

Living with painful diabetic neuropathy

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Chapter 10

Impact Paragraph



Impact Paragraph

Besides a contribution to scientific knowledge, the results of this dissertation can have a broader societal impact. This impact paragraph aims to describe the societal impact of the scientific results on the application and implementation in healthcare, to whom our findings are relevant, and it proposes addresses activities for knowledge transfer.

Relevance

DM and its complications, is a burdensome disease that has a huge impact on daily lives and on society. In 2016, there were an estimated 1.1 million DM patients in the Netherlands and the estimated total economic burden of DM was € 6.79 billion (1). On top of this, approximately 25-50% of the patients with DM experiences neuropathic pain (2-4), leading to even more disability and therefore costs for society (5, 6).

When treatment of the underlying disease fails, it is important that healthcare providers help the patient to deal with his/her complaints, to promote physical fitness and to stimulate participation in daily life activities in order to improve QoL, to prevent further complications, and from this, to minimise further societal and healthcare costs. This is also acknowledged by the Dutch Association of Medical Specialists (FMS), who published a vision document for 2025 in which four main priorities are formulated: 1) optimising QoL, 2) patient centred health care, 3) disease prevention & functional maintenance of disease, and, 4) self-management, e-health, wearables & big data (7).

This dissertation highlights the high daily life burden for patients with PDN. In line with the modern approach to complex diseases as defined by the FMS, it focusses on improving QoL and daily life functioning in patients with PDN, hereby presenting a holistic personalized interdisciplinary biopsychosocial analyses of PDN-related problems and providing directions for future treatments that aim to help patients cope with PDN-related complaints.

Network medicine

DM is a common multidimensional condition and daily management is burdensome and long-term complications occur frequently. It is known that adequate management of DM and prevention of complications requires attention to many more aspects of one's health than glucose regulation alone. In DM, the patient is encountering many health care providers over short periods of time and there is a continuous focus on glucose regulation, skin care, dietary restrictions, and prevention/treatment of hypertension and/or dyslipidaemia. When PDN is also present, pain specialists and other medical specialist or therapists may get involved. In order to prevent non-compatible or even contradicting advices regarding DM management, pain and being physically active despite pain, it is

essential that healthcare providers work together and speak the same language. For example, all healthcare providers should be aware of the patient's medical concerns regarding DM and PDN. At the same time, these risks should not be magnified and/or exaggerated as this can potentially induce fear of avoidance behaviour. From this point of view, all healthcare providers should also know the actual physical capabilities of the patient, so that good self-care and physical activity can be promoted within the boundaries of what is possible and safe for this individual. This dissertation adds knowledge about how to approach PDN from an interdisciplinary perspective.

The discussion section *Diabetes and Chronic Pain; bridging the gap* provides the outlines of an ICF-based biopsychosocial framework that can be used for the problem analysis and treatment of patients with PDN. Within the field of rehabilitation medicine, this way of thinking and working is already quite common; the physiatrist plays an important role within the rehabilitation team, coordinating the medical and paramedical care around one patient, and seeking help from other healthcare providers where needed. However, in order to achieve true holistic patient centred care, it is important to implement and integrate a biopsychosocial way of thinking in the daily working routines of *all* health care providers. For this, network medicine is key; healthcare providers need to start reaching out to one another, within and beyond the walls of healthcare institutions.

This paradigm shift requires the education and training of medical specialists, paramedics, general practitioners, psychologists and all other involved healthcare givers. Also, healthcare institutions should facilitate network medicine by supporting multidisciplinary team meetings, within and beyond the walls of their own institutions. In addition, electronic patient files should be redesigned to support network medicine, in the way that relevant patient data should be accessible to all involved healthcare providers, while also being adequately protected to ensure data security.

Research should be done on the role of health insurance companies with regard to the reimbursement of network medicine. In the field of rehabilitation medicine in the Netherlands, the current healthcare financing reimburses direct patient contact, while indirect patient related time, such as multidisciplinary consultations, is, with a few exceptions, not reimbursed. This means that it can be more feasible for healthcare providers to treat patients individually, instead of working together with other healthcare providers. It is recommended that the government investigates opportunities on how financial structures can be redesigned so that preventive medicine and network medicine can be facilitated, as increasing evidence shows that personalized medicine that aims to improve QoL and daily life participation results in the prevention of complications of chronic diseases, which may lead to lower health care costs in the long run (8).

E-health

Individuals with DM experience a high burden of disease and they frequently have to consult healthcare providers for glycaemic control, diabetic foot care, medication switches, blood check-ups etc. A pain rehabilitation programme addressing the biopsychosocial components of pain in order to improve daily-life functioning, usually involves multiple weekly sessions with the therapist team for a period of several weeks, causing an additional burden for patients. E-health may be a way to decrease this burden as patients don't need to travel to see a doctor and/or other healthcare provider.

There are different types of e-health. A real-life consultation with a healthcare provider can be replaced by a phone or video call (telemedicine). Mobile telephones with camera technology allow to share images such as photographs of pressure ulcers. In addition, electronic health record systems can be used for electronic administration of measures which can be stored in databases (9). Occasionally, aspects of the physical examination may be undertaken virtually, such as the demonstration of certain movements, which may allow an initial treatment plan to be started (10). E-health can also refer to online treatment modalities, such as diabetes self-care programs or pain rehabilitation programs. In the case of diabetes and diabetic foot management, several digital and online treatment options are available (11, 12). For PDN, an online ACT therapy was developed, which showed to not be feasible in the current form as completion rates did not achieve the pre-specified feasibility target (13). In the field of pain rehabilitation, telemedicine and e-health approaches are gradually being developed and tested, with many studies focusing on lessons learned and barriers to using e-health solutions (10). The COVID-19 pandemic accelerated the development of these e-health solutions, as treating and supporting people with non-urgent and long-term conditions at a distance from healthcare providers became imperative (10).

Currently, the COVID-19 pandemic has been around for a year, and we have learned that e-health can provide us with more opportunities than we may have imagined before. More specifically, in the field of pain rehabilitation, our team has experienced that it was feasible to provide (parts of) a pain rehabilitation treatments via videoconferencing during the COVID-19 pandemic (14). It is not yet known whether these treatments were equally effective, and more research should be done on this. Given the high burden of medical visits for PDN patients, it seems apparent to further investigate e-health methods for this group of patients.

Knowledge transfer

This dissertation illustrates how complex and multidimensional PDN can be, both physically and mentally, and it underpins the need for a personalized biopsychosocial approach. Especially our lessons learned are valuable for researchers and clinicians, as they offer

a new starting point for further development of treatments for patients with PDN. New studies using a single-case or randomized controlled trial design, are advised to further investigate and confirm clinical effectiveness of a multidisciplinary rehabilitation treatment for diabetes related disability and/or PDN. In case of proven effectiveness, this treatment can be included in Dutch and international guidelines. To disseminate the scientific results of this dissertation, presentations on national and international conferences were and will be given for researchers and healthcare professionals. The results from all our studies have already been published in international scientific journals.

References

1. Peters ML, Huisman EL, Schoonen M, Wolffenbuttel BHR. The current total economic burden of diabetes mellitus in the Netherlands. *Neth J Med.* 2017;75(7):281-97.
2. Daousi C, MacFarlane IA, Woodward A, Nurmikko TJ, Bundred PE, Benbow SJ. Chronic painful peripheral neuropathy in an urban community: a controlled comparison of people with and without diabetes. *Diabet Med.* 2004;21(9):976-82.
3. Davies M, Brophy S, Williams R, Taylor A. The prevalence, severity, and impact of painful diabetic peripheral neuropathy in type 2 diabetes. *Diabetes Care.* 2006;29(7):1518-22.
4. Abbott CA, Malik RA, van Ross ER, Kulkarni J, Boulton AJ. Prevalence and characteristics of painful diabetic neuropathy in a large community-based diabetic population in the UK. *Diabetes Care.* 2011;34(10):2220-4.
5. Schmader KE. Epidemiology and impact on quality of life of postherpetic neuralgia and painful diabetic neuropathy. *Clin J Pain.* 2002;18(6):350-4.
6. Peltier A, Goutman SA, Callaghan BC. Painful diabetic neuropathy. *BMJ.* 2014;348:g1799.
7. Vision Document 2025. Utrecht: Dutch Association of Medical Specialists (FMS); 2017.
8. DiBonaventura MD, Cappelleri JC, Joshi AV. Association between pain severity and health care resource use, health status, productivity and related costs in painful diabetic peripheral neuropathy patients. *Pain Med.* 2011;12(5):799-807.
9. Köke AJ, Smeets RJ, Schreurs KM, van Baalen B, de Haan P, Remerie SC, et al. Dutch Dataset Pain Rehabilitation in daily practice: Content, patient characteristics and reference data. *Eur J Pain.* 2017;21(3):434-44.
10. Eccleston C, Blyth FM, Dear BF, Fisher EA, Keefe FJ, Lynch ME, et al. Managing patients with chronic pain during the COVID-19 outbreak: considerations for the rapid introduction of remotely supported (eHealth) pain management services. *Pain.* 2020;161(5):889-93.
11. Hazenberg C, Aan de Stegge WB, Van Baal SG, Moll FL, Bus SA. Telehealth and telemedicine applications for the diabetic foot: A systematic review. *Diabetes Metab Res Rev.* 2020;36(3):e3247.
12. Celik A, Forde R, Sturt J. The impact of online self-management interventions on midlife adults with type 2 diabetes: a systematic review. *British journal of nursing (Mark Allen Publishing).* 2020;29(5):266-72.
13. Kioskli K, Scott W, Winkley K, Godfrey E, McCracken LM. Online Acceptance and Commitment Therapy for People with Painful Diabetic Neuropathy in the United Kingdom: A Single-Arm Feasibility Trial. *Pain Med.* 2020;21(11):2777-88.
14. Baadjou VA, den Hollander M, van Meulenbroek T, Verbunt JA, Timmers I. Clinicians' initial experiences of transition to online interdisciplinary pain rehabilitation during the COVID-19 pandemic. *JRM-CC.* 2020;3:1000036.