare professional** *Therapeutic approach* *Understanding and empathy* **-Potential advantages of living with peripheral neuropathy.** *Unintended consequences* *Resilience*
2. Alkandari, M, Ryan, K, & Hollywood A. (2019). The experiences of people living with peripheral neuropathy in Kuwait—A Process Map of the Patient Journey. (published, *Pharmacy*, 7(3), 2019)	To examine and chart the patient healthcare pathway of people living with peripheral neuropathy in Kuwait including referrals, investigations and general management	-Semi-structured interviews were conducted with 25 participants -Interviews were transcribed and translated into English then coded using NVivo 12 -Four individual patient journeys were mapped out in detail, then compared and condensed into a single process map -The remaining 21 interviews were then reviewed to ensure the final map represented all patient journeys	The pathway reported by the participants identifies similar difficulties including: **-The lack of psychological support** **-Administrative issues** *Long waiting referral periods* *Loss of medical documents* *Shortage of specialists* *Lack of centralized electronic medical records* **-Inadequate medical care** *Shortage of new treatments* *Deficient follow-ups*
3. Alkandari, M, Ryan, K, & Hollywood A. (2019). People's experiences living with peripheral neuropathy in Kuwait: A qualitative study. *Chronic Illness*. (submitted November 2019)	To explore the experiences of people living with peripheral neuropathy in Kuwait, particularly the coping and management employed	- Semi-structured interviews were conducted with 25 participants, transcribed using NVivo 12 programme manually coded -Themes and subthemes were then identified using thematic analysis	The three major themes and subthemes identified: **-Treatment beliefs** *Perceived effectiveness of treatments* *Seeking alternative treatments* **-Barriers to pain management** *Side effects of medications* *Relationship with the healthcare professionals* *Lack of information and access to healthcare* **-Impact on quality of life** *Impact on work* *Social consequences* *Physical and psychological consequences*

6.1 Summary of results

The key results of the three studies (systematic review, process map and interview study) shall now be discussed in more detail.

6.1.1 Systematic review study

The systematic review was aimed at exploring the psychological and social experiences of people living with peripheral neuropathy, while also examining their self-management techniques on the global scale. Following the review of the 23 studies selected, the quality was appraised based on the Critical Appraisal Skills Programme (CASP) checklist. Further data extraction and synthesis were performed, and the complete methodology employed resulted in three primary themes being identified namely: Is the body sick or the mind; the relationship between the patient and the healthcare professional; and potential advantages of living with peripheral neuropathy. The theme ‘Is the body sick or the mind?’ was based on three subthemes, including the physical symptoms and their associated consequences, the psychological consequences and the coping strategies. While the physical symptoms commonly identified were stabbing pain, burning sensations, pins and needles and extreme sensitivity to touch, the consequences included lack of sleep and memory loss. The psychological consequences identified from the review were depression, isolation and fear. Coping strategies included having the presence of a positive attitude, engaging in manageable activities such as simple physical exercise, and talking to friends. The second theme of the ‘relationship between the patient and the healthcare professional’ indicated that there were two common areas; the therapeutic approach and understanding and empathy. Dissatisfaction as well as satisfaction were observed from the analysis. While some people sensed that the therapy they received was not effective enough to cure them, some were happy with the treatment they received and the conduct and rapport of healthcare professionals, especially those attending cognitive behavioural therapists. The lack of understanding shown by health professionals and lack of trust evidently had a negative effect on the emotional state of individuals and caused frustration. Moreover, it also left them wishing that their healthcare professionals would interact with empathy and compassion to reduce their feelings of helplessness and distress.

A novel concept was identified in the theme ‘potential advantages of peripheral neuropathy’. This was born of two subthemes; namely the unintended consequence of the pain and resilience. Unintended consequence of the pain included a shift from thinking about their pain, to rendering selfless help, and an element of camaraderie and empathy for other individuals living with peripheral neuropathy. Resilience was identified as ranging from being inherent to that which was developed in a few patients along the various stages of disease progression. The latter helped the participants develop a more positive outlook to life, accepting their condition and finding happiness from accomplishing daily tasks irrespective of the pain. Collectively, these findings demonstrated that for the peripheral neuropathy treatment to be considered comprehensive, both the body and the mind need support. Bodily support can derive from the administration of suitable medications. However, support of the mind can only come from proper understanding of the emotional, psychological and social difficulties faced by peripheral neuropathy patients. To develop an understanding of all of these factors, it was vital to construct a picture of the patient journey traversed by persons living with peripheral neuropathy. The journey would involve starting from the earliest level of seeking medical care, at the local primary clinic, and progressing to the most specialised place for management of peripheral neuropathy in Kuwait, the national hospital for neurology. Consequently, this led to the concept of the process map study.

6.1.2 Process map study

This was a qualitative study that aimed to explore the experiences of people living with peripheral neuropathy by examining the healthcare pathway in Kuwait from the patient perspective. Accordingly, observing the various steps in a patient’s journey was made possible through the use of process mapping which was used because it allows the researcher to centre on one process, the describing of the non-value in that process and the use of small implementable steps (Timothy *et al.*, 2010).

Hence, the implementation of a process map to improve the efficacy of the journey of individuals living with peripheral neuropathy was chosen for this study. The first map was formed using comprehensive, rich data from the interviews of four participants, followed by additional reviews of the map using the interviews of the other 21 participants. Overall, the process map specified the perspectives of individuals living with peripheral neuropathy with respect to how they were clinically managed, how they managed their own pain and any coping techniques they employed.

The methodology adopted was an intensive one. First, potential participants were identified from among the patients presenting to the outpatient clinic at the national hospital for neurology. These target individuals were presented with information packages. Study enrolment was implemented by assessing the study eligibility of each interested patient who contacted the researcher. After conducting semi-structured interviews with the 25 participants who all lived with peripheral neuropathy in Kuwait, the data was transcribed, translated and analysed. Individual experiences were considered, and four individual patient journeys were selected based on the eloquence and richness of the data. The four journeys were plotted as process maps and combined to form one comprehensive process map. The remainder of the data from the other 21 participants was layered on to this process map to create one final process map, which was reflective of all the findings from the 25 participants. Common findings identified were then compared with the management guidelines for peripheral neuropathy, employed in a developed nation like the United Kingdom.

In the primary care clinics where the journey started, due to shortage of healthcare staff, there was a long queue and long waiting times. Some people relied on bypass methods to secure care faster; using their social influence or bribing hospital staff to get ahead in the queue. Consultation times were as short as five minutes. Prescriptions provided were mainly for general pain management. Depending on the patient’s condition and the physician’s discretion, the referrals to doctors in the general hospital were made. Waiting periods generally ranged from 2-8 weeks, but if the paper medical files or referral documents were lost, the waiting periods extended to up to 12 weeks. Part of the process involved the repeating of most of the lab investigations, before prescribing medications. Furthermore, the patient had to attend multiple referrals at the general hospital level, before finally reaching the neurologist. The full journey to attending the neurologist could span a period of 3-6 months, depending on the waiting list. Along with advanced investigations and neurology-specific tests such as loss of protective senses and reflexes, the neurologists would also repeat previous investigations. If the treatment at that level did not provide sufficient relief, then the participants reported being finally referred to the neurology specialist/ consultant at the national hospital for neurology, after a waiting period of 3-6 months. The waiting period could extend to 1 year if the documents were lost throughout this period. It was only at this point that all essential investigations were conducted, and the participant received a structured pharmacological regimen. While some participants circled in this cycle of referrals and medical management, some chose to exit and to also attend alternative therapy. Thus, the participants reported similar healthcare pathways for their peripheral neuropathy despite their presenting complaints. They also faced various difficulties including lack of psychological support, administrative issues and inadequate medical care in the form of shortage of new treatments and deficient follow-ups.

Mapping the patient journey in Kuwait established the existence of a common pathway of referral from the local primary clinic to the general hospital, and finally to the national hospital of neurology. There was a need for a more strategic approach in the three main areas as evidenced following the comparison of the process to the UK standard of care. Specifically, the areas required included non-pharmacological support, organisational systems and medical care. Treatment in Kuwait was concentrated mostly, or rather, entirely on the pharmacological management of symptoms alone as opposed to the information sessions, counselling sessions and psychological support practiced in the UK. There were long waiting referral periods in Kuwait, which were attributed to a lack of proper structured communication between healthcare staff, loss of medical documents, shortage of specialists and lack of a centralised electronic medical records system. This was exacerbated by a self-referral system which bypasses the main referral system. However, the study also showed the existence of similar pharmacological treatments to those indicated by the UK's National Institute for Health and Care Excellence (NICE) and the International Association for the Study of Pain (IASP) guidelines, except that some medicines were unavailable. From this process map study, the importance of medical management was clear. However, there was a vital need to establish whether the participants were adhering to their medical management plan, and also to seek further evidence on how they were coping with their condition, and any management strategies they were adopting.

6.1.3 Interview study

The interview study was conducted with the aim of exploring the experiences of people living with peripheral neuropathy in Kuwait, with a focus on coping and management strategies, including medications. For this stage of the research, the methodology adopted was similar to the initial phase of the methodology used in the process-map study. Specifically, the same dataset generated from the semi-structured interviews was used in this study. Following the coding process using NVivo software, the thematic analysis of these semi-structured interviews helped to identify three major themes. Namely, treatment beliefs, barriers to pain management and the impact on quality of life. Treatment beliefs indicated two subthemes: perceived effectiveness of treatments, in relation to over-the-counter products and the seeking of alternative treatments such as complementary and alternative therapies and herbal therapy. Barriers to pain management included side-effects of medications, which decreased medication adherence, and strained relationships with healthcare professionals. Moreover, further barriers existed because of lack of information (regarding their disease, its prognosis and treatments available), and access to healthcare. Participants held negative views about certain prescribed medications. Furthermore, the strained relationships with healthcare professionals were attributed mainly to the short consultation spans, and the lack of empathy from the treating physician. Moreover, the healthcare professionals primarily focused on the medical management of physical symptoms, while almost completely ignoring the importance of behaviour change or coping with the illness. Impact on quality of life was reflected mainly in three sections; impact on work, social consequences and physical and psychological consequences. Impact on work showed the workplace to be an unsupportive environment. Social consequences related to social isolation and loneliness, and feeling strong emotional disturbances of fear, anger and stress. Participants felt a loss of independence and helplessness in being unable to fulfil family roles. Physical and psychological consequences included stress, discomfort and fear, resulting in mood swings and emotional outbursts, lack of sleep and a sense of vulnerability due to physical symptoms.

6.2 Links to the literature

The results of this thesis, which consisted of a collection of the above referenced papers, were not only in agreement with the observations made elsewhere in the world regarding peripheral neuropathy, but also led to the contribution of novel concepts to the field. The literature associations of each study are mentioned below.

The systematic review paper was one of its kinds. The overall evidence from the studies in this review supported the existence of a relationship between the mind and the body for people with peripheral neuropathy. This was supported by the first theme identified. Six studies were identified which provided insights into the physical, mental and emotional experiences of people living with peripheral neuropathy which outlined problems with sleep, stress, anxiety, fright, depression and relationships with other people (Closs *et al.*, 2009; Krohne & Ihlebaek, 2010; Osborn & Smith, 2006; Ownby & Dune, 2007; Paton *et al.*, 2014; Sofaer-Bennett *et al.*, 2007a). Krohne and Ihlebaek (2010) had concluded that the mind has the capacity to either amplify or minimise the level of pain experienced by individuals. Consequently, this led to the concept of the importance of identifying the subthemes examining the relationship between the body and the mind. Among the physical symptoms identified, the intensity of physical discomforts in the form of stabbing and burning pain, pins and needles and extreme sensitivity to touch was notable. Hensing, Sverker, and Leijon (2007) had described how a simple stimulus like the touch of a night dress was perceived as a massive stimulus which reminded the individual of pain. Metin and Arslan (2018) described the sleep disturbances and memory loss, which were a few of the consequences of physical symptoms identified during thematic analysis. The common psychological consequences highlighted by people living with peripheral neuropathy, included depression, isolation and fear. Lonnstedt *et al.* (2011) had quoted the higher incidence of depression leading to a negative attitude towards life in older people with peripheral neuropathy. However, previous studies have shown that individuals were able to cope with peripheral neuropathy by transforming their negative experiences into positive coping strategies to manage their pain (Forsberg, Ahlstrom, &Holmqvis, 2008; Sofaer-Bennett *et al.*, 2007a). This was in agreement with the coping strategies identified. Various other researchers had described the negative experiences of people living with peripheral neuropathy in relation to the therapeutic approach and lack of understanding and empathy from healthcare professionals (Lonnstedt et al., 2011; Morley, Briggs, &Chumbley, 2015; Snelgrove&Liossi, 2009; Taverner, Closs, & Briggs, 2014). The same was in accordance with the second theme identified in the systematic review study, where the participants reported feeling distressed, helpless and dissatisfied and yearning for empathy, trust and better communication with healthcare staff. Though Sofaer-Bennett *et al.* (2007a) and Kanera, van Laake-Geelen, and Ruijgrok (2018) have reported individuals discussing the positive impacts of living with peripheral neuropathy; this was never addressed as a theme in its own right. This systematic review bridged that gap by identifying this theme and explaining the concepts of resilience, and the unintended benefits of living with pain which included the self-less helping mentality and actions leading to a greater feeling of satisfaction and self-worth. Since the thesis findings were in accordance with those of Sofaer-Bennett *et al.* (2007a), who observed that the traditional approach purely focuses on pharmaceutical remedies and often does not consider the ability of the mind to manage physical pain, the importance of the psychological aspect was reinforced.

A close analysis of the patient journey map and a comparison of this map with the standard level of care practiced in the UK, highlighted that a much more strategic approach is required in three main areas. These areas include non-pharmacological support, organisational systems and medical care. Hensing *et al.* (2007) had detailed exaggerated pain and the consequences of chronic pain in neuropathic patients. They had conducted an interview study with 39 patients suffering from neuropathic pain, to explore dilemmas experienced with the aim of improving care and rehabilitation. Among their results which were categorised as dilemmas, disturbances, consequences and managements, the concept of hypersensitivity to external stimuli was similar to that observed in this study where the touch of a nightdress triggered a massive stimulus. Eccleston*et al.* (2014) sought to evaluate whether Internet-delivered psychological therapies improve pain symptoms, reduce disability, and improve depression and anxiety for adults with chronic pain. They described how in the UK, those living with peripheral neuropathic pain and their families are given information regarding the causes of the disease, treatment and prognosis. Such support is provided alongside psychological support via counselling sessions guided by qualified psychologists. This reflected the gap in the lack of provision of non-pharmacological support which was observed in Kuwait. Eskandari, Abbaszadeh, and Borhani (2013) had conducted a qualitative study to describe the barriers of the health care process in rural societies in Iran. They determined that the long waiting times for referrals in Iran were due to the lack of adequate governmental referral system, lack of connection between different levels of the referral system, self-referential and bypassing of the referral system, including insufficient knowledge about the referral system. This can be related to the results described in Kuwait. Eskandari *et al.* (2013) also detailed improvement strategies that were successfully implemented in Iran. Examples of these strategies included coordination between different levels of the referral system, strengthening the public sector of the system, increasing public awareness about the referral system, and preventing self-referral, which shall serve as the solution for the long referral waiting times observed in Kuwait. Process mapping carried out in New Zealand had established the importance of utilising process maps in the healthcare system (Kumar, 2018). Donna (2015) had outlined the benefits of electronic medical records by describing the capture of point of care data that informs and improves practice through quality improvement projects, and practice level interventions and informative research. Lack of centralised electronic medical records was a common cause of administrative issues observed in Kuwait, and keeping in mind the latter studies, the suggestion of the scope for improvement. Moreover, regarding medical care differences, the UK National Institute for Health and Care Excellence (2013) and the International Association for the Study of Pain (2010) demonstrated that diabetics are usually prescribed carbamazepine (200-400 mg) or gabapentin (300-1200 mg) tablets as the first line treatment, which wasn’t followed in Kuwait. Nor was there an availability of capsaicin cream.

The majority of the associations to the literature were observed in the interview study. This study provided insight into the experiences of peripheral neuropathy patients in Kuwait, with a focus on coping and management strategies. Allegri *et al.* (2016) had compiled the treatment recommendations made by the advisory board comprising of pain specialists, in which they described the use of over-the-counter remedies in the treatment of localised neuropathic pain; a practice which formed a major part of the theme of treatment beliefs in the interview study. However, Mehuys *et al.* (2019) had reported the substantial concern over the perceived need for pain medication and the perceived potential for harmful effects (e.g. fear for addiction) regarding the practice of self-medication. They had conducted a cross-sectional observational study in a large population, with the intent to identify the pain characteristics and medication used in individuals who self-medicate their pain with over-the-counter analgesics. The findings of this study indicated that 40% of the sample demonstrated substantial concern about the perceived need for pain medication and the perceived potential for harmful effects, thus cautioning others regarding the practice of self-medication. Additionally, the use and effectiveness claimed by resorting to complementary and alternative therapy for alleviating pain was similar to those reported by Baute *et al.* (2019). They found that the efficacy in alleviating the symptoms of peripheral neuropathy, from the strongest level of evidence to the least, included lifestyle modifications. Such changes included exercise and diet; supplements including B12, alpha lipoic acid, acetyl-L-carnitine, and vitamin D in deficient patients; followed by acupuncture and yoga. The fear of side-effects of medications, which was a major barrier to pain management, has been referenced by many in the literature (Goldman & Epstein, 2011; Osterberg & Blaschke, 2005; Polinski *et al*., 2014). While Morrell *et al.* (1986) had found that the time the physician spent in health education and the effects of treatment had an important bearing on patient satisfaction. In our study, many participants reported this as a reason for the strained relationship with the healthcare professional, which added to the barriers for pain management, the long referral times and lack of empathy. The influence of physician practice behaviours on patient satisfaction was discussed by Robbins, Bertakis, and Helms (1993).

Regarding the final theme of the impact on quality of life, parallels were found between the findings of this study and those made by Aloisi, Berlincioni, and Torta (2016). In this regard, patients developed a fear of becoming weak or disabled and of their increasing dependency on family and friends, as disclosed by several participants in the present study. They determined that personal relationships were primarily challenged by a reduction in the patient’s quality and/or number of personal relationships, which was similar to those reported in this study.

6.3 Implications for theory

The implications for theory are an essential part of this research, where the theoretical underpinning of each study will be discussed. The systematic review study was based on the concept of the biopsychosocial model of health and illness which states that the workings of the body, the mind and the environment all affect each other. Previous reviews had focused on treatment methods used in peripheral neuropathy and the effectiveness of different management options. However, none of the reviews explored the experiences of people living with the condition, especially regarding the impact of peripheral neuropathy on the psychological and social experiences. Consequently, this led to the need for a systematic review which would bridge this gap.

The systematic review study confirmed the importance of biopsychosocial health. The study could identify the biological and psychological aspects from the first theme which was “is the body sick or the mind?”. The relationship between the patient and the healthcare professionals was the theme connecting this research to the environment or sociological aspect of peripheral neuropathy. The last theme of potential advantages of living with peripheral neuropathy was a novel theme which confirms the importance of the biopsychosocial model. The information gathered by conducting this review probed the need for similar research in Kuwait and led to the idea of conducting the process map study. Most research conducted in the Arab region has only reported the prevalence of peripheral neuropathy (El Sissi*et al.*, 2010; Jambart *et al.*, 2011), while research focusing on patients' experiences in the Middle East was lacking. Hence, this justified the aim of the process map paper.

Healthcare process mapping was described by Timothy *et al.* (2010) as a novel form of clinical audit that examines how to manage the patient journey, using the patient’s perspective to identify problems and propose improvements. In this process, it is vital that the management of a specific condition or treatment should be separated into a series of consecutive events or steps (activities, interventions or staff interactions, for example). Such a step allows the resultant data to be used in redesigning the patient pathway, to improve the quality or efficiency of clinical management and to alter the focus of care towards activities most valued by the patient. Since similar steps were not undertaken in Kuwait when examining individuals living with peripheral neuropathy, the process map study was conceived. The process map created, helped the researcher identify pertinent issues that, if rectified, could help in improving the patient journey. Moreover, it could also contribute to betterment of the patient's health status. Additionally, effective doctor-patient communication has always been mentioned as having a major impact on patient care. The thematic analysis of the process map study highlighted this void. The results and findings of both the systematic review and process map studies were used to format the interview study.

The interview study aimed to understand the experiences of people living with peripheral neuropathy and improve their physical and psychological treatment programmes in the State of Kuwait. Semi-structured interviews were used to gain insight into the lives of people living with peripheral neuropathy.
Thematic analysis of the interview transcripts identified three main themes related to the experiences of people living with peripheral neuropathy: the treatment beliefs, barriers to pain management, and impact on the quality of life. The identification of themes within the data was interpreted using thematic analysis. A framework was constructed as a result of the application of interpretivism which enhanced comprehension of the experiences of individuals living with peripheral neuropathy while also presenting an opportunity to interpret the experiences using the themes. Ethnography is an alternative theoretical approach that could be used to explore cultural phenomena. Through it, the researcher looks for patterns in the behaviours and thoughts of the individuals in their daily life (Moser & Korstjens, 2018). By using ethnography, the researcher would aim to expand their comprehension of the culture. Ethnography is a means to represent graphically and in writing the culture of a group. To provide an alternative perspective on the experiences of people living with peripheral neuropathy, the theoretical approach of ethnography has the potential to shed further light on this phenomenon. In short, the theory of the biopsychosocial model used in the systematic review study led to the conception of the process map study. Together, these two studies resulted in the interview study which identified the personal experiences of people living with peripheral neuropathy.

6.4 Implications for research

6.4.1 Strengths and limitations

The strengths and limitations of the studies in this thesis will now be discussed. The systematic review paper had many major strengths. The study used not only the CASP checklist to assess the quality of each study before inclusion, but also the breadth of evidence used helped to reduce information overload by eliminating irrelevant or weak studies, identifying the most relevant papers, distinguishing evidence from opinion, assumptions, misreporting and belief. Moreover, it assessed the validity of the study, its usefulness and clinical applicability, while also recognising any potential for bias. Additional strengths existed in the synthesis of these studies which was conducted to identify commonalities in the findings. Moreover, the collaboration of the researcher with an experienced second reviewer; a librarian trained at validating literature searches, constituted an additional strength. The main limitations lie in excluding studies published in languages other than English and missing out on the patient experience in the Middle East (as the review was based mainly on 23 studies, none of which reflected those conducted in the Middle East). The process mapping article had the strength of a high level of patient involvement and the wide range of individuals interviewed. The study was hampered by the unavailability of a centralised electronic medical records system to confirm the diagnosis and treatment being followed in locations or clinics other than the National Hospital for Neurology. Also, the age criteria was a limitation because younger people, aged 18-34, were not represented. So, it was not possible to explore how similar their experiences are to those reported here. Additionally, only individuals living with peripheral neuropathy were interviewed, and the healthcare staff and family members were excluded as the researcher chose to do so. This choice was a deliberate one, as the patient perspective has always taken precedence over other factors when trying to decipher and improve the patient journey. The interview study had many strengths, similar to the semi-structured nature of the interview. A qualitative study based on a semi-structured interview enhanced its flexibility and sensitivity, helped gather in-depth, rich data which could be utilised for a vast analysis to identify the most important themes. As in other qualitative studies, rich data helped avoid compromising the reliability of the data. This was reflected in the results of the research which identified key themes surrounding the perspectives of people living with peripheral neuropathy in Kuwait and their attitudes towards the treatment and practices of the healthcare professional. Limitations of the study included the comparatively small sample size. Since the study was qualitative, its results cannot be generalised to the entire population, but they are transferable and apply to people living with peripheral neuropathy who may have the same experiences.

6.4.2. Future directions

Keeping in mind these strengths and limitations, the implications for research are multifold. The systematic review study was the first one of its type and could identify that there was very little literature on peripheral neuropathy focusing on the Middle East; none existed in Kuwait. Hence, further in-depth research should be carried out focusing on the Middle East, and in particular Kuwait. Future research should also try to include studies published in languages other than English. There is a need for funding and further research in understanding the impact of non-pharmacological treatment options to improve physical and psychological well-being in individuals living with peripheral neuropathy as one of the major themes identified was “is the body sick or the mind”. Future studies should include comprehensive interviews with individual family members and medical staff to fully explore their problems and issues, from the social context. Once the findings and suggestions reported below under implications for practice are adopted, further studies must be conducted employing a mixed qualitative approach, such as a combination of observation and in-depth interviews. Such an approach would provide deeper insights and therefore a broader perspective to identify areas for improvement. Future studies should also focus on the impact of multidisciplinary rehabilitation interventions that target factors from different biopsychosocial domains. These would examine the individual's biological, psychological, and social factors, to discover how and why diseases occur. They should also consider the impact of behavioural therapy and the acceptance of commitment therapy for individuals living with peripheral neuropathy. Moreover, there is also a need for conducting further scientific research to establish the benefit of alternative and complementary therapies on peripheral neuropathy management.

6.5 Implications for practice

This research has helped identify numerous areas for improvement in current clinical practice in Kuwait that would benefit from being addressed. From the medical care perspective, there is a need to treat not only the body, but also the patient’s mind. The management of a condition does not end once medication is prescribed. Physical, psychological, and emotional support should be made available from healthcare professionals, family members and friends through the provision of counselling, information sessions and the forming of patient support networks. One option would be to establish a 24 hour helpline, which people can use to discuss any doubts they have regarding their peripheral neuropathy condition (NHS, 2019). Such a helpline is a standard practice within the National Health Service (NHS) in the UK. Setting up an organised counselling network in clinics and hospitals is also expected to be beneficial in alleviating stress, fear, depression and other psychological concepts identified to be associated with peripheral neuropathy. Healthcare professionals should encourage alternative methods of treatment and coping strategies. Nevertheless, regulations should be put in place to promote these self-management techniques. Moreover, such regulations should also prevent harmful establishments, particularly those advertising false information guaranteeing cures or faster recovery. From the administrative perspective, the healthcare sector should seek to monitor and implement strategies to facilitate and effectively manage the patient journey. Establishing centralised referral pathways and increasing the quality and quantity of healthcare staff to meet the increasing needs of peripheral neuropathy patients in Kuwait. Implementing such strategies is vital given the increasing percentage of diabetics. These are eminent needs identified by this research. Moreover, training must be provided to healthcare staff to rediscover the lost values and attributes of compassion, trust and good communication. There should be policies in place to encourage employers to provide workplace assessments, to modify the seating and work desk as per the physical needs of the affected employee and above all instil a sense of support for those living with peripheral neuropathy.

Furthermore, the use of Patient Reported Outcome Measures (PROMs) can be implemented. Patient Reported Outcome Measures consist of a set of questions that patients are asked to complete regarding their illness, symptoms and the quality of their daily life. These can also act as a means of quantifying interventions at the service or healthcare level. Moreover, they ensure these factors are measured from the viewpoint of the patient. The resultant data can be assessed and relayed back to healthcare services to improve patient journeys. In addition, the progress of the patient can also be monitored using Patient Reported Outcome Measures. For greater efficacy, it is best that Patient Reported Outcome Measures are established by a range of groups including the patients, researchers and professionals. Thus, this would guarantee that the Patient Reported Outcome Measures would include both elements that patients and healthcare professionals deem important (Healthcare Improvement Scotland & the Universities of Glasgow and Dundee, 2012).

Patient Reported Outcome Measures can be more beneficial the more comprehensive and employ a holistic strategy that includes emotional, mental, physical and societal elements, in addition to supplying data on health. This thesis outlines the relationship between healthcare staff and their patients. Moreover, it indicates how such relationships can influence the results of care management and patient fulfilment. The findings of this thesis have indicated that peripheral neuropathy impacts an individual’s physical, emotional, societal and mental state. Accordingly, it has underlined the need to implement a patient-centred strategy in Kuwait regarding peripheral neuropathy care, to ensure enhancement of patient management.

6.5.1 Recommendations based on cultural context

The implications for practice would be incomplete without mention of the recommendations in the context of culture. The Ministry of Health in Kuwait is the major administrative body for healthcare in the country. The primary suggestion which stems from this research is for the Kuwaiti Ministry of Health to develop processes to facilitate an improvement in the overall patient experience of people living with peripheral neuropathy. The initial step would involve a review of the practices of medical and administrative staff at Kuwaiti hospitals. The Ministry should also offer suitable training to healthcare professionals and administrative staff on best practice guidelines for the treatment and management of peripheral neuropathy.

In comparison with UK guidelines, there is a need to format guidelines regarding the intervals for assessment and reviewing changes in medication. For example, reviews of when to escalate from 1st to 2nd or 3rd line treatment and to improve the follow-up process. New treatments could then be introduced with caution, including assessments of their efficacy in the Kuwaiti context. An updated electronic healthcare plan should be introduced to the healthcare system, which could be used by healthcare professionals to note on-going progress and to consider the introduction of new management plans for those living with peripheral neuropathy.

The Ministry of Health should also develop a system that aids healthcare professionals in raising awareness of the nature and consequences of peripheral neuropathy. Such a system can take the form of counselling and prevention clinics, continuing professional development or public information sessions. The system should also help in reviewing the medical history of people living with the condition and managing the process of prescribing the appropriate medication. An updated electronic referral system is needed in Kuwaiti hospitals to improve the efficiency of processes, and appropriate training on using this system should be provided. In addition, a more robust system for the documentation of the treatment journey should be pursued, with peripheral neuropathy patients requiring regular follow-ups to improve their treatment process and quality of life. These follow-ups, which should occur at regular intervals, should consider the condition of the patient, as well as disease progression and response to medication. The Kuwaiti Ministry of Health should mandate the follow-up process for the benefit of people living with the condition.

There is also a need to proactively prevent people from developing peripheral neuropathy. Since lifestyle disorders, especially diabetes mellitus is a primary risk factor, efficiently locating groups within populations at increased risk of type 2 diabetes can help in curbing the rising numbers. By changing the current legislation, risk factor diagnosis could be performed and this would help to lessen or ease the risks. Examples of such legislation include the Patient Protection and Affordable Care Act of 2010 (section 4302) in the United States (Hill, Nielsen & Fox, 2013). Concerning this legislation, a number of schemes (e.g. Medicaid) can be employed to alter regulations or identified behaviour that is external to a clinical setting. Such alterations allow equal availability of good health benefits and it also inspires healthy habits.

The prevalence of diabetic neuropathy is very high in Kuwait (Ahmed *et al.*, 2017). Therefore, there is a need for a large multicentre study to assess the national prevalence of diabetic neuropathy and the practices used to manage this disease. Furthermore, many patients reported inadequate relief of their diabetic neuropathy from the prescribed medication. One potentially beneficial recommendation is for physicians and pharmacists managing diabetic neuropathy to follow and use the most effective medications for the patients based on the patient response and international recommendations for the management of diabetic neuropathy. Moreover, the physicians should increase screening for individuals living with diabetic neuropathy and for those with diabetes alone, to act as a prevention method. Various proposed methods do exist, including the use of direct methods and diagnostic criteria when diagnosing diabetic neuropathic pain. Other methods include enhancement of patient knowledge of the disease through educational sessions and the continuation and assisting with selected medications. As diabetes medications evolve into better treatments, the patient’s selection should also evolve, thereby, opening up different means of treatment or ways to treat the pain.

6.6 Conclusion

This research has explored the experiences of people living with peripheral neuropathy. Chapter 3 summarised the current existing qualitative literature on the experiences of people living with peripheral neuropathy and the themes identified included: is the body sick or the mind, the relationship between the patient and the healthcare professionals, and potential advantages of living with peripheral neuropathy. These highlight the importance of providing physical and psychological care, the need to improve the healthcare professionals-patient relationship, and for the first time, identified the potential advantages of living with peripheral neuropathy as a major theme. The literature identified, focussed on populations in the West and the lack of literature on Kuwait. Subsequently, this led to chapter 4, which detailed a process map of the patient journey for people living with peripheral neuropathy in Kuwait. Mapping the patient journey in Kuwait showed some similarities to the UK, in terms of pharmacological treatment, except that some medicines were unavailable. The research findings in Kuwait identified the existence of similarities in the patients' healthcare pathways for peripheral neuropathy. They reported various difficulties including a lack of psychological support, administrative issues and inadequate medical care. The map also indicated the need for an integrated referral approach, the use of technology for electronic medical recording and report transmission. Moreover, the findings indicated the need for education on self-management, coping strategies and treatment options for people living with peripheral neuropathy. The process map study highlighted the need to explore the experiences of people living with peripheral neuropathy in Kuwait with emphasis on coping and management strategies, and their experiences with using different medications. Chapter 5 then continued the process by exploring the issues raised through semi-structured interviews with people living with peripheral neuropathy in Kuwait. The interviews identified three major themes; specifically, treatment beliefs, the barriers to pain management, and the impact on quality of life. Overall, the thesis identified a gap which can be addressed by the recommendations suggested. Patient experience and management of peripheral neuropathy in Kuwait is not yet as advanced as that in the West. However, this can be improved, if treatment is not just restricted to pharmacological management of physical symptoms, but encompasses a holistic approach, taking into consideration the psychological, emotional and social aspects, as well as providing health information. The research reported in this thesis has demonstrated that it is not just the body that is affected in peripheral neuropathy, but also the mind. This thesis highlighted the need to improve existing management of peripheral neuropathy in Kuwait by focusing on the implementation of patient-centred care.

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Appendix 1: Ethical approval from the University of Reading Ethics Committee (UREC – 16/46)

University of Reading

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Professor Kath Ryan
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31 January 2017

Dear Kath

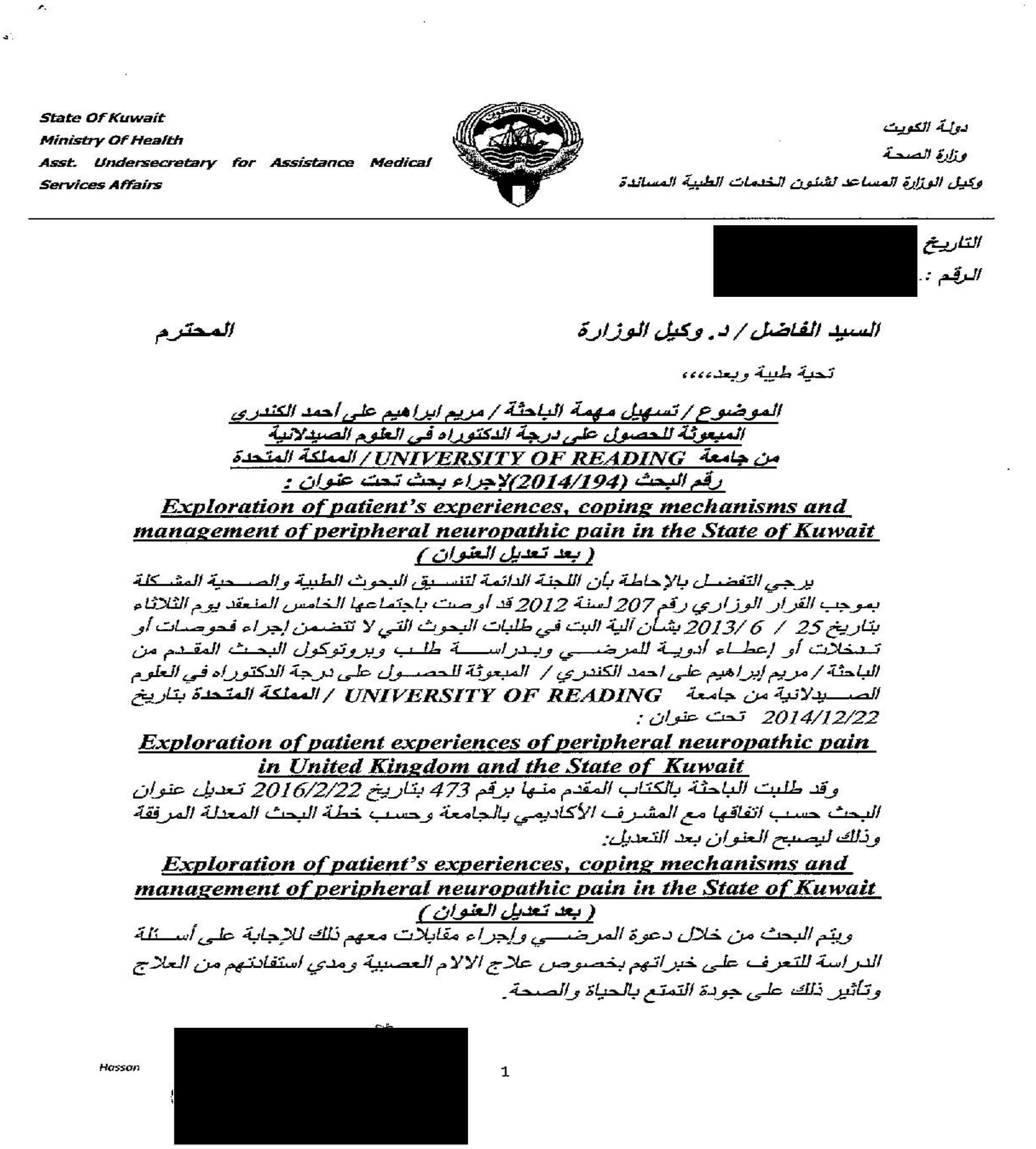
UREC 16/46: Exploration of patients' experiences, coping mechanisms and management of peripheral neuropathic pain in the State of Kuwait. *Favourable opinion*

Thank you for the response (email dated 8 December 2016, and including attachment, refers) addressing the issues raised by the UREC Sub-committee. On the basis of these responses, the revised documentation, and our recent telephone conversation, I can confirm that the Chair is pleased to confirm a favourable ethical opinion.

Please note that the Committee will monitor the progress of projects to which it has given favourable ethical opinion approximately one year after such agreement, and then on a regular basis until its completion.

Please also find attached Safety Note 59: Incident Reporting in Human Interventional Studies at the University of Reading, to be followed should there be an incident arising from the conduct of this research.

Appendix 2: Ethical approval from the Standing Committee for Health and Medical Research Coordination in the Ministry of Health in Kuwait (Ref no: 194/2014)



State Of Kuwait
Ministry Of Health
Asst. Undersecretary for Assistance Medical Services Affairs

دولة الكويت
وزارة الصحة
وكيل الوزارة المساعد لشئون الخدمات الطبية المساندة

التاريخ
الرقم :. [redacted]

السيد الفاضل / د. وكيل الوزارة المحترم

تحية طيبة وبعد،،،

الموضوع / تسهيل مهمة الباحثة / مريم ابراهيم على أحمد الكندري
المبعوثة للحصول على درجة الدكتوراه في العلوم الصيدلانية
من جامعة UNIVERSITY OF READING / المملكة المتحدة
رقم البحث (2014/194)لإجراء بحث تحت عنوان :

Exploration of patient's experiences, coping mechanisms and management of peripheral neuropathic pain in the State of Kuwait
(بعد تعديل العنوان)

يرجي التفضل بالإحاطة بأن اللجنة الدائمة لتنسيق البحوث الطبية والصحية المشكلة بموجب القرار الوزاري رقم 207 لسنة 2012 قد أوصت باجتماعها الخامس المنعقد يوم الثلاثاء بتاريخ 25 / 6 / 2013 بشأن آلية البت في طلبات البحوث التي لا تتضمن إجراء فحوصات أو تدخلات أو إعطاء أدوية للمرضي وبدراسة طلب وبروتوكول البحث المقدم من الباحثة / مريم إبراهيم على احمد الكندري / المبعوثة للحصول على درجة الدكتوراه في العلوم الصيدلانية من جامعة UNIVERSITY OF READING / المملكة المتحدة بتاريخ 2014/12/22 تحت عنوان :

Exploration of patient experiences of peripheral neuropathic pain in United Kingdom and the State of Kuwait

وقد طلبت الباحثة بالكتاب المقدم منها برقم 473 بتاريخ 2016/2/22 تعديل عنوان البحث حسب اتفاقها مع المشرف الأكاديمي بالجامعة وحسب خطة البحث المعدلة المرفقة وذلك ليصبح العنوان بعد التعديل:

Exploration of patient's experiences, coping mechanisms and management of peripheral neuropathic pain in the State of Kuwait
(بعد تعديل العنوان)

ويتم البحث من خلال دعوة المرضي وإجراء مقابلات معهم ذلك للإجابة على أسئلة الدراسة للتعرف على خبراتهم بخصوص علاج الالام العصبية ومدي استفادتهم من العلاج وتأثير ذلك على جودة التمتع بالحياة والصحة.

Hassan [redacted] 1

State Of Kuwait
Ministry Of Health
Asst. Undersecretary for Assistance Medical Services Affairs

دولة الكويت
وزارة الصحة
وكيل الوزارة المساعد لشئون الخدمات الطبية المساندة

التاريخ : ....
الرقم : ....

فأننا نوصـــي بالموافقة على تعديل العنوان وخطة الدراســة وإجراء البحث عن طريق دعوة المرضـــي لإجراء المقابلات معهم للإجابة على أســئلة الدراســة مع مراعاة التزام الباحثة بالمحافظة على حقوق المرضي المشاركين بالبحث بالخصوصية وسرية المعلومات وعدم تداولها خارج إطار البحث والحصول على الموافقة المستنيرة المسبقة من المرضي البالغين / كاملي الاهلية المشاركين بالبحث *(Informed Consent)*.

برجاء التفضل بالإطلاع والتوجيه بما ترونه مناسباً نحو مخاطبة الجهات ذات الصلة موضـوع البحث **(الســادة / مدراء المناطق الصـحية والمسـتشـفيات والسـيدة / د. مدير الإدارة المركزية للرعاية الصـحية الأولية والسـيد الدكتور: مدير مسـتشـفى ابن سـينا للجراحات التخصصية)** بهذا الشأن للعمل على تسهيل مهمة الباحثة والايعاز للأقسام ذات الصـلة بموضـوع البحث لدعوة المرضـي لإجراء المقابلات معهم وإجراء الدراســة وفقاً للضوابط المنظمة لذلك.

السادة/ مدراء المناطق الصحية المحترمين
السيدة/ د. مدير الإدارة المركزية للرعاية الصحية الأولية المحترمة
السيد/ د. مدير مستشفى ابن سينا المحترم

وتفضلوا بقبول فائق الاحترام،،،

[redacted]

الدكتور/ جمال منصور الحربي
الوكيل المساعد لشئون الخدمات الطبية المساندة
رئيس اللجنة الدائمة لتنسيق البحوث الطبية والصحية

[redacted]

[redacted]

د/ خالد السهلاوي
وكيل وزارة الصحة

+مرفقات

- كتاب السيد / وكيل الوزارة رقم 153 بتاريخ 2015/7/26

[redacted]

2

State of Kuwait
Ministry of Health
Asst. Undersecretary for Assistance Medical Services Affairs

Date: **28/02/2016**
No.: **839**
Dr. Undersecretary Respectable

Greetings,

Subject: Facilitating the Mission or Researcher/ Mariam I A A Al-Kandari who is delegated to obtain the PhD in Pharmacological Sciences from University of Reading/ United Kingdom
Research No.: 194/2014 to conduct a research entitled
Study of "Exploration of patients' experiences, coping mechanisms and management of peripheral neuropathic pain in the State of Kuwait".
(After changing the title)

Please be Informed that the Standing Committee for Health and Medical Research Coordination (SCHMRC) formed by the Ministerial Resolution no. 207/2012 recommended in its fifth meeting held on Tuesday, 25/06/2013 regarding the mechanism of considering the research applications that do not involve conducting medical tests or interventions or giving medications to patients. When investigating the application and protocol of the research submitted by the researcher/ Mariam I A A Al-Kandari/ delegated for obtaining the degree of PhD in Pharmacological Sciences from University of Reading/ United Kingdom dated 22/12/2014, entitled:

"Exploration of patients' experiences, coping mechanisms and management of peripheral neuropathic pain in the State of Kuwait".

(After changing the title)

The research shall be performed by inviting and interviewing the patients to answer the questions of the study. This will allow them to explain their experiences of peripheral neuropathic pain (PNP), the benefits of treatment and their effects on quality of life and health.

Therefore, **we recommend approving the change of title and study plan while conducting the research** by inviting and interviewing patients to answer the questions of the study. The researcher should ensure the participating patients' rights and the confidentiality of information while not disclosing them outside the framework of research. She should obtain the prior informed consent for the adult patient having full capacity.

Please be informed and advice the necessary action to be made such as addressing the relevant authorities of subject matter of the research (**M/S: Managers of Health Areas and hospitals, Mrs. Manager of the Central Directorate for Preliminary Healthcare and Dr. Manager of Ibn Sina Hospital for Specialized Surgeries**) in this regard to facilitate the mission of the researcher while notifying the relevant departments to invite the patients to hold interviews with them and conducting the study according to the applicable controls.

Best Regards,

Signed & Sealed

Dr. Jamal Mansour Al Harbi

Asst. Undersecretary for Assistance Medical Services Affairs

Head of the Standing Committee for Health and Medical Research Coordination

Attachments:

- Undersecretary's Letter No. 153 dated 26/07/2015

السيد/ الوكيل المساعد لشئون الخدمات المساندة رئيس لجنة البحوث المحترم،،،

تحية طيبة وبعد،،،

وارد
مكتب الوكيل المساعد
لشئون الخدمات الطبية المساندة
لجنة الأبحاث
رقم : [redacted]
التاريخ: ٢٢ / ٢ / 20١٦

<u>الموضوع: تعديل عنوان البحث رقم (2014/194)</u>

بالإشارة الى الموضوع اعلاه، يرجى التكرم بالموافقة على تعديل عنوان البحث الذي سبق الموافقة عليه رقم (2014/194) وهو:

Exploration of patient experiences of peripheral neuropathi pain in United Kingdom and the State of Kuwait.

ليصبح العنوان الجديد:

Exploration of patient's experiences, coping mechanisms and management of peripheral neuropathic pain in the State of Kuwait.

ولا يوجد بالبحث اي تجارب طبية او استخدام ادويه او التدخل في بروتوكولات علاج المرضى. ويتعهد الباحث بالمحافظة على الخصوصية وسرية المعلومات وعدم تداولها خارج اطار البحث.

وتفضلوا بقبول فائق الاحترام،،،

<u>مقـــدم الطلـــب</u>

الباحثة: مريم ابراهيم علي الكندري

التوقي [redacted]

Mr. U Asst. Undersecretary for Assistance Medical Services Affairs
Respectable

Greetings

Subject: Changing the Research Title No. 194/2014

In reference to the above subject, you are kindly requested to approve the change of research's title, which was previously approved under no. 194/2014, entitled:

Exploration of patient experiences of peripheral neuropathic pain in United Kingdom and the State of Kuwait

So that the new title shall be:

Exploration of patients' experiences, coping mechanisms and management of peripheral neuropathic pain in the State of Kuwait".

The research has no medical experiences or using medications or interventions in patients' treatment protocols. The researcher undertakes to ensure privacy and confidentiality of information while not using the same outside the scope of research.

Best Regards,

Applicant

Researcher: **Mariam I A A Al-Kandari**

Signature: **Maryam**

Appendix 3: Interview schedule

Interview schedule (for researcher)

Actions before interview

1. Request participant's permission to audio-record the interview.
2. Explain confidentiality arrangements.
3. Check whether participant has any further questions.
4. Ask participant to complete consent form and give participant a copy of additional information letter and consent form.

Hello and how are you today?

Just to confirm once again that you will be involved in an interview for the sake of a research study on peripheral neuropathic pain. Are you happy to proceed?

IMPORTANT – questions may be omitted depending on relevance to the interviewee.

I would like to ask a few questions to get us started

- Tell me about your pain.

  Prompts – onset, main symptoms, diagnosis, treatment (medical, complementary and self-help), understanding/explanation of pain, impact on daily life (including physical, psychological/emotional and social).

- How does it make you feel?
- What did you know about PNP before you were diagnosed with it?

Now, I'd like to ask you some more specific questions if that's okay?

- Has your experience of symptoms changed over time? How has it changed?
- Do you explain these types of symptoms to other people? If so, how do you explain them? How do other people respond?
- What about the way that other people see you? How effective do you feel medical treatment has been on treating your pain? Do you still feel pain, despite taking medication? Do you feel you need additional help? What kind?
- Do you have any particular ways of coping (medicinal or practical or mental strategies)?

Finally, I'd like to ask you if there are any related issues that you would like to discuss, that we may have missed during the course of our conversation or is there anything you would like me to explain?

Bring interview to a formal close

The purpose of my research is to try to draw conclusions and make recommendations to improve the overall management of patients with peripheral neuropathic pain in the State of Kuwait.

I would like to thank you for your time and contribution to this work. If there is anything you want to ask me, or you would like to get in touch please feel free to contact me at any time by email.

Thank you again for your time.

Appendix 4: Published in *Pharmacy*

pharmacy

Article

The Experiences of People Living with Peripheral Neuropathy in Kuwait—A Process Map of the Patient Journey

Maryam Alkandari, Kath Ryan and Amelia Hollywood *

School of Pharmacy, University of Reading, Reading, RG6 6AP, UK
* Correspondence: A.Hollywood@reading.ac.uk

Received: 4 July 2019; Accepted: 22 August 2019; Published: 30 August 2019

Abstract: Peripheral neuropathy is a neurological disease characterised by pain, numbness, tingling, swelling or muscle weakness due to nerve damage, caused by multiple factors such as trauma, infections and metabolic diseases such as diabetes. In Kuwait 54% of the diabetic population, has peripheral neuropathy. In this exploratory, qualitative study conducted in Kuwait, 25 subjects with peripheral neuropathy took part in one-on-one, semi-structured interviews lasting 45–60 min. Interviews were transcribed, translated into English and coded using NVivo 12. Four individual patient journeys were mapped out in detail, then compared and condensed into a single process map. The remaining 21 interviews were then reviewed to ensure the final map represented all patient journeys. Participants reported similar healthcare pathways for their peripheral neuropathy and faced various difficulties including lack of psychological support, administrative issues (long waiting referral periods, loss of medical documents, shortage of specialists and lack of centralized electronic medical records) and inadequate medical care (shortage of new treatments and deficient follow-ups). Mapping the patient journey in Kuwait showed similar pharmacological treatment to UK guidelines, except that some medicines were unavailable. The map also indicated the need for an integrated referral approach, the use of technology for electronic medical recording and report transmission, alongside education on self-management, coping mechanisms and treatment options for people living with peripheral neuropathy.

Keywords: peripheral neuropathic pain; diabetes; patient experiences; process map; Kuwait healthcare

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1. Introduction

Peripheral neuropathy is a common neurological disorder affecting people from both developed and developing countries. It can be caused by various conditions such as vitamin deficiency, traumatic injury, alcoholism, immune system diseases, viral infections or most commonly diabetes [1–3]. In 74–82% of people, the cause can be determined by a combined approach of patient medication history, examinations and ancillary testing [4]. Symptoms of peripheral neuropathy include sensory symptoms (e.g., numbness and tingling), weakness, autonomic symptoms (e.g., impotence, orthostatic hypotension and sweating abnormalities) or neuropathic pain (burning, stabbing, electrical) [5]. Kuwait is a high-income country providing a high standard of health and social services to its citizens with health indicators similar to those of highly developed countries [6]. The most common causes of peripheral neuropathy in Kuwait are diabetes and lower back pain as discussed below [7]. Furthermore, the incidence of diabetes in the adult population in Kuwait is one of the top five in the world, with 18% of the population (424,000 in 2019) diagnosed as diabetic. This number has increased dramatically in the last decade [8].

Pharmacy **2019**, *7*, 127; doi:10.3390/pharmacy7030127

The prevalence of peripheral neuropathy in the general population (worldwide) is 2.4% and increases to an estimated 8% in those older than 55 years [9,10]. In Western societies, the most common cause is diabetes mellitus, with a prevalence of peripheral pain in diabetics ranging from 30–66% [11–14]. In a population-based study in the Netherlands diabetes was found to be the third main cause of peripheral neuropathy [15]. Hall et al. [16] found that there were approximately 15.3 cases of neuropathic pain for every 100,000 individuals in the United Kingdom between 1992 and 2002 and since then this ratio has been increasing every year. In Kuwait, in 2010, peripheral neuropathic pain was estimated to affect around 39% of the diabetic population [17]. Like elsewhere in the world, the incidence and prevalence of diabetes also increases dramatically with age in Kuwait, which indicates a rise in the number of people who will have to live with peripheral neuropathy [18]. In addition, lower back pain is prevalent among Kuwaitis, which leads to peripheral neuropathy. In Kuwait, the prevalence of lower back pain among 10-18 year-olds was found to be 58% (51% in males and 65% in females), increasing with age in both males and females, thus increasing the risk for developing peripheral neuropathy [19].

In western countries, multidisciplinary care for people living with peripheral neuropathy is encouraged and receiving a wide range of additional support allows people to manage their own condition [20]. Most research conducted in the Arab region has only reported the prevalence of peripheral neuropathy [21,22] and research focusing on patients' experiences in the Middle East is lacking. The main purpose of this research was to explore the experiences of people living with peripheral neuropathy by examining the healthcare pathway in Kuwait from the patient perspective. The healthcare pathway will be examined in terms of referrals, investigations and general management. This paper uses the technique of process mapping to chart the journey experienced by people living with peripheral neuropathy in Kuwait and to compare that journey with standards existing in peripheral neuropathy care in Western countries. Process mapping allowed us to see and understand the patient's experience [23] by separating the management of peripheral neuropathy and its treatment into a series of consecutive events or steps (for example, activities, interventions or interactions with healthcare professionals).

2. Materials and Methods

2.1. Study Design

This qualitative study aimed to explore the pathway of standard care for the management of people living with peripheral neuropathy in Kuwait and to develop a schematic process map of the patient journey based on their experiences. The process map was then compared with existing guidelines in the UK, where the National Institute for Health and Care Excellence (NICE) and the International Association for the Study of Pain (IASP) guidelines are used.

2.2. Study Setting

The study was conducted at Ibn Sina Neurology and Neurosurgery Hospital, the tertiary centre to which neurology patients are referred by neurology specialists in general hospitals. The principal investigator informally observed people living with peripheral neuropathy that attended the outpatient clinic of Ibn Sina Hospital, to familiarise themselves with the healthcare setting.

2.3. Recruitment Strategy

A study summary was provided to the neurologists attending the outpatient clinics to identify potential participants meeting the eligibility criteria (aged over 18 years, diagnosed with peripheral neuropathy, resident in the State of Kuwait, speaking Arabic or English). The nursing staff distributed an information pack (consisting of an invitation letter, patient information sheet and pamphlet with further contact details) to potential participants. Interested people contacted the principal investigator via phone or email.

Recruitment started in February 2017 and was completed within two weeks. Of ninety-five potential participants, twenty-seven contacted the principal investigator (28% response rate). After obtaining consent, the principal investigator undertook an in-depth review of the medical records of these outpatients to confirm that they met all the inclusion criteria. Two people were excluded because one did not meet the age criteria (was under 18 years old) and the other was excluded on the grounds of having neurological problems other than peripheral neuropathic pain. Therefore, twenty-five people (20 Kuwaiti and 5 Non-Kuwaiti) were deemed eligible for inclusion in the study.

2.4. Data Collection

A semi-structured interview guide was used to explore people's experiences. Participants were asked initial demographic questions, including age, sex and nationality, along with questions regarding comorbidities and duration of peripheral neuropathy (see Table 1). The interview proceeded with open-ended questions that began by broadly asking about their pain and then moved on to more specific questions about the healthcare they received in terms of medical treatment, medication and whether they felt anything was missing from their care. The interview guide was developed from the literature, taking into consideration the culture and healthcare system in Kuwait. The healthcare system in Kuwait is comparable with Western processes in terms of referrals from primary care to hospital settings, however long referral times and a lack of specialist care, such as psychological services, are key differences.

Table 1. Characteristics of people living with peripheral neuropathy in Kuwait.

Characteristics		**Observations (*n* = 25)**
Nationality	Kuwaiti	20
	Non-Kuwaiti	5
Sex	Male	12
	Female	13
Age (years)	Range	35–82
	Mean (Standard Deviation)	55 (SD = 10)
Comorbidities	Type 2 Diabetes Mellitus	16
	Hypertension	10
	Dyslipidaemia	8
Duration of peripheral neuropathy (years)	Range	3–30
	Mean (Standard Deviation)	13.76 (SD = 7.4)

Interviews began in March 2017 and were conducted over a period of a year. Participants were assigned study specific numbers and initials to anonymize their identity. Each participant was interviewed individually in a private room in the hospital, in the language of their choice (English or Arabic). Out of the five non-Kuwaiti participants, three preferred English. All Kuwaiti participants preferred Arabic. Interviews lasted 45–60 min and were audio-recorded. The English interviews were fully transcribed in English; the Arabic interviews were transcribed in Arabic and later translated into English. From the twenty-five transcripts, six were selected for review to ensure that the transcriptions and translations were accurate. Four transcripts were reviewed by an academic lecturer at the Languages Centre at the University of Jordan, who was proficient in both Arabic and English; and two by a bilingual physician at the Department of Community Medicine and Behavioural Sciences, Kuwait University. All reviews confirmed that the transcriptions and translations were accurate and consistent.

2.5. Data Analysis

The transcripts were transferred to NVivo12 software [24] for data management and analysis. The data was initially manually coded inductively after familiarization and then by a combination of text search queries and coding queries and then extracted to generate a preliminary report which helped to plot the patient journey process map, which in turn aided in identifying the weaknesses in the existing patient care pathway. It also helped to formulate suggestions for improvement, propelled by the implicit and explicit deductions made by the researchers. Validation was ensured not only by prolonged engagement but also by peer debriefing.

A planned approach for producing a process map was applied to the data to ensure a comprehensive representation of the patient journey [25]. Four transcripts were chosen based on their rich data (eloquence of interviewee, length of interview, severity of pain) to plot four individual pathways. These pathways were compared to identify similarities (such as referrals and pharmacological treatments) and differences (such as disparities in referral time and waiting periods). These were combined to make a preliminary process map which reflected even the minutest details for example, signs, symptoms, investigation results, physical examinations, referral systems, follow-ups and their current situation. This was expanded into a second version by layering on details from the twenty-one remaining transcripts, which involved adding further detail and clarification to the preliminary process map drafted from the initial four participants. After multiple iterations, a simplified and condensed process map (see Figure 1) was produced that captured the journey for all people living with peripheral neuropathy in Kuwait.

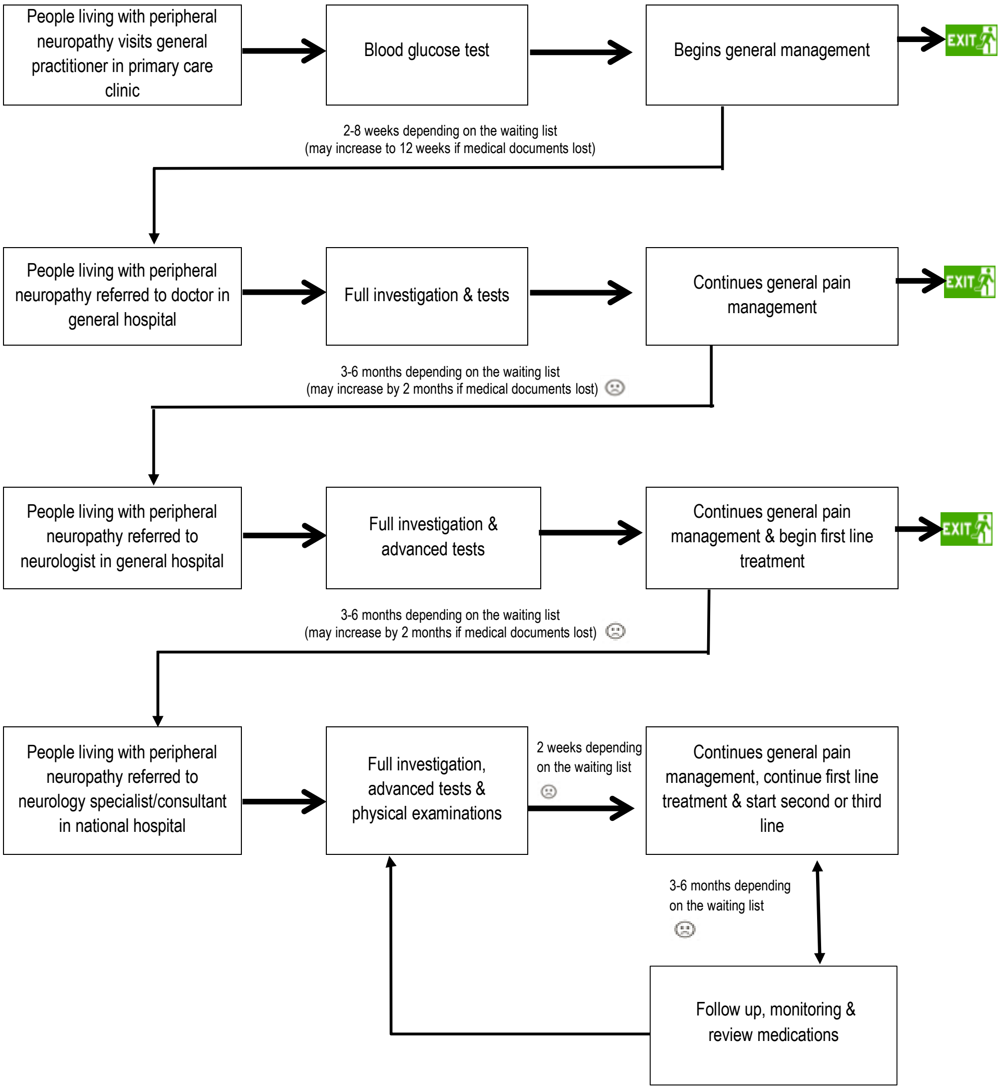

Figure 1. A Process Map of People Living with Peripheral Neuropathy in Kuwait.3.1. Primary care clinic—the journey starts.

Figure 1. A Process Map of People Living with Peripheral Neuropathy in Kuwait

2.6. Ethical Consideration

Ethical approval was obtained from the University of Reading Ethics Committee (UREC–16/46) as well as the Standing Committee for Health and Medical Research Coordination (SCHMRC) in the Ministry of Health (MoH) in the State of Kuwait (Ref no: 194/2014).

3. Results

The primary focus of this paper is to explore people's experiences with peripheral neuropathy and identify the care pathway in Kuwait. The results were derived from interviews with people attending the outpatient clinic of Ibn Sina Hospital. Most participants were Kuwaiti (n = 20), with an average age of 55 years (SD = 10) and had been living with peripheral neuropathy for an average of 14 years (SD = 7). Further details of the participant characteristics can be found in Table 1.

The main symptoms experienced by people living with peripheral neuropathy were neuromuscular; and their most frequent complaints were physical pain in the feet, hands, extremities, back, leg and knees, as well as numbness and tingling. Close analysis of the interviews showed that subjects experienced similar treatment and care pathways despite differences in the presentation of their complaints. The process map of the outpatient journey, as described by patients in Kuwait and as depicted in Figure 1, shows a referral from a local primary clinic to the general hospital, where people living with peripheral neuropathy would see a general doctor and a neurologist, then on to a specialist/consultant at the national neurology hospital.

3.1. Primary Care Clinic—the Journey Starts

Administrative issues at the primary clinic were strongly evident to most of the people living with peripheral neuropathy. There were usually only a few members of staff (doctors or nurses) on duty at the clinic and this led to a long queue of people and long waiting times.

> *Some people living with peripheral neuropathy feel more pain while sitting on cold seats, awaiting their turn to see the doctor—Female, 82 years old, living with peripheral neuropathy for 20 years.*

Some people were able to bypass the long waiting time by using their social influence (connections) in healthcare. Kuwait also has a green card system that is intended to function as a waiver of such waiting periods, to ensure that old people, for example, have short or even no waiting times and can complete their hospital visits quickly. For some participants, however, this card did not seem to fulfil its function.

> *Once, I entered the staff room to tell them that they must let me enter and see the doctor fast, as I had a green card and the right to see the doctor fast . . . One of them replied that I should wait, as there is someone preceding me in the queue and there are others who suffer from rheumatism too—Female, 82 years old, living with peripheral neuropathy for 20 years.*

To also cut the waiting time, some people relied on other bypass methods, such as giving bribes to the porters.

> *I had to wait a month and a half and I also needed Wasta (a gift or bribe) to get the magnetic resonance image—Male, 35 years old, living with peripheral neuropathy for 15 years.*

> *The Bengali porter, who knows everyone inside the clinic, is given two or five Kuwaiti Dinars to help in getting a faster service, some others call their doctor friends and other acquaintances to help them avoid these queue systems—Male, 62 years old, living with peripheral neuropathy for 10 years.*

Furthermore, participants thought that the care given by some doctors, inside the consultation rooms, did not meet their expectations.

> *There was a doctor who keeps speaking on the phone and does not care about my sick condition or doesn't tell me to sit or not—Female, 82 years old, living with peripheral neuropathy for 20 years.*

This participant commented that her Kuwaiti senior friends would rather use their health insurance to go to a private hospital. The Kuwaiti government levies around two percent of a public servant's salary in taxes and retirees receive a health-card entitling them to free care in all private hospitals.

At the primary clinic, the doctor was engaged with the patient for less than five minutes, during which time their medical history was quickly assessed; a judgement was made about which laboratory tests to conduct, such as blood glucose (see Table 2) and the doctor reviewed the current treatment of symptoms. A variety of problems were reported from the patients' perspective, including various areas of patient care and prescription difficulties.

Table 2. Investigational procedures carried out for people living with peripheral neuropathy in Kuwait.

Centre	Investigational Procedures Performed
Primary clinic-general practitioner	Blood routine, random blood sugar, fasting blood sugar and postprandial blood sugar for diabetics
General hospital-doctor	Blood routine and HbA1c (glycosylated haemoglobin)
General hospital-neurologist	Blood routine, HbA1c and other blood test, advanced neurological investigations: loss of protective Sense, +1 of reflex ankle-vibration- pin prick- gait
National hospital-neurology specialist/consultant	Physical examinations, full neurovascular examination, nerve conduction study and foot care diabetic peripheral neuropathy. Investigation and examination: HbA1c and other blood tests

Prescriptions usually included general pain management using basic analgesics (see Table 3).

Unfortunately, the doctors here are not very familiar with this matter but only give the painkillers, do not treat the disease and pain, do not tell me what this pain is and do not treat the inflammation—Female, 45 years, living with peripheral neuropathy for 9 years.

Table 3. Treatment options provided for people living with peripheral neuropathy in Kuwait. * The current study showed that people with peripheral neuropathy, who are mainly diabetics, were not using Carbamazepine 200–400 mg tablets or Gabapentin 300–1200 mg tablets as first line medications.

General pain management	ketoprofen (Fastum 2.5%) Gel	1
	etoricoxib (Arcoxia) 30 mg tablets	1
	ibuprofen (Ibuprofen) 200–400 mg tablets	10
	acetaminophen (Acetaminophen) 500 mg tablets	5
	alpha-lipoic acid (Thiotacid) 600 mg tablets	2
	vitamin b complex (B complex) 500 mg tablets	7
First line treatment *	pregabalin (Lyrica) 75–150 mg tablets	8
	Tricyclic antidepressants (TCAs): Amitriptyline (Tryptizol) 25–150 mg tablets	1
Second line treatment	Selective serotonin and norepinephrine reuptake inhibitor (SSNRI): duloxetine (Cymbalta 60–120 mg capsules and Cymbatex 30 mg capsules)	1
Third line treatment	Opioids: tramadol (Tramol) 50 mg Tablets	1

Depending on the duration of their symptoms, intensity of pain and response to the prescribed medication, the patient will obtain a standard or an emergency referral from their primary care general practitioner to the general hospital.

> *They give a medical appointment for three months or two or two and a half months and if you missed your medical appointment, it is a big problem—Female, 56 years old, living with peripheral neuropathy for 30 years.*

Due to the long waiting periods, and sometimes feeling a lack of care from doctors, some patients exited mainstream care to try alternative therapies such as acupuncture, massage, sujok (a Korean method of reflexology) and herbal medicine.

3.2. General Hospital—Multiple Referrals

3.2.1. Referral to Doctors in a General Hospital

Administrative problems during referral mean it can take anywhere between 2 and 8 weeks to get an appointment at the general hospital depending on the waiting list in the local area. Since Kuwait does not have a centralized electronic medical record system, the paper medical files or referral documents play an essential role in the care of patients. These documents might get lost or go missing from the clinic or the patient might lose their referral letter. In such cases, there are detrimental consequences. The patient may have no option but to repeat the whole process of opening a file and getting a referral letter, thus increasing the waiting period to as much as 12 weeks. This long waiting time usually tests the patience of the individual or causes them to seek alternative therapies.

> *My file was lost. When I went to the general hospital and showed them my referral paper, they said to go back to the clinic and reopen a new file and then come. It took me another three months to finally meet this doctor as I had to wait again—Male, 62 years old, living with peripheral neuropathy for 10 years.*

Doctors in the general hospital have to repeat the entire process by conducting basic laboratory tests, such as HbA1c and other procedures, such as advanced neurological investigations, to ensure there is a full investigation. They then continue appropriate pharmacological treatment, often without adequate patient notes and lack of proper communication and cooperation with their peers. Furthermore, there are time pressures and a heavy patient load. Table 3 presents the medication prescribed for general pain management.

> *If you see a doctor, you find him either on leave or travelling and thus you have to go to another doctor who does not know anything about your condition. So, the two doctors are the same but the second one prescribes the medication and the diagnosis. Days are passing in my life and I still feel pain and loss at the same time—Female, 55 years old, living with peripheral neuropathy for 30 years.*

Depending on factors such as their symptoms, response to medicine and social status people were prescribed medications and asked to return for follow-up after a few weeks or months. Some people did not visit the doctor for follow-up for various reasons, including the effort involved, enduring the waiting time and the possibility of administrative problems, for example, their record not being available. Other people preferred to send their relatives or a representative to the pharmacy to get a repeat prescription without even seeing the doctor. Prescriptions could be repeated numerous times, without a requirement to reassess the patient's condition.

> *In Kuwait, doctors pay no attention to the nature of the pain. They only give the patient painkillers and never know the cause—Female, 45 years old, living with peripheral neuropathy for 9 years.*

3.2.2. Referral to Neurologist in General Hospital

If deemed necessary, people may also be referred by the doctor in the general hospital to a neurologist in the same hospital. There are only five general hospitals that provide healthcare to approximately 4 million people living in Kuwait. An appointment might take 3–6 months depending on the waiting list and may even extend for a further two months due to the loss of medical documents in between. Some patients felt that their doctor did not give them their full attention.

> *The doctor should know the medical record of the patient before the patient enters. Here, doctors turn to the computer or read the medical record during meeting the patient, rather than giving us their full attention—Male, 47 years old, living with peripheral neuropathy for 3 years.*

The neurologist usually repeats the full investigations, as done by their predecessor but also adds advanced investigations along with conducting further neurology-specific tests, such as the assessment of degree of loss of protective senses and reflexes and continues appropriate pharmacological treatment as mentioned in Table 3. If the patient still shows no or minimal improvement, they will be referred to the national hospital for neurology treatment. People living with peripheral neuropathy also reported exiting at this point to try alternative medicine.

3.3. National Hospital for Neurology—Ultimate Destination for Peripheral Neuropathy Care

The delay in getting an appointment for referral to the national hospital for neurology, including the waiting period and possible extension time of 3–6 months, plus another 2 months in case of loss of medical documents, inevitably added to the difficulties caused by administrative problems. This led to weariness and frustration for most patients, although some received quicker referrals due to their social influence or high economic status.

> *Long referrals of up to a year! And pain still continues … I think if the whole subject was based on money, they would pay more attention—Female, 63 years old, living with peripheral neuropathy for 24 years.*

The neurology specialist/consultant at the national hospital started from the beginning once again in terms of history taking, examinations and treatment. They conducted full laboratory investigations including HbA1c and a physical examination, placing specific emphasis on neurovascular examinations (see Table 2). Nerve conduction studies and advice on podiatry care for people with diabetic peripheral neuropathy were also provided here (16 of the 25 people interviewed, had type 2 diabetes mellitus). Again, depending on the level of their symptoms, as well as the progress of their disease or their response to medication, people could be further referred to another experienced neurology specialist/consultant in the same hospital.

At this stage, patients received a structured pharmacological regimen, similar to the UK guidelines for peripheral neuropathy pain care, consisting of anticonvulsants as the first line of treatment. If there was an inadequate response, the patient received the second line of treatment and if needed, there was an escalation to the third line of treatment, which included opioids. Table 3 reflects the pharmacological treatment options that were reported. Some patients also exited at this point hoping for better symptomatic management and care from alternative medicine.

> *Okay, I am always in pain . . . ., I think Ginseng tablets are the best solution . . . . it takes less time to manage my pain levels . . . . I myself decided to take it but I asked the doctor if I could keep using it; he said, "You know if you feel good about, no problem using it"—Female, 56 years old, living with peripheral neuropathy for 7 years.*

> *I massage my fingers, close my hands and move my hand in warm water for some time... I move my fingers, put them in warm water and I massage them again so the pain goes—Male, 62 years old, living with peripheral neuropathy for 10 years.*

In general, participants who stayed within the national healthcare system continued the cycles of monitoring and repeat prescriptions for medication with very little improvement in their health. Furthermore, some patients were concerned that they knew very little about their disease or its progression, while others felt disappointed that they were not referred for psychological or dietary support or given any information about alternative therapies.

> *If they (seminars) are available in the national hospital, it will be so helpful and should be given to patients—Male, 43 years old, living with peripheral neuropathy for 4 years.*

> *The doctor prescribed only the medication but never gave any psychological support or referral for psychological counselling—Female, 60 years, living with peripheral neuropathy for 4 years.*

Participants described various difficulties, caused by, in their opinion, not receiving satisfactory care. Patients reported a lack of awareness about their disease and the treatments available, which in turn caused anxiety regarding the progress of their disease. They reported staffing and management issues such as a shortage of healthcare professionals that was evidenced by the long waiting times, not only to see the doctor but also the few very busy nursing staff. Participants also mentioned several administrative problems, such as long waiting time for referrals that were exacerbated by the unavailability or loss of medical records. The lack of universal electronic medical records also meant the unnecessary repetition of history taking, examinations and full investigations. Social practices, such as giving gifts and bribes to porters, helped a few people to bypass waiting lists and receive more medical attention and a better quality of care.

Many patients chose to exit the traditional care pathway to try alternative therapies at different points during their patient journey, especially when they felt frustrated waiting for their appointments or when they did not get the expected care from the medical team or relief from symptoms by following the prescribed medications. Many reported trying self-help options such as ignoring the pain, exercising, dietary change (by seeking out a dietician and educational sessions from private hospitals or Dasman Diabetes Centre in the public sector). Alternative therapies were obtained from the hospital for Islamic Medicine in the public sector or private massage parlours functioning independently or as a part of well-known private hospitals such as Dar Al Shifa Hospital. Most people living with peripheral neuropathy wanted to receive further psychological support and education sessions to help them cope better with their condition.

4. Discussion

This patient journey map is the first of its kind in the Middle East for peripheral neuropathy, though there have been other patient journey exercises conducted in other therapeutic fields such as irritable bowel syndrome in Dubai, Qatar, Kuwait and Saudi Arabia [26]. This process map depicts the journey experienced by patients from the primary clinics to the national hospital of neurology. A close analysis of the patient journey map and comparison with standard care in the UK [27] identified both similarities and differences in the healthcare pathway. Similar referrals, investigations and pharmacological treatment were identified, however the range and availability of healthcare services differed. The comparison highlighted that in Kuwait highlighted that a much more strategic approach is required in three main areas including non-pharmacological support, organizational systems and medical care.

4.1. Psychological Support

There are three factors that play an important role in pain perception—namely psychological, psycho-behavioural and psychosocial components [28,29]. Many participants in this study reported that their pain had influenced their mood, sleep, relationships and functional capacity. This finding is similar to research reported by Hensing et al. [30] in 2007 that showed examples of exaggerated pain and consequences of chronic pain in neuropathic patients, where the touch of a nightdress triggered a massive stimulus, which in a healthy patient would be negligible.

In the UK people living with peripheral neuropathic pain and their families are given information regarding the causes of the disease, treatment and prognosis alongside psychological support via counselling sessions guided by qualified psychologists [31]. Treatment in Kuwait, however, depends on the pharmacological management of symptoms alone. According to World Health Organization (WHO), effective management of patients' emotional distress has contributed to the success of primary healthcare, by utilizing the tool of reassurance [32], which places emphasis mainly on patient education and counselling. Improvement in this area to help people living with peripheral neuropathy in Kuwait is highly recommended.

4.2. Administrative Problems

In Kuwait, waiting times for referrals from the general practitioner in the primary clinic to the doctor in the general hospital took anywhere between 2 and 8 weeks, to the neurologist in the general hospital another 3–6 months and to the neurology specialist/consultant in the national hospital another 3–6 months. In case of loss of medical records, these times were extended to up to 12 weeks, 8 months and 8 months respectively. The above findings regarding long waiting times for referrals in Kuwait are similar to a study conducted in 2011–2012 in rural areas of Iran that identified inadequacies in the government healthcare referral system [33]. The Iranian study highlighted specific issues with the referral system such as a lack of communication between different levels of the system itself. In addition, the study showed that people living with peripheral neuropathy possessed insufficient knowledge of the system, self-referred or bypassed it entirely. The referral system in Kuwait, from the patient's perspective, could be improved by coordination between different levels of the referral system, strengthening the public sector of the system, increasing public awareness about the referral system and preventing self-referral, similar to those improvements implemented in Iran [33].

There is no centralized electronic medical record system in Kuwait, which leaves physicians with no choice but to hold bulky paper files, most of which are loosely arranged and often lost during referral. Consequently, succeeding specialists prefer to repeat all tests and treatments instead of spending time deciphering the patient history in the file or communicating with the previous physician. In conjunction, patients are asked to repeat their histories at every stage of the journey. This leads to an inability of the treating physician to visualize the treatment of a patient as a whole [34]. Electronic medical records could therefore potentially reduce delays and overall staff workload. Technological advancements and electronic medical records can have a significant impact on a referral system. They can improve quality of care, patient outcomes and safety through improved management, reduction in medication errors and reduction in unnecessary investigations. Furthermore, they can improve communication by phone, email and face-to-face among primary care providers, patients and other providers involved in care [35]. Electronic medical records have been demonstrated to improve efficiencies in workflow through reducing the time required to create charts, improving access to comprehensive patient data, helping to manage prescriptions, improving scheduling of patient appointments and providing remote access to patients' charts. Electronic medical records capture point-of-care data that informs and improves practice through quality improvement projects, practice-level interventions and informative research [35]. The suggestion of Aij et al. [36] in the Netherlands, for example, that hospitals and healthcare providers should source third party consultants to train management on how to manage and implement solutions, could be a useful recommendation based on the results of this current study. If this was implemented, the patient journey could be redesigned to avoid repetition, remove inconsistencies and create greater standardization across related departments and organizations [37].

4.3. Medical Care

Table 3 shows that pharmacological treatment of peripheral neuropathic pain in Kuwait aligns with the UK NICE and IASP guidelines, except that many diabetics are not prescribed carbamazepine (200–400 mg) or gabapentin (300–1200 mg) tablets as first line treatment [27,38]. Furthermore, topical applications such as capsaicin cream, are not available. Tramadol was rarely used to treat people experiencing diabetic peripheral neuropathic pain. However, the availability of these other medications and training for personnel to use and prescribe them would help people manage their peripheral neuropathy more effectively. Guidelines regarding the intervals for assessment and reviewing changes in medication, for example, when to escalate from 1st to 2nd or 3rd line treatment, could improve the follow-up process. New treatments could then be introduced carefully and with the assessment of their efficacy in the Kuwaiti context.

4.4. Implications for Research

The main strength of this study is the high level of patient involvement and the wide range of individuals interviewed. Patient perspectives are not routinely explored through research in Kuwait. There are several limitations, however, that have implications for how future research studies in this area are designed and implemented. This study was hampered by the unavailability of a centralized Electronic Medical Records (EMR) system to confirm the diagnosis and treatment being followed in locations or clinics other than the National Hospital for Neurology. Another limitation was the age range of participants which meant younger people, aged 18–34, were not represented so it was not possible to explore how similar their experiences are to those reported here.

The recommendations outlined in this article could become the basis for further qualitative research in the area. For example, observational studies could assess the success of implementation of recommendations and procedures suggested in the treatment of people living with peripheral neuropathy in Kuwait. At the same time, in-depth interviews with individual family members and medical staff could be undertaken to fully explore their problems and issues. A mixed qualitative approach such as observation and in-depth interviews would provide deeper insights and therefore a broader perspective.

4.5. Implications for Practice

In terms of current practice, this study highlights people living with peripheral neuropathy in Kuwait report a lack of psychological and psychosocial care. This could be addressed by healthcare providers introducing psychological support via counselling sessions, guided by qualified psychologists, to their standard care. Furthermore, the overall medical system could be enhanced by addressing the identified issues with communication and organization. With regard to communication, perceptions of treatment for peripheral neuropathy could be improved by focusing on the doctor/patient interaction, along with relationships within the multidisciplinary team. Medical professionals could create a culture of mutual respect and cooperation among both medical and administrative colleagues to view patient care as a collective and collaborative effort [39]. Furthermore, in regard to administrative issues, a way to address the current deficit would be to employ a more organized approach to the care pathway, in particular the use of electronic medical records.

5. Conclusions

This map of the patient journey of people living with peripheral neuropathy is a fresh representation that Kuwaiti health officials and medical personnel might find helpful in visualizing the process from the patient's perspective. The study and journey map provide evidence based on interviews that there are several shortcomings and weaknesses in the medical and administrative systems, at all levels (primary and secondary care) in Kuwait, which people living with peripheral neuropathy have to overcome. The process map indicates where changes can be made to improve patients' experiences and potentially their satisfaction with their healthcare and treatment. By addressing administration, medical care and psychological support issues highlighted in this study, people living with peripheral neuropathy could experience more positive treatment outcomes.

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