Making medical

Treatment decisions in Dutch sciatica care and the relevance of medicalization for health policy making

Wieteke van Dijk

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Making medical

Treatment decisions in Dutch sciatica care and the relevance of medicalization for health policy making

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Promotoren:
Prof. dr. G.P. Westert
Prof. dr. P.P.T. Jeurissen

Copromotoren:
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Prof. dr. R.H.M.A. Bartels
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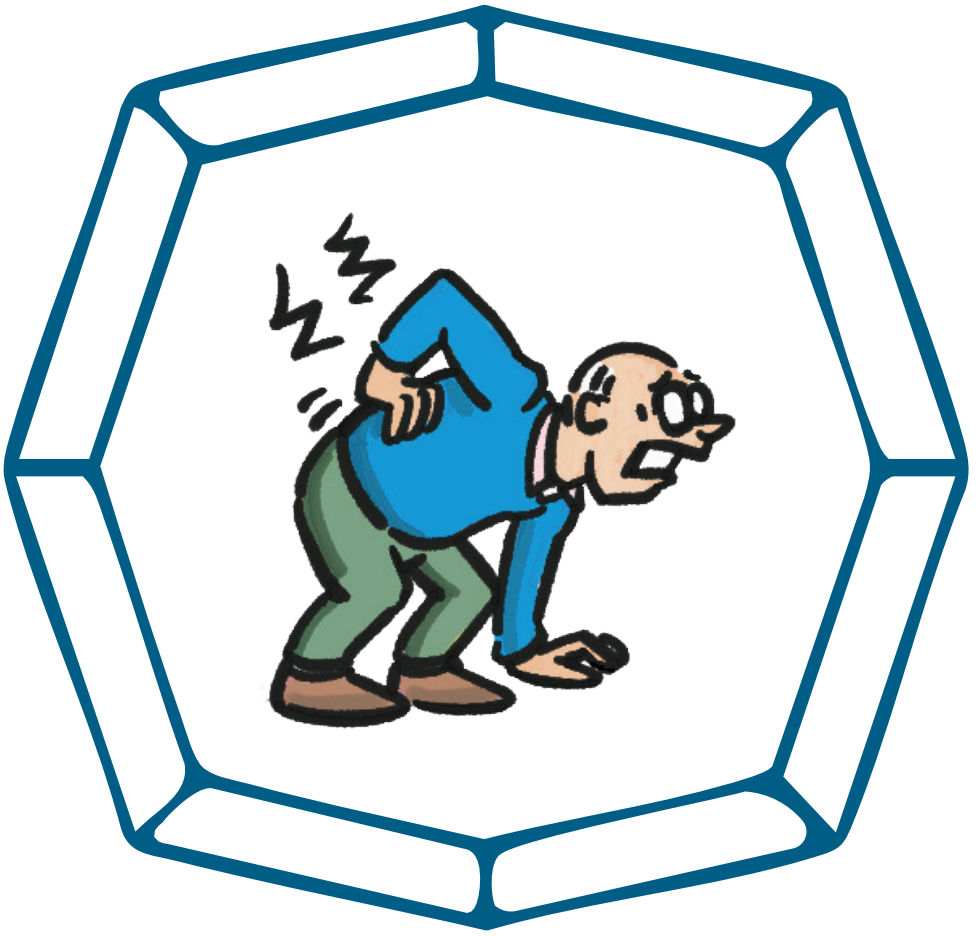
Table of contents

Summaries

Appendices



Chapter 1

Introduction

The use of healthcare increased in the Netherlands, resulting in an exponential increase in costs (Rijksinstituut voor Volksgezondheid en Milieu 2018). It is predicted that healthcare spending in 2040 will be doubled compared to 2015, which implies an increase in the percentage of the BBP spent from 12,7% to 16,4% (Rijksinstituut voor Volksgezondheid en Milieu 2018). This ongoing increase is unsustainable: workforce shortages rise and public and individual spending on healthcare suppresses other relevant (public) goals (Wetenschappelijke Raad voor het Regeringsbeleid 2021). The rise in healthcare use is partly due to an aging population but also influenced by an ever-rising supply of new solutions for new and existing problems (Wetenschappelijke Raad voor het Regeringsbeleid 2021). These problems are not new per se, but their medical explanation and/or medical treatment sometimes are. The expansion of medicine into new areas of human experience is what we call medicalization.

Medicalization in itself is a neutral development, although it increases healthcare use and costs (Bell 2017). Medicine and medical development have also improved the quality of life and life expectancy. However, not every problem might benefit from medical involvement and resources might bring more prosperity when spent elsewhere. A better understanding of how medicalization occurs and what mechanisms drive care-seeking could increase the use of solutions that help people address problems outside the healthcare system. This thesis attempts to add to this understanding. In the remainder of this introductory chapter, I dive a little deeper into the concept of medicalization and its scientific development. Furthermore, I introduce the topic of the case study that was performed: treatment decisions in Dutch sciatica care. I will also elaborate somewhat on the setting in which Dutch sciatica sufferers can seek medical assistance. Finally, the research questions and further outline of the thesis are presented.

Medicalization and healthcare

Medicalization is the process in which a situation that was previously not considered medical is increasingly understood as a medical problem, possibly or probably treatable or manageable with medical assistance (Conrad 1992). From epilepsy, the flu, vascular disease, depression, and sleep apnea to premenstrual syndrome: everything that is nowadays considered as a disease or another form of a medical problem, was once defined as 'medical' and was thus 'medicalized'. This makes medicalization in essence the gaze through which people experience their physical and mental being and symptoms. The shortest definition of medicalization possible is: "making medical" (Conrad 2013). Originally, the process of medicalization was regarded as black and white: a phenomenon is or is not regarded as medical. However, there is also a relative component to it: actors involved might have an ambiguous feeling towards the medicalization of the problem at hand. They might doubt whether something 'truly' is a medical problem or a physical outing of another situation, like sleep deprivation after the loss of a loved one. Medicalization can thus also be regarded relatively.

Medicalization can be regarded as a social constructionist concept. The key element of social constructionism is to consider knowledge, facts, and experiences as interpreted, developed, and constructed in interaction (Conrad and Barker 2010). Social constructionism is therefore a perspective or theory of knowledge that considers all human knowledge and understanding as a social construction: people build knowledge and meaning in interaction and in doing so they incorporate facts and -for example- biological measures into their cultural and social construction of their understanding of the world (Sandro 2016). Social constructionism is even more relevant in the context of medicalization research when the traditional distinction between illness and disease is regarded. Traditionally, the distinction between disease and illness was made to separate the biological status of unhealthy (disease) from the personal experience of feeling unhealthy (illness) (Mol 2002). This could lead to the impression that disease is an absolute, indisputable fact, while illness is a subjective perception. Applying a social constructionist perspective to this distinction illustrates that this distinction is not as absolute as it might seem. Illness experiences are fed and influenced by the biological facts and symptoms that define a disease (Leynen, De Backer et al. 2006). Although diseases might appear to be defined strictly on scientific facts, the discovery and interpretation of biological phenomena or physical symptoms as a disease is the work of human beings and not necessarily a value-neutral process (Mol 2002). Discoveries are preceded by choices about the questions and answers they pursue, and in which research population they are pursued. For example, heart disease and heart attacks were diagnosed

less quickly and adequately in women than in men for a long time, because they do not present themselves in the same way in women as they do in men. Because research after heart disease and heart attacks was performed almost exclusively on male subjects, this was unknown, resulting in less adequate diagnosis and care for women. Heart disease is not the only example, demonstrating that discovering, researching, or defining a disease is not necessarily a value-neutral endeavor (Maas and Appelman 2010, Mauvais-Jarvis, Bairey Merz et al. 2020).

Medicalization from a historical perspective

The concept of medicalization originates mostly outside of the medical sciences, in the social and humanitarian sciences (Hofmann 2016). It was introduced some 50 years ago. Scholars of the seventies, such as Illich and Zola, noted that the influence of medicine over broader aspects of life was increasing, resulting in increasing social control over people's behavior and opinions (Zola 1972, Illich 1976). Illich is generally understood as one of the founding fathers of the theory of medicalization, although he never used the term (Busfield 2017). Zola introduced 'medicalization' for this phenomenon. Zola stated that medicine was replacing the institutions that traditionally had shaped society, such as religion and law. Although this notion of the extending power of medicine was not new at that time, Zola was one of the first to criticize the assumed neutrality of this process (Busfield 2017). Illich stated that this process was not only not neutral, but also came with the intended effect of physicians' expansion drift (Illich 1976).

After the introduction of the concept of medicalization in the seventies, the perspective on medicalization broadened in the eighties and nineties. In the eighties, Conrad and Schneider made a distinction between three levels of medicalization: the conceptual, institutional, and interactional (Conrad and Schneider 1980). On the conceptual level, medicalization means a medical vocabulary is adopted to describe a problem. For example, epileptic seizures used to be regarded as an unexplanatory or a punishment from God, until epilepsy as a disease was defined and named. On the institutional level, the medical understanding of a problem translates into for example policies, programs, and reimbursement schemes. For example, in the Dutch healthcare system, all health insurers are required to reimburse the use of the care covered by the standard package. Institutionalizing the standard package in this way, automatically also created an overview of what one might expect from Dutch healthcare. On the interactional level, a medical diagnosis and treatment are applied during the exchange between doctor and patient, possibly addressing problems that could also be regarded as non-medical. For example, when doctors

prescribe sleeping pills for patients who suffer from grief due to the loss of a loved one.

With the further development of the concept of medicalization, its definition also developed. In 1992 Conrad published an influential definition: "*Medicalization consists of defining a problem in medical terms, using medical language to describe a problem, adopting a medical framework to understand a problem, or using a medical intervention to 'treat' it"* (Conrad 1992). In this paper from 1992, Conrad also emphasized that medicalization is a gradual process, of which the definition of the problem at hand is the key element. In 2013 Conrad further simplified the definition of medicalization, stating that its essence is 'making medical' (Conrad 2013).

Medicalization on the interactional level

While the body of literature addressing medicalization is voluminous, the share of empirical work lags. This especially counts for studies at the interactional level (Halfmann 2012). Yet, research on the interactional level might assist most in giving insight into the elements that influence healthcare use and help-seeking behavior, because this is the level on which consumption occurs. However, scholars who study medicalization in the interaction between patient and practitioner, find that this is more complex and diverse than the concept suggests at first glimpse. The results suggested that a relative amount of medicalization might occur: a problem seems to be medicalized, but when the researcher unravels what happens in the interaction between patient and physician, this medicalization appears to be contested and not absolute. For some of these authors, the developments in the definition of medicalization cast the net too wide to be of empirical use. To shed more light on the nuances of medicalization in interaction, sub-concepts that zoom in on the patient-physician interaction were developed: reluctant medicalization and ambivalent medicalization.

Ambivalent medicalization was described by Crowley-Matoka and True within the setting of a United States primary veterans clinic (Crowley-Matoka and True 2012). They noticed that pain seemed not entirely medicalized here, because of its subjectivity and interiority. The interviewed and observed physicians struggled when treating pain because they felt inadequately trained to distinguish 'real pain' from opioid addiction or 'pain playing'. Physicians knew that they might face legal consequences if they would prescribe opioids too easily. Nonetheless, severe pain was common among the veterans at the clinic, making opioid treatment appropriate. Physicians felt trapped between these two ways of perceiving

the situation, they felt insufficiently trained, which resulted in an ambivalent perspective on pain treatment and the medicalization of pain.

With reluctant medicalization, the actors involved in the treatment decision are reluctant to apply medical treatment to a problem for which they suspect non-medical origins. Moloney introduced this nuanced sub-type of medicalization "*to highlight the disparity between self-reported attitude and action and note that embodying these contradictions enables patients and physicians to inhabit a liminal state between pathology and normalcy*" (Moloney 2016, p.2). In this case, patients who visited their primary care physician for sleeplessness received a prescription for sleeping pills, despite the non-medical explanations for the complaint that the physician or patient gave. Both patients and physicians were reluctant to apply a medical label or solution to the problem at hand but did so either way because medication appeared the fastest or most accessible solution. They both felt they lacked better alternatives to 'treat' the problem.

The possible medicalization of sciatica as a central case study

Sciatica is an interesting case from the perspective of medicalization because sciatica pain can be excruciating and disabling, and yet sciatica most often has a positive natural course. From this introduction, one might think that no medical involvement is necessary when someone suffers from sciatica. Indeed, some patients do not consult a medical professional. These are mostly people who are familiar with the problem or who suffer from mild complaints. For the patient group that was included in this study, the pain and impact on everyday living from sciatica was so big, that they felt it necessary to consult a medical practitioner. So, the medicalization of sciatica complaints in the absolute definition, the involvement of medicine with the problem, is not questioned here.

However, since natural recovery is a realistic scenario, the relative amount of medicalization and the timing of intervention is essential. This case study allowed me to study the nuance of medicalization in the interaction between patient and physician. I tried to discover from a medicalization perspective if there were factors that contributed to the choice for the more medical intense treatment option, surgery, over conservative treatment of pain medication, and watchful waiting. And, when and by which of the actors' treatment choices in this situation are affected. A better understanding of the factors that contribute to the more intensive treatment option, adds to the understanding of medicalization on the interactional level.

Sciatica

Sciatica most often results from one or more herniated lumber intervertebral discs, pushing on the leg nerve and causing pain in the leg (Stafford, Peng et al. 2007, Konstantinou and Dunn 2008). Sciatica pain differs from case to case but can be excruciating at the time. Some patients report tremendous suffering, which sometimes even invoked thoughts of suicide (Goldsmith, Williams et al. 2019). Sciatica can be treated conservatively and surgically. A small subsample is at risk for permanent neurological damage and should receive surgery immediately. However, the natural course of sciatica is usually positive. Over 90% of patients recover naturally (Gibson and Waddell 2007) and over 70% within 12 weeks (Vroomen, De Krom et al. 2002). Conservative treatment involves less invasive treatment, with pain treatment and adaptations in daily life (Ong, Konstantinou et al. 2011). Clinical guidelines advise patients to remain active, but this is not always possible (Ong, Konstantinou et al. 2011, NHG-Standaard 2015). Pain scores of surgically treated patients improve faster than those of conservatively treated patients. However, this difference has disappeared within half a year after the onset of complaints, and after two years 20% of patients in both treatment arms reported unsatisfactory treatment outcomes (Peul, van den Hout et al. 2008). Surgery involves a higher risk of complications (Solumsmoen, Bari et al. 2021) and takes a larger cut from healthcare resources than conservative treatment, but when costs of productivity losses are included this difference reverses (van den Hout, Peul et al. 2008). Robust cost-effectiveness studies comparing both treatments over longer periods are scarce and of low quality (Hall, Konstantinou et al. 2019).

In the Netherlands, a typical care path for a sciatica that receives surgery involves subsequently a General Practitioner (GP), a neurologist, and a neurosurgeon. The GP guideline advises pain medication and staying active for as much as possible for the first six to eight weeks (NHG-Standaard 2015). Some patients might benefit from guidance from a physiotherapist to remain active. Although Dutch GPs can order imaging, the guideline advises against this. When complaints do not improve enough within six to eight weeks, the GP can refer to a neurologist. The neurology guideline advises to confirm the accuracy of the diagnosis (Nederlandse Vereniging voor Neurologie 2008). The neurologist can order imaging, but this is not regarded as necessary to confirm diagnosis (Koes, van Tulder et al. 2007). The guideline advises imaging when surgery is considered, or when there are indications for underlying causes other than sciatica. The neurologist should further reassess the pain medication and discuss treatment options such as surgery with the patient. Surgery is not recommended in the first three months, unless for very severe complaints. In the following three months, the preference gradually

evolves to surgical treatment. When surgery is pursued the patient is referred to the neurosurgeon or orthopedic surgeon. The surgeon requires imaging to determine the likely effectiveness of surgery. When both the patient and surgeon agree with surgery, the surgeon will operate.

All decisions should be made with the patient, using shared decision making (SDM) (Elwyn, Frosch et al. 2012). In SDM the physician shares the options and evidence regarding a treatment option, while the patient shares his or her preferences and personal situation (Joseph-Williams, Elwyn et al. 2014). When brought together, the best decision for the specific patient should be made. In this case study I interviewed patients, general practitioners, neurologists, and neurosurgeons about their experiences with sciatica and sciatica treatment options, and how they experienced the decision-making along this care path.

Societal context of medicalization and use of healthcare resources

When asked about the most important thing in life, Dutch people consequently answer: being in good health (RIVM 2011). This seems to be an unequivocal answer. However, how we perceive our health status and what we experience as poor health are less unequivocal concepts than one might think. What we consider good or poor health is largely influenced by how we interpret and explain our physical and physiological state and experiences (Dunning, Heath et al. 2004). The counterpart of health, sickness, is also less unambiguous than we might think. One might feel ill without finding a physical or physiological explanation for the complaints, and one can get diagnosed with a disease without feeling sick. In addition, the individual experience of, and individual coping with identical health statuses might differ. For example, in a situation that one person accepts, someone else might seek medical assistance. Over time both an individual's and the societal threshold for 'good' or 'bad' health may lower or rise. In other words: what we consider healthy or unhealthy and whether we regard a problem as a medical problem depends on the situation and the interpretation.

This also means that healthcare utilization does not need to be static: it (partly) depends on social and societal norms, and might thus possibly be influenceable. In a time of ever-rising healthcare costs and increasing healthcare scarcity, a better understanding of how medicalization occurs could help to influence this phenomenon and lessen healthcare utilization.

Apart from the perspective of the person coping with a (medical) problem, the organization of the society and the healthcare system might influence behavior. In

healthcare systems in which one or more professions act as gatekeepers, such as the Netherlands, access to a medical specialist is indirect. This might prevent the overuse of specialist care, but it could also lower the threshold for care-seeking (Shumsky and Pinker 2003, Wammes, Jeurissen et al. 2014). For example, the threshold to consult a gatekeeper such as a general practitioner or a midwife for a relatively mild complaint might be lower than for a specialist such as an internist or gynecologist. This is one of the central arguments for a gatekeeper system because easy access to care is meant to improve healthcare equality and equity. One of the arguments against is the fear of delayed diagnosis (Greenfield, Foley et al. 2016). Other variables that foster or limit healthcare access are financial aspects, such as high deductibles or high out-of-pocket spending, which affects groups with lower incomes most (Quintal and Lopes 2016). In healthcare systems with staff or other shortages, waiting times will rise and quality of care may decline.

As mentioned, the Dutch care path for sciatica patients possibly involves two types of medical specialists, apart from the GP. In the Dutch healthcare system, the involvement of specialist care leads to additional costs for users. In the Dutch healthcare system of universal insurance coverage, all citizens have an obliged deductible (currently of €385). GP consults are exempt from this deductible, although this does not hold for the research the GP may order, such as imaging. Follow-up care is charged from the deductible, so after receiving a referral for a medical specialist, patients start making costs. Furthermore, several separate smaller deductibles might be in place, for example for specific pain medication. Although the financial burden hereof can be substantial for lower-income families, the Dutch healthcare system is generally understood as highly financially accessible (Osborn, Squires et al. 2016).

While the Dutch healthcare system is regarded as accessible and of high quality, its affordability is an increasing problem (Rijksinstituut voor Volksgezondheid en Milieu 2018). This makes cost-containment policies necessary (Stadhouders, Kruse et al. 2019). However, this is not the only problem of the Dutch healthcare system. Availability of care is also under pressure, due to increasing labor shortages, which decrease the accessibility of care (Wetenschappelijke Raad voor het Regeringsbeleid 2021). To maintain access to care, labor demand should be decreased in some way (Sociaal Economische Raad 2020). To lower or control the claim of healthcare demand over the total governmental budget and the total available workforce, the Dutch Ministry of Health, Welfare and Sport and other relevant parties, currently foster a debate about appropriate care (*passende zorg)* in the Netherlands (Ministerie van Volksgezondheid Welzijn en Sport, ActiZ et al.

2022). The Dutch National Health Care Institute presented the four characteristics of appropriate care (Zorginstituut Nederland 2020):

- Appropriate care is care that is available for a reasonable price;
- Appropriate care is, when possible, accessible nearby patients;
- Appropriate care is care about which patients and their treating physicians share decisions;
- Appropriate care considers disease, but also health and a person's capabilities.
- Appropriate care brings together several aspects that are considered important for the long-term availability of the healthcare system and for the improvement of quality of care. Such as fiscal sustainability (1) and shared decision making (3). Appropriate care combines appropriate healthcare use with a well-organized healthcare system (Zorginstituut Nederland and Nederlandse Zorgautoriteit 2020). If appropriate care lives up to its promises, it lessens the burden of the demand for care on money and labor, keeping healthcare more accessible.

Research goal and questions

Given the increasing pressure of rising healthcare costs and upcoming healthcare scarcity, a better understanding of the mechanisms of medicalization might assist in forming policies that help lower healthcare demand. Medicalization is in popular terminology often perceived as 'medicine going wrong', associated with the overuse of healthcare resources, of doctors treating nonsense complaints, or of treatment thresholds sunken too low to be of relevant value (Moynihan, Heath et al. 2002). This introduction so far indicates that medicalization is not a static appropriating process, pulling 'non-medical' problems into the medical realm. However, there remains a lack of clarity about what medicalization entails and how it occurs. Especially in the empirical and practical sense, there are several gaps to be filled. For example: can findings from medicalization research be relevant for policy making? In this thesis, I aim to improve the understanding of the relationship between medicalization and healthcare use.

To do so, I focus on treatment decisions in sciatica care in the Netherlands. How do patients and physicians regard the problem and experience of sciatica, how do they decide between less or more medical interventions, and about the timing of intervention? What are the key moments in this care pathway? When focusing on the interaction between patient and physician, do specific nuances of medicalization occur? And so, which?

The research questions of this thesis are:

- How is medicalization defined in empirical research?
- To what extent and in what form is medicalization present in the Dutch context of sciatica treatment?
- How do Dutch sciatica patients and their physicians decide between more and less intensive (medialized) treatment options?

Answering these questions hopefully adds to the understanding of the rationale of healthcare consumption. It might also contribute as a specific, societal perspective on the gap between future healthcare demand and healthcare supply, and contribute to the discussion about appropriate care (*passende zorg)* (Raad voor Volksgezondheid & Samenleving 2022).

Further outline of the thesis

To be able to answer the research questions, first I will unravel the usefulness and meaning of medicalization as a concept in empirical research. Therefore, the result of a scoping review after the definition of medicalization in empirical research is presented in **Chapter 2.** This study answers the question: *how is medicalization defined in empirical research and how do the definitions differ from each other?*

While working on the central topic of this thesis, I also engaged in the debate about medicalization and overdiagnosis. This is not a formal chapter of this thesis, but I included it as an intermezzo in **Chapter 3**.

In **Chapters 4 and 5** the case study of this thesis is presented: treatment decisions for sciatica patients on the interactional level, and the relevance of possible medicalization of sciatica treatment for decision-making in sciatica treatment. **Chapter 4** therefore answers the question: *How do the understanding and opinions of Dutch physicians and patients regarding sciatica and its treatment contribute to the understanding of medicalization on the interactional level?*

Chapter 5 identifies key moments for decision-making in the sciatica care pathway, and maps the drivers and arguments in the decisions among involved stakeholders. This study aims to contribute to the understanding of these key moments and the position the different actors hold, to improve shared decision-making in clinical practice.

In the **final Chapter**, I combine what is learned in the previous chapters and translate these findings to medicalization studies and literature. Most importantly, I relate the outcomes of my research to the aims of policy making and appropriate care [passende zorg]. I conclude that medicalization is a broad and diverse concept, and the outcomes of medicalization research are not directly applicable for use in policy making. Medicalization is and remains a relevant concept. However, to achieve demedicalization it is probably more useful to use an indirect approach and focus on related, contextual factors (macro and meso) that influence decisions on the micro level. This can be a relevant lesson for the current discussion about appropriate care.

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Chapter 2

Medicalization defined in empirical contexts - a scoping review

Wieteke van Dijk, Marjan J. Meinders, Marit A.C. Tanke, Gert P. Westert, Patrick P.T. Jeurissen.

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Abstract

Background

Medicalization has been a topic of discussion and research for over four decades. It is a known concept to researchers from a broad range of disciplines, including medical sociology, (bio)medicine, medical anthropology and philosophy. Medicalization appears to be a concept that speaks to all, suggesting a shared understanding of what it constitutes. Conceptually, the definition of what medicalization constitutes of has evolved over time.

Methods

We performed a scoping review on the empirical research on medicalization, to gain more insight in the empirical understanding of the concept of medicalization. The screening of 3027 papers resulted in the inclusion of 50 empirical studies in the review.

Results

The empirical application of the concept of medicalization proved quite diverse. The used definitions could be divided into 10 categories, which differed from each other subtly though importantly. The ten categories could be placed in a framework, containing two axes. The one axis represents a continuum from value neutral definitions to value laden definitions. The other axis represents a continuum from a micro to a macro perspective on medicalization.

Conclusion

This review shows that empirical research on medicalization is quite heterogeneous in its understanding of the concept itself. This reveals the richness and complexity of medicalization, once more, but also hinders the comparability of studies.

Keywords
Medicalization, scoping review, empirical research

Background

Development of the concept medicalization and adjoining fields

While the definition and understanding of medicalization has evolved over time, there has never been a broad consensus on its meaning (Davis 2010). The debate started in the seventies with the notion that medicine increasingly gained social control (Busfield 2017). Irving Zola stated that society's explicit wish for medicine to use its controlling potential resulted in medicalization (Zola 1972). He stated that medicine was replacing the traditional institutions that 'shaped' society, such as religion and law (Busfield 2017). Ultimately, this resulted in more reliance on experts (Zola 1972). Zola criticized the assumed neutrality of this process (Zola 1972). According to Illich, medicine gained power at the expense of people's natural competences (Illich 1976). This social control of medicine over people's lives led to iatrogenic effects. Illich considered physicians' imperialism central to this process. Although Illich never defined medicalization, he is generally understood as one of the founding fathers of medicalization. Both Zola and Illich considered social control central to medicalization.

The feminist critique on medicalization centers also on social control as a central element, yet here the focus lied on medicalization resulting in professionals, traditionally men, gaining power and agency over women's health, bodies and reproductive processes. Medical care surrounding pregnancy and delivery is an example of a well-developed field within this literature, (Oakley 1984, Barker 1998) but the range of topics is extensive (Mchugh and Chrisler 2015). While medicalization is seen as inseparably gendered by some, recently attention was drawn to the medicalization of male issues, such as erectile dysfunction (Wentzell 2017), soldiers war trauma (Riska 2013) and male menopause (Vainionpää and Topo 2006).

The conceptual understanding of medicalization has shifted over time. In 1992, Conrad defined medicalization as: "*Medicalization consists of defining a problem in medical terms, using medical language to describe a problem, adopting a medical framework to understand a problem, or using a medical intervention to "treat" it*" (Conrad 1992, p.211). Social control was not at the core of this influential definition and no special attention was drawn to the actors of this process. During the past decennia, a shift in the 'engines of medicalization' has been noticed, placing more emphasis on divers contributors towards medicalization, such as industry and patients (Ballard and Elston 2005, Conrad 2005). This broader perspective served a more comprehensive understanding of medicalization. For example, it provides the

possibility to study positive effects of medicalization (Sadler, Jotterand et al. 2009, Earp, Sandberg et al. 2015).

Hofmann has argued that medicalization has become too much of an all-embracing term, and has lost its critical value (Hofmann 2016). Furthermore, it has been argued that by focusing on the definitional issue of medicalization, which Conrad deemed key (Conrad 1992), the applied nature of medicine was overlooked (Davis 2010). Sulzer explained this divide by making a distinction between the *de jure* (definitional) side of medicalization, and the *de facto* side (in practice, treatment-related) (Sulzer 2015).

Parallel to the field of medicalization, adjacent research fields have developed, such as pharmaceuticalization and biomedicalization. Pharmaceuticalization is "*the process by which social, behavioural or bodily discomforts are treated, or deemed to be in need of treatment/intervention, with pharmaceuticals by doctors, patients or both*" (Abraham 2010). Biomedicalization constitutes intensified medicalization, transformed and boosted due to techno scientific innovations such as whole genome sequencing, transplant medicine, molecular biology and probably -in the end- biologically customized medicine (Clarke, Shim et al. 2003). Both are conscious of the corporate interests of companies, technological changes, consumerism, the influence of the media and risk (Bell and Figert 2012). Both processes define similar mechanisms to medicalization. Therefore, it's disputed whether either constitutes a new, unique process (Clarke, Shim et al. 2003), or in fact represent a subset of medicalization (pharmaceuticalization) or an intensified form of medicalization (biomedicalization) (Conrad 2013).

Scientific literature on medicalization

The scientific literature that focused on medicalization is multifaceted and addresses many topics. Most of the work is conceptual, discussing its occurrence and essence. Empirical studies that systematically gather and analyze data are relatively rare. A large share of the literature consists of 'discussion papers': well-informed and well-founded articles that discuss the medicalized status of a problem or situation. A short and non-exhaustive list of topics includes the medicalization of sleep; (Hislop and Arber 2003) hyperactive behavior in children; (Rafalovich 2013, Singh and Wessely 2015) self-injuring acts; (Ekman 2016) and risks and genetic markers (Shostak, Conrad et al. 2008, Gotzsche, Jorgensen et al. 2014). Although the conceptual understanding of medicalization has gained tremendously by discussion papers, they also illustrate the divide between theory and empiricism. Although discussion papers support the conceptual development,

a major drawback is that their empirical rigorousness is uncertain. Therefore, this review focuses on the empirical use of the concept of medicalization.

Aim of the study: to reach a comprehensive oversight of definitions of medicalization in empirical studies

The growing body of conceptual literature on medicalization underlines the necessity of a clear understanding of its use in empirical research. How the concept holds in empirical use has not been reviewed yet. Because a definition is a crucial starting point of a study, shaping its frame and nudging the interpretations of its results, this is a logical starting point for a review. Therefore, we categorized the various definitions used in empirical research and illustrate their similarities and differences. Further insight into the empirical understanding of medicalization could also provide insight into the comparability and replicability of empirical studies.

Data and methods

Given the aims of this study, a scoping review research design was adopted. Scoping reviews are a relatively new type of review, that are characterized by the intention to 'map' a certain research area to reach overview of what is known about the subject and where possible unanswered questions remain (Levac, Colquhoun et al. 2010). Arksey and O'Malley provided a useful framework to perform scoping reviews, of which the execution is elucidated in the following paragraphs (Arksey and O'Malley 2005).

Identifying the research question

The process of a scoping review is not linear but iterative, encouraging researchers to be reflexive and repeat a step when necessary (Arksey and O'Malley 2005). This has proven to be very relevant to this exercise. Our review process started with the research question 'What is empirically known about medicalization?' To answer this question, all peer-reviewed research that primarily investigates medicalization was collected. This is part of step 2 to 4 of the process of a scoping review. While performing these steps we discovered that studies that addressed medicalization used different definitions of the research subject. The differences between the definitions varied strongly, and we learned that before the outcomes of studies can be mapped, insight into their different definitional starting points was required. Therefore, the research question was iteratively adjusted to: 'How is medicalization defined in empirical research and how do the definitions differ from each other?'

Identifying relevant studies

A systematic search strategy was conducted in April 2014 in PubMed®, Web of Science®; Sociological Abstracts®; PsychInfo®; EMBASE®; Philosophers Index®; EBSCO®; and CINAHL®. References including any of the relevant keywords in title or abstract were included. Biomedicalization was included among the keywords. Searches were conducted in both British and American spelling. Duplicates, non-English references, and non-peer reviewed articles (editorials, letters, conference papers, book chapters, and dissertations) were excluded.

Inclusion and exclusion criteria

The screening process was conducted in two phases. In the first phase, WvD screened for eligibility of the references on title and abstract. In the second phase, WvD and NdV screened the remaining full-texts for eligibility.

In phase one, articles that present original, empirical research with medicalization as main research topic were included. General discussions, anecdotic evidence, secondary analysis of existing data or single case studies were excluded. We chose to limit the period an article could address to the period post-World War two because we aimed to address medicalization in a contemporary context. We limited the inclusion to studies conducted in high-income countries, to ensure that the research context would be comparable. Whether the country was a high income country was determined with the World Bank website (accessed on 02-03-2015). Bell & Figert argue that the emphasis within the medicalization debate lies largely on the Western context, limiting its perspective (Bell and Figert 2012). We agree, yet we are convinced that medicalization can consist of something entirely different in the context of limited resources and little medical assistance in low income countries, compared to medicalization within affluent countries with abundant access to medical care. To improve the understanding and mechanisms of medicalization in the context of many and few health care recourses was not the subject of this review. Finally, the review was restricted to peer-reviewed articles written in English.

Charting the data

In phase two the requirement of a definition of medicalization was added. Studies that failed to report how they defined medicalization were excluded. During this process, WvD and NdV met regularly for discussion. Some studies provided an overview of the medicalization debate, mentioning several definitions of it, and failed to formally finalize the definition they would use. In such cases, we chose to

retrieve the final definition. An overview of the data retracted in this process can be found in the online supplemental material of this article.

Collating, summarizing and reporting the results

The definitions used varied, but could be grouped together in categories. To reach a sensible overview, WvD and MM independently ordered the definitions. They met several times to discuss and finalize the ordering. To allocate the definitions, they focused on shared themes to be identified by signal words and phrases.

Results

The initial search resulted in 7308 potential articles of which 4281 were duplicates, resulting in 3027 unique articles. Of these 3027 article, 2977 were excluded for reasons mentioned in the methods section. Figure 1 represents the identification and selection process.

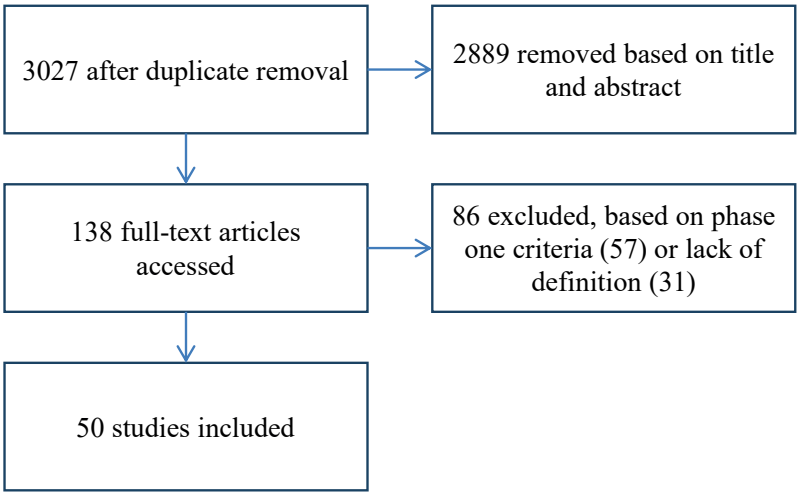

FIGURE 1 - *Selection procedure of included studies*

The categories allocated to a framework containing the two axes

The resulting 50 definitions were charted into ten categories. These are presented in Figure 2. Most authors quote a definition or refer to known definitions. Conrad and Zola are most often mentioned. Few authors are represented more than once among the included studies, only Barker (Barker 2008, Barker 2011, Barker 2014),

Clarke (Clarke and Lang 2012, Clarke 2013), and Vainionpaa & Topo (Vainionpää and Topo 2005, Vainionpää and Topo 2006). Both studies of Vainionpää & Topo belong to one definition category. The studies of Barker and Clarke & Lang/Clarke were allocated to different categories.

Two definitions could not be allocated, because they combined distinctive elements from across the spectrum (Bell 2010, Padamsee 2011). An overview of the 50 selected studies can be found in the online supplemental material of this article.

The ten categories were allocated on different positions in a framework containing two axes: one addressing the value position of the definition and the other addressing the micro/macro focus of the definition. Definitions that are value-laden include a judgment of the consequences and desirability of the process of medicalization that they describe. Value-neutral definitions do not include such a judgment. Definitions with a micro focus concentrate on the individual. Definitions on the other axis concentrate on the societal implications of medicalizing a situation.

The ten categories are illustrated in Table 1. The table shows a definition from one of the included studies for each category. Further, this table provides a fictive example for each of the categories, to illustrate how the different definitions can address other health related situations and healthcare areas.

Year of publication nor topic were related to the categories. The 50 allocated studies were for the most part published after 2000. Several subjects are represented across the different categories, including pregnancy, children's behavioral problems, and cosmetic surgery. The medicalization of sleep is subject of studies on the ends of the different axes. Geographically the North-American continent is dominant with 19 of studies conducted in the USA and 11 in Canada (separate analysis). Several European countries are represented: the UK (10); Finland (4); Sweden (2); the Netherlands (1); France (1); Ireland (1). One study was conducted in New Zealand. The country of origin of the respondents could not be determined for one study (Bransen 1992).

FIGURE 2 - *Framework of the categories of definitions of medicalization across the axes of micro/macro focus and value-neutral/value-laden*

Table 1 - *Overview of categories of the definitions of medicalization, the articles utilizing those definitions, an example as used in one of the articles and a fictive practical example*

Distinctive definition, answering the question 'What constitutes medicalization?'	**Studies**	**Definition used**	**Fictive example**
Making medical	(Williams, Seale et al. 2008)	"Medicalization is (ideally) a non-judgmental term, referring simply to the process of 'making medical'" (Williams et al., p.252)	All of the below
Making an experience medical	(Barker 2008) (Becker and Nachtigall 1992) (Bransen 1992) (Clarke 2013) (Gammell and Stoppard 1999) (Holmqvist 2009) (Hyde, Treacy et al. 2006) (Westfall and Benoit 2004)	""Medicalization," or the processes by which an ever wider range of human experiences come to be defined, experienced, and treated as medical conditions" (Barker p. 21)	Signaling a rare case of feeling bloated as irritable bowel syndrome, a night of bad sleep as insomnia or normal-range shyness as social anxiety disorder
Making a problem medical	(Arney and Rafalovich 2007) (Barker 2014) (Elston, Gabe et al. 2002)	"Medicalization consists of defining a problem in medical terms, using medical language to describe a problem, adopting a medical framework to understand a problem, or using medical intervention to treat it" > quotes from Conrad, 1992 (Elston et al., p. 577)	Attempting to improve a negative self-image by means of cosmetic surgery
Making an ordinary biological process or behavior medical	(Adams 2013) (Barker 2011) (Coveney, Nerlich et al. 2009) (Hogle 2001) (Jacob, Gagnon et al. 2014) (Moloney, Konrad et al. 2011) (Parry 2008)	"Medicalization is the process by which formerly normal biological processes or behaviors come to be described, accepted, or treated as medical problems" (Moloney, Konrad & Zimmer, 2011, p. 1429)	Approaching the aging body through a medical perspective, attempting to repair natural decline

Table 1 - *Continued*

Distinctive definition, answering the question 'What constitutes medicalization?'	Studies	Definition used	Fictive example
Making a non-medical problem medical	(Kilty 2012) (Lee, Macvarish et al. 2014) (Malacrida 2004) (Merianos, Vidourek et al. 2013) (Neiterman 2013) (Polonijo and Carpiano 2008) (Schierenbeck 2010) (Torres 2014) (Venn, Meadows et al. 2013)	"A process by which non-medical problems become defined and treated as medical problems, usually in terms of illnesses or disorders" > quotes Conrad, 2000 (Neiterman, 2013, p.114)	Medical professionals attending people who experience loneliness and prescribing antidepressants and/or welfare arrangements
Expansion of medicine into other areas of life	(Binney, Estes et al. 1990) (Clarke and Lang 2012) (Fainzang 2013) (McLeod, Pescosolido et al. 2004) (Selin 2011) (Vainionpää and Topo 2005) (Vainionpää and Topo 2006)	[Medicalization] "refers to the ways in which medicine expands into new arenas" (Vainionpaa & Topo, 2005, p. 842)	Creating calm and teachable schoolchildren by neutralizing unwanted behavior with pharmaceuticals
Changing social norms through medicine	(Boero 2007) (Van Brummen and Griffiths 2013) (Harvey 2013) (Norris, Horsburgh et al. 2011) (Thomas-MacLean 2004)	"This refers to an intricate social process involving the dominance of biomedical paradigms and authoritarian models of health care in which illness experiences are understood as biological and individualistic" (Thomas-McLean, 2004, p. 630)	Change in perspective about desirability of the birth of children with severe birth defects or chromosomal defects due to possibility and acceptability of prenatal testing
Changing social norms about deviance through medicine	(Melick, Steadman et al. 1979) (Rafalovich 2005)	"I use the term "medicalization" to refer to the process by which deviant acts (a) become understood to originate from a medical cause and are therefore perceived to be beyond an individual's control; and (b) are believed to be treatable through medical knowledge and the application of techniques by medical experts" (Rafalovich, 2005, p. 26)	Regarding criminal acts the result of sickness rather than badness

Table 1 - *Continued*

Distinctive definition, answering the question 'What constitutes medicalization?'	**Studies**	**Definition used**	**Fictive example**
Transferring self-determination and decision making from lay people to the medical profession	(Oinas 1998) (Calnan 1984)	"The medical profession, on behalf of industrialism, has not only duped the public into believing that they have an effective and invaluable body of knowledge and skills but have created a dependence through the medicalization of life which has now taken away the public's right to self-care" (Calnan, 1984, p. 561)	People changing their daily routine on doctors orders to meet the conditions of their complex treatment regime, for example in case of hiv-infection or Parkinson's disease, while they felt more well and secure in their personal rhythm
Transferring self-determination and decision making from lay people to the medical profession for the purpose of social control	(Brubaker 2007) (Chang and Christakis 2002) (Hislop and Arber 2003) (Moreira 2006)	[Medicalization is a] "process of social control whereby both deviant behavior and natural life events are reconstructed as illnesses or disorders and placed under the jurisdiction of the medical profession" (Hislop & Arber, 2003, p. 816)	Patients in long stay mental health care expected to live according to the institutional daily schedule, surrendering their privacy and autonomy to clinicians and other professionals
Not allocated	(Bell 2010) (Padamsee 2011)	The definition and treatment of life problems, processes, or deviance in medical terms (Paramsee, 2011, p. 1342) Medicalization of infertility, or its treatment as a pathological condition rather than a natural or social one (Bell, 2010, p. 631)	

Ten categories of medicalization

Each category is discussed with reference to Figure 2, starting with the four categories ranging from top left to bottom left. These four categories all have a micro perspective, but differ in the extent to which they are value-laden. The definition that is most value-neutral focuses on experiences and their medicalization. Eight studies use definitions that can be allocated to this category (Becker and Nachtigall 1992, Bransen 1992, Gammell and Stoppard 1999, Westfall and Benoit 2004, Hyde, Treacy et al. 2006, Barker 2008, Holmqvist 2009, Clarke 2013). Barker defines medicalization as "the processes by which an ever wider range of human experiences come to be defined, experienced, and treated as medical conditions" (Barker 2008). An example could be experiencing a few nights of bad sleep and interpreting this as insomnia.

The next category concerns the medicalization of a problem: "Medicalization consists of defining a problem in medical terms, using medical language to describe a problem, adopting a medical framework to understand a problem, or using medical intervention to treat it" (Elston, Gabe et al. 2002). This definition is quoted from Conrad (Conrad 1992). Three included studies used this definition (Elston, Gabe et al. 2002, Arney and Rafalovich 2007, Barker 2014). Where experiencing stood central in the previous definition, in this definition something can only get medicalized if it is first reframed as problematic. For example, cosmetic procedures are not ordered when one does not regard a cosmetic 'defect' as problematic.

In the third of these four definitions, the definition of medicalization requires for something ordinarily biological to be present to get medicalized: "Medicalization is the process by which formerly normal biological processes or behaviors come to be described, accepted, or treated as medical problems" (Moloney, Konrad et al. 2011). Seven studies use such a definition (Hogle 2001, Parry 2008, Barker 2011, Moloney, Konrad et al. 2011, Adams 2013, Jacob, Gagnon et al. 2014). This definition states only the treatment of ordinary differences to be medicalization. This makes it a less value-neutral definition than the previous category, because it makes an implicit distinction between ordinary and non-ordinary differences. An example for a non-ordinary difference is a medical intervention against the natural decline of the aging body.

The fourth category defines medicalization as: "A process by which non-medical problems become defined and treated as medical problems, usually in terms of illnesses or disorders" (Neiterman 2013). Problems that were previously not regarded as medical in nature come to be medically treated. This definition was

stated in nine studies (Malacrida 2004, Polonijo and Carpiano 2008, Schierenbeck 2010, Kilty 2012, Merianos, Vidourek et al. 2013, Neiterman 2013, Venn, Meadows et al. 2013, Lee, Macvarish et al. 2014, Torres 2014). This definition makes a distinction between medical and non-medical problems, implicating that the difference between the two groups is apparent. For example, home care professionals attending lonely people, and providing them with antidepressants to improve their wellbeing could be seen as medicalizing a non-medical problem.

For other definitions, the other end of the horizontal axis is more distinctive, focusing on the macro outcomes of medicalization. This holds for the three categories on the right site of the framework. Here, medicalization: "refers to the ways in which medicine expands into new arenas" (Vainionpää and Topo 2005). Seven studies state such a definition (Binney, Estes et al. 1990, McLeod, Pescosolido et al. 2004, Vainionpää and Topo 2005, Vainionpää and Topo 2006, Selin 2011, Clarke and Lang 2012, Fainzang 2013). Those who use this definition focus on how medicalization increases the jurisdiction of medicine over more aspects of life. An example could be an increasing percentage of children who are treated for behavioral deviations in schools, which increases the influence of medicine within the educational system.

Other definitions go one step further, including not only the expansion of medicine into other areas of life, but also subsequently changing the social norms surrounding it: "This refers to an intricate social process involving the dominance of biomedical paradigms and authoritarian models of health care in which illness experiences are understood as biological and individualistic" (Thomas-MacLean 2004). These definitions are more value-laden, as is represented by the other axis in the framework. Such definition is provided by five of the included studies (Boero 2007, Norris, Horsburgh et al. 2011, Harvey 2013, Van Brummen and Griffiths 2013). As a result of medicalization, the way people perceive a situation alters. For example, increasing availability and acceptability of prenatal tests might influence the perceived desirability of the birth of children with (major) birth defects.

The next category, in the right bottom of Figure 2, focuses on the changing norms surrounding deviance: "I use the term "medicalization" to refer to the process by which deviant acts (a) become understood to originate from a medical cause and are therefore perceived to be beyond an individual's control; and (b) are believed to be treatable through medical knowledge and the application of techniques by medical experts" (Rafalovich 2005). According to this definition, deviance becomes

to be understood as a result of sickness rather than badness. Two studies provide a definition from this category (Melick, Steadman et al. 1979, Rafalovich 2005). The category addressing deviance was placed underneath the category addressing social norms in general terms, because the term deviance in itself contains a value judgment.

The second axis concerns the values included in the definition. The remaining three categories are most illustrative for this axis, and are placed in the center of Figure 2. The one end of this axis concerns the definitions that do not draw a (moral) judgment about the content or consequences of medicalization. When medicalization is defined as 'making medical' no consequence is predicted for society or the power-balance therein. Williams et al. define medicalization as "(ideally) a non-judgmental term, referring simply to the process of 'making medical' (Williams, Seale et al. 2008). According to this definition, everything that belongs to the jurisdiction of medicine was once medicalized.

When medicalization is defined as "the transfer of knowledge from the lay people to the medical profession for the purpose of social control", medicalization is perceived as an imperialist effort of the medical profession, overruling lay autonomy, representing the other end of this axis. This includes a strong power related and value-laden consequence of medicalization as an integral aspect of the definition. In the words of Chang and Christakis: "Medicalization refers to the process by which certain behaviors or conditions are defined as medical problems, and medical intervention becomes the focus of remedy and social control" (Chang and Christakis 2002). Four of our included studies stated such definition (Chang and Christakis 2002, Hislop and Arber 2003, Moreira 2006, Brubaker 2007). An example could be the daily regime in long term care, overruling people's preferences and autonomy with mandatory schedules.

The definition that states that medicalization is the transfer of knowledge and decision making from lay people to the medical profession is less value-laden. Calnan states: "The medical profession, on behalf of industrialism, has not only duped the public into believing that they have an effective and invaluable body of knowledge and skills but have created a dependence through the medicalization of life which has now taken away the public's right to self-care" (Calnan 1984). Medicalization, in this definition, compromises the right of self-determination, yet it does not explicitly accuse doctors of trying to gain more influence. Two studies use a definition from this category (Calnan 1984, Oinas 1998). An example could be

that people are urged to change their daily routines when faced with a complicated treatment regime that could intervene with their food intake or activities.

Discussion

This scoping review and the resulting framework provide several insights on the composition and heterogeneity of medicalization research. With regard to the scoping exercise, we found 31 studies with medicalization as its subject failed to define medicalization. Valid, replicable empirical research defines the process under study.

Second, the research topics are not related to the categories of definitions. For example, studies about sleep were present across several categories in the spectrum, including the two ends of the value axes. This illustrates that even within the research field of medicalization, the same subject can be studied from different angles. It also complicates the comparability of results.

Third, in spite of the diversity in definitions, the sources that the studies based their definitions upon were dominated by one author. In 20 of the 50 studies Conrad is either quoted or referred to, as a single author or in shared authorship. While Conrad's perspective on medicalization has evolved over the decennia, his 1992 definition remains a point of reference (Conrad 1992). The variation presented in this review thus starts from a small number of sources and scholars sometimes rephrase the definitions they attribute to Conrad.

These three findings add up to an important discussion point on the relevance of definitions for this research field. Medicalization research has always had a strong qualitative focus, explicating different aspects and nuances of the phenomenon. This review did not have the goal to disqualify this rich literature or to unify the perspective on the phenomenon.

The goal was to map the definitions, to illustrate the diversity of the field. Differences between studies' definitions can be justifiable, but it is nonetheless relevant and informative to notice these differences. Furthermore, our research shows that researchers who study medicalization chose different angels in their operationalization of the concept. This parallels the conceptual variety. However, this variety also illustrates that empirical studies will always be context dependent

and will highly relate on the case study at issue. Internal validity will exceed the external validity. This makes it difficult to align conceptual and empirical work.

Our research resulted in a framework that can be used by scholars to classify their work and that of others. Nonetheless, a framework like ours raises new discussions. For example, the framework illustrates how definitions vary in value ladenness. However, we maintain that the *results* of medicalization can never be regarded as neutral. Another critical remark can be made with regard to the micro/macro axis. Opposite to the micro oriented definitions, a definition on the macro level can make it more difficult to identify the individual consequences. It can have important consequences for both research and policy making. For example, if the focus lies solely on the macro consequences of a newly medicalized situation, the individual benefits of becoming a certain diagnosis can easily be overlooked. Avoiding this problem by choosing the most neutral definition, 'the process of making medical', seems to address this problem. Yet, this definition is possibly too general to be of empirical use. This reveals a trade-off between specific and general understandings of medicalization.

A possible limitation of this study is that the review process was guided by the empirical studies that were identified. When the empirical studies do not cover all definitions of medicalization, the resulting framework cannot be used to conclude that every conceptual definition of medicalization has been applied empirically. Furthermore, we did not address whether the chosen definition was the most valid one per study. This makes it impossible to state anything about the empirical applicability of the definitions.

This scoping review showed that empirical research about medicalization has a broad scope. This portrays the richness and variety of the field. Nonetheless, we reveal that the understanding of what medicalization constitutes of differs as much within empirical studies as it does in the conceptual literature. Future research should be attentive to these differences, defining their study subject accurately, to enable the further development of the concept and to bridge the divide between the conceptual and the empirical literature.

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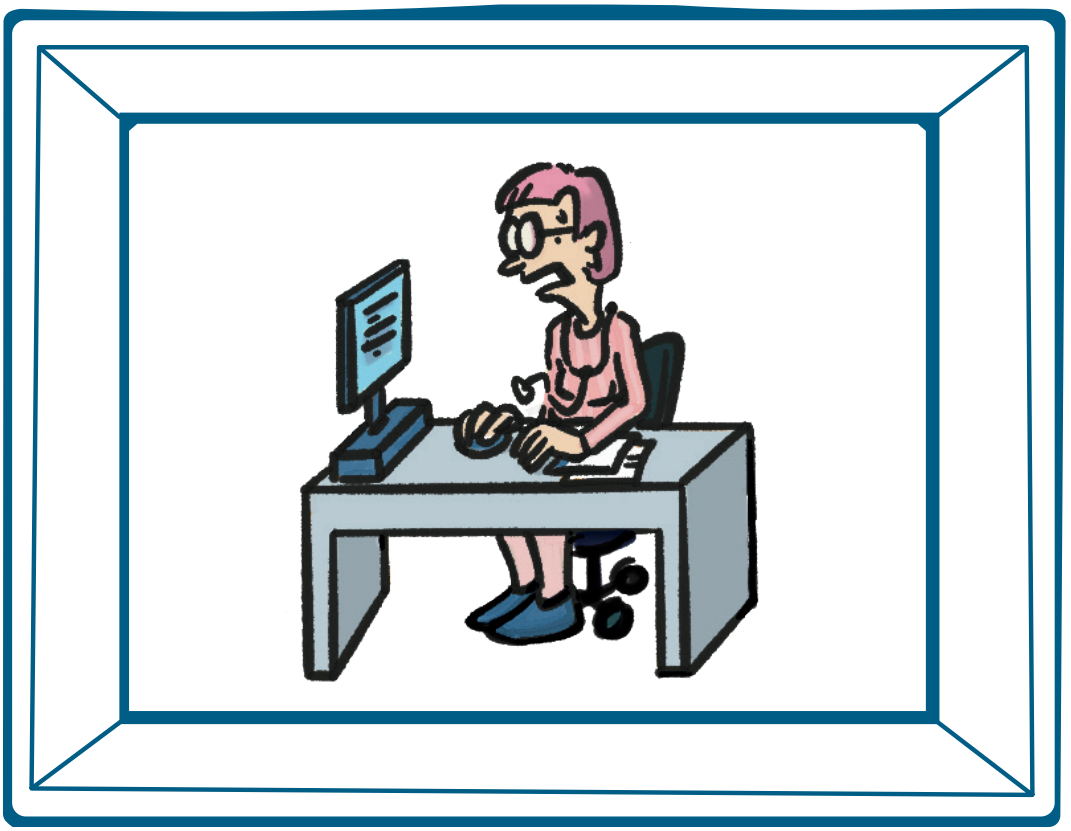

Chapter 3 - Intermezzo

Perspective: Medicalisation and Overdiagnosis: What Society Does to Medicine

Wieteke van Dijk, Marjan J. Faber, Marit A.C. Tanke, Patrick P.T. Jeurissen, Gert P. Westert.

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Abstract

The concept of overdiagnosis is a dominant topic in medical literature and discussions. In research that targets overdiagnosis, medicalisation is often presented as the societal and individual burden of unnecessary medical expansion. In this way the focus lies on the influence of medicine on society, neglecting the possible influence of society on medicine. In this perspective, we aim to provide a novel insight into the influence of society and the societal context on medicine, in particularly with regard to medicalisation and overdiagnosis.

Keywords
Medicalisation; Overdiagnosis; Society

Introduction

The concepts of overdiagnosis and medicalisation are related, but not the same (Hofmann 2016). Overdiagnosis can be defined as: "[t]he detection of abnormalities that are not destined to ever bother us" or "that will never cause symptoms or death" (Welsh, Schwartz et al. 2011). By medicalisation we mean: "defining a problem in medical terms, usually as an illness or disorder, or using a medical intervention to treat it" (Conrad 2005). Medicalisation is not by definition a negative development, medicalising certain situations has had tremendous benefits (Earp, Sandberg et al. 2015). This in contrast to overdiagnosis, in which the 'over' inherently indicates excess (Carter, Rogers et al. 2015). Both overdiagnosis and medicalisation result in more people receiving a medical diagnosis. However, the origin of this expansion differs. Medicalisation often concerns new diagnoses, based on a widened understanding of human situations that usually benefit from medical involvement. It thus widens the boundaries of medicine. Overdiagnosis, instead, starts inside of medicine, addressing the problem of people receiving a unbeneficial diagnosis (Hofmann 2016, Morrison 2016). Both processes do not just happen. Medicalisation is created by a specific set of cultural and social conditions, and can be pushed by forces in and outside of medicine (Conrad 2005, McLellan 2007). Overdiagnosis can also be influenced by cultural and societal conditions, yet the current discussion focuses primarily on forces inside medicine. In recent years, both concepts are becoming more alike, and differences are not always clear (Hofmann 2016).

However, *how* the process of medicalisation takes place is not resolved with these definitions, nor is the possible influence of society on medicine, medicalisation and overdiagnosis addressed. In this perspective we illustrate how societal developments can result in both medicalisation and overdiagnosis. We need to bear in mind that society often has a interest in more medicine for its inhabitants, to help its inhabitants but also to depoliticise social problems (Rose 2007). This will help us get a better grasp on 'how medicalisation influences medicine and overdiagnosis'.

Medicalisation as a sociological concept

Research after overdiagnosis often frames medicalisation as the result of forcing unnecessary medicine into people's lives. Although this fits remarkably well with Ivan Illich' well known view on medicalisation and iatrogenic harms –introduced in his ground-breaking Medical Nemesis from the 70s (Illich 1976)- it also pushes the discussion towards 'what medicine does to people'. This can easily result in a view of patients as the passive recipients of medicine's well meant mission creep. By doing

so we lose track of how medicalisation in its turn is also changing -in fact shaping- modern medicine.

While the historic perspective on medicalisation blamed medical imperialism for clinical, social and cultural iatrogenisis (Illich 1976), contemporary analysts emphasize that medicalisation is context dependent, involving actors such as the pharmaceutical industry, the media, consumers and/or, biotechnology (Conrad 2005). Doctors are not necessarily amongst the drivers of this process and sometimes fundamentally act as gatekeepers.

Nonetheless, research often focuses on one dominant cause, like that after disease mongering blaming the pharmaceutical industry for selling sickness and pushing medicalisation (Moynihan and Cassels 2005). Sociology has a broader perspective and approaches medicalisation as a social process, influenced by many actors (Conrad 2005). Society's norms and values develop at a continual pace, influencing all of us in our perception of health, what constitutes a medical problem, and who should be consulted when experiencing a problem that can be perceived as medical (Moynihan and Cassels 2005, Sadler, Jotterand et al. 2009, Conrad 2013). As a result the definition of health and illness develops. Therefore, medicalisation should rather be regarded as a continuum than as a dichotomy, as problems can be regarded more or less as medical and can be treated more and less intensive. This is an addition to traditional definitions of medicalisation, which disregard the extent to which a situation or condition is medicalised.

Societal implications of overdiagnosis

When discussing overdiagnosis and its consequences the underlying assumption seems to be that diagnosing is an objective and strictly medical procedure, which physicians would accomplish beautifully if they would only have the perfect knowledge. Besides the conceptual omissions in this interpretation of overdiagnosis (Hofmann 2014), it is also untrue: disease and illness are not merely given biological facts but social constructions as well (Freidson 1971, Conrad and Barker 2010). The discussion whether disease can be defined entire value-free or is unavoidably value-laden remains unsettled, although all agree that values do have a role in the perception of disease (Kingma 2014). Societal actors such as governmental agencies can press their values on the health system by policy making or prioritising certain diseases or treatments.

An example of how 'disease' is more complex than a biological fact is the current scare for and treatment of hypertension. Firstly, this condition is in itself nothing

more than a diagnosis based on a cut-off point. In the end, this diagnosis solely serves to identify a risk factor for cardiovascular conditions, such as heart attack and stroke (Appel 2003, Moynihan and Cassels 2005). Secondly, in the focus on lowering this risk with pharmaceutical treatment we may overlook that hypertension is one of several risk factors, and, even more important, can be lowered or prevented with lifestyle change (Whelton, He et al. 2002). By looking at hypertension from a purely medical view, other risk factors such as an unhealthy diet, obesity and physical inactivity are easily overlooked. Furthermore, these risk factors are strongly related to socio-economic determinants such as education and occupation, with the result that those that lose out economically are also losing out healthwise. Focussing on pharmaceutical quick-fixes instead of addressing the underlying socio-economic problems possibly leads to more inequality, both globally (Clark 2014) and nationally. As Conrad and Barker put it: "*it seems that we have a social predilection toward treating human problems as individual or clinical –whether it is obesity, substance abuse, learning difficulties, aging, or alcoholism- rather than addressing the underlying causes for complex social problems and human suffering*" (Conrad and Barker 2010). This does not mean that medicalising a situation rules out simultaneous action on its social and political determinants. Physicians can be amongst the most passionate proponents of societal change for some of the medical problems they face in their practices, such as stricter regulations for tobacco industry, sugar-taxes on beverages and calls for obesity prevention (Mann 1997, Weisberg 2002, Mytton, Clarke et al. 2012). Nonetheless, by our tendency to seek medical solutions for social problems, we medicalise social issues such as inequality, deviance and abnormality and locate the sources and solution of these problems increasingly on the individual level (Conrad and Barker 2010).

Medical solutions for societal questions: three examples

In the previous paragraphs we have shown that medicalisation is more than the result of objective choices made within medicine. Here we illustrate this with three examples in which societal influences affect the use of medical resources: the care for mentally disabled, the increased attention for treatment of Alzheimer disease and mild cognitive impairment for the elderly, and the medicalisation of childbirth. We chose these three examples to illustrate how societal developments and medicine can interact. Comparable developments are detectable in all areas of healthcare. We choose examples that differ with regard to the influence of medicalisation and overdiagnosis. We did so to illustrate that although they are often related; they are not mutually dependent and can occur separately.

Mental disability can prevent people from full participation in society. Those with severe mental disability often have the mental abilities of a young child and cannot live unassisted. Mentally retarded people are able to function more independently but often require assistance in various living areas. The number of mentally disabled has not increased over the last decade in the Netherlands and the division of those with severe mental disability (IQ score below 50), moderate mental disability (IQ scores between 50 and 70) and those deemed mentally retarded (IQ scores between 70 and 85) was stable over this period (Woittiez, Ras et al. 2012). Overdiagnosis seems not to be present in this case. Nonetheless, the costs for care and assistance for people with mental disabilities has increased with 7.3% annually, in the period 2007-2011 (Ras, Verbeek-Oudijk et al. 2013). The increase in costs can only partly be ascribed to increases in wages and is for the larger part the result of increasing demand among people with moderate mental disability or mental retardation (Ras, Verbeek-Oudijk et al. 2013). The number of beds for inpatient care did increased with 3.4% annually during this same period (Van der Kwartel 2012). Recent policy adjustments are aimed at interrupting this trend, but effects are not observable yet. What is happening here? The threshold for receiving institutional care has lowered towards higher IQ scores (Woittiez, Ras et al. 2012). What does this imply? Can the mentally impaired not hold pace with the increasing complexities of modern society? Is this supply-induced demand, resulting from provider interest? Do we lose our 'patience' with slow adaptors? Or is more institutional care the medicalised answer of a society that ultimately values economic efficiency over inclusiveness? The lowering of indication thresholds is probably not solely driven by medical professionals but by societal demand as well.

The second example shows that the impact of medicalisation may differ as a result of local cultural context. Due to the aging populations of most western countries the number of people that will receive the diagnoses Alzheimer Disease (AD) and mild cognitive impairment (MCI) is increasing. At the same time, AD and especially MCI are not uncontested as they might medicalise normal aging. A striking illustration is the discussion in the UK about early detection of Alzheimer Disease. Governmental policy stimulates doctors and practices to increase their number of dementia diagnoses, to benefit patients with earlier diagnosis and better treatment (Older People & Dementia Team 2012). Doctors disagreed, stating that earlier diagnosis has no proven benefit, MCI does not necessarily result in dementia and overdiagnosis looms (Couteur, Doust et al. 2013, Brunet 2014). This is an example of doctors acting as gatekeepers to prevent further medicalisation and overdiagnosis.

Furthermore, what distinguishes MCI or even AD from 'normal' cognitive aging is still unclear after a century of research (Whitehouse 2006). This further emphasizes how disease thresholds and diseases are socially constructed (Whitehouse 2001). More poignant is how cultural norms and contextual factors influence how medicalisation takes place. The Darthmouth atlas shows the percentage of people over 65 filling at least one prescription of dementia medication in 2010 in the United States. Percentages differ between regions, ranging from 3.7 to17.1% (1). This reveals large practice variation within the US. Striking as this is, the figure conceals how high a percentage as low as 3.7% might be from another cultural perspective. In the Netherlands, 1.2% of people over 65 used dementia medication at least once in 2013 (2). The prevalence of dementia is slightly higher in the Netherlands than in the US (OECD 2015). Overdiagnosis does not seem to be present here, but over- or undertreatment may be at stake (Carter, Rogers et al. 2015). This cannot be determined here. What we do know is that people with advanced AD more often receive long term care in the Netherlands than they do in the US (Takizawa, Thompson et al. 2015). It is not obvious whether use of pharmaceuticals or intuitional care constitutes of more medicalisation as both use medical language, medical assistance and a share of the healthcare budget. A highly relevant but understudied research question is how overdiagnosis and medicalisation drive different treatment options across different countries and communities.

Childbirth is one of the examples where medicalisation has had significant benefits, diminishing the chances of maternal and child mortality. Access to medical care in case of complications during pregnancy or birth is essential. However, there is an ongoing debate whether nowadays the standard care for pregnancy in most western countries involves too much medicine and is beyond the point of provable benefit (Welch, Schwartz et al. 2011). Childbirth is an example of how medicalisation can be regarded as a continuum: Less medicalised assistance in pregnancy and birth, as provided by a midwife, differs in intensity of medical intervention from gynaecological and surgical interventions. Midwife assisted birth can thus be considered a less medicalised situation.

A well-established example of increasing medicalisation for childbirth is caesarean section rates (CSR). It is known that CSR vary greatly between countries and that these rates increased in the last decennia in many countries (Declercq, Young et al. 2011). The WHO regards a CSR between 10% and 15% ideal and states that no reduction in maternal and newborn mortality outcomes at the population level are found at a CSR higher than 15% (World Health Organization 2015). Higher percentages, at least on group level, could thus be interpreted as an indication

of overdiagnosis. Most western countries exceed this percentage, which ranged in Europe from 14.8% in Iceland to 52.2% in Cyprus in 2010 (Macfarlane, Blondel et al. 2015). In the US 31.8% of live births was delivered by CSR in 2007 (Declercq, Young et al. 2011). The choice for CSR depends on many variables on the individual and health system level (Vimercati, Greco et al. 2000, Malacrida and Boulton 2012). The percentage of women preferring CS varies between countries, but never exceed 14 percent (McCourt, Weaver et al. 2007). In the Netherlands, the CSR is 17.0%, the third lowest level in Europe (Macfarlane, Blondel et al. 2015). Nonetheless, the percentage of homebirths is decreasing, while the use of epidurals increases and the CSR rises, indicating that that childbirth is in the process of being further medicalised in the Netherlands as well (Christiaens, Nieuwenhuijze et al. 2013). This example illustrates that many factors can contribute to medicalisation, on several levels.

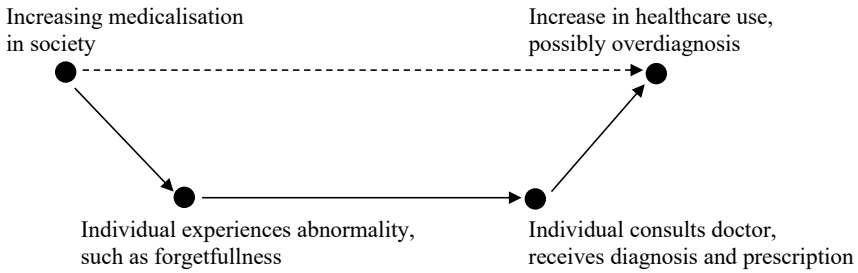

FIGURE 1 - *Coleman's boat*

The dual relationship between overdiagnosis and medicalisation

The three examples illustrate that the societal context influences medical decision making as well. We illustrated how medicalisation can occur on its own regard and how it can lead to overdiagnosis. Coleman's boat shaped scheme provides a nice metaphor to illustrate this. Crucial to this metaphor is the relation between macro and micro developments. Consider medicalisation as a macro condition: a set of societal norms and values, influencing us all. This influences behaviour and expectations on the micro level, in the consultation between doctor and patient, allegedly resulting in more diagnoses and treatments. As a macro result, an increasing use of healthcare and possibly overdiagnosis is detected. For example: within a more medicalised society, acceptance of forgetfulness amongst the elderly decreases. As a result elderly people grow more conscious of their forgetfulness and consult their physicians more often and probably earlier than they would have

done otherwise, resulting in an increasing number of diagnoses and prescriptions. This probably leads to overdiagnosis and further medicalisation.

The metaphor stops here, but we suggest adding another relation. An extra dotted arrow should be drawn from macro result to macro condition, indicating that a macro result in turn also influences the macro condition. In this case, overdiagnosis further enhances medicalisation. The suspected mechanism behind this lies in the increasing societal consciousness of conditions and its treatments, decreasing the individual and societal tolerance to endure everyday complaints.

To conclude

In this perspective, we argue that instead of solely a result of medicine, medicalisation and overdiagnosis consists of social cultural processes that take place both in *and* outside medicine. Medicalisation entails a complex set of drivers, including interests, existing institutional rules, and the way society defines 'disease' and 'normality'. Both overdiagnosis and medicalisation push healthcare consumption and lead to additional healthcare costs. Medicalising a situation can improve the health status of new patients. The question remains whether the possible benefits are worth the individual suffering, iatrogenic damage or social exclusion that can also be the result of it. To answer this question, medicalisation and overdiagnosis need to be analysed in a broader context, also taking into account societal aspects.

Medicalisation should be perceived as a societal phenomenon; as a multiplayer game, involving societal forces, institutional rules and stakeholder interests. Medicalisation and overdiagnosis hold an ambivalent relationship. Medicalisation partly follows from overdiagnosis in the doctor's office. At the same time, due to increasing medicalisation at the macro level overdiagnosis on the micro level is induced. Societal developments and values thus influence the practice of medicine. This is a relationship we all should be conscious of, because in the end, there are limits to what medicine can improve both on an individual and a societal level.

Notes

http://www.dartmouthatlas.org/data/map.aspx?ind=245 (accessed on May 1st, 2015).

Own calculations, based on https://www.gipdatabank.nl/default.asp (accessed on May 1st, 2015).

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Chapter 4

Medicalization of sciatica and its treatment

Wieteke van Dijk, Marjan J. Meinders, Marit A.C. Tanke, Eva W. Verkerk, Gert P. Westert, Patrick P.T. Jeurissen.

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Abstract

Sciatica is a common back problem with a generally positive natural course. This interview study was performed to gain increased insight into ambivalent and reluctant medicalization on the interactional level regarding the perceptions of Dutch patients and physicians about sciatica and its treatment options as a case study. While the concept of medicalization was introduced decades ago, nuanced perspectives on medicalization on the interactional level—ambivalent and reluctant medicalization—were added recently. Interviews were conducted with 10 patients and 22 clinicians and analyzed using these perspectives.

The findings show that patients and clinicians share the problem definition of sciatica, which is stated to be the essence of medicalization. They differ from each other regarding the preferred course of action after diagnosis. Ambivalent and reluctant medicalization both highlight that medicalization in practice is often an uncertain and contested process, with medical intervention as a compromise result. In this case, the problem was not in the diagnosis but in reaching a treatment compromise, considering how much discomfort due to sciatica a patient could handle.

Introduction

Sciatica is a back problem that can be quite disabling, but it has a positive natural course in general. This means that for most patients, the chance of a natural recovery is high. The individual clinical path is often difficult to predict; treatment decisions are, therefore, always made in an uncertain context. Treating a problem with medical intervention, while its natural course is positive, can be considered medicalization. Although this may seem inadvisable, in cases where patients suffer from severe pain and are unable to perform their normal activities, surgical treatment is most often effective in reducing such complaints. Medicalization literature reveals that the medicalization of a problem or situation is not absolute or static but can be negotiated in the interaction between patient and physician. This makes the decision-making process regarding sciatica treatment an interesting case to study medicalization. We, therefore, pursue the following line of inquiry: *How do the understanding and opinions of Dutch physicians and patients of sciatica and its treatment contribute to the understanding of medicalization on the interactional level?*

Medicalization

When the term medicalization was introduced in the 1970s, the increasing social control of medicine over people's lives was an essential element of its definition, either through the unlimited expansion drift of physicians (Illich, 1976) or the inevitable reliance on experts that the growing influence of medicine on society entailed (Zola, 1972). Although medicalization is a complex process, its essence can be captured as "*making medical*" (Conrad, 2013): problems or situations that were not previously considered medical come under the jurisdiction of medical professionals and treatment.

Medicalization can occur on three levels: the conceptual, institutional, and interactional (Conrad and Schneider, 1980). On the conceptual level, medical vocabulary is adopted to describe a problem. On the institutional level, the medical understanding of a problem can translate into programs, reimbursement schemes, etc. On the interactional level, a medical diagnosis and treatment are applied during the exchange between doctor and patient, possibly addressing problems that could also be seen as non-medical (Conrad and Schneider, 1980). Research has concentrated mostly on the conceptual and institutional levels (Moloney, 2016). Medicalization or resistance to medicalization on the interactional level has received less attention (Halfmann, 2012).

Traditionally, the medical profession was understood to be the driving force behind medicalization. In 2005, Conrad nuanced this assumption, illustrating that medicalization since the eighties was also, or even more so, driven by biotechnology, consumers, and managed care (Conrad, 2005). In 2013, he added, "*Physicians' roles are now more subordinate in medicalization, often becoming gatekeepers for the expansion or extraction of medicalization*" (Conrad, 2013). The role of physicians in medicalization remains important. Because physicians are trained and inclined to reduce individual suffering, they are willing to apply medical interventions. In doing so, they support the medicalization of problems they may typically regard as non-medical. This dilemma is present on all levels of medicalization, but presumably is most poignant in face-to-face encounters with patients. In an interaction, both patient and physician sometimes need to negotiate their personal ambivalence towards medical and non-medical definitions of a problem and its treatment options (Malacrida, 2004, Kokanovic et al., 2012). For example, an Australian interview study revealed that patients and practitioners were ambiguous about the diagnosis of depression in primary care, mostly because they felt that the medical model could not sufficiently address social contexts or personal problems (Kokanovic et al., 2012). Patients felt that they had to turn to their GP in the absence of better suited forms of help, while their GPs could not help them with their non-medical problems.

On ambivalent medicalization and physician subjectivity, Crowley-Matoka and True studied physicians' perspectives on pain and pain treatment in US veterans (Crowley-Matoka and True, 2012). They revealed a complex interplay for physicians struggling with painkiller prescriptions. Physicians had difficulty distinguishing pain as a "true" phenomenon from unwillingly supporting a dependency on painkillers, the latter for which they might face legal consequences. Physicians were ambivalent towards the use of painkillers and were cautious not to be tricked into prescribing them unnecessarily (Crowley-Matoka and True, 2012).

In addition to ambivalent medicalization, the medicalization of a problem can also be "reluctant" or "incomplete". Moloney showed that this holds for the medicalization of sleep among patients and physicians (Moloney, 2016). She introduced the phrase "reluctant medicalization" *"to highlight the disparity between self-reported attitude and action and note that embodying these contradictions enables patients and physicians to inhabit a liminal state between pathology and normalcy"* (p. 2). Although patients and physicians provided several non-medical explanations for sleeplessness, such as stress, aging, or grief, consults often ended with a prescription. Reluctant medicalization adds to but differs from

ambivalent medicalization in the sense that reluctant medicalization allows for a conscious discrepancy between views and behaviors, whereas with ambivalent medicalization, the person's view of the problem at hand (such as "real" pain) is regarded with ambivalence and not necessarily the following actions.

Medicalization can also be bi-directional. This is the case when processes of medicalization and de-medicalization occur simultaneously. For example, lactation consultants in the US contribute to the medicalization of breastfeeding by reinforcing the medical definition, but also contribute to the de-medicalization by challenging constructions of breastfeeding pathology and medical intervention (Torres, 2014). In Quebec, Canada, the medicalization of pain relief during delivery was "*at the same time, de-medicalized and medicalized, depending on which level we analyze*."(Arnal 2020, p.19). In a layered analysis, Arnal revealed how the goal to de-medicalize childbirth in Quebec, especially the use of epidurals during childbirth, simultaneously evoked processes of medicalization and de-medicalization on the interactional, conceptual, and institutional levels. In addition to the nuances of medicalization, the different perspectives on pain are also relevant to this study.

Pain

With a diagnosis of sciatica, physicians and patients are faced with the problem of the latter's pain. Sciatica differs from some other forms of back pain in that sciatica has an identifiable cause. Research on patients' views on back pain and sciatica is well developed (Goldsmith et al., 2019, Ryan and Roberts, 2019, Hopayian and Notley, 2014). However, pain is a notoriously difficult symptom for both patients and physicians (Crowley-Matoka and True, 2012). Patients who suffer from lumbar radicular pain describe their experience as excruciating suffering that can sometimes even invoke thoughts of suicide (Goldsmith et al., 2019). Patients feel that their lives are put "on hold" by the pain and think that physicians do not assign sufficient credence to these aspects of the problem (Ryan and Roberts, 2019).

The uncertainties of pain also reflect on the treating physicians. In their study on physicians' ambivalent medicalization of pain, Crowley-Matoka and True noticed that physicians treating pain patients "*often feel a deep sense of vulnerability, unease, and even failure*" (2012, p. 701). Pain is often perceived as a biomedical, individual property, but it is, in fact, also deeply intersubjective, and the experience of pain is shaped by factors such as prior experiences, class, sex and gender, and ethnicity (Jackson, 2011). The complexities of pain and its treatment can be disempowering for physicians as well as patients (Crowley-Matoka and True, 2012).

For sciatica patients, the pain can be excruciating. Nonetheless, the natural course of sciatica is usually positive. Additionally, sciatica is not a contested illness, so the involvement of medicine and health professionals on the institutional and conceptual level seems not to be questioned (Dew et al., 2016). Because medicalization is layered and multidimensional (Dijk et al., 2020, Ballard and Elston, 2005), in this study, we reflect on ambivalent, reluctant, and bi-directional medicalization in the context of sciatica treatment decisions on the interactional level.

Sciatica and its treatment in the Dutch context

The distinctive symptom of sciatica is pain radiating to the leg, often combined with numbness in part of the leg, muscle weakness, and/or reflex changes (Konstantinou and Dunn, 2008). Sciatica is caused by the herniation of one or more lumbar intervertebral discs, which can be observed on a MRI scan (Stafford et al., 2007). When neurological functions are at risk, immediate surgery is needed. However, for the vast majority of sufferers, the natural course of sciatica is favorable: more than 90% of patients recover naturally (Gibson and Waddell, 2007), 70% within 12 weeks (Vroomen et al., 2002).

Patients can be treated conservatively, with painkilling and daily life adaptations, or surgically. Surgery is more invasive and has more potential adverse effects than conservative treatment. Pain scores of surgically treated patients improve at a faster pace than those of patients who receive conservative treatment, although this difference has disappeared after one year (Peul et al., 2008). Surgery is more expensive than conservative treatment, costing, on average, €1819 (£1449/$2832) more than conservative treatment (Van Den Hout et al., 2008).

In the context of the Dutch healthcare system, this cost difference is mostly a societal consequence and not an individual one, as healthcare insurance covers all costs that exceed the mandatory annual deductible of EUR385 (USD465). In the Netherlands, all residents are obliged to purchase statutory health insurance from private insurers, which covers all necessary curative care that is part of the benefit package. This is financed through a nationally defined, income-related contribution, a government grant for the insured below age 18 and community-rated premiums set by each insurer (everyone with the same insurer pays the same premium, regardless of age or health status) (Wammes et al., 2017). Low income families and individuals receive government support to pay their insurance and deductible. GP consulting costs are excluded from the mandatory deductible to keep the threshold to consult them as low as possible. Referrals and invoicing

mainly pass through IT systems, with patients only receiving the invoice for their deductible. The Dutch healthcare system is regarded as highly accessible, although low income can still be a threshold for some (Osborn et al., 2016).

Dutch patients with prolonged sciatica go through a tiered patient journey involving the General Practitioner (GP), a neurologist, a neurosurgeon, and possibly other professionals such as physiotherapists and pain specialists (Figure 1). Typically, sciatica patients visit their GP, who makes a clinical diagnosis. According to the Dutch GP clinical practice guideline, all patients should start with conservative treatment, which involves pain medication, patient education about the natural course of sciatica, and advice to stay as active as possible (Nhg-Standaard, 2015). After six to eight weeks of conservative treatment without sufficient improvement, the GP can refer the patient to a neurologist (Nhg-Standaard, 2015). According to the neurology clinical guidelines, the neurologist should confirm the diagnosis clinically and discuss treatment options. The neurologist has the option to order imaging, though this is not considered necessary for diagnosis (Koes et al., 2007). According to the neurology clinical practice guideline, the final choice of treatment should be made by the patient, who should be informed about the advantages and disadvantages of all treatment options (Nederlandse Vereniging Voor Neurologie, 2008). Surgical treatment is not recommended in the first three months. During the subsequent three months, the preference in the guidelines gradually shifts towards surgery. If the neurologist and patient decide to pursue surgical treatment, the patient is referred to a neurosurgeon or orthopedic surgeon. Imaging is necessary for surgical treatment, and the surgeon will discuss whether surgery is likely to be beneficial for each individual patient. In case of mutual agreement, the patient undergoes surgery. Patients who improve and recover quickly without surgery most often only consult their GP and/or physiotherapist.

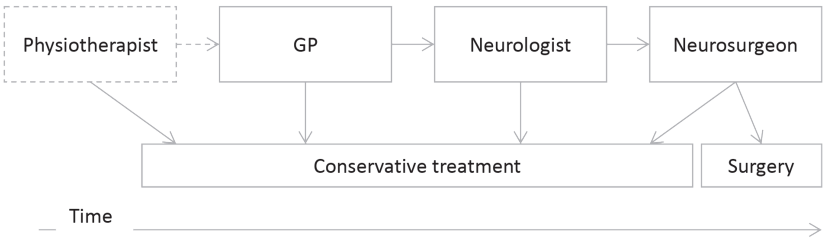

FIGURE 1 - *Typical patient journal of a patient with prolonged sciatica*

Methods

The reporting standards of O'Brien at al. were followed throughout this study (O'brien et al., 2014).

Qualitative approach and research paradigm: The qualitative approach was based on Grounded Theory. However, as medialization should not be regarded as a theory (Conrad, 2013), the aim of this research was not to add to the theory of medicalization, but to "*contribute to a growing scholarly discourse, building and strengthening our understanding of medicalization, yet eschewing the strictures of a fully articulated theory*"(Conrad 2013, p.201). Because the purpose of this qualitative study was to gain insight into how patients and physicians perceive sciatica, the research paradigm is constructivist.

Researcher characteristics: The interviewer was a PhD student in her mid-twenties with a background in social sciences. She had experienced a sciatica episode herself about five years previous to this study, which recovered naturally within four weeks using painkillers. The interviewer's position made it possible to have an open conversation with all interviewees; patients appreciated that she understood the pain and the limitations that result from it. While physicians were sometimes skeptical about a social sciences perspective on this issue, it opened the discussion, and they were willing to explain every step they took carefully, as their counterparts had no medical background.

Context: The professionals were all interviewed in their work context, in their examining room or office. The patients were mostly interviewed in person, in their homes (6), by telephone when they specifically required this (2), in the healthcare setting (1) or in their work office (1). The place of the interview was determined by the interviewee, the interviewer travelled to keep the inconvenience as low as possible for them.

Sampling strategy: Sampling was diverse because possibilities and response differed per group of respondents. The physicians were approached through the personal networks of the project team, snowballing, and in the case of the GPs, via the working group "movement disorders" of the Dutch General Practitioners' Society. To recruit patients, participating physicians were asked to distribute an information leaflet about the research project. One neurologist and one neurosurgeon sent a leaflet and a letter to a sample of eligible patients stating their support of the research project. This resulted in four interviews. To complement this sample, an

online call was posted on the website of the Dutch patient association for sciatica. This resulted in five interviews. One patient was contacted through the personal network of one of the researchers.

The diverse groups of professionals that were interviewed were based on the care paths as prescribed in the guidelines and the personal experience of the researcher. However, after only three interviews with physiotherapists, it became clear that they did not regularly treat sciatica patients. We therefore decided not to pursue further interviews with physiotherapists. As a research team, we deliberated whether this decision could impact the data saturation of the study. We concluded that because the physiotherapists all stated to have no actual experience with patients who faced treatment decisions for sciatica, further enquiry was probably not of added value. For patients and the other groups of physicians, data saturation was pursued.

Ethics: Informed consent was obtained verbally from the professionals and in writing from patients. Anonymity was guaranteed. Physicians nor patients were informed about participation of others they might know (except for the patients who received a letter from their treating physician). All interviews were recorded with permission, transcribed verbatim and shared with the respondents. One physician replied to the transcript, adding some nuance to some of his statements. The edited transcript was included in the analysis. As ethical approval is not required for this type of study under Dutch law, an exemption was obtained by the Medical Ethics Committee of our hospitals' region (dossier nr. 2015-1760).

Data collection methods and instruments: The data was collected through means of in-depth interviews. The interviews took place between August 2015 and June 2016 and lasted 49 minutes on average with clinicians and 44 minutes with patients. Analysis started simultaneously and was finished in early 2017.

Units of study: A total of 32 interviews were conducted: 6 neurosurgeons (NS), 6 neurologists (N), 7 general practitioners (GP); 3 physiotherapists (PT), and 10 patients (P). Inclusion criteria were experience with treating sciatica patients for the professionals and actual or recent (not specified) experiences with sciatica for patients.

The interview guides for patients and clinicians addressed topics related to sciatica diagnosis, treatment options and preferences. The patients' guide also focused on the experience of living with sciatica and the personal patient journey. It was not deemed necessary to adjust the interview guides throughout the research.

The interviews were semi-structured: during each interview a series of topics was addressed, but depending on the conversation and natural flow, several questions were available to address each topic in more depth and the sequence of the questionnaire was open. The patient interviews opened with the broad question "you are dealing with/have dealt with sciatica, tell me, what happened?" This opened a conversation about the patient's experiences, in which the interviewer attempted to mingle as little as possible, channeling the conversation back to the sciatica topic when necessary. Physicians interviews were more structured, having more time constraints.

Data processing: Thematic analysis was supported with Atlas.ti (version 7.2) (Braun and Clarke, 2006). The interviews with clinicians and patients were analyzed separately. The transcripts of the interviews with physiotherapists were included in the analysis. X1 [first author] analyzed all clinicians with X2 and all patients with X3. To reach intercoder reliability, they discussed the results of the separate analyses, compared codes, and discussed similarities and differences in interpretation. They repeated this process every 2–3 interviews. The goal was to reach and use a comparable codebook, but to remain able to distinguish nuances and differences. X1, X4, and X5 discussed the outcomes on the level of patients and physicians. This step was only taken at the end of the coding process, to distinguish the themes that could be revealed from all codes together.

Techniques to enhance trustworthiness: Throughout the process of data collection and analysis the research team met regularly to discuss the progress of the study and to refresh its aim. Steps of triangulation, member check, and reflexion on sampling and saturation are reported above.

Results

Analysis revealed four themes that influenced the sciatica treatment decisions and the opinions and preferences of patients and physicians. These were the problem definition of sciatica, the period after diagnosis, and two types of arguments for intervention: pain and acceptance, and paid labor and self-employment. The clinicians are presented as one group because the analysis revealed no consequent differences between GPs, neurologists, and neurosurgeons.

Problem definition of sciatica

The first identified theme was the problem definition of sciatica. All respondents accepted the biomedical explanation of sciatica: an intervertebral disk bulges

and pushes on a nerve that runs to the leg, causing pain. Patients and physicians thus share the definition of sciatica, which has been called the key aspect of medialization (Conrad, 2005). Patients started with an enormous amount of pain, most often in their leg, and most often occurring spontaneously. They ended with an explanation for this pain that defined their leg pain as a back problem. Accepting that they suffer from a back problem could be regarded as the first step towards the medicalization of this problem, because if patient and physician do not share the (medical) definition of the problem, a treatment decision is impossible to reach.

The consequences of the definition were interpreted less unanimously. For physicians, the presence of a bulge was not enough for diagnosis. Sufficient complaints corresponding with the place of the bulge were required to diagnose sciatica: *"Trouble is, if you look at the entire process, like you say, of the therapist and neurologist, GP and neurosurgeon, there will undoubtedly be one practitioner who says: 'It's a herniated disk'. While the neurosurgeon might say 'That's a small bulge to me. I do not call that a hernia.' It's hard to say as well: what percentage of patients have a hernia? Because, actually, to my knowledge, we still do not have good criteria for a hernia on an MRI [scan]. A herniated disc as a diagnosis is actually not just a radiological assessment, but also clinical examination and an MRI."* (NS4).

Physicians stated that many people have some bulging on one or more discs of their spine, causing no symptoms: *"A hernia is an anatomical substrate, a bulge, but in essence it is pressure on a nerve root. But it is what they call the radicular syndrome which he is suffering from. I see this all the time: 'he suffers from his hernia'. He does not suffer from his hernia, he suffers from the consequences of his hernia. Many hernias are completely asymptomatic."* (N1).

Where patients were willing to accept the medical definition of their problem, physicians shared the problem definition but were ambivalent to apply this definition uncritically. Similar to the US veteran doctors who were ambivalent towards pain and pain treatment (Crowley-Matoka and True, 2012), these Dutch physicians ambivalence focused on "true" sciatica: symptoms in combination with a bulge.

Patients explained their complaints in terms of how nerve pressure in the lower back relates to pain in the leg. Two patients stated that they could feel the bulge pressing on the nerve in their backs. Furthermore, most patients placed a large trust in the power of imaging to confirm the diagnosis: *"Assessing whether it is a hernia [without a scan] is only speculating, of course. A scan says more than speculations. And*

that photo definitely showed that a bulge pushed against the nerve. Yes, very simply, any specialist can see and say that kind of radiating pain relates to that level." (P1).

The physicians' nuance of requiring clinical proof to also match symptoms was not as readily repeated by the patients as the problem definition. Since this sample of patients all started their patient journey with the required symptoms matching a bulge, the idea that a bulge can be present without matching symptoms was an abstract notion for them.

The period after diagnosis

The second theme was the different views of patients and clinicians about the period following the diagnosis. For patients, this period was surrounded with uncertainty. They did not know what to expect from the sciatica itself, they did not know if they could expect any natural recovery, nor when, and they did not know how they could expect to function in their daily lives and work in the coming weeks. Several patients did not feel recognized in this fear and uncertainty, which exceeded the assessment of the factual situation: *"I went to my neurologist with the question: 'Is this normal? Do you see this more often? Or is it an exception? Can I expect more recovery after nine months?' And I know that that will become increasingly difficult as the time goes by. I want to do everything I can to promote recovery. (...) He stood by his opinion, that surgery is not useful, physiotherapy is not useful, there are no ways to improve nerve recovery. So he said: 'I can do absolutely nothing for you, hopefully it will improve and possibly you will keep residual symptoms.' So..."* (P10).

The uncertainty of not knowing how long complaints would last and having no idea of the timeline was very difficult to cope with for patients. Not only for their own wellbeing, but also in relation to family and work demands: *"I thought 'well, okay, yes you can look at it that way as well'. I will just call my work: 'guys, I'm not doing well, you will see me in about three months, or something'. So, um, well, that was a severe disappointment, as you can imagine."* (P11).

The interviewed physicians showed empathy for sciatica patients, stating they understood the impact of their complaints on their daily lives: *"You'll survive, but it can affect your functioning seriously. Certainly, during a short period of time. Well, sometimes longer. If you are unlucky [it will bother you] the rest of your life."* (GP4).

While they claimed to understand the uncertainty that patients face, clinicians had their own struggles with it. They were aware of the positive natural course of sciatica complaints. However, they all made the connotation that they could not

make reliable predictions on the individual level: *"So you can only say to a patient, statistically you have a good chance that it will go away by itself. Yet, for you as an individual I do not know, we'll have to wait. So how will it go? And that's the tricky thing: it is not related to how much pain a person has or how big the bulging disc looks, we don't have much to go on."* (N3). As time passes, the positive natural course of sciatica recovery can occur: *"What I'm trying to do is buy time. To buy time, so that the swelling shrinks a bit. I also explain it like this to people. Especially with a fresh hernia, usually there still is some moisture in there, which you can see quite nicely on the scan. (...) After some time, when the swelling is gone and the bulge has shrunk, it may be that the nerve has just enough room and gives no further complaints. And then we do not need to do anything."* (NS1).

The best advice physicians could give was to give the natural course more time, without any guarantees. While receiving a diagnosis and pain treatment was a relief for patients, they quickly found out that there were new uncertainties, such as the time that should pass before improvement could be expected, or, if not, until surgery would be scheduled.

These perceptions of the uncertainty surrounding sciatica related to the notion of reluctant medicalization (Moloney, 2016). Because of the uncertainty, both physicians and patients were in a liminal state between waiting and action. Physicians did not want to act too early, to give the natural course time to progress, but patients had difficulty handling not only the pain and limitations but also the uncertain duration of it.

Overall, most patients stated to have followed the advice of their doctors. Only one of the patients actively pursued surgical treatment because he believed it to be his best option. Some patients recalled that they participated in the final treatment decision, but all reported the physicians' advice to be dominant. All patients understood the guideline advice of 6–8 weeks conservative treatment provided by their GP as a strict rule. They experienced this as mandatory waiting time before they could see a neurologist. The few patients that were referred to the neurologist (or even emergency care) sooner seemed to feel the need to apologize for being an exception.

Arguments for intervention: Pain and acceptance

The third theme regarded pain as a reason for prompt surgery. This reason was accepted by all clinicians. Patients who were in severe pain and for whom pain treatment did not work sufficiently, should receive early surgery: *"This sounds all*

very conservative, yet when someone, within those weeks, those two months, hits the ceiling because of his pain and he does not react to medication at all, of course I do not let him suffer for two months." (N3).

However, this unanimity was somewhat reluctant: *"Yes, well, that's the handicap of pain, it's subjective."* (GP2); *"Some patients I know very well, so I know that when they come in they really are in a lot of pain. But, there is also a group that comes in and I think, well, you always have a lot of pain. So, um, yeah, pain perception is, is a very important thing in this regard. So this you have to handle this very carefully, as a general practitioner. And you have to think, hey, should I focus only on pain relief, or should I try to do something about how they deal with the pain?"* (GP1).

Here, ambivalent medicalization seemed present, regarding the medicalization of pain as a reason for earlier surgical treatment. All physicians accepted surgery as a correct result for people who were in too much pain to cope. However, determining how much pain was too much proved difficult, and patients were met with some skepticism. The patients' accounts illustrated that people differ in their tolerance of pain. For example, one patient could not stand the pain and wanted a quick solution: *"I have to get rid of that pain. Pain, there's nothing worse than pain. And once you yourself feel that pain you will change your tune."* (P1). Another patient adapted even beyond her own boundaries and managed all aspects of life even with pain: *"Because you get used to pain. Like driving my car, in the beginning you think, maybe I should not drive, I didn't dare because I thought I might hit someone. But I drive now, and the clutch is on the left and sometimes it stalls, well, too bad. You learn to adjust."* (P7).

Arguments for intervention: Paid labor and self-employment

This final theme illustrates how, in addition to pain, economic reasons could allow for earlier intervention. Some physicians were willing to refer earlier or schedule surgery earlier, especially when a patient was self-employed: *"It depends on those things. The degree of pain, the reaction to pain medication, the degree of disability, the type of work the patient does. Someone sitting in the office who can walk around a little and says 'I'll be fine', is a different patient than someone who has to sell fish at the market and otherwise has no income. These are two different patients who might have equal pain, but who experience different restrictions because of it."* (N3).

A similar opinion is as follows: *"And then it comes down to how much is someone suffering? If a patient is self-employed and he is responsible for his income and he does not have any income when he is sitting at home with sciatica, then I am willing to*

arrange surgery earlier. I'd be somewhat more inclined to operate on someone like that than, so to speak, with exaggeration, someone who does nothing the entire day. Then it does not matter much. It is the whole context of the person, that sounds very holistic, but it does matter. Age, mobility, employment status, what are the symptoms? It is not just one of those things." (NS5).

However, one surgeon was not as willing to consider a patient's economic situation: *"No. That's what I tell the patient. I tell them: 'I do not care if you are a construction worker or a teacher, or self-employed. This has no effect on your pain or your problem'. That is very annoying, I get it. It can be a factor, but I'll never tell someone who is self-employed 'You'd better quickly have an operation, because then you'll be recovered more quickly'. That's not true either."* (NS4).

For patients, their economic reality was also a reason to push for recovery, especially if self-employed: "*They have all been fantastic. The care is good, it's all good. Only, for us, the waiting was all too long*. Interviewer: and is that the hardest because of the pain or because of being unable to work? *The pain and being unable to work, both. I have three months, that depends on how you are insured [as a freelancer], but I have to pay the first three months myself. So you want to get back to work as soon as possible."* (P4).

All patients emphasized their work or family demands. All expressed an ardent desire to know when they would be able to function fully in their daily tasks. For some, surgery appealed more strongly because of the programmatic certainty associated with it, in terms of a clear date and a clear message to communicate to their employer. Natural recovery has an unpredictable course and some patients seemed worried that their occupational physician would find them lazy for waiting it out.

The findings in this theme seemed more in accordance with reluctant medicalization than with ambivalent medicalization. Both physicians and patients struggled with the influence of the non-medical factor of work or family demands. Although all acknowledged that these were not strictly medical factors, some physicians regarded them as an acceptable argument on which to base a decision for surgical treatment. Reluctantly, they let the non-medical arguments advance the decision for the more intensified medical treatment, lowering the chance for natural recovery.

Discussion

This study was performed to gain insight into medicalization on the interactional level, with the perceptions of patients and physicians on sciatica and its treatment options as a case study. The analysis revealed that the factual, biomechanical diagnosis of sciatica does not equal medical intervention for physicians. Whether they accept surgery as a suitable solution to the problem depended on contextual factors. Surgery was more justified when non-medical factors, or pain (if believed), urged toward rapid intervention. Physicians thus treated the pain resulting from the sciatica rather than the problem of sciatica on its own account.

For patients, the presence of a herniated disk, preferably made visible with a scan, equaled a medical problem. They did not necessarily demand surgery, but they did struggle with the uncertainty surrounding the natural course. For patients, the symptoms occurring from the bulge were the reason to seek medical aid. This aid was not always received in the form of a cure, but often in the form of painkilling and an explanation for the pain, and the advice to wait for natural recovery.

This reveals interesting differences between patients and physicians in the problem definition of sciatica, but mostly in the resulting necessary actions. The definitional aspect has been called the key aspect of medicalization (Conrad, 2005). This study illustrates that the practice of medicalization, at the interactional level, can transcend the definitional issue. Physicians and patients shared the problem definition of sciatica. Physicians presented a bio-mechanical explanation for the sciatica pain, and patients accepted and incorporated this definition. Thus, for sciatica, the involvement of medicine was undisputed. The dispute lied in the treatment decisions following the diagnosis.

Here, the notions of ambivalent and reluctant medicalization might be relevant. These have highlighted that medicalization in practice is often an ambivalent and contested process, with medical intervention as a compromise result (Zarhin, 2015, Kokanovic et al., 2012, Moloney, 2016, Crowley-Matoka and True, 2012). Reluctant medialization allows for discrepancies between views and behaviors. Involved parties can differ and negotiate between a problem as a "true" medical problem, its most appropriate "treatment," medical or non-medical, and alternative explanations or problems. The resulting medicalization might be unsatisfactory to all involved, to some degree, and is therefore reluctant. For ambivalent medicalization, the ambivalence lies in the discovery of the "true" patients amongst those who may not suffer enough or who fake their disease. There is not necessarily ambivalence in

applying the medical solution to those deserving, but the separation of the wheat from the chaff can put enormous weight on the shoulders of physicians.

Interestingly, examples of both ambivalent and reluctant medicalization were revealed in the analysis of the results. If the definitional aspect of medicalization would be regarded as central, ambivalent medicalization would appear to be on the foreground. If this was the essence of medicalization of sciatica on the interactional level, physicians needed to identify the patients whose herniated disk budged on the nerves running to their leg, and who suffered from appropriate matching symptoms.

However, as mentioned earlier, this problem transcends the definitional level. In reality, this issue is more complex than diagnosing the problem; the presence of a bulge, verified or not through imaging, symptoms such as pain, and societal demands, such as work, make up an individual puzzle. The problem of sciatica is not central in the interaction between patient and physicians, but the amount of discomfort that a patient can handle in his or her daily life, considering that sciatica is present. This allows for multiple forms of sciatica and dealing with sciatica in practice. Mol illustrated how one "simple" disease, atherosclerosis, could be perceived, experienced, and enacted slightly differently by all actors involved (2002). Different definitions of atherosclerosis could be simultaneously true. Actors in the medical interaction, both patients and physicians, can differ in how they perceive atherosclerosis, or sciatica.

Reluctant medicalization emphasizes a disparity between views an behaviors and allows negotiation between normalcy and pathology (Moloney, 2016). In other words, reluctant medicalization allows for variation in the enactment of medicine in the interaction. In the case of sciatica in the Dutch context, not diagnosing is the problem, but to reach a treatment compromise considering how much discomfort from the sciatica a patient can handle. After having diagnosed the problem sufficiently, Dutch physicians allowed non-medical arguments and pain to push towards medical intervention. Patients who received the medical advice to wait some more for natural recovery sometimes received this advice reluctantly. For physicians, a referral for surgery based on pain was also sometimes given reluctantly. Therefore, reluctant medicalization appears to be most suitable in this instance.

The findings illustrate that sciatica is relevant to study the possible involvement of social arguments in treatment decisions. The occurrence of sciatica is age

related, with a peak in incidence between 50–60 years of age (Stafford et al., 2007). Therefore, it can collide with patients' labor, social and family demands. Sciatica diagnosis and treatment can be a reason for prolonged work absence. Although the Netherlands can be considered a welfare state, the institutional arrangements for sick-leave and job security have been reduced over the years. Patients might thus find themselves trapped in a demanding context of uncertain employment and pressure to limit sick-leave. This context can collide with the treatment guidelines or physicians' perspectives. Physicians and patients that do reach the decision to pursue surgery seem to compromise on using medical interventions based on social arguments. In economic terms this might make sense if surgical intervention enables patients to return to work earlier. This is however not certain and never predictable on the individual level.

However, it is important to reflect on ambivalent medialization a bit further, because in the work of Crowley-Matoka and True, the conceptual level of medicalization appears to interfere with the interactional level of "doing medicine" (Crowley-Matoka and True, 2012). When physicians are responsible to apply medical definitions to real patients, in interaction, they will always meet patients that do not perfectly fit this definition but still claim the diagnosis. In this study, the interviewed physicians also often made a link to the conceptual level. This was the case when they stressed that a herniated disk needs to be accompanied by matching symptoms to meet the problem definition. However, when enacting this concept of the problem of sciatica, this did not result in opposing perceptions between patients and physicians. In the case of sciatica, the conceptual level does not collide as much with the interactional level, as was the case for physicians' perspectives on pain and pain treatment for US veterans.

Bi-directional medicalization did not appear to be present in this case. Bi-directional medicalization occurs when medicalization and de-medicalization occur simultaneously. Instances of bi-directional medicalization are probably more likely to be found when the medicalization of a problem is studied on more than one level. In this case physicians made a link to the conceptual level, but this did not collide with their work on the interactional level.

A possible limitation of our study concerns the sampling of patients. We interviewed only patients with severe complaints. Despite a broad recruitment strategy, it proved almost impossible to reach patients with lesser complaints and swift natural recovery. Furthermore, all interviewed patients were either treated within the healthcare system or recently discharged from it. This excludes patients

who manage this problem outside of the healthcare system. Nonetheless, most of the interviewed patients did not attempt to manage their complaints outside of the medical trajectory, excluding one, who visited a chiropractor as well as a neurologist. Furthermore, the study focused on this problem in the patient-physician interaction. In addition, because the interviews with physiotherapists revealed that they were not involved in treatment decisions, no more than three physiotherapists were interviewed, and they were not included in the analysis. Nonetheless, our findings do not exclude the possibility that there are sciatica patients who seek solutions outside of the traditional healthcare system. It would be interesting to study whether such people apply another perspective to this problem or self-medicalize (Fainzang, 2013).

Conclusion

This study reveals that the medicalization of a problem can be negotiated on an individual level and can be far from a dichotomous state, even when opting for medical intervention. For Sciatica, in the Dutch context, medicalization on the interactional level exceeds the definitional aspect: despite a shared definition between patient and physician, the solution to the problem of sciatica is negotiated in interaction and can be understood as an example of reluctant medicalization. This study adds to the understanding of medicalization on the interactional level, and to the further development of the nuances of medicalization, reluctant and ambivalent medialization.

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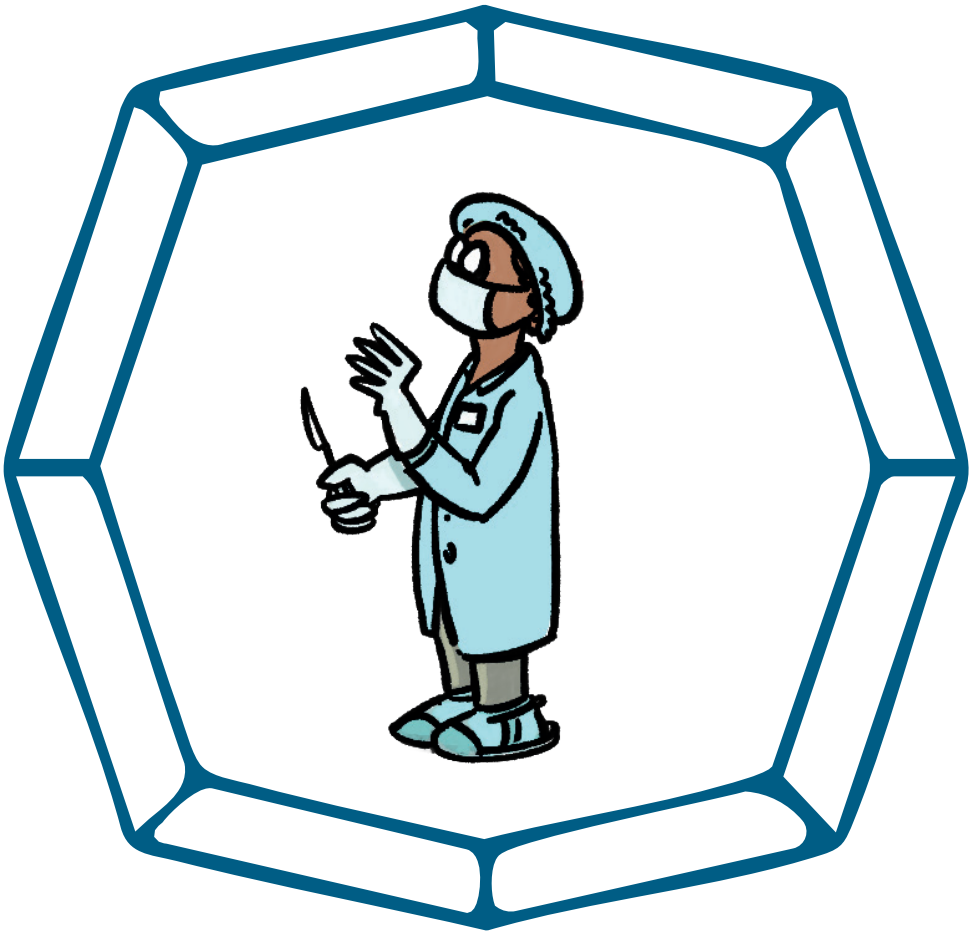

Chapter 5

A cascade of decisions meet personal preferences in sciatica treatment decisions

Wieteke van Dijk, Marit A.C. Tanke, Marjan J. Meinders, Eva W. Verkerk, Patrick P.T. Jeurissen, Gert P. Westert.

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Abstract

Study Design
An in-depth interview study including patients, general practitioners, neurologists and neurosurgeons.

Objective
To gain insight in decision-making in sciatica care, by identifying patients' and physicians' preferences for treatment options, and the differences between and within both groups.

Summary of Background Data
Sciatica is a self-limiting condition, that can be treated both conservatively and surgically. The value of both options has been disputed and the care pathway is known for a substantial amount of practice variation. Most Dutch patients are taken care of by general practitioners before they are referred to hospital-based neurologists, who might refer to a neurosurgeon, who can perform a surgical intervention. Dutch sciatica care thus follows the principles of stepped care, and a cascade of decisions precedes surgery. Better understanding of the decision-making within this cascade might reveal opportunities to improve shared decision making and to reduce unwarranted practice variation.

Methods
Interviews with 10 patients and 22 physicians were analysed thematically.

Results
While physicians were confident of their clinical diagnosis, patients preferred confirmation trough imaging to exclude other possible explanations. Furthermore, many patients showed reluctance towards the use of (strong) opioids, while all physicians favoured this and underlined the benefits of opioids in the management of sciatica complaints, to buy time and to allow patients to recover naturally. Finally, individual physicians differed strongly in their opinion on benefits and optimal timing of surgical treatment and epidural injections.

Conclusions
Dutch sciatica care is characterized by a cascade of decisions preceding surgery. Preferences differ within and between patients and physicians, which adds to the practice variation. To improve decision making, physicians and patients should

invest not necessarily more in the exchange of options or preferences, but in making sure the other understands the rationale behind them.

Summary box

What is already known on this topic – Sciatica can be treated conservatively and surgically and is known to have a large practice variation.

What this study adds – the decision making process in sciatica treatment includes two critical steps: (i) diagnosing of the problem, and (ii) deciding on the type of treatment. For patients certainty of diagnosis was most important, while for physicians timing and type of intervention was most important.

How this study might affect research, practice or policy – this study reveals that individual preferences guide decision in sciatica care, possibly resulting in high practice variation. Implementing shared decision making in this care pathway as a strategy to reduces unwarranted practice variation can be improved.

Introduction

Sciatica can be managed both conservatively and surgically. In the Netherlands, sciatica care is organized following the stepped care principle, involving a GP as gatekeeper for hospital care, and a hospital-based neurologist, before a neurosurgeon is consulted. Therefore, a chain of decisions and referrals precede surgery. Both the diagnostic process as well as timing of surgical treatment and the (societal) value of surgery over conservative treatment are topics of ongoing discussion, and practice variation has been widely reported (Weinstein, Lurie et al. 2006, Peul, van den Hout et al. 2008, van den Hout, Peul et al. 2008, Jacobs, van Tulder et al. 2011). This practice variation may be driven by both differences between and within patient and provider preferences (Bederman, Coyte et al. 2011). This makes the management of sciatica of interest. Which preferences of patients and physician(s) shape these decisions?

In the Netherlands, the GP is the point of entry for non-acute health complaints. For sciatica, the GP guideline advises conservative treatment for 6-8 weeks, combining a strategy of watchful waiting, informing the patient and providing painkillers. If the patients' complaints last longer, the GP can refer to a neurologist (Nederlands huisartsen genootschap). Neurologists can confirm the diagnosis and might order

imaging. However, the neurologists' guideline advises against imaging, unless surgery is considered or there is doubt about underlying cause or pathology (Nederlandse Vereniging voor Neurologie 2008). Recent research showed that only 11% of Dutch neurologists routinely order imaging (ter Meulen, Overweg et al. 2020). Apart from conservative options, the neurologist can also prescribe more invasive pain treatments, usually performed by a pain team. In case of persisting complaints the patient might be referred to a neurosurgeon or orthopaedic surgeon to consider surgery. The Dutch neurosurgery guideline advices not to perform surgery on patients with less than 8 weeks of complaints, and proposes surgery after more than 6 months of complaints without any proper improvement (Nederlandse Vereniging voor Neurologie 2008). In the intermediary period natural recovery could occur. Therefore a shared decision on treatment should be pursued with the patient. A multidisciplinary guideline exists, of which the implementation faces difficulties (Hofstede, Marang-van de Mheen et al. 2013).

Resuming, Dutch sciatica care is characterized by involvement of multiple stakeholders, uncertainty in the aetiology of the disease, and uncertainty about the value of diverse treatment options in each step of the care pathway. As a result, practice variation in sciatica care persists, despite efforts to harmonize care processes. Shared decision making (SDM) is warranted in this situation, because given the uncertainties, patients preferences are extra important to take into account. However, research on the actual preferences that guide the different stakeholders in their decision making process is not available. This qualitative study aims to: 1) identify key moments in this care pathway; and 2) map the drivers and arguments in the decisions among the involved stakeholders.

Materials and methods

Qualitative methods were appropriate for this research question, because the goal was to discover underlying arguments and considerations. Ethical approval is not required for this type of study under Dutch law. This was confirmed by an exemption by the Medical Ethics Committee of our hospitals' region. The COREQ checklist for reporting on qualitative research was followed and is included in the attachment (Tong, Sainsbury et al. 2007).

Data collection

WD conducted in-depth semi structured interviews with sciatica patients (10), physiotherapists (3), general practitioners (7), neurologists (6) and neurosurgeons

(6). Respondents were purposively recruited. Respondents were approached in several ways. The physicians mostly with snowballing, after first contacts were made through the personal networks of the project team. For the GP's, the working group "movement disorders" of the Dutch General Practitioners' Society was contacted. Physicians were asked to distribute a leaflet among eligible patients in their practice. Additionally, an online call on the website of the Dutch association for sciatica was placed. One patient was reached through the personal network of one of the project group members. We aimed to reach a diverse sample of representatives from all stakeholders involved in sciatica care.

The semi-structured interview guide for physicians contained prompts and questions about experiences with care for sciatica patients and the deliberations regarding treatment alternatives. The interview guide for patients focused on the personal patient journey and deliberations patients recalled regarding their treatment decisions. Table 1 provides an overview of the composition of the sample of physicians, table 2 provides an overview of the composition of the sample of patients.

Table 1 - *Basic characteristics of the sample of physicians*

	Gender	Years of clinical experience	How often do you encounter sciatica patients in your practice, as estimated by respondent	Duration of interview in minutes
GP1	Female	5	Bimonthly	42
GP2	Male	31	Monthly	42
GP3	Male	24	Bimonthly	34
GP4	Male	13	Bimonthly	60
GP5	Female	10	Monthly	40
GP6	Male	16	Twice a month	52
GP7	Male	15	Twice a month	31
PT1	Male	15	Rarely	61
PT2	Male	8	Quarterly	52
PT3	Male	7	Bimonthly	79
N1	Male	20	Daily	63
N2	Female	27	Daily	25
N3	Male	18	Daily	60
N4	Male	8	Daily	30
N5	Male	6	Daily	43
N6	Male	4	Daily	51
NS1	Male	6	Daily	48

Table 1 - *Continued*

	Gender	Years of clinical experience	How often do you encounter sciatica patients in your practice, as estimated by respondent	Duration of interview in minutes
NS2	Male	3	Daily	56
NS3	Male	10	Daily	23
NS4	Male	11	Daily	59
NS5	Male	1	Daily	60
NS6	Male	12	Daily	61

The interviews with physiotherapist quickly revealed that, although they treated patients with back complaints, their involvement in patients with severe sciatica complaints (with surgery as a treatment option) was limited. As the decisional trajectory towards surgery was our main topic, we decided not to pursue further interviews with physiotherapists.

Table 2 - *Basic characteristics of the interviewed patients*

	Gender	Age category	Occupation	Duration of complaints in weeks	Duration of the interview in minutes
P1	Male	50s	Truckdriver	16	79
P3	Male	50s	Manager	16	36
P4	Male	40s	Electrician (self-employed)	16	31
P5	Female	30s	Psychiatric home carer	16	49
P6	Female	30s	Housewife	16	26
P7	Female	30s	Dialysis nurse	20	40
P8	Male	60s	Truckdriver	6	23
P9	Female	30s	Nurse in psyciatry	102	40
P10	Male	60s	Retired	52	42
P11	Male	50s	HRM manager	5	65

During the interview patient 2 appeared to have misunderstood the inclusion criteria. He suffered not from sciatica. Therefore, this respondent was excluded from the analysis.

Data analysis

All interviews were transcribed verbatim and anonymised. Thematic analysis was conducted with three coders (WD, X2, an X3), using Atlas-ti®(Scientific Software Development GmbH 2013). WD and X2 coded and analysed all physicians, WD and X3 coded and analysed all patients. First, a sample of the same two interviews was coded separately. Next, the coders compared their findings and discussed shared themes. Then each coded two more interviews, further developing the code-scheme. The previously coded interviews were re-read using the improved code-scheme, to check if coding could be more accurate. The team selected and translated (from Dutch) the key quotes that illustrated the themes. Literal translation was pursued, with respect to the natural 'flow' or 'stammer' in a quote.

Results

Four steps in the care process proved relevant for the clinical pathway of patients. These were uncertainty about the diagnosis, analgesia, epidural injections and surgery. Patients and physicians differed in opinion on the subjects of a certain diagnosis and analgesia. They had relatively similar opinions with respect to the different treatment options. Different options existed on the topic of surgical treatment, within both the group of patients as well as the group of physicians. A summary of the positions of patients and physicians on the four steps is presented in table 3.

Table 3 - *A summary of the perspectives of patients and physicians on the four main topics*

	Certainty about the diagnosis	**Analgesia**	**Epidural injections**	**Surgery**
Patients	Some uncertainty remained unless diagnosis was confirmed with an MRI scan	Reluctant towards opiates	Relatively reluctant to receive epidural injections	Ambivalent opinions, some fear surgery
Physicians	Certain about diagnosis, no imaging required	In favour of painkilling, opiates if necessary	Critical about the benefit of epidural injections	Ambivalent opinions about the medical value of surgery

Certainty and diagnosis

After the onset of sciatica, two prominent decisions or conflicts appear, concerning 1) diagnosing sciatica and the need for MRI-imaging to confirm the diagnosis; 2) the appropriate timing for referral to the hospital. Physicians felt confident about diagnosing sciatica, although the GP's mentioned that they sometimes doubted their diagnosis. They would discuss such doubts with their patients and generally would wait to see how symptoms developed. GP's acknowledged that their first objective in patients with subjected sciatica is to help the patient through the first period of pain and restricted mobility, rather than to determine the 'true' diagnosis rapidly. When patients did not improve, or pushed for referral, GP's would refer to a neurologist earlier than the 6-8 weeks suggested in the guideline. However, because of waiting lists, these patients often waited a few weeks before a specialist was available, and the total duration of complaints generally exceeded 6 weeks.

Patients understood the 6-8 weeks of conservative treatment by the GP as mandatory 'waiting time', after which their diagnosis would be confirmed by a specialist and with an MRI scan. When a neurologists deemed the scan to be unnecessary, patients were disappointed. Physicians were conscious of such patient expectations. Some kept refusing, others gave in:

> *"Sometimes you notice within a minute that whatever you say, it won't matter. […] And in such cases you can say 'according to the guideline you are not entitled to a scan'. But I am not treating the guideline, I am treating the patient. In my experience, if you do not refer such a patient for a scan, if you do not manage to get the patient to understand, and you kind of quarrel with the patient, next month you will receive information from another hospital and they'll have made the scan." (N3)*

> *"Actually, I never have angry patients because they want surgery per se. I do have patients who are angry because they are refused to get a MRI. But I consider that to be something different. Why is that different? Because it is not related to the decision to pursue surgery or no surgery. When deciding to pursue surgery or not you always have the patients best interest at hart." (N4)*

> *"Sometimes I notice that patients first of all need more certainty about their diagnosis. And when they do have that certainty, they can accept that. This also depends on what they can expect from surgery. How long will the recovery take? How will surgery influence their quality of life,*

afterwards? In my experience, people sometimes say: 'well, let's wait a little bit more'. They are scared of surgery and have lots of fears about it. For example, the fear that for surgery they need to receive general anaesthesia, and they don't want to. This can all play a role in the decision making." (GP6)

Both neurologists and neurosurgeons stated that they generally did not need a MRI scan to confirm the diagnosis. They trusted their clinical judgement and only required imaging for a-typical cases. For patients, this was difficult to grasp. All patients whose diagnosis was not confirmed by a scan kept 'doubting' their diagnosis.

"So I say, dear neurologist, that's not my spine. That's a model on a table, my spine is in my back. And you think you can see on that model what's wrong with my back? I thought I came here for a scan and to find out what's in my back. No, he says, that MRI is only needed for the specialist pain team." (P10)

Analgesia

When it comes to analgesia, patients were hesitant towards using them, especially opioids, while physicians advocated their benefits. Patients were critical towards potential side effects, but accepted using them after either the GP, neurologist or pain specialist explained their benefits. They feared to become dependent on opioids and were afraid of using strong painkillers.

"It is a mixed feeling, I would prefer to quit all medication. I would prefer to, but I also notice that the medication is necessary to be able to move. That's a very strange balance. It don't think it's right, I struggle with it. Because I feel as if I do not function as the real me." (P10)

"Don't reduce your medication too soon, because you need it, take it slow. I thought, well okay, if he says so… because I need someone to slow me down." (P11)

"Did it help? The pain medication? Well, not at first. Then we got Tramadol as well and that didn't work either, and then in combination with paracetamol, that knocked me of my feet. Then I just, eh, it was like I was totally drunk." (P4)

Physicians were aware of this hesitance, and stimulated patients to use pain killers to give natural recovery more time. Physicians also stated that they usually followed the WHO analgesic ladder and prescribed stronger medications when necessary, which is supported by the guidelines. They tried to explain why more aggressive painkillers, such as opioids, could be designated for these complaints. Not all patients were equally reluctant to use these medications under the circumstances, but all distrusted opiates.

> *"Because, many patients resist using pain medication. Because they are scared of its side effects, or because they fear that they will be unable to feel the sciatica get worse. You have to discuss these fears, because people might push for surgery to avoid pain medication." (N3)*

> *"I almost never meet people who do not want pain medication. Because if it is really a radicular syndrome, well… then you want something… yes, then you really want something. So that is not really a problem. But they do experience difficulty from the side effects. Mostly with the morphine, the opioids. Yes, that makes people drowsy, it makes it difficult to go to the toilet, they are really bothered with it. So, that are problems you meet, but well, they have no other option." (GP1)*

> *"Lots of the people I treat need a revision of their pain medication. That is sort of related to who is prescribing. Of course, there a lot of literature about this topic and there also is some fright at the side of the professional, but when people are in a lot of pain you need to prescribe a lot of painkilling quickly. You better start with opioids and then reduce to paracetamol, compared to starting with paracetamol and a bit of this and a bit of that. You see? That's following the WHO pain ladder from bottom to top. But with acute pain you'd better follow it from top to bottom. Yet I do notice, although I cannot support this notion with literature, but I do notice that GP's are careful to be too aggressive with painkilling, so I often meet people who are still in quite some pain." (N5)*

Epidural injections

For epidural injections differences were found among physicians, more so than among patients. Some physicians prescribed them regularly for sciatica, although in this small sample there were more opponents than proponents. One neurologist was a strong believer in epidural injections and was setting up a randomized controlled trial to prove their effectiveness.

"Why do I prefer epidurals? Because, in my experience it works well, although there are always patients for whom it does not work. Those patients are quick to call and ask for another, the following step." (N5)

"And treatment by epidural injection, do you prescribe that as well? Yes, sure. Especially with elderly people, with lots of other morbidities or when you think: 'in this case surgery is really unpleasant, but she has so much pain'. Then we use them sometimes. Or people of whom you think 'well, I have doubts about the amount of compression and the test injection worked very well'. And when the neurosurgeon says: 'I think this compression is to limited for surgery to be of use'." (N6)

However, apart from two proponents, physicians were sceptical and had had more negative than positive experiences. Patients were also moderately inclined against epidural injections, but were willing to give it a try for the doctors sake.

"So they discussed it: surgery or an epidural injection? On the one hand I did not want an injection, because I did not believe it would work. On the other hand, if they I advise it you have to be open to it." (P1)

"So I had a pain blocker [epidural injection], but that didn't work at all. No, it didn't help? No, those never help, those pain blockers. I've spoken with so many people who had one, but it never helps." (P8)

Surgery

Proponents and opponents of surgery were found amongst both physicians and patients. Opposing patients expressed fear and doubted the effectiveness of the procedure. Patients that proposed for surgery underlined the difficulty of their personal situation and hoped for quicker recovery than with conservative treatment.

"Yes, well, choice, they let me choose, surgery or rest. But it was so troublesome that I said if surgery will help, then why not?" (P3)

"I am scared of surgery, because I am a nurse myself and I know how to judge the evidence. And people tell me that surgery is not scientifically proven to be effective." (P7)

"Yes, well, it is quite an operation. I know I'll probably be home within a night, but still, I found it a bit scary, to do. Also because there is another

herniated disk underneath. When the one is removed, what will the other do? How will the scare tissue develop? Yeah, I did read a lot about it. So yes… In a way, I think, I'm… I'm a bit scared to get the surgery done." (P9)

Opposing physicians underlined that they wanted to maximise the chance of natural recovery, that they did not want to misuse public money, and that they feared the chance of complications or irreparable damage of a surgical treatment. On the other hand, proposing physicians focussed on (the possibility of) quicker recovery with surgery, fewer residual complaints and earlier work resumption. Notably neurologists held strong views, either pro or con, which influenced their referring behaviour.

"Too easy access to surgery can be deadly for patients. Deadly, really? Literally, because of the risk of complications, but also because some patients are operated on who would have recovered without surgery. And surgery always does harm as well." (N1)

"Those large studies of Peul, the Sciatica trials, conclude that you should not operate. All neurologists have read that. All policy makers have read that. (...) But that interpretation is completely wrong. What they really say is that íf you do want to perform surgery, do it quickly." (NC6)

Interviewer: "And of 5 assessments [of MRI scans], overall, how many proceed to surgery? Respondent: I estimate about 60%. Three out of five. Why do those other two do not receive surgery? Yes, that depends. Partly, I think, it is patient related, like when complaints have decreased, that the situation is improving. Sometimes patients refuse surgery. Or patients want to wait, when they hear about other treatment options. Sometimes they chose one of the other treatment options. And sometimes they just don't want surgery. Or, but that is really rare, if I think the risks of surgery are too high, I'll try to steer them towards an alternative option. That are the patient related aspects. And then there are, well, the MRI related aspects, so to speak, when the MRI does show a herniated disk but it is an a-typical case. Or the MRI does not show deviations that can explain the complaints. Or the deviations do not correspond to the complaints." (NC2)

"People do have strong preferences about surgery or not. They really have. When people are self-employed and cannot miss the earnings of

3 months of working, well yes, that is an argument for surgery. I listen to what people say. I do, I do have a certain advice in mind, but then you get into a dialogue, and then you migrate towards an advice that suits them." (N2)

Discussion

The results of this study give insight into the critical decision making steps in the care pathway of sciatica. The two key elements are: (i) diagnosis of the problem, and (ii) deciding on the type of treatment. The position that patients and their physicians took differed, also within the groups of patients and physicians.

For patients, certainty about their diagnosis was most important. They preferred the evidence of MRI-imaging. This is congruent with earlier research, which showed that patients placed much emphasis on the need for a confirmed diagnosis, as a starting point for further treatment decisions (Ong, Konstantinou et al. 2011, Hopayian and Notley 2014). Patients' preference for imaging is well known, although not fully understood (Traeger, Reed et al. 2018). A systematic review of qualitative studies about patients with low back pain and sciatica concluded that for patients imaging gives more certainty and excludes other possible explanations (Hopayian and Notley 2014). The patients we interviewed experienced the first weeks of GP-led conservative treatment as mandatory waiting time before they would receive a scan for confirmation.

Physicians seldom felt that they required imaging to confirm the diagnosis. This holds especially for neurologists and neurosurgeons. This is concurrent with research that showed that 89% of Dutch neurologists only order imaging under specific circumstances, such as after a long period of pain or with an abnormal neurological exam (ter Meulen, Overweg et al. 2020). For 27% of these neurologists, the patient requesting for an MRI is also sufficient reason to order imaging. For physicians, the presentation of sciatica is often so recognisable that confirmation by imaging is not required. Patients find this difficult to grasp.

Amongst physicians, the timing of intervention was the main subject of discussion. Physicians differed strongly in their opinions about the benefits of surgical or conservative treatment, especially with regard to the timing of surgery. In the Dutch context, the neurologist appears to be the most influential decision maker here: he or she can accelerate or delay the decision to pursue surgical treatment, and decides about the timing of involvement of the neurosurgeon. Between approximately

six weeks and six months after complaints have started, patients with persisting symptoms see a neurologist, who, with the patient, drives the decision about conservative treatment or surgical intervention. Without referral to a neurosurgeon, surgery is highly unlikely within the Dutch context. Of course, neurosurgeons can delay surgery further. Yet, they are unable to make it happen earlier.

The interviewed sciatica patients were reluctant to use strong painkillers. This is congruent with earlier research that reports relatively reserved use of opioids in the Netherlands (Galvez 2009, Gauld, Bryant et al. 2015, Wagemaakers, Hollingworth et al. 2017). Nevertheless, the use of analgesia has increased dramatically over the last decades (Wagemaakers, Hollingworth et al. 2017). Broad concern has risen about opioid use and epidemics of opioid deaths, especially in the United States (Rudd, Aleshire et al. 2016). In the Netherlands this does not seem an immediate problem, as problematic use of opioids is relatively rare and at the fourth lowest level in the EU (European Monitoring Centre for Drugs and Drug Addiction 2017). This study suggests that physicians were less scared of opioids than their patients.

Implications for practice

This study gives some indications for why practice variation still prevails in sciatica treatment. Personal preferences of patients and physicians guide decisions, within the boundaries set by guidelines and evidence. Based on this observation, SDM, as a strategy to reduce unwarranted practice variation, can be improved. A basic model to reach SDM is by following three steps: choice talk, option talk, and decision talk (Elwyn, Frosch et al. 2012). While Dutch patients are aware that there is a choice in this situation and do form individual preferences, this study suggests that that the underlying, supporting process of deliberation is not fully developed. As a result, individual preferences of either the patient or the physician guide the care pathway more strongly than acknowledged or preferrable. To improve SDM Dutch physicians and patients should invest not necessarily more in the exchange of options or preferences, but in making sure the other understands the rationale behind them, as well as the applicability of the situation to the patient's individual context. This means not only presenting the treatment options, but an in depth discussion of which option is most fitting for what situation, and why both parties in the conversation think so. The revised model of the three steps of SDM places active listening and deliberation at the centre (Elwyn, Durand et al. 2017). Implementation of this improved model would possibly bridge the gap between patients and physicians in this stage of decision making. Implementing SDM in clinical practice takes training, practice and requires adjustment in the way physicians were used to work (Ankolekar, Dahl Steffensen et al. 2021). For the implementation of SDM in

this care pathway, explicating the benefits and risks, adjusted to the situation of the patient, could be included more prominently in the clinical guidelines.

Strengths and limitations

One major strength of our study is that we have added the perspective of all important physicians involved. We learned that a range of physicians, notably neurologists, have a profound influence on patients' chances to receive surgery. The neurologist times the moment of referral to the neurosurgeon, and thereby strongly influences the timing of surgery. Patients' expectations or preferences appeared to be influential, be it moderated through the guidance of the physicians they met. Since our sample covered neurosurgeons working both in public and private clinics and patients that underwent surgery in public hospitals or private clinics, our interviews reflect a broad sample of physicians and patients in this decision making process in the Dutch context. Though we included all important physicians involved in the care pathway, the inclusion of pain specialists might have contributed to the further understanding of the use of painkillers and opiates.

An important limitation of this study is that we were unable to reach patients who had complaints for less than 6 weeks. Furthermore, we may have missed typical patients who bypass classical care pathways. However, bypassing the GP is uncommon in the Netherlands, because a referral by a GP is needed to get hospital care. Further, GP consultations are fully covered by health insurance without any co-payment (Wammes, Jeurissen et al. 2017).

Conclusion

In conclusion, this study shows how the stepped care pathway of sciatica patients in the Netherlands is influenced by individual patient and physician preferences. The neurologist appears to be of central influence. To improve SDM, investments should be made in the deliberation about options and preferences and in a better understanding of the underlying rationale for an individual patient and the physician.

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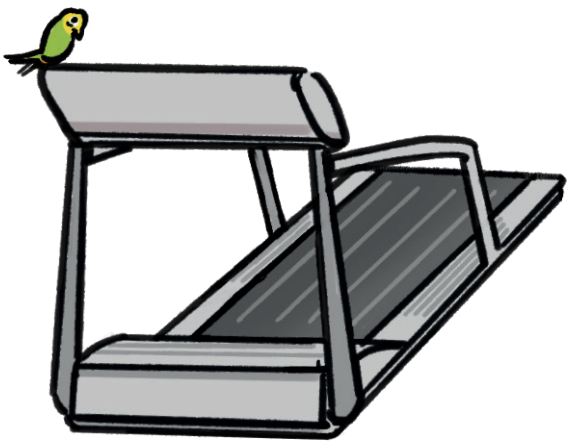

Chapter 6

General discussion

Medicalization is a concept to which most people can relate, lay people as well as scholars and physicians. While it has been subject of scientific debate and study for over 5 decades, empirical research about it lags behind. The literature on medicalization is mostly conceptual, and empirical literature testing the theory in empirical practice is only limited available. This holds especially true for research on the interactional level: the direct communications between patients and professionals. The small amount of research after medicalization on the interactional level that is available has hardly reached the conceptual discussions. As a result, the research field can be perceived as fragmented and repetitive, with limited feedback between empiricism and theory. Another underdeveloped area within the research field is that of the application of the theory of medicalization to clinical practice and policy making.

In this thesis, I aim to bridge these gaps. I translate the findings from my case study on the interactional level to both the concept of medicalization and their impact on the understanding of healthcare utilization. I also reflect on the relevance of medicalization for broader current developments such as appropriate care [*passende zorg*].

The empirical setting that fuels this, is the context of treatment decisions in Dutch sciatica care. How do patients and physicians regard the problem and experience of sciatica, how do they decide between less or more medical interventions and the timing of intervention? Do patients and physicians share treatment decisions, or is one of the parties dominant over the other? And do I see nuances of medicalization present in these treatment decisions?

The main topic of this thesis is the relevance of the concept of medicalization for policymaking, to bend the curve of increasing healthcare costs. In the following sections, I first summarize some information about medicalization that enables any reader to read this discussion independently. Then, the findings of the research chapters are outlined, by answering the research questions. I then proceed with the lessons from this thesis, the reflections, and their relevance for appropriate care [*passende zorg*]. This is followed by an explanation of the strengths and weaknesses of this thesis. I close this chapter with a personal reflection on a decade of involvement in medicalization research and the general conclusion.

The research questions were:

- How is medicalization defined in empirical research?
- To what extent and in what form is medicalization present in the Dutch context of sciatica treatment?
- How do Dutch sciatica patients and their physicians decide between more and less intensive (medialized) treatment options?

What any reader 'needs to know' about medicalization, to read this chapter

The history of medicalization and medicalization research was explained elsewhere in this thesis (see chapters 1 and 2 or (Davis 2010, Busfield 2017)). To make it possible to read this chapter independently and to support the conclusions I draw, I need to introduce a few principles regarding medicalization that this thesis builds on.

I will explicitly state the definition of medicalization that I prefer and find most useful to understand medicalization. As the remainder of this discussion will show, defining medicalization is a quest in itself. Both the topic of study and the moral position of the researchers can influence the perception and definition of medicalization (Kostko 2023). In my opinion, the best definition of medicalization strives for a value-neutral description of the development. The level that the topic is studied on (macro-meso-micro) should be made explicit but is less central to the definitional aspect. I, therefore, opt for Conrad's most recent definition: making medical (Conrad 2013).

I explicitly state 'strive for a value-neutral description', because medicalization is not intrinsically neutral. This is another essential element of the concept. Medicalization has and has had tremendous benefits. It has improved quality of life, has lowered the impact of disease or impairments, has reduced stigma, and has saved many lives. If you follow the definition that medicalization equals 'making medical', everything that medicine does these days has once been medicalized. Medicalization in itself is thus not problematic per se. However, like every development, it has its downsides. For one, Illich, one of the founding fathers of medicalization stated that the power of medicine and doctors undermined the people's autonomy and self-sustainability (Illich 1976). For him, the damage medicine might do (what he called "iatrogenic harm") did not outweigh the benefits. Science and developments that are perceived as progress on the one hand, can unintentionally and unconsciously strengthen social differences or inequalities on the other (Maas and Appelman 2010).

One example hereof in the field of medicalization is that of the medicalization of educational disabilities. These disabilities and diagnoses are presented as biological given conditions, but research revealed that receiving a diagnosis for underperformance in school is also context dependent, whereby age, gender and race are highly influential and different diagnoses are available and applied (Coutinho, Oswald et al. 2002, Dhuey and Lipscomb 2010, Shapiro 2022). This is referred to as medicalization of underperformance (Conrad 1975). The stratified application of different diagnoses, possibly for comparable performance and differences, results in a different (re)allocation of chances and resources: "*White children have higher probability of special education receipt than comparable children of color for academic difficulties, but lower probability for behavioral difficulties, and girls have lower probability than comparable boys overall*" p.1 (Fish 2022, p.1). Medicalization labels children differently and relatively early in life, possibly influencing their school success later on. Thus, medicalization is not necessarily neutral. And finally, while medicalization might relieve stigma, it also might create new stigma (Kvaale, Haslam et al. 2013). For example, when busy or unruly children are classified as 'probably on the spectrum' and thus are treated differently (Scherzer 2023).

Solving a problem through medicine might not be the best solution, neither for the person, nor for the society at large. Medical involvement demands a share of the limited resources of a healthcare system, both in terms of time and money. Spending them on problems that could be solved or improved elsewhere, leads to the observation that medicalization might displace the cure of problems that benefit more from medical involvement. The displacement of higher-value care by new treatments and technologies is a known problem and proven for at least the Dutch healthcare system (Stadhouders, Koolman et al. 2019). As explained in the introduction of this thesis, affordability as well as availability are an increasing problem, worldwide and in the Dutch healthcare system (Osborn, Squires et al. 2016, Wetenschappelijke Raad voor het Regeringsbeleid 2021). Labor shortages are high and rising (Wetenschappelijke Raad voor het Regeringsbeleid 2021). If a problem could equally successful or better be addressed outside of the healthcare system, it would increase the value of care and slow the rise of healthcare expenditure.

A final relevant topic to mention is the logical counterpart of medicalization: demedicalization. Demedicalization entails the opposite development of medicalization: problems, symptoms, or experiences that are no longer viewed as a medical problem and/or in need of medical treatment (Halfmann 2012). The definition of demedicalization is far less elaborate or developed than that of medicalization, most authors define it simply as "a problem that no longer retains

its medical definition" p.224 (Conrad 1992). Demedicalization is far less researched than medicalization, and probably also less common (Halfmann 2012). An often-cited example of demedicalization is the removal of homosexuality from the Diagnostic and Statistical Manual of Mental Disorders (DSM) in 1973 (Schwanberg 1986). Examples of absolute cases of demedicalization are rare, although relative cases of lessening medical involvement or less intensive treatment should be plenty available.

In the following sections, I summarize the answers to the research questions.

How is medicalization defined in empirical research?

In chapter 2 of this thesis, I performed a scoping review that revealed that medicalization is defined very differently in different empirical studies. In this review, all empirical research with medicalization as its research subject was retrieved. The analysis revealed that the definitions used in medicalization research are quite diverse and could be categorized into 10 categories, varying on two axes. The one axe distinguished between value-laden and neutral definitions, the other between a macro and a micro perspective on medicalization. To illustrate, one of the categories was 'making a non-medical problem medical', which includes a value statement about the nature of the problem and also chooses the individual (micro) perspective as a starting point. Another definition was 'expansion of medicine into other areas of life' which is focused on the macro level and does not judge the topic at hand.

The results of these findings indicate that it can be very difficult to compare or combine research about medicalization because the perspectives on the subject are quite different. The same subject can be studied using different definitions. This in itself is unproblematic and can be a strength of the research field. Especially when the different levels, micro-meso-macro, are addressed. Some authors do realize that medicalization can occur differently on different levels and that these effects can also interact with each other (Torres 2014, Arnal 2020). These positive exceptions illustrate that medicalization often is not absolute but depends on the situation and chosen perspective. For example, Torres showed that lactation consultants in the US contribute to the medicalization of breastfeeding by reinforcing the medical definition, but also contribute to the de-medicalization by challenging constructions of breastfeeding pathology and medical intervention (Torres 2014).

However, such examples are rare, both in the combination of different levels and the attention to the possibility that different developments can occur on different levels (Halfmann 2012). Studies often use different definitions and interpret

medicalization as an absolute state, which hinders the comparability of studies and makes it difficult to draw overall conclusions about the concept.

To what extent and in what form is medicalization present in the Dutch context of sciatica treatment?

The case study I performed about sciatica treatment decisions revealed medicalization in this context. Patients and physicians shared the problem definition of sciatica: physicians presented it to patients and patients accepted and incorporated this definition. The definitional aspect traditionally is seen as essential to medicalization: when patients and physician share a problem definition, medicalization is present (Conrad 1992). Incomplete or contested medicalization is often the case when the medical definition of a problem is topic of discussion. However, in this case, the discussion about the involvement of medicine and especially the intensity of treatment started thereafter. In this case, it was not the problem definition but the treatment decisions, that were contested. This gives some 'error' with the traditional perspective on medicalization because that implies unanimity after definition and diagnosis.

The notion of reluctant medicalization proved to be more suitable to the situation. In my case study, the 'condition' of sciatica and how to define this in itself was not central in the interaction between patient and physician, but the amount of uncertainty and pain that the patient can handle in their everyday life was. Non-medical arguments influenced expectations and treatment decisions. Such as demands from family or work life, or uncertainty of timing of recovery and the impact thereof on employability. Reluctant medicalization is medicalization on the interactional level, where the patient and the physician, one of them or both, are actually reluctant to medicalize a problem or complaint, but still do so as they see no suitable alternative. The actors involved are conscious of alternatives outside of medicine but do not deem it possible to use those. In this case, actors acknowledged the possible benefits of prolonged conservative treatment but sometimes did not see another option than to choose the more invasive treatment option of surgery. Resulting in more medical involvement than they actually would have wanted.

This has two implications. One: medicalization exceeds the definitional aspect. Any individual who is facing a medicalized problem, physician or patient, might resort to medical involvement while they doubt its necessity, due to other compelling arguments. Traditional medicalization research does not allow this involvement and would conclude this situation as medicalized in total, despite the 'messy'

reality. Research after medicalization should thus apply a broader view than only focusing on the definition. This is not to say that a non-medical argument can never prompt medical involvement. However, explicit attention to the distinction between medical or biological arguments and more personal or societal ones gives both patient and physician a better insight into what drives their decision-making process and what expectations of its outcomes they both have. Second, this is also very relevant for the macro level. When addressing lower-value care or when aiming to demedicalize a problem, policymakers should also look further than only the definition of a problem. Some of the social or societal arguments can be influenced by regulations. For example, the design of disability regulations and sick leave might drive individual medical decision-making. The chance of loss of job or income after prolonged sick-leave, stimulates individuals to pursue a fast outcome. Although it is impossible to predict the duration of sciatica on the individual level, planning surgery and time for recovery might give more certainty than watchful waiting.

How do patients and physicians decide between less or more medical intervention, when facing (medical) problems and their different treatment decisions?

Amongst physicians a difference in the perspective on the choice for intervention and timing of intervention was present. They differed strongly in their opinions about conservative and surgical treatment and their benefits and timing. While General Practitioners (GPs) were inclined to refer their patients to a neurologist after the prescribed period of conservative treatment of 6 to 8 weeks, neurologists were less unanimous in their timing of referral to surgical treatment by a neurosurgeon. Neurosurgeons on their part also had different opinions about the best moment for surgical treatment but were unable to make patient referrals happen earlier. Patients appeared not to differ notably in treatment preferences. Most stated to rely strongly on their physician's advice. Therefore, the position of the neurologist was key in this care path.

The personal preferences of patients and mostly physicians guided the decisions, within the boundaries set by guidelines and evidence. In the answer to the previous research question, I concluded that non-medical arguments were influential in the decision-making process and should be made explicit. The answer to this research question underlines this once again because physicians differed in their views on the extent to which these types of arguments may influence the decision. Since the scientific evidence leaves some room for interpretation, this shows again that all arguments should be explicitly addressed.

Did the decision-making process align with shared decision making (SDM)? Although the conditions for SDM seemed to be met at first sight, it appeared that the deliberation about the situation and the treatment options fell somewhat short, resulting in sub-optimal SDM. Dutch patients were aware that there was a choice in this situation and they formed preferences. However, the choices and preferences, both of patients and physicians, were not debated explicitly. Especially the arguments that were non-medical were not made as explicit. As a result, decisions were not truly shared.

The overall aim: the relationship between medicalization and overuse of healthcare resources

I now move away from the specific findings of this thesis, towards the relevance of these findings for the overall question: how can knowledge about medicalization be relevant for policymaking that aims to bend the curve of increasing healthcare costs? In this regard, I address three subtopics, ordered from more to less directly related to the results of my studies. First, I reflect on the impact of my findings on the micro-meso-macro perspective on medicalization and policy making. Second, I focus on the relationship between medicalization and healthcare utilization. Finally, I make a connection to the current Dutch policy discussion about appropriate care [*passende zorg*].

Implications for and relations between the micro, meso, and macro level concerning the medicalization of problems and policy-making

In the eighties, Conrad and Schneider made a distinction between three levels of medicalization: the conceptual, institutional, and interactional levels (Conrad and Schneider 1980). To connect to contemporary word usage I use the distinction between the micro, meso, and macro levels, instead of the interactional, institutional, and conceptual levels. I consider these terms equal. This distinction has proven very relevant in this thesis: the scoping review revealed that definitions of medicalization can be categorized into these three levels. The case study also showed that medicalization on the interactional level showed nuances that a conceptual discussion might overlook. It is not one of the three levels that is most important for medicalization, and the different levels interact (Torres 2014, Arnal 2020).

Micro or interactional level

Zooming in on the individual level, this thesis confirmed that the medicalization of a problem can be the result of a partly unwanted compromise, driven by non-medical arguments, such as uncertainty about the problem at stake or fear of job

loss. This is in line with previous studies that address the micro level (Moloney 2016, Bell 2017, Arnal 2020). These can strictly speaking be non-medical arguments or non-medical problems, but they can steer the discussion to a medical solution. This means that non-medical problems, or the results of a problem, are pulled into the medical domain. This can push towards intervention even when the medical evidence would advise prolongation of conservative treatment.

At the micro level, patients and physicians should be aware and make explicit which non-medical arguments are important to them and how they value these arguments in the face of scientific evidence. Such conversations about evidence, preferences and values are known as shared decision making (SDM). Physicians prefer SDM in decision making and incorporating this can support them in their work (Shinkunas, Klipowicz et al. 2020). SDM is complicated and exceeds the transfer of knowledge. Central to SDM is active listening and deliberation (Elwyn, Durand et al. 2017). For most physicians, the implementation of SDM into their way of working takes practice and training and requires adjustments (Ankolekar, Dahl Steffensen et al. 2021). This does not only hold for physicians, patients should also be supported in their share in SDM (Elwyn, Frosch et al. 2012). It is however worth striving for because improved deliberation and decision making could decrease medicalization.

Meso or institutional level

While the meso level was not directly addressed in my study, meso-level aspects have a profound influence on the possible medicalization of a problem. The meso level is most often studied in isolation within the medicalization research field. Examples address the representation of the coverage of a problem/diagnosis in newspapers and media or the representation and development of a diagnosis and treatments in guidelines (Vainionpää and Topo 2006, Seale, Boden et al. 2007, Williams, Seale et al. 2008, Crowley-Matoka and True 2012, Moynihan, Cooke et al. 2013). Both aspects could be at stake in this situation, whereby the guideline stands out. As indicated, sciatica and its treatment decisions allow for personal choice. The advice or preference in treatment options within the Dutch guidelines gradually shifts over time from conservative treatment to surgical treatment. This is explainable, and beyond my expertise to judge. However, in my opinion, the guideline does lack reflection hereon and it does not address how different treatment choices might contribute to the medicalization of a problem or to lower-value care. When evidence allows for certain degrees of freedom in the treatment advice, in which personal circumstances might be of influence, guidelines could make this more explicit.

Macro or conceptual level

Medicalization research on the macro level is mostly conceptual and addresses medicalization as an absolute: is a problem medicalized or not (Conrad 1975, Conrad 2007, Conrad, Mackie et al. 2010, Moloney, Konrad et al. 2011, Fainzang 2013, Rafalovich 2013)? This approach fuels conceptual discussions and possibly public debate. But, it is often stated as an absolute yes or no, losing scientific precision and thus relevance. It might also tempt decision-makers and policymakers to regard medicalization within medicine as absolute, where my case study shows that in reality can be far more nuanced and complex. On the macro level, the relative position of medicine to other policy fields should be taken into account, when addressing medicalization. For example, the regulations for access to benefits from the welfare system or the conditions under which paid sick-leave is available might influence individual medical decision making. If medicine has the lowest threshold to find support when dealing with a problem, it remains attractive to medicalize non-medical problems and arguments.

It remains relevant to discuss the (possible) medicalization of problems on the macro level, although it is perhaps not the most scientific rigorous discussion. Developments such as upcoming labor shortages and their consequences for the future availability of healthcare, for example that of long-term care, should be known to everyone. This is so urgent, that an open public debate is designated. There are plenty of examples imaginable of problems or the way we deal with problems that would be suitable for such a debate: what does it mean to age and get older, possibly facing a decline in mobility and independence, and for what can we expect people to prepare for themselves? How should we interpret and perceive risk and what amount of uncertainty is acceptable in, for example, pregnancy or unexplained symptoms? And, in relation to the healthcare system: how do we want to design solidarity in healthcare and how far does this extend (Raad voor Volksgezondheid & Samenleving 2017)?

Several governmental advisory bodies and public figures do attempt to prompt such debates, such as the Council for Public Health & Society (RVS)(Raad voor Volksgezondheid & Samenleving 2024), the Netherland Scientific Council for Government Policy (WRR) (Wetenschappelijke Raad voor het Regeringsbeleid 2021) or, to give one example, psychiatrist Damiaan Denys (Denys 2020). These efforts are most often broader discussions about accessibility to and priority in healthcare, more than specific discussions about medicalization. Perhaps these discussions lend themselves to a citizen forum or another form of citizen participation (Bijlmakers, Jansen et al. 2020). These are relevant discussions, it is however unknown if and how they would influence the medicalization of problems.

While the micro-meso-macro level distinction is relevant, it can be challenging to translate this into real situations. I therefore elaborate somewhat on one example in box 1, to illustrate what I mean by incorporating the macro, meso, and micro levels. I zoom in on the diagnosis and treatment of ADHD in Dutch schoolchildren. This example is not exhaustive and cannot be, because ADHD is a diagnosis that is often associated with unwanted medicalization (Raad voor Volksgezondheid & Samenleving 2017). In the remainder of this chapter I move somewhat more away from the direct findings of my case study, in to the broader lessons for medicalization and policy making.

Box 1 – An illustrative example: hyperactivity and ADHD in Dutch children

On the macro level, worldwide (Conrad and Bergey 2014) and in the Netherlands (Raad voor Volksgezondheid & Samenleving 2017), there are concerns about the medicalization of children's behavior and the number of ADHD diagnoses (Attention Deficit Hyperactivity Disorder) and subsequent medication use (Quarsie, Tiggelman et al. 2024). Worldwide the percentage of children receiving this diagnosis is increasing, with prevalence estimates differing between countries from 2,2% to 17,8% (Skounti, Philalithis et al. 2006). The lifetime prevalence of ADHD in the Netherlands was estimated at 3,6% in 2023 (ten Have, Tuithof et al. 2023). In the Netherlands, the number of people newly presenting in the GP's office and receiving an ADHD diagnosis per year increased from 9,6/3,7 per 1000 (males/females) to 17,4/10,8 per 1000 between 2011 and 2021. This increase is probably mostly attributable to new diagnoses in people over 11, because the percentage of parents reporting hyperactive behavior in their children younger than 11 remained stable between 2014 and 2022, at 2,1%. Medication use has also risen tremendously in the past decades, whereby the number of adult users has recently surpassed that of youth users (Stichting Farmaceutische Kengetallen 2022). The number of children under 18 using medication has stabilized since 2020 and even decreased a little (minus 2%). This is a recent development, as the percentage of children between 4 and 18 using ADHD-medication quadrupled from 1% in 2003 to almost 4,5% in 2013 (Gezondheidsraad 2014).

On the meso level, the influence of the school system and environmental factors and stimuli are often named as influential for the perception of the behavior of children. While the personal environment of course is individual, environmental factors and stimuli are also influenced by meso or macro actors, such as municipality policy. For example, the amount of green space

in the surrounding of children's homes is related to the chance of children using ADHD medication, with a larger chance of use in urban areas with little green space (de Vries and Verheij 2022). Concerning the context of school and school systems, teachers are often influential in 'identifying' ADHD patients and encouraging parents to consult a physician (Sax and Kautz 2003). Systemic factors influencing teachers' perceptions and experiences with children's behavior are factors such as the ethnic composition of the class (Fish 2022) and class size (Joshi and Angolkar 2018).

The micro level is the level at which an individual pursues and receives a diagnosis. ADHD is included in the DSM (Diagnostic and Statistical Manual of Mental Disorders). It can be diagnosed when several symptoms are present over at least 6 months. The most well-known symptoms of ADHD are hyperactivity, impulsivity, and the inability to concentrate for longer periods. On the micro level, not only individual characteristics (symptoms) are influential in receiving an ADHD diagnosis. Age is strongly related to receiving an ADHD diagnosis while in school, with younger children having higher chances (Batstra 2013).

Perhaps the situation surrounding ADHD in young children in the Netherlands is already changing somewhat, since the number of children using medication is stabilizing after years of increase. ADHD diagnosis and medication use in young children has received attention from concerned (governmental) agencies in the past decade, among which the Health Council of the Netherlands (Gezondheidsraad 2014) and the Council for Public Health & Society (Raad voor Volksgezondheid & Samenleving 2017). Nonetheless, it remains important to take macro and meso factors into account when addressing personal problems or when making policy. In the introduction chapter I already mentioned that over time both the individual's as the societal threshold for 'good' or 'bad' health may lower or rise. The medicalization of children's behavior on the different levels can influence each other, and these levels may increase or decrease the effect sizes on the other levels. Diagnosis and treatment can be a great relief and support for an individual child or it's family, but on group level a steep increase in diagnoses might indicate that growing up unconcerned in the Netherlands, is under pressure. Whether the number of children receiving a diagnosis or medication is too high is difficult to determine and benefits or harms are mostly individual. This is a struggle on itself, mostly related to the overdiagnosis debate. On a group level, explanations for the increase and thereby possibilities for intervention are plausible. While age is an individual characteristic, the age composition of a class might influence all children present. Green space

in the near surroundings – probably associated with playing outside – can be increased, just as class size or outdoor play time during schooldays. It is thus also a choice to medicalize this individual behavior, on a group level, as other areas of life can be adjusted to influence children's behavior.

Medicalization, healthcare utilization, and too much medicine

Medicalization research often does not connect to healthcare usage discussions, with rare exceptions excluded (Conrad, Mackie et al. 2010, Moloney, Konrad et al. 2011). This does not alter the fact that medicalization by definition leads to healthcare use and, when problems or their treatment options are medicalized 'unnecessarily', also to overuse of healthcare resources. As indicated in this chapter so far, it is however difficult to draw direct connections between medicalization and lowering healthcare use or costs. This will always be difficult, but other concepts are probably more useful to address this connection more directly. Especially overdiagnosis and overtreatment, and related terms, are relevant.

The discussion about overdiagnosis in relation to medicalization and too much medicine was boosted by the British Medical Journal (BMJ) in 2002 with an editorial titled "*Too much medicine? Almost certainly*" (Moynihan and Smith 2002). This editorial was the start of an ongoing discussion that is still hosted on The BMJ website today. One influential connected article defines overdiagnosis as: "*An (asymptomatic) person is diagnosed with a condition; that diagnosis does not produce a net benefit for that person*"; and overtreatment as: "*Provision of treatment with no net benefit by individual clinicians to their patients*" (Carter, Rogers et al. 2015). A commission of The Health Counsel of the Netherlands in which I participated revealed cases of overdiagnosis and overtreatment in the Dutch situation[1]. The large benefit of overdiagnosis research compared to medicalization research is that the first is often quantified, whereas medicalization research tends to be qualitative in nature. This is probably partly due to their different backgrounds, as medicalization research has a history in the social and societal sciences, where overdiagnosis comes from within medicine and epidemiology (Van Dijk, Faber et al. 2016). Research about overdiagnosis attempts to pinpoint clearly how many patients do (not) benefit from diagnosis or treatment, addressing a wide range of topics and diseases and most notably public screening research (Jorgensen and

1. The cases that were included were: Cholesterol-lowering drugs for everyone, antacids for babies with reflux, hormone replacement therapy for postmenopausal women, advanced scanning techniques for pulmonary embolism, and PSA tests for prostate cancer.

Gotzsche 2009, Krogsboll, Jorgensen et al. 2012, Moynihan, Doust et al. 2012, Miller, Wall et al. 2014, Saquib, Saquib et al. 2015).

Apart from scientific research after medicalization, overdiagnosis, overuse and other related concepts, the scientific debate about their relative position and relatedness to one another also thrives. Often, medicalization is positioned as the umbrella-term, encompassing all other terms (Carter, Rogers et al. 2015). I believe that medicalization and overdiagnosis are related, but that this relation is more complex than stating that overdiagnosis is a precise and clean-cut subsection of the messier, socially constructed term of medicalization (Hofmann 2016). Therefore, I participated in this debate by writing a viewpoint that pointed out that both medicalization and overdiagnosis are socially constructed (Van Dijk, Faber et al. 2016). See the intermezzo in chapter 3 of this thesis. This prompted three interesting responses from known authors in this field, Carter (Carter 2017), Wardrope (Wardrope 2017), and Hofmann (Hofmann 2017), to which I wrote a reply (Van Dijk, Faber et al. 2017). Since the relationship between overdiagnosis and medicalization was not a central topic to this thesis, I do not elaborate on it further. For interested readers I include the commentaries and my response in the appendix.

There is far more to overdiagnosis research than this. For the sake of this discussion chapter, I want to mention one important downside that overdiagnosis research unfortunately shares with medicalization research: it remains difficult if not impossible to predict which patients do benefit from diagnosis and which turn out to be overtreated. As one author stated: "*… it is challenging measuring overtreatment because it requires defining what appropriate care is, and quantifying benefits and harms when the evidence for these are often incomplete or poorly documented. In addition, the threshold between appropriate and inappropriate care can vary among patients and patient groups, and it is often unclear whose values and preferences should determine what a benefit or harm is from a treatment or procedure*" (Ooi 2020, pp.407-408). That there is overuse of healthcare is undisputed and proven. In 2017 The Lancet published a series about 'Right care', estimating that up to almost 75% of treatment given for specific diagnoses would be overuse (Brownlee, Chalkidou et al. 2017). However, again, the difficulty lies in identifying value of care for specific patients. This is a difficult task to come to grips with and also difficult to explain to the lay public. In the public discussion about medicalization that I mentioned earlier about macro perspectives on medicalization, too much medicine and the adverse effect of overdiagnosis could also have a place.

Too much medicine and its societal implications: appropriate care

Dutch society is facing a major challenge when it comes to healthcare and future access to healthcare. On the one hand labor shortages rise, on the other affordability is under pressure (Rijksinstituut voor Volksgezondheid en Milieu 2018). Currently, there is much attention to appropriate care [*passende zorg*] in Dutch healthcare and healthcare policymaking. With appropriate care the attempt is made to combine knowledge about the difficulties that face access to healthcare, patient involvement and (scientific) knowledge about the downsizes of medicine, such as overdiagnosis and medicalization. Public agencies such as the Ministry of Health, Welfare and Sport, the National Health Care Institute, the Dutch Healthcare Authority, and several scientific associations and health insurers promote appropriate care and point out its ethical imperative. The Dutch National Health Care Institute presented the four characteristics of appropriate care (Zorginstituut Nederland 2020):

- Appropriate care is care that is available for a reasonable price;
- Appropriate care is, when possible, accessible close to patients;
- Appropriate care is care about which patients and their treating physicians share decisions;
- Appropriate care considers disease, but also health and a person's capabilities.

The ethical imperative of appropriate care is real. And the only way to address the (future) scarcity in healthcare is by combining all possible knowledge and imperatives, into one comprehensive approach. In that sense the joint effort to promote appropriate care is admirable.

However, from experience with the perspective of medicalization, I do see some risks. One, like with medicalization, the broadness of the concept threatens to turn it into everything and nothing. Having an agreed-upon concept and agreeing that it is important does not automatically constitute knowledge about what care is appropriate, let alone for whom. Next, the four characteristics of appropriate care threaten to overlook the societal context in which a healthcare system is situated. Healthcare is also a market in which people and businesses make their living, and external factors and extrinsic stimuli push upon this market. This is true for all healthcare providers, but those positioned outside of the benefit package are even less restrained by the countervailing powers of the Dutch healthcare system. This holds for provers of private care, for example those of health checks. This is an area of private care in the Netherlands that I gained some insight into during my time with the Celsus academy, which I illustrate in Box 2 (Stadhouders, Van Vliet et al. 2024). Health care provision that deliberately is not a part of the benefit package

or of a nationwide screening program, is in-appropriate care by nature. Yet, it can be attractive for people to pursue on their own initiative. The balance between quality of care, spill-over from the private sector to regular care and the division of labor, money and shortages, should not be overlooked by focusing only on appropriate care. And finally, as this thesis showed, sharing decisions in itself is not enough to prevent medicalization. Both physicians and patients should be capable of participating in SDM. Both should weigh the medical evidence and non-medical arguments that might influence the outcomes of the decision-making process. Both should take the context in which they operate into account, to some extent.

The movement towards appropriate care should learn from other concepts and developments and address these pitfalls. If they do not, the resulting multi-interpretability will be of benefit for parties that want to protect their interests. It will require courage and perseverance of all parties involved to make it happen. In the end, medicalization, overdiagnosis, appropriate care, and all other concepts and research fields that try to lessen wrongdoings or overuse in healthcare stumble upon the same fact: healthcare is people's work and work is behavior. Changing behavior, and expectations, requires overcoming resistance, long-term commitment, and precisely orchestrated checks and balances.

Box 2 – Experiences of Dutch users of Health checks

During my time with the Celsus Acedamy, I performed a small qualitative research commissioned by the Dutch Ministry of Health Welfare and Sport, after the use of and perspective on health checks of Dutch citizens (Van Dijk, Van Haren et al. 2017). In the definition of what we called health checks, the fact that this was a diagnostic test without medical indication and did not take place as part of population screening stood central.

I interviewed 19 users and 4 experts about health checks. The interviews with users resulted in 7 themes:
Users did not discern between indicated and non-indicated tests;
Users resorted to a health check under one of 3 conditions: they had some general 'vague' symptoms, they wanted to experience the health check, they wanted to monitor their health;
All users were reassured after the check, even when its result gave reason to consult with regular medicine;
For users, the reliability of the test equaled the reliability of the performer of the test;

None of the users had altered their lifestyle due to the test results;
Cost was no objection towards taking a health check, except the (pricy) total body scan;
Users regarded health checks as part of prevention and a healthy lifestyle.

In conclusion, it appeared that users did not regard health checks critically. For example, they did not mention diagnostic uncertainty or the chance for false positives or negatives. Their thoughts on costs did not exceed the direct purchase of the test, possible follow-up costs within the healthcare system were viewed as indicated costs. Health checks did seem to support these users by temporarily removing concerns about their general health. Nonetheless, their health literacy in this domain appeared less than optimal, something they did not reflect on themselves.

Strengths and weaknesses

Empirical research after medicalization is scarce, even more so for studies on the interactional level. A strength of this thesis is that it combines a precise review exercise after the application of medicalization in empirical research, which is a novelty in this research field, with an in-depth case study after the occurrence of medicalization in real life. This enables me to reflect on medicalization as a concept, fueled by evidence from the case study. This also made it possible to zoom in on the decision-making process on the interactional level and shared decision making therein, against the background of the concept of medicalization.

Specific for the empirical research, a strength is the inclusion of the important physicians in the whole of the care path. However, in retrospect, the inclusion of pain specialists might have added to the validity of the study. This might have contributed to a better understanding of the use of painkillers and epidural injections. It also proved difficult to find patients who were willing to participate, especially patients with lesser or shorter complaints. It also focused on patients who handled this situation within medicine and excluded those who managed it without medical intervention. The addition of observations would possibly have improved the understanding of the situation at hand and the decision-making moments therein more. Another weaker point is the fact that this thesis relies on just one case study.

Looking back, it may have been a bit naïve to start a case study after the medicalization of a problem that turned out to be so undisputedly received as medical. This however did enable me to look a layer deeper into medicalization and look beyond the absolute level of medicalization. None of the involved physicians questioned their involvement in this care path. Medicalization in the absolute sense was thus not a point of discussion. What most physicians did mention in the interviews, was that the distinguishing feature of sciatica is also present in people without complaints. Sciatica is coursed by one or more lumbar intervertebral discs being herniated and pushing on a nerve, combined with complaints that match the location of the bulge (Stafford, Peng et al. 2007). So, for physicians, the presence of a herniated disk on an MRI scan was not enough to diagnose sciatica, they required matching complaints. In this regard, the definition of sciatica was somewhat disputed. However, since our case study addressed and only included patients that matched this requirements, in this context the definition was undisputed. Perhaps a future study including patients with less clearcut diagnosis would find other nuances than I did, regarding the definitional side of sciatica.

Finally, I would like to end this section with some reflection not on my work, but on the concept of medicalization. Throughout this and previous chapters I have made some comments about the applicability of the concept in scientific research, and in particular the aggregation and transportation of findings into conclusions. This thesis was not designed nor the place to dissect and reject the concept as a whole, but in my experience, its scientific robustness falters in empirical research. And I am not the first to be critical about it. The adoptive father of medicalization, Conrad, himself states that medicalization is "*more of a conceptual framework with interconnected observations and ideas than a full-blown theory*" (Conrad 2013, p.200). Halfmann, amongst others, finds the concept and the definition of 'making medical' all too all-encompassing to be of distinctive value (Halfmann 2012). Rose wrote a short but compelling article stating that medicalization cannot be the conclusion of an analysis because it is far too much connected to modern peoples and societies: "*We relate to ourselves and others, individually and collectively, through an ethic and in a form of life that is inextricably associated with medicine in all its incarnations. In this sense, medicine has done much more than define, diagnose, and treat disease—it has helped make us the kinds of living creatures that we have become at the start of the 21st century*." (Rose 2007, p.701). Medicalization is an attractive concept. It is recognizable and probably a 'true' phenomenon. Yet it is mostly used in a descriptive way and is also very difficult to operationalize and test in scientific research. This is a profound weakness of the concept.

Box 3 – the relevance of medicalization for policymaking

I wrote a book chapter about the relevance of medicalization for policy-making (Van Dijk 2018). The chapter aimed to determine whether the concept of medicalization could be of relevance for policy that aims to lower healthcare use and costs.

The chapter concludes that medicalization does indeed lead to more healthcare use and costs. The medicalization of problems and symptoms leads to 'new' diseases and syndromes. However, while medicalization does support the description of more medicine and healthcare, it does not or hardly helps distinguish between what part of this is too much. Therefore, the concept of medicalization is not useful to reduce healthcare use and cost.

This has several causes. Medicalization is about more healthcare and medicine use, but what is too much remains a moral judgment. This is highly contextual and subjective, and medicalization is too much of a broad concept to make this difference. Without an explicit and clear definition and operationalization of medicalization, which is typically not provided, application of the term to policy is not useful. Other concepts such as overdiagnosis or overtreatment are more useful for making decisions about less healthcare utilization (Carter, Rogers et al. 2015). These concepts also have their difficulties, but they do focus on whether medicine does not reach its goal or is even harmful, for example by determining how many people should be screened to save one life.

The methodological difficulties of medicalization are too ample to reach a similar concrete conclusion. Because of the many definitions of medicalization, studies are incomparable. Because of all the conceptual discussion about the essence of medicalization, empirical research is rather scarce. It has proven difficult if not impossible to quantify medialization, beyond the point of all or nothing. While medicalization has started as a critical term, it has become more of a descriptive one.

These factors make medicalization less useful for policy-making, aimed at lessening the use and cost of healthcare and medicine. This does not alter the fact that it would be useful to have a societal discussion about the areas and phases of life that seem more susceptible to medicalization, such as aging, pregnancy, and children's behavior. What does it mean to age and what added value can and should medicine have? This can however not be captured in straightforward cost-saving policies.

Personal reflections, after over a decade in medicalization research

Over a decade ago I started this research thesis with the Celsus Academy, a research group dedicated to scientific contribution to slow down the increase in healthcare spending. One of the Celsus Academy's results was a book dedicated to affordable healthcare, in which I wrote a chapter about the relevance of medicalization for policy-making. I summarize the conclusions that are relevant for this discussion in box 3 (Maarse, Tanke et al. 2018). One of the reasons that this thesis took much more time than anticipated, lies in the conclusion of my book chapter: medicalization is not suitable as a distinguishing concept for policy making, and it appears not to contribute usefully to the essence of sustainable healthcare: less healthcare use. This conclusion was inevitable, but quite a deception after years of hard work. It also hindered the further exploration of the combination of medicalization and policy-making research, which we wanted to pursue as well.

Now, after over six years of experience with one of the largest health insurers in the Netherlands, in the role of policymaker nonetheless, I can only confirm my earlier conclusion. In my experience, medicalization as a term for unwanted or misunderstood increase in healthcare use is still readily used. Not only by health insurers but more so by governmental representatives and healthcare professional advocates. The increased pressure of labor shortages on the current and future availability of healthcare fuels the call for demedicalization even more. This is however a goal that proves hard to reach. This is not only due to the complexity and elusiveness of the concept itself but also to the interests and advocacy of parties that could lose due to demedicalization.

Ironically, this brings medicalization back to its origin in the sense that it, to some extent, is again associated with social control. But not in the same way as it was originally, of the doctor controlling the (female) patient, but more so of the doctor's advocates -and other advocates, including those of health insurers- controlling the distribution of influence and money across healthcare. As influence and money equals access, it’s social control at the macro level, if you will.

To keep healthcare accessible in the coming decades demedicalization is necessary. Not only in terms of problems being re-defined as non-medical and as solvable outside of the healthcare system but also in the sense that medicine as a social institution should lower its grip on society. It is however highly questionable whether this ambition can succeed, also because the scarcity strengthens the position of healthcare organizations and professionals. The countervailing powers of the system, in the Dutch case government and healthcare insurers, are up for a challenge.

In conclusion

The goal of this research was to shed more light on what medicalization entails and to better understand the relationship between medicalization and healthcare utilization. This is to support policymaking aimed at bending the curve of healthcare costs.

Medicalization turns out to be a broad and diverse concept, without a uniform understanding of what it entails. As this thesis shows, empirical research after medicalization could be divided into 10 categories, based on the definition of medicalization used. And in the analysis and interpretation of the results of my case study, I found the most compelling arguments for the rather nuanced, complex notion of reluctant medicalization. This is, paired with the 10 categories, a complication for a straightforward application of medicalization to policy making. Also this only addresses the concept itself, not even its application to all possible diseases, problems, conditions, and experiences that people might medicalize. Let alone the application of its logical counterpart: de-medicalization, about which far less is known.

Thus, the outcomes of medicalization research cannot be straightforwardly plugged into policy. That does not mean that medicalization research is useless. Medicalization does have appeal and is a strong conversation starter. Medicalization is an ever-relevant concept and helps to understand both the position of and the debate about health and medicine within society and people's lives. It can help us understand the appeal of medical support when facing a wide range of difficulties in people's lives. Policy should take the possible medicalization effect and influence of non-medical arguments in treatment decisions into account. A societal debate about the possible medicalization of areas of life and living and the de-medicalization thereof might be beneficial. But to apply concrete policies, other concepts are more useful. The current discussion about appropriate care should learn from the history of medicalization and commit to putting precise checks and balances into place, and avoid getting stuck in only a conceptual discussion.

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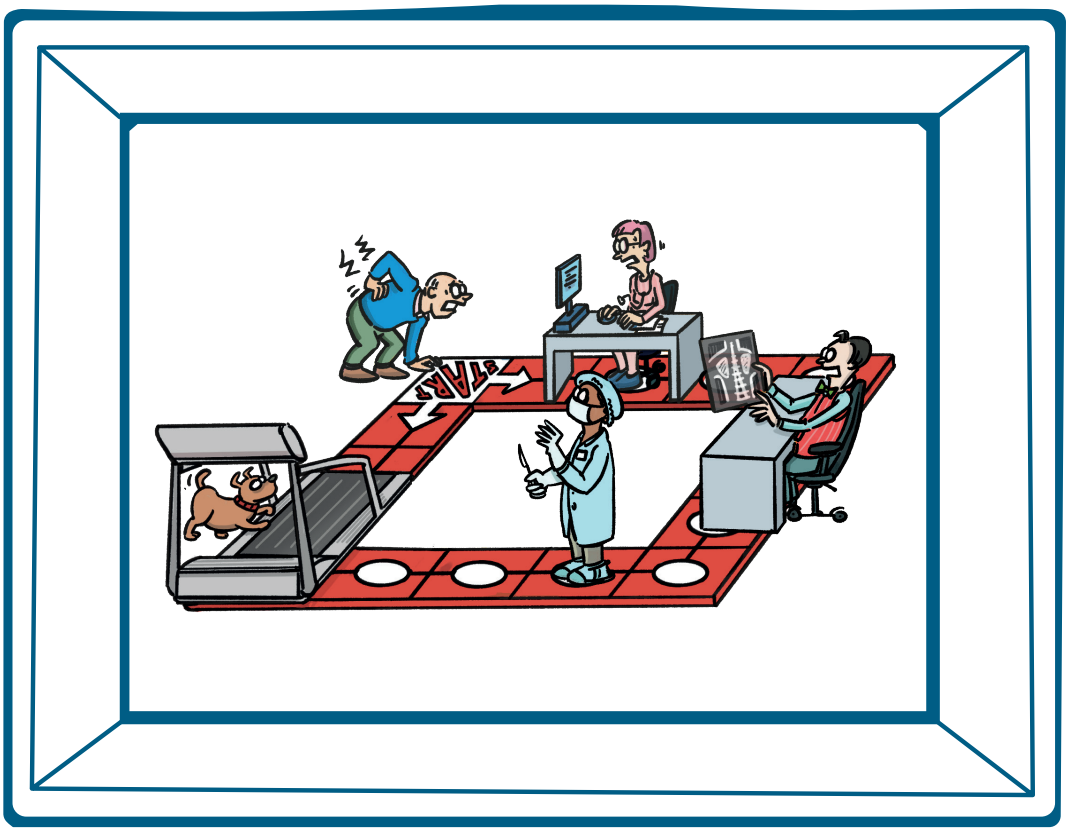
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Summaries

Summary

Healthcare costs in the Netherlands are rising at a higher rate than the increase in gross national product. This increase is unsustainable. Workforce shortages rise whereas public and individual spending on healthcare suppresses other relevant (public) goals. It is important to get a grip on the rise in healthcare expenditures. To curb healthcare costs and their increase, it is often said that further 'medicalization' should be prevented. Medicalization is the development in which people increasingly seek a solution for their problems in the medical domain.

Medicine, and thus medicalization, have contributed to a better quality of life and an increased life expectancy. However, the medical solution is not necessarily the most cost-effective solution to every problem. In some cases, investments in education or prevention are more cost-effective in achieving the same goal. A better understanding of what medicalization entails and how it occurs can assist in forming a more cost-effective health policy that slows the increase in healthcare spending.

Medicalization research has a history of over fifty years. However, in the empirical and practical sense, several gaps remain today. How insights into the relationship between healthcare use and medicalization can be used for health policymaking has not been studied yet. This thesis provides an improved understanding of the relationship between medicalization and healthcare use, specifically in sciatica treatment. This is done by answering the following research questions:

1. How is medicalization defined in empirical research?
2. To what extent and in what form is medicalization present in the Dutch context of sciatica treatment?
3. How do Dutch sciatica patients and their physicians decide between more and less intensive (medialized) treatment options?

Chapter 2 presents a scoping review that addresses the definitions used for medicalization in empirical research. A total of 3027 records were screened, resulting in the inclusion of 50 empirical studies. The empirical application of the concept of medicalization was quite diverse in those studies. The definitions of medicalization used in empirical research were grouped into 10 categories, placed in a framework covering two axes. One axis represents a continuum from value-neutral definitions to value-laden definitions. The other axis represents a continuum from a micro to a macro perspective on medicalization.

The reviewed studies covered this full spectrum and therefore it was concluded that empirical medicalization research is heterogeneous in its understanding of the concept. This makes it difficult to compare or combine research about medicalization. Also, the same subject can be studied using different definitions. In itself, this is not problematic and it can be a strength. However, this hinders the external validity of the research field and makes it impossible to draw overall conclusions about the concept.

Chapter 3 presents a viewpoint on the relationship between medicalization and overdiagnosis. In overdiagnosis research, medicalization is often used as an umbrella term, encompassing concepts including overdiagnosis, overtreatment, and the like. Medicalization and overdiagnosis are related concepts, but this relation is more complex than stating that overdiagnosis is just one part of the bigger -messier- concept of medicalization. Furthermore, medicalization in itself influences overdiagnosis. Therefore, the presented viewpoint aims to provide insight into the influence of society and the societal context on medicine, particularly regarding medicalization and overdiagnosis. Since the relationship between overdiagnosis and medicalization was not a central topic to this thesis, I include this viewpoint as an intermezzo between the empirical chapters.

In Chapter 4 the results of the case study about the extent of medicalization of sciatica in the Dutch care path is described. The treatment of sciatica is interesting in the context of medicalization because it can be an invasive problem, that is however most often resolved naturally when not treated. There is a large variation in the invasiveness of the treatment options, ranging from conservative to a surgical procedure. The decision for the treatment option is made in consultation between the patient and the physician. On this level, nuanced perspectives on medicalization have been developed: ambivalent and reluctant medicalization. To get more insight into the decision-making process and the presence of medicalization therein, a study using qualitative interviews was performed. Interviews with 10 patients and 22 clinicians were performed.

This showed that patients and physicians shared the problem definition of sciatica. This is stated to be the essence of medicalization. In the case of incomplete or contested medicalization, the medical definition of a problem is topic of discussion. However, in this case, it was not the problem definition but the treatment decisions that were contested. Reaching a conclusion about a referral or treatment in the interaction between patient and physician was not about the sciatica per se, but about the amount of uncertainty and pain that the patient could handle. Non-

medical arguments influenced expectations and treatment decisions. The notion of reluctant medicalization proved to be more suitable to the situation than that of ambivalent medicalization.

Chapter 5 elaborates on the decision-making process in this case study and the presence of shared decision-making (SDM) therein. While the decision-making process is presented as quite straightforward in the guidelines, this is also a situation known for its practice variation. Individual preferences of both patients and physicians drive decisions, and preferences differ within groups. Physicians, and notably neurologists among them, differed strongly in their opinion on the timing and benefit of surgical treatment and epidural injections.

Shared decision-making could be improved. At first sight, the conditions for SDM seemed to be met, but the deliberation about the rationale behind personal preferences or choices was not always shared nor understood. The possible influence of non-medical arguments on this treatment decision was often not addressed.

In the discussion chapter I circle back to the aim of this thesis: to establish the relevance of the concept of medicalization for policymaking, to bend the curve of increasing healthcare costs. The distinction between micro, meso, and macro levels of medicalization that emerged in the results of the scoping review is not new for the concept of medicalization, but it remains very relevant. Medicalization can be present on all three levels and the levels can interact and influence each other. Individual treatment decisions (micro level) are influenced by conditions set at the meso and macro level. For example, the case study from chapters 4 and 5 showed that non-medical arguments were influential. These non-medical arguments are influenced by macro policies in other areas than health policy, such as sick leave and unemployment policies. This is relevant for health policy because it shows that other policy areas can have an impact on how much we have to invest in healthcare.

It remains however difficult to draw a direct relation between medicalization and healthcare overutilization. Medicalization is a diffuse concept that is difficult to operationalize. Concepts such as overdiagnosis and overtreatment can probably be more useful to pinpoint overutilization. Unfortunately, they share with medicalization that it remains difficult, if not impossible, to predict which patient will benefit from diagnosis or treatment and which patient will not. The concept of medicalization remains attractive and can fuel a societal debate about the possible

medicalization of areas of life, and whether medical involvement would benefit or harm. For policy-making, however, other concepts are more useful.

A new discussion in Dutch healthcare and policymaking is that about appropriate care [*gepaste of passende zorg*]. Appropriate care attempts to build bridges between the known problems of Dutch healthcare, including declining access to care, proper patient involvement, and knowledge about the downsides of medicine, such as overdiagnosis and medicalization. Appropriate care can learn from decades of medicalization research. For example, as is seen with medicalization, appropriate care risks becoming an umbrella term, with little distinguishing capacity. Furthermore, sharing decisions with the patient is a moral imperative, but a shared treatment decision does not automatically take contextual or societal arguments into account. When non-medical arguments are influential, this should be mentioned and discussed. Finally, in my experience as a policymaker with a large health insurer, appropriate care threatens to become more of a lobbying mechanism for vested interests than a movement that improves the future accessibility of healthcare. Appropriate care should attempt to exceed the current conceptual discussion and invest in applied knowledge and precise checks and balances, to secure the future of healthcare.

Nederlandse samenvatting

De zorgkosten in Nederland stijgen en nemen alsmaar toe, sneller dan de toename van bruto nationaal product. Deze stijging is niet vol te houden: er zijn steeds minder arbeidskrachten beschikbaar voor de zorg en de uitgaven aan de zorg verdringen die aan andere publieke functies zoals onderwijs of defensie. Ook drukken de zorgkosten op het besteedbare inkomen van mensen. Daarom is het belangrijk om grip te krijgen op de uitgaven aan de zorg en de stijging daarin.

Wanneer het gaat over het beteugelen van de zorgkosten en van de stijging ervan, wordt ook vaak gezegd dat verdere 'medicalisering' moet worden voorkomen. Medicalisering is de ontwikkeling waarbij mensen voor steeds meer problemen een oplossing zoeken in het medische domein. De gezondheidszorg, en dus medicalisering, hebben bijgedragen aan een betere kwaliteit van leven en aan het verhogen van de levensverwachting. Maar, niet voor elk probleem is de medische oplossing de beste. Het is ook mogelijk dat een euro die wordt uitgegeven in de gezondheidszorg méér oplevert als die wordt besteed aan een ander maatschappelijk doel, zoals bijvoorbeeld onderwijs of preventie. Het is dus begrijpelijk dat er gezocht wordt naar meer 'grip' op medicalisering, als daarmee onzinnige zorg kan worden voorkomen.

Het begrip medicalisering bestaat al meer dan 50 jaar, maar er is relatief weinig empirisch onderzoek naar gedaan. Zo is nog niet onderzocht hoe inzichten in de relatie tussen zorggebruik en medicalisering kunnen worden gebruikt voor gezondheidszorgbeleid. Dit proefschrift daagt bij aan een beter begrip van deze relatie, in het bijzonder bij de behandeling van een rughernia. Daartoe worden de volgende onderzoeksvragen beantwoord:

1. Hoe wordt medicalisering gedefinieerd in empirisch, wetenschappelijk onderzoek?
2. In welke mate en in welke vorm is medicalisering aanwezig bij rughernia-behandelingen in Nederland?
3. Hoe beslissen Nederlandse rughernia patiënten en hun behandelaren over de keuze tussen meer en minder gemedicaliseerde behandelopties?

Hoofdstuk 2 presenteert een *scoping review* naar de definities die worden gebruikt voor medicalisering in empirisch onderzoek. In totaal werden 3027 referenties gescreend, wat resulteerde in de inclusie van 50 empirische studies in het review. De empirische toepassing van het concept medicalisering bleek erg divers.

De definities bleken gegroepeerd te kunnen worden in 10 categorieën, die op twee variabelen, ofwel assen, van elkaar verschillen. Op de ene as staat een continuüm van waardeneutrale tot waardegeladen definities. Op de andere as staat een continuüm van een micro- tot een macroperspectief op medicalisering. De categorieën van definities bestreken dit volledige spectrum. Daarom werd geconcludeerd dat empirisch onderzoek naar medicalisering heterogeen is. Dat maakt het moeilijk om verschillende onderzoeken naar medicalisering onderling te vergelijken of te combineren. Ook kan hetzelfde onderwerp onderzocht zijn aan de hand van verschillende definities. Op zichzelf is dit niet problematisch, het kan een kracht zijn van het onderzoeksveld. Echter, dit toont ook aan dat de externe validiteit van het onderzoeksveld beperkt is en het maakt het onmogelijk om algemene conclusies te trekken over het concept.

In hoofdstuk 3 is een viewpoint over de relatie tussen medicalisering en overdiagnose opgenomen. In onder zoek naar overdiagnose wordt medicalisering vaak gebruikt als een overkoepelende term, die concepten overspand zoals overdiagnose, overbehandeling en dergelijke. Medicalisering en overdiagnose zijn verwante concepten, maar deze relatie is complexer dan te stellen dat overdiagnose slechts een specifiek deel is van het grotere, complexe medicaliseringsconcept. Bovendien beïnvloedt medicalisering ook overdiagnose. In het viewpoint onderbouw ik dat de maatschappelijke context ook een invloed heeft op overdiagnose, en op medicalisering. Omdat de relatie tussen overdiagnose en medicalisering geen centraal onderwerp was in dit proefschrift, neem ik dit viepoint op als een intermezzo tussen de empirische hoofdstukken.

Hoofdstuk 4 beschrijft de resultaten van de case study over de mate van medicalisering bij de behandeling van een rughernia. De behandeling van een rughernia is interessant vanuit het perspectief van medicalisering omdat het een invasief probleem kan zijn, maar ook gekenmerkt wordt door een positief natuurlijk beloop. Er zijn conservatieve en invasievere behandelopties. De beslissing over de behandeling wordt door de patiënt en behandelaar samen genomen. Op dit niveau van patiënt en behandelaar zijn genuanceerde perspectieven op medicalisering ontwikkeld: terughoudende en ambivalente medicalisering. Om meer inzicht te krijgen in het besluitvormingsproces en de aanwezigheid van medicalisering daarin, is een interviewstudie uitgevoerd met 10 patiënten en 22 behandelaren.

Uit de analyses van de interviews kwam naar voren dat artsen en patiënten de probleemdefinitie van een rughernia delen. Een probleem een medische definitie geven wordt gezien als de essentie van medicalisering. In het geval van

onvolledige of betwiste medicalisering is de medische definitie van een probleem het onderwerp van discussie. In dit geval ging de discussie echter niet over de medische aard van het probleem, maar over de intensiteit en timing van de behandeling. De bereikte conclusie over een behandelkeuze of een doorverwijzing ging niet over de rughernia zelf, maar over de hoeveelheid onzekerheid en pijn die de patiënt aankon. Niet-medische argumenten beïnvloedden de verwachtingen en behandelbeslissingen. Terughoudende medicalisering was meer van toepassing op deze situatie dan ambivalente medicalisering.

Hoofdstuk 5 gaat dieper in op het besluitvormingsproces en op de aanwezigheid van gezamenlijke besluitvorming daarin (SDM). Hoewel de behandelopties voor een rughernia in de richtlijnen vrij eenduidig worden omschreven, wordt de praktijk gekenmerkt door praktijkvariatie. In dit onderzoek bleek dat individuele voorkeuren van zowel artsen als patiënten de behandelbeslissingen beïnvloedden. Ook verschilden de voorkeuren binnen de deelgroepen. Artsen, en met name neurologen, verschilden sterk van elkaar in hun opvatting over de beste timing van chirurgische behandeling en in hun opvatting over het te verwachten effect van een operatie of een epidurale injectie.

De gezamenlijke besluitvorming voor dit onderwerp zou verbeterd kunnen worden. Hoewel er op het eerste oog sprake lijkt te zijn van gezamenlijke besluitvorming, bleek vaak toch dat de overwegingen die achter een voorkeur of keuze staken niet altijd werden uitgesproken. Ook werd de mogelijke invloed van niet-medische argumenten op de behandelkeuze vaak niet besproken.

In het afsluitende discussiehoofdstuk kom ik terug op het doel van dit proefschrift: de relevantie van het concept medicalisering vaststellen voor gezondheidszorgbeleid, om de stijging van de kosten voor de gezondheidszorg af te vlakken. Het onderscheid tussen het perspectief op medicalisering op micro- meso- en macroniveau is niet nieuw voor dit onderzoeksveld, maar het blijft relevant. Medicalisering kan op elk van de drie niveaus aan de orde zijn en de niveaus kunnen elkaar beïnvloeden. Individuele behandelbeslissingen (microniveau) kunnen worden beïnvloed door contextuele kaders die op meso- of macroniveau worden bepaald. De casestudy uit hoofdstukken 4 en 5 liet bijvoorbeeld zien dat niet-medische argumenten van invloed waren op de behandelkeuzes bij een rughernia. Deze niet-medische argumenten worden mogelijk weer beïnvloed door macrobeleid op andere beleidsterreinen, zoals rondom ziekteverlof of arbeidsongeschiktheid. Dit is relevant voor gezondheidszorgbeleid omdat het

laat zien dat andere beleidsterreinen een invloed hebben op hoeveel we moeten investeren in de gezondheidszorg.

Het blijft echter moeilijk om een directe relatie te leggen tussen medicalisering en overmatig gebruik van gezondheidszorg. Medicalisering is een diffuus begrip dat moeilijk te operationaliseren is. Begrippen als overdiagnose en overbehandeling zijn waarschijnlijk nuttiger om overmatig gebruik van gezondheidszorg te concretiseren. Helaas delen ze met medicalisering dat het moeilijk is, zo niet onmogelijk, om vast te stellen welke patiënt wel of geen baat zal hebben bij een diagnose of behandeling. Medicalisering blijft aantrekkelijk en toegankelijk als term en kan een maatschappelijk debat aanwakkeren over de mogelijke medicalisering van problemen die bij het leven horen, of over hoeveel invloed van de gezondheidszorg gunstig of ongunstig is voor de samenleving. Voor beleidsvorming zijn andere concepten echter nuttiger.

Een recente discussie in de Nederlandse gezondheidszorg en zorgbeleid is die over gepaste of passende zorg. Passende zorg probeert een brug te slaan tussen de bekende problemen van de Nederlandse zorg, zoals afnemende toegang tot zorg, gezamenlijke besluitvorming, en kennis over de nadelen van de geneeskunde (inclusief overdiagnose en medicalisering). Passende zorg kan leren van de decennia van onderzoek naar medicalisering. Want net als met medicalisering dreigt passende zorg een overkoepelende term te worden, met weinig onderscheidend vermogen. Bovendien is gezamenlijke besluitvorming een morele plicht, maar een gedeeld besluit houdt niet per se rekening met contextuele of maatschappelijke overwegingen. Wanneer niet-medische argumenten van invloed zijn in de spreekkamer, moeten die expliciet worden gemaakt. Tot slot merk ik als beleidsmaker bij een grote zorgverzekeraar dat passende zorg meer een lobbymechanisme voor gevestigde belangen dreigt te worden dan een beweging die de zorg ook in de toekomst toegankelijk houdt. De discussie rond passende zorg zou het conceptuele niveau moeten overstijgen en moeten investeren in toegepaste kennis en in nauwkeurige *checks and balances*, om de toekomst van de Nederlandse gezondheidszorg daadwerkelijk te verbeteren.

Publiekssamenvatting

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Wanneer het gaat over het beteugelen van de zorgkosten en van de stijging ervan, wordt ook vaak gezegd dat verdere 'medicalisering' moet worden voorkomen. Medicalisering is de ontwikkeling waarbij mensen voor steeds meer problemen een oplossing zoeken in het medische domein. De gezondheidszorg, en dus medicalisering, hebben bijgedragen aan een betere kwaliteit van leven en aan het verhogen van de levensverwachting. Maar, niet voor elk probleem is de medische oplossing de beste. Het is ook mogelijk dat een euro die wordt uitgegeven in de gezondheidszorg méér oplevert als die wordt besteed aan een ander maatschappelijk doel, zoals bijvoorbeeld onderwijs of preventie. Het is dus begrijpelijk dat er gezocht wordt naar meer 'grip' op medicalisering, als daarmee onzinnige zorg kan worden voorkomen.

Het begrip medicalisering bestaat al meer dan 50 jaar, maar er is relatief weinig empirisch onderzoek naar gedaan. Ook is er weinig bekend over de relatie tussen medicalisering, beleid en zorgkosten. Dit proefschrift had als doel de relevantie van medicalisering voor gezondheidszorgbeleid te onderzoeken. Gezien de onbekendheid van dit onderwerp is gestart met een review naar medicalisering in empirisch onderzoek. Daarnaast is een casestudie uitgevoerd, naar de eventuele medicalisering van rugherniabehandelingen in Nederland, waarbij ook is ingezoomd in de besluitvorming tussen patiënten en behandelaren. Dit proefschrift beantwoordt volgende onderzoeksvragen:

1. Hoe wordt medicalisering gedefinieerd in empirisch, wetenschappelijk onderzoek? [Hoofdstuk 2]
2. In welke mate en in welke vorm is medicalisering aanwezig bij rughernia-behandelingen in Nederland? [Hoofdstuk 4]
3. Hoe beslissen Nederlandse rughernia patiënten en hun behandelaren over de keuze tussen meer en minder gemedicaliseerde behandelopties? [Hoofdstuk 5]

Hieronder vat ik de uitgevoerde onderzoeken en hun uitkomsten samen. Ik begin met wat relevante achtergrondinformatie over de ontwikkeling van het begrip medicalisering. Daarna vat ik de uitkomsten van de twee onderzoeken elk samen. Vervolgens bediscussieer ik de relevantie van deze uitkomsten voor gezondheidszorgbeleid.

50 jaar medicalisering

Medicalisering als term en onderzoeksgebied is afkomstig uit de sociale wetenschappen en de antipsychiatrie beweging en startte in de jaren zestig en zeventig van de vorige eeuw. Bekende auteurs uit dit tijd zijn Illich en Zola. Zola stelde dat traditionele instituties die de samenleving vorm hadden gegeven, zoals religie en de wet, geleidelijk vervangen werden door de gezondheidszorg. Hij introduceerde 'medicalisering' als omschrijving hiervoor. Illich beschrijft in zijn bekende boek 'Limits to medicine' een vergelijkbaar proces, dat hij toeschreef aan 'expansiedrift' van artsen. Hij gebruikt hiervoor overigens niet de term 'medicalisering'.

Medicalisering begon dus als een kritisch perspectief. In de jaren tachtig en daarna verbreedde deze zienswijze. Conrad en Schneider introduceerden een onderscheid in drie niveaus van medicalisering: het conceptuele, het institutionele en het interactionele niveau.

- Medicalisering op het conceptuele niveau vindt plaats als een probleem voortaan in medische termen wordt omschreven en begrepen. Zo werden epileptische aanvallen opgevat als onverklaarbaar of een straf van God, tot er een medische verklaring voor kwam.
- Medicalisering op het institutionele niveau gaat over de vertaling van medische problemen in protocollen en regelgeving. Een voorbeeld is het Nederlandse basispakket, dat door het ZorgInstituut wordt vastgesteld. Zorgverzekeraars zijn verplicht de zorg in het basispakket voor hun verzekerden te vergoeden. De institutionalisering van dit basispakket geeft rechtszekerheid, maar het geeft ook een blauwdruk van wat er van de gezondheidszorg in Nederland verwacht mag worden en met welke problemen mensen wel en niet in de gezondheidszorg terecht kunnen.
- Tot slot is er medicalisering op het interactionele niveau. Dit vindt plaats als in de interactie tussen dokter en patiënt een medische oplossing wordt gevonden voor een probleem waar de patiënt mee kampt. Dit is bijvoorbeeld het geval als een arts slaapmedicatie voorschrijft voor iemand die slechter slaapt omdat hij of zij een geliefde is verloren en rouwt.

Een meer algemene definitie die Conrad in 1992 presenteerde, is als volgt: "*Medicalisering bestaat uit het definiëren van een probleem in medische termen, het gebruik van medische terminologie om een probleem te omschrijven, het gebruik van een medisch kader om een probleem te begrijpen, of het gebruik van medische interventies om een probleem te behandelen*" [eigen vertaling]. In de toelichting hierbij stelt hij dat de definitie van een probleem als 'medisch' het kernelement van medicalisering is. In 2013 scherpte Conrad zijn definitie verder aan tot "Medisch maken" [eigen vertaling].

Recenter zijn er ontwikkelingen in het onderzoek naar medicalisering die een genuanceerdere en specifiekere definitie van medicalisering noodzakelijk maken. Twee onderzoeken bestudeerden medicalisering op het interactionele niveau en ontwikkelden verschillende, nieuwe nuances op de definitie van medicalisering. Daarbij is het onderscheid tussen 'terughoudende medicalisering' en 'ambivalente medicalisering' van belang:

- Terughoudende medicalisering werd ontwikkeld door Moloney. Zij onderzocht de interactie tussen huisartsen en patiënten met klachten van slapeloosheid. Ze stelde vast dat zowel patiënten als artsen verklaringen en mogelijke oplossingen voor het probleem buiten het medische domein zochten. Denk aan een slechtere slaap door stress of zorgen en mogelijke verbetering bij een betere slaaphygiëne en meer ontspanning. Maar toch kwamen patiënten na het consult vrijwel altijd naar buiten met een recept voor slaapmedicatie. Hoewel zowel de arts als de patiënt zeiden eigenlijk terughoudend te willen zijn met het medicaliseren van dit probleem, was dat toch de uitkomst. Dit omdat ze het gevoel hadden geen betere oplossingen beschikbaar te hebben.
- Ambivalente medicalisering is beschreven door Crowley-Matoka en True in de context van artsen in de Verenigde Staten die veteranen behandelen in eerstelijns centra. Pijn en pijnbehandeling is een terugkerend probleem voor deze patiëntgroep, maar afhankelijkheid van (pijn)medicatie en verslavingen komen ook regelmatig voor. Artsen die bewust een verslaving in stand houden of voeden kunnen daarvoor worden vervolgd. De artsen in deze studie hadden een ambivalente verhouding ten opzichte van de medicalisering van pijn ontwikkeld, omdat ze het moeilijk vonden om het onderscheid te maken tussen 'echte' pijn en voorgewende pijn.

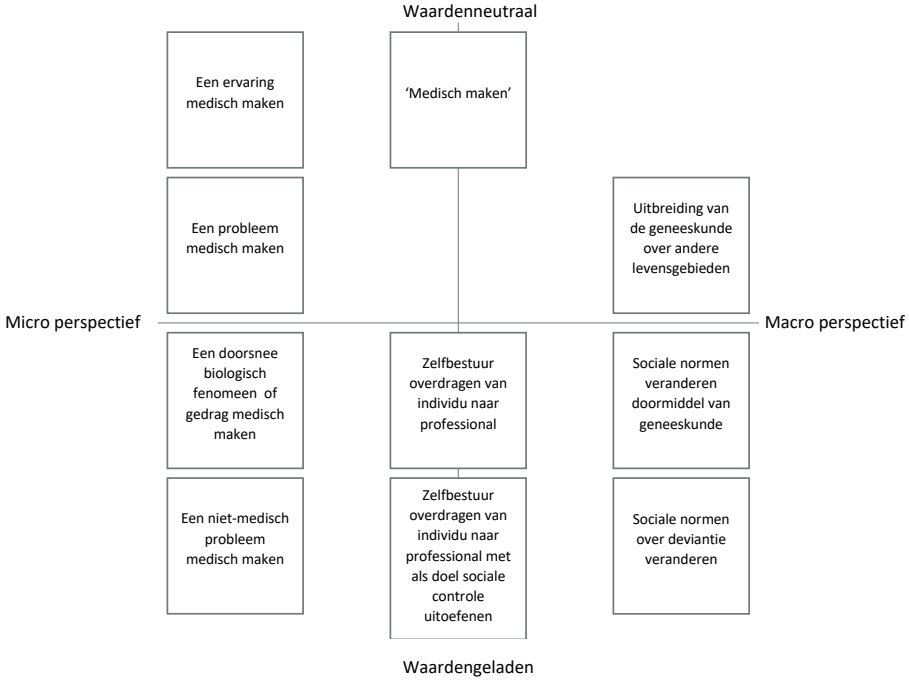
Het verschil tussen deze twee perspectieven op medicalisering op het interactionele niveau ligt tussen de probleemdefinitie en de oplossing. Bij terughoudende medicalisering staat de diagnose niet zozeer ter discussie, maar wel de medische

verklaring en oplossing hiervoor. Betrokken partijen gaan in onderhandeling over probleem en oplossing en kunnen allebei -deels- ontevreden zijn met de gemedicaliseerde uitkomst van de onderhandeling. In het geval van ambivalente medicalisering wordt de medische aard van het probleem en de oplossing niet ter discussie gesteld. Maar de ambivalentie ligt in het onderscheid tussen 'echte' patiënten en de patiënten die de diagnose niet voldoende of zelfs helemaal niet verdienen.

De definitie van medicalisering in empirisch, wetenschappelijk onderzoek

Om de eerste onderzoeksvraag te kunnen beantwoorden heb ik een *scoping review* uitgevoerd. Een *scoping review* is een systematische manier om alle literatuur over een onderwerp in kaart te brengen, met als doel om een overzicht te geven van wat al bekend is over het onderwerp en waarover nog kennis ontbreekt. Voor dit *scoping review* zijn 3027 gepubliceerde, Engelstalige onderzoeken beoordeeld. Hieruit zijn de onderzoeken geselecteerd waarbij sprake was van voldoende empirische onderbouwing én een heldere definitie van het begrip 'medicalisering' – het ontbreken daarvan maakt studies immers moeilijk met elkaar te vergelijken.

Van de resterende 50 studies hebben we per studie in kaart gebracht hoe zij medicalisering definieerden en waar de studie over ging. De definities bleken gegroepeerd te kunnen worden in 10 categorieën, die op twee variabelen, ofwel assen, van elkaar verschilden. Dit is weergegeven in de volgende figuur:



FIGUUR 1 - *Categorieën van definities van medicalisering in empirisch, wetenschappelijk onderzoek*

- Op de ene as staat het perspectief van de definitie. Aan het ene uiterste van de as staan de definities die gericht zijn op het individu (micro) en aan het andere uiterste staan de definities die gericht zijn op het niveau van de samenleving (macro). Daartussen liggen de definities die weliswaar het micro perspectief overstijgen, maar ook niet expliciet macro uitkomsten adresseren.
- De andere as gaat over de waarde-geladenheid van de definitie: aan het ene uiterste staan de definities die neutraal zijn opgesteld en geen (impliciet) oordeel uitspreken over medicalisering. Aan het andere uiterste staan de definities die wel een oordeel bevatten over medicalisering.

Ter illustratie van de fundamentele verschillen tussen twee uitersten in dit definitiemodel: één van de categorieën is 'een niet-medisch probleem medisch maken'. Dit gaat over individuele ervaringen, en heeft dus een micro-perspectief. Daarbij ligt er een waardeoordeel in de definitie besloten: het gaat expliciet om niet-medische problemen. Een andere categorie van definities is 'uitbreiding van de geneeskunde over andere levensgebieden'. Een definitie als deze heeft een macro-perspectief en er spreekt geen waardeoordeel uit.

De voornaamste conclusie van dit *scoping review* is dat het onderzoek naar medicalisering heel gevarieerd is. Medicalisering lijkt eenduidig in populair taalgebruik, maar het empirisch onderzoek ernaar laat zien dat de definitie ervan varieert. Dit maakt de onderlinge vergelijkbaarheid van studies niet groot, omdat ze conclusies trekken over nét iets anders. Met andere woorden: de externe validiteit van dit onderzoeksveld is niet hoog. Dit is op zichzelf niet problematisch, zolang hiermee voldoende rekening wordt gehouden. Verschillende perspectieven kunnen elkaar versterken. Onderzoek naar de impact van medicalisering op de verschillende niveaus (micro, meso, macro) kan elkaar aanvullen en verrijken. De voorwaarde is dan wel dat auteurs rekenschap afleggen over het perspectief dat ze hanteren (bij de definitie die ze gebruiken) en dat ze hun uitkomsten relateren aan het gekozen perspectief. Dat gebeurt lang niet altijd en dat maakt dat het onmogelijk is om de resultaten te combineren tot een overstijgende conclusie. Studies kunnen enkel op hun individuele merites beoordeeld worden.

Casestudie: rugherniabehandeling in Nederland

Het *scoping review* leverde veel informatie op over hoe medicalisering wordt gezien in wetenschappelijk onderzoek. Om meer inzicht te krijgen in eventuele medicalisering in de Nederlandse zorg en de mechanismen die daaraan ten grondslag liggen, heb ik een casestudie uitgevoerd naar medicalisering bij rugherniabehandelingen. De behandeling van rughernia's is interessant in relatie tot medicalisering omdat er een grote variatie is in gemaakte behandelkeuzes: van conservatief (wachten tot het over gaat, eventueel met pijnmedicatie) tot invasief (een rugoperatie). Welke beslissingen nemen patiënten en behandelaren in deze situatie? Een beter begrip van de factoren die bijdragen aan de keuze voor intensievere behandeloptie, draagt bij aan meer inzicht in het optreden van medicalisering.

Rughernia: wat is het en hoe wordt het behandeld

Een rughernia kan gepaard gaan met veel pijn en kan zeer beperkend zijn voor het dagelijks leven van een patiënt. Tegelijkertijd is het natuurlijk beloop ervan over het algemeen gunstig: 90% van de patiënten geneest vanzelf en bij 70% van de patiënten gebeurt dit binnen 12 weken. De klachten die met een rughernia gepaard gaan worden veroorzaakt doordat een tussenwervelschijf uitstulpt tussen de rugwervels en drukt op een zenuw die naar het been loopt. Hierdoor ervaart de patiënt pijn in één van de benen. Die pijn kan invaliderend zijn en patiënten zijn vaak een periode niet in staat om te werken of hun andere taken te vervullen.

Hoewel de kans op spontaan herstel groot is, is het nog niet mogelijk om op individueel niveau te voorspellen wat het beloop zal zijn. Nederlandse patiënten die last van een rughernia krijgen, gaan over het algemeen eerst naar hun huisarts. De huisarts kan de diagnose stellen op basis van het klinisch beeld. De richtlijn voor huisartsen raadt aan om patiënten 6 tot 8 weken conservatief te behandelen met pijnstilling en beweegadvies. Daarna kan de huisarts de patiënt doorverwijzen naar de neuroloog, als er onvoldoende herstel is. De neuroloog beoordeelt de patiënt opnieuw en stelt eventueel de pijnbestrijding bij. Zowel de huisarts als de neuroloog kunnen een MRI-scan laten uitvoeren. Zowel de richtlijn voor huisartsen als die voor neurologen raden een MRI-scan af als er sprake is van eenduidige symptomen. De neuroloog kan de patiënt doorverwijzen naar de neurochirurg, als een herniaoperatie een reële behandeloptie is. Ook de neurochirurg beoordeelt de patiënt opnieuw en kan eventueel een rugherniaoperatie uitvoeren, waarbij de uitstulping wordt weggehaald.

Een rughernia kan conservatief of invasiever, zoals operatief, behandeld worden. Conservatieve behandeling is pijnstilling en afwachten van het beloop. Patiënten krijgen dan het advies zo veel als mogelijk normaal te blijven bewegen. Als dit niet snel genoeg tot verbetering van de klachten leidt, komen andere behandelmogelijkheden in beeld. De invasieve behandeling is een operatie waarbij de uitstulping die drukt op de zenuw weggenomen wordt. Er is ook nog de mogelijkheid van epidurale injecties: dit zijn pijnstillende injecties die het gebied rondom de tussenwervelschijf verdoven en zo de pijn verlichten en meer beweging mogelijk maken. Dit geeft de patiënt wat armslag en het lichaam meer tijd en gelegenheid voor natuurlijk herstel.

Medicalisering bij rugherniabehandelingen

Er is geen uniforme, perfecte behandelkeus voor een rughernia. De beste behandeling verschilt per patiënt en is er vooral van afhankelijk of er natuurlijk herstel optreedt, hoe lang dat duurt en hoeveel pijn en impact van de rughernia de patiënt kan combineren met zijn of haar dagelijks leven. Zowel arts als patiënt kunnen dit niet goed voorspellen. Juist daarom is dit zorgtraject zo interessant vanuit het perspectief van onderzoek naar medicalisering: gezien de kans op natuurlijk herstel is de intensiteit van de behandeling en de timing daarvan essentieel. Wanneer is het moment om tot drastischer maatregelen over te gaan? Met andere woorden: wanneer wordt een rughernia meer of minder gemedicaliseerd en welke argumenten zijn daarbij belangrijk?

Aan dit onderzoek deden alleen patiënten mee met langduriger klachten, bij wie het natuurlijk herstel niet direct inzette. Hierdoor stond de medicalisering van dit probleem in absolute zin (de verklaring van het probleem als 'medisch') niet ter discussie. Maar in dit onderzoek kon ik een laagje dieper kijken en de recentere genuanceerdere perspectieven op medicalisering onderzoeken. Ik interviewde patiënten (10), huisartsen (7), neurologen (6) en neurochirurgen (6).

Met patiënten ging het gesprek over hoe zij de periode van de herniapijn ervaren hadden, welke behandelopties ze hadden en welke keuzes ze daarin gemaakt hebben en waarom. Met de professionals gingen de gesprekken over of zij regelmatig herniapatiënten troffen in hun werk en hoe zij de diagnose stelden. Hoe legden zij een hernia uit aan hun patiënten? Welke behandelopties en mogelijkheden voor ondersteunend onderzoek hadden zij en hoe keken ze naar die verschillende mogelijkheden? Wanneer stuurt een professional een patiënt door naar een andere zorgverlener?

De analyse van de interviews leverde verschillende inzichten op. De belangrijkste daarvan voor deze samenvatting zijn de definitie van het probleem, timing van doorverwijzing en de verschillende argumenten voor interventie. De definitie van het probleem werd gedeeld door artsen en patiënten: artsen gaven een biomedische verklaring van een uitstulpende tussenwervelschrijf en patiënten accepteerden en reproduceerden die. Hierover was geen discussie. Maar in de opvolging van het probleem was er minder sprake van eensgezindheid. Patiënten accepteerden de definitie maar konden die niet moeiteloos voor zichzelf accepteren als er geen beeldvorming was gedaan, ter verificatie. Voor artsen was de klinische diagnose wel onbetwist. Zij legden dan weer veel nadruk op het feit dat mensen zonder klachten ook een hernia kunnen hebben. Voor een 'echte' rughernia moeten er corresponderende pijnklachten zijn. Voor de patiënten was dit onderscheid moeilijk te bevatten.

Over de volgende stap, kiezen uit de behandelopties en het onderhandelen tussen onzekerheid, pijn en individuele kenmerken waren zowel patiënten als behandelaren minder eenduidig. Voor patiënten was de hoeveelheid pijn die zij hadden en de mate waarin ze hun dagelijks leven daaromheen konden inrichten erg relevant. Ook kon de ene patiënt beter omgaan met de onzekerheid van de onvoorspelbaarheid van het traject dan de andere, en dat maakte een planbare operatie voor sommige patiënten een aantrekkelijk alternatief. De geïnterviewde artsen verschilden sterk in hun opvattingen over timing van de intensievere interventies en ook over de werkzaamheid van epidurale injecties. Dit had effect op

hun doorwijsgedrag. Met name neurologen waren erg invloedrijk in dit zorgtraject omdat zij al dan niet doorverwijzen naar de neurochirurg. Met de timing van die doorverwijzing konden zij de duur van het zorgtraject en daarmee de kans op natuurlijk herstel beïnvloeden.

In deze casestudie werden onderzoeksvraag 2 en 3 beantwoord. Het korte antwoord op de tweede onderzoeksvraag was: ja, er is medicalisering aanwezig bij rugherniabehandelingen in Nederland. Dat was vrij snel duidelijk: patiënten en behandelaren deelden de definitie van het probleem en geen van beiden trok de betrokkenheid van de gezondheidszorg bij dit probleem in twijfel. Interessanter was het of hier sprake is van ambivalente of terughoudende medicalisering. Hoewel er elementen van beide herkenbaar waren in de analyse, was terughoudende medicalisering prominenter aanwezig. In de afweging en timing van besluiten ging het niet zozeer over de probleemdefinitie, maar vooral over de hoeveelheid ongemak die de patiënt aankon, de mate waarin pijnstilling kon helpen om tijd te overbruggen en de onzekerheid van het beloop. Patiënten die het advies kregen nog even te wachten met ingrijpen hadden hier soms moeite mee. Artsen verwezen soms met tegenzin door, ook als zij zelf inschatten dat tijd de belangrijkste factor was voor het herstel.

Ten aanzien van de derde onderzoeksvraag werd duidelijk dat de besluitvorming in dit zorgtraject werd beïnvloed door individuele voorkeuren van zowel de patiënt als de arts. De behandelbesluiten en besluiten over doorverwijzingen werden niet altijd gezamenlijk genomen, door die vaak onuitgesproken voorkeuren. Dit leidde ertoe dat er nog altijd veel variatie in het behandeltraject kon bestaan.

Discussie: toepasbaarheid van medicalisering voor gezondheidszorgbeleid

Medicalisering is een aantrekkelijke term die veel mensen aanspreekt en die gevoelsmatig snel te begrijpen is. Echt grip krijgen op medicalisering en het concretiseren blijkt echter nog niet zo makkelijk. Uit het *scoping review* dat ik uitvoerde kwamen maar liefst tien categorieën van definities naar voren. Er is dus geen uniform begrip van wat het precies inhoudt. In de casestudie vond ik weliswaar dat de medicalisering van rughernia's in absolute zin niet ter discussie stond, maar ook dat er vooral sprake is van een genuanceerde, complexere versie van terughoudende medicalisering. In de onderlinge interactie spelen de individuele voorkeuren van patiënten en behandelaren een rol, maar maakten beide partijen die voorkeuren lang niet altijd expliciet. Hierdoor werd er niet altijd gezamenlijk besloten.

Wat leert dit ons over medicalisering als concept en welke lessen kunnen we trekken voor gezondheidszorgbeleid dat 'grip' geeft op verdere medicalisering? Ten aanzien van het concept medicalisering laten de resultaten van mijn deelonderzoeken zien dat behandelbeslissingen niet altijd gemaakt worden op basis van medische argumenten. De voorkeuren van de behandelaar en patiënt spelen een rol, maar ook de context waarin de patiënt leeft en werkt. Dat wisten we al, maar dit onderzoek maakt duidelijk dat medicalisering geen absolute staat is, maar het deels ongewenste en terughoudende resultaat kan zijn van een interactie tussen arts en patiënt. De argumenten en factoren die in dat gesprek belangrijk zijn voor beide partijen, zijn soms ook te beïnvloeden via andere wegen dan via de gezondheidszorg.

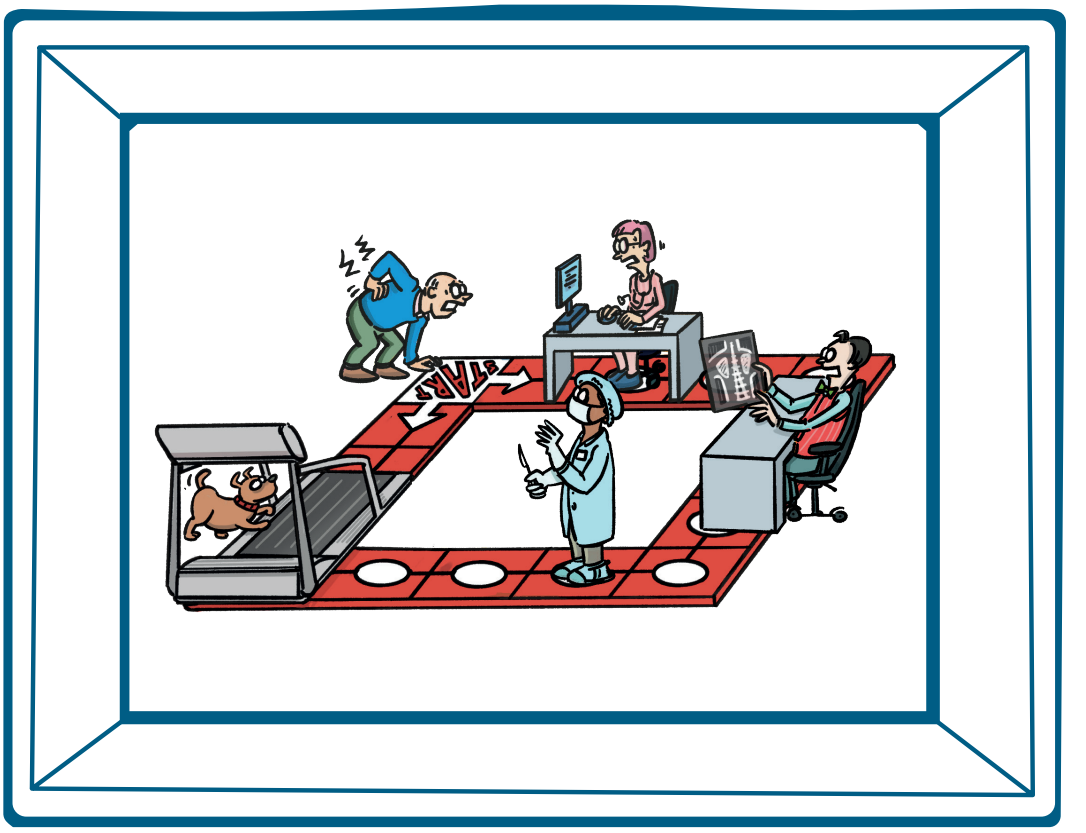
Dat is relevant voor gezondheidszorgbeleid, omdat het laat zien dat andere beleidsterreinen hun weerslag kunnen hebben op hoeveel geld en arbeid we in de gezondheidzorg moeten steken. Als rugherniapatiënten zich geen zorgen hoeven te maken over hun inkomen als ze thuis komen te zitten, zijn ze mogelijk eerder bereid de onzekerheid van het wachten op natuurlijk herstel te accepteren. Door samenhangend beleid te maken op verschillende terreinen hoeft de gezondheidszorg niet het snelste redmiddel voor elk probleem te leveren.

Tegelijkertijd is gebleken dat medicalisering een diffuus begrip is dat moeilijk te operationaliseren is in onderzoek. Met andere woorden: het is moeilijk meetbaar en concreet te maken. Het is ook moeilijk te vertalen naar concrete aandoeningen en behandelingen, of naar individuele situaties. Hiervoor zijn concepten als overdiagnose en overbehandeling meer geschikt, al hebben die met medicalisering gemeen dat het nog moeilijk is voor de individuele patiënt te voorspellen of die baat zal hebben bij de diagnose. Dat maakt het lastig vertaalbaar naar beleid. Het concept blijft echter aansprekend en relevant voor de maatschappelijke discussie over de plek die zorg inneemt in de samenleving, ook ten opzichte van andere beleidsvelden zoals onderwijs, welzijn en sociale zekerheid.

Ook kan het concept van medicalisering een rol spelen in de actuele discussie *binnen* het zorgveld met betrekking tot het begrip 'passende zorg': het beoogde antwoord op de schaarste in de zorg van de toekomst. Het doel van passende zorg is om nu en in de toekomst onderbouwd te kiezen voor behandelingen met medische meerwaarde, die niet onnodig op de arbeidsmarkt en het zorgbudget drukken. De discussie over passende of passende zorg wordt onder andere gevoerd door organisaties als het ministerie van VWS, Het Zorginstituut, vertegenwoordigers van artsen en zorgaanbieders, zorgverzekeraars en patiëntvertegenwoordigers.

Net als met medicalisering dreigt passende zorg een overkoepelende term te worden, met weinig onderscheidend vermogen. In de discussie over passende zorg gaat het uiteindelijk ook over de verdeling van middelen als geld en invloed over alle partijen. Als beleidsmaker bij een grote zorgverzekeraar merk ik dat passende zorg meer een lobbymechanisme voor gevestigde belangen dreigt te worden dan een beweging die de zorg ook in de toekomst toegankelijk en betaalbaar houdt. De discussie rond passende zorg zou het conceptuele niveau moeten overstijgen en moeten investeren in toegepaste kennis en in nauwkeurige *checks and balances*, om de toekomst van de Nederlandse gezondheidszorg daadwerkelijk te verbeteren.

S


TAR

Appendices

Dankwoord

Mijn naam staat voor op dit proefschrift, maar het is dankzij alle fijne en betrokken mensen om mij heen dat dit boekje er is. Ik streef ernaar dit dankwoord kort en bondig te houden en selecteer daarom de meest direct betrokkenen voor een persoonlijke noot. Dit proefschrift heeft de nodige tijd gekost en zonder alle steun, interesse en vriendschap van de mensen om mij heen was het me niet gelukt.[1]

Patrick, ik bewonder in jou hoe jij je werkdruk en werklust weet te combineren met betrokkenheid en interesse in anderen. Het lezen van manuscripten ("ergens in De Stapel") schoot er wel eens bij in, maar dat zette je altijd recht. Daarnaast had jij altijd het beleidsinhoudelijke en economische perspectief paraat, als Gert en ik iets te sociologisch werden. Dankjewel voor je doorzettingsvermogen, je vertrouwen en je betrokkenheid.

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1. Ik kan het toch niet laten ook Elles, Wytske, Jolien, Ilse, Marloes, Roza, Anke, Nelleke, Dineke, Yvonne, alle VGZ-collega's en in het bijzonder Anneloes, Seyno, Lennert en Marjolein te noemen. En natuurlijk mamma, pappa, Han, Derk, Kertu, Marluus, Marco, Cecile, Sijmen, Rinske en Nout (en Robin, Frans, Benthe, Sybe en Tyska). Bedankt voor het oppassen en voor alle vriendschap, gezelligheid, boekenclubs, pour-it-outs, betrokkenheid en interesse voor en steun bij mijn proefschrift van de afgelopen jaren!

Mijn tijd bij het Radboudumc begon niet bij IQ-healthcare. Voor ik aan mijn promotietraject begon heb ik eerst een eenjarig project bij -toen nog- de afdeling Health Evidence, en daarna een eenjarig project bij de afdeling Neurologie afgerond. Bij HEV ontmoeten Tessel en ik elkaar op kamer 3.10. We hadden en hebben veel gemeen en tegenwoordig zien we elkaar met al ons kroost op de kinderboerderij: wie had dat gedacht, 14 jaar(!) geleden? Bij Neurologie werkte ik gelijk op met Frouke, die ook recent gepromoveerd is. Geweldig dat we het toch maar mooi allebei hebben volbracht!

Ik wil ook alle collega's van IQ-healthcare bedanken voor alle gezelligheid en uitjes, in het bijzonder mijn Celsus-collega's. Karel-Peter, Angelique, Hilly en Jolanda waren in mijn tijd Celsus-intimi en allemaal super betrokken: heel veel dank! En Celsus was lang niet zo leuk en leerzaam geweest zonder Niek, Joost, Inger, Florien en Floris: heel erg bedankt voor jullie gezelligheid, behulpzaamheid en de vele discussies. Met Niek, Florien en wijlen plant Henk deelde ik met veel plezier onze troosteloze kelderkamer. Joost en ik konden heerlijk kibbelen, aangevuld met 'rechtse praat' van Floris. En de kletspraatjes met Inger op Lync fleurden de dagen op. Dankzij jullie had ik altijd zin om naar mijn werk te gaan. Het was moeilijk paranimfen te kiezen uit al deze Radboudvrienden, maar ik ben heel blij dat Joost en Tessel achter mij staan tijdens de verdediging.

Alleen voor Guido maak ik een uitzondering in de scheiding tussen werk en privé van dit dankwoord. Ik heb dit promotieonderzoek afgerond in mijn eigen tijd en dus in ons eigen huis. En daar was jij er, samen met Simon, Douwe en Spijkertje. Dankjewel dat je me bleef motiveren om het af te maken en voor je steun en relativering. Zonder jullie had ik het niet zo lang volgehouden.

Research Data Management paragraph

This study was conducted following the Netherlands Code of Conduct for Research Integrity.

Ethics and privacy

The empirical studies in this thesis were not subject to the Dutch Medical Research Involving Human Subjects Act (WMO). An exemption was obtained from the Medical Ethics Review Committee 'METC Oost-Nederland' (2015-1760). The privacy of the participants in the study was warranted by the use of anonymization. Informed consent was obtained verbally from the professionals and in writing from patients. The sensitivity and confidentiality of the raw qualitative data makes sharing of the data without compromising confidentiality and privacy impossible, therefore consent for sharing of the raw data was not asked from the participants.

Data collection and storage

The data that was created for this thesis' case study was obtained through interviews with respondents, that were recorded and transcribed. The data were anonymized during transcription. However, because patients and physicians also shared personal details and experiences in the interviews, individuals are possibly traceable through the transcripts. During the research phase, the transcripts were stored and analyzed on the department server and were only accessible by project members working at the Radboudumc. After analysis and publication, the data were archived at the department server, with strictly restricted access.

Data sharing according to the FAIR principles

It is the policy of Radboudumc to comply with the FAIR principles and share with the scientific community any data obtained in research projects, as long as ethical and legal regulations permit it. Because no consent was obtained for reuse, the data collected for this thesis was archived with closed access. The retention period for these data expired 10 years after the METC exemption (2015-1760) on April 30, 2025. After the thesis defense, the data will be destroyed.

Curriculum vitae

Professional experience

2014-now	Senior policy developer with Cooperation VGZ
2018-2024	Policy developer with Cooperation VGZ
2018-now	Senior policy developer with Cooperation VGZ.
2013-2018	PhD candidate with Radboudumc, Nijmegen.
2012-2013	Scientific researcher with the Radboudumc, Nijmegen. Department of Neurology.
2011-2012	Scientific researcher with the Radboudumc, Nijmegen. Department of Health Evidence.
2011	Scientific researcher with Radboud University, Nijmegen. Faculty of Management Sciences.

Education

2013-2018	Radboudumc; PhD; IQ Healthcare; Celsus Academy.
2009-2010	Radboud University Nijmegen; Master Milieu- Maatschappij-wetenschappen, Faculty of Management Sciences.
2007-2009	Radboud University Nijmegen; Research Master Social Cultural Science, Faculty of Social Sciences.
2004-2007	Radboud University Nijmegen; Bachelor Sociology, Faculty of Social Sciences.
2006-2008	Radboud University Nijmegen; Minor public administration, Faculty of Management Sciences.
2005-2008	Radboud university Nijmegen, Honors program.
1998-2004	Carolus Clusius College, Zwolle. Pre-university education.

Scientific publications

- Stadhouders, N, Van Vliet, E, Brabers, A, Van Dijk, W, Onstwedder, W. (2023). Should Commercial Diagnostic Testing Be Stimulated or Discouraged? Analyzing Willingness-to-Pay and Market Externalities of Three Commercial Diagnostic Tests in The Netherlands. BMC Health Service Research DOI: https://doi.org/10.21203/rs.3.rs-1833777/v1
- Van Dijk, W, MAC Tanke, MJ Meinders, E Verkerk, PPT Jeurissen, G Westert (2022). A cascade of decisions meet personal preferences in sciatica treatment decisions. BMJ Open Quality DOI: 10.1136/bmjoq-2021-001694
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- Van Dijk, W, M. Meinders, M. Tanke, G. Westert and P. Jeurissen (2020). "Medicalization Defined in Empirical Contexts – A Scoping Review." International Journal of Health Policy and Management 9(8): 327-334
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Reports

- Gewoon even kijken of ik nog gezond ben. Ervaringen met health checks. Celsus report, first author, 2017.
- 10 jaar Zvw: zijn de ambities waargemaakt? KIZ: over kwaliteit en veiligheid in zorg, third author, 2017.
- Keuzes in het verzekerde pakket: mag de burger er ook iets van vinden? Houdingen van burgers t.a.v. vruchtbaarheidsbehandelingen in het verzekerde pakket. Celsus report, second author, 2016.
- De relatie tussen behandelduur en behandelsucces in de GGZ. Celsus report, third author, 2016.
- Verspilling in de langdurige zorg. Een verkenning van de literatuur. Celsus report, first author, 2015.
- Consultatie van patiënten in de besluitvorming over het basispakket. Onderzoeksrapportage voor ZonMw project, first author, 2012.

Other relevant activities

2017 Commissielid Maat houden met medisch handelen – Gezondheidsraad

PhD portfolio of Wieteke van Dijk

Department: **IQ Health**
PhD period: **01/12/2013 – 01/04/2018**
PhD Supervisor(s): **Prof. dr. G.P. Westert; Prof. dr. P.P.T. Jeurissen**
PhD Co-supervisor(s): **Dr. M.J. Meinders; Dr. M.A.C. Tanke**

Training activities	Hours
Courses	
Winteracademie economie en beleid (2014)	28.00
RU - Management voor Promovendi (2015)	84.00
RIHS - Introduction course for PhD candidates (2015)	15.00
Radboudumc – Scientific Integrity	28.00
RU – Academic writing for PhD Candidates (2016)	84.00
RU - Education in a Nutshell (2016)	28.00
Radboudumc - Implementatiecursus van IQ Healthcare (2017)	28.00
RU - Qualitative Research Methods and Analysis (2017)	84.00
Examination Board EMWO - BROK course and examination (2017)	42.00
Seminars	
Radboud Grand Rounds (8x)	2.00
Radboud Research Rounds (5x)	1.25
Conferences	
British Sociological Association - Medical sociology conference (2015) – poster presentation	0.25
Preventing overdiagnosis 2017: towards responsible global solutions (2017) – oral presentation	0.50
Radboudumc - PhD retreat (2014, 2015, 2016)	1.00
Celsus-Talma inventational conference: 'Steeds meer zorg, een betaalbare oplossing?' – poster presentation	0.25
Afsluitend Celsus congres en presentatie van de Celsus boekenreeks 'Vijf jaar Celsus, academie voor betlaabare zorg' – poster presentation	0.25
Teaching activities	
Lecturing	
Coordinator and lecturer of the BMS 'Financial Sustainability and Solidarity in Healthcare: The Dutch Healthcare System's Challenges' (2015, 2016, 2017)	30.00
Supervision of internships / other	
Supervision of internship, research project (2018)	12.00
Total	**468.7**

&

About the author

Wieteke was born in Zwolle on the 27th of February 1986. She completed her VWO (pre-university education) in 2004 at the Carolus Clusius College in Zwolle. She subsequently studied Sociology at the Radboud University Nijmegen, obtaining her bachelor Sociology in 2007 and the Research Master Social and Cultural Science: Comparative Research on Societies in 2009. In 2010 she obtained the Master Environment and Society Studies, also at the Radboud University.

In 2011 she started as a researcher at the Radboudumc. Before starting her PhD project, she first finished two one-year research projects. One about the consultation of patient advocates in governmental advisory about the basic healthcare package. In the other she developed an early stage Parkinson's Disease start-medication decision aid. In November 2013 she started her PhD with the Celsus Academy at IQ Healthcare.

After a little over four years at IQ healthcare, Wieteke took a position with Cooperation VGZ as policymaker. Currently she is a senior policy maker acute care.

Wieteke lives with Guido, their sons Simon and Douwe, and their lovebird Spijkertje in Nijmegen.

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Appendix

Table 2 - *Overview of included studies in ….*

Authors	Year	Title	Journal
Adams	2013	Medicalization and the Market Economy: Constructing Cosmetic Surgery as Consumable Health Care	Sociological Spectrum: Mid-South Sociological Association
Authors	**Year**	**Title**	**Journal**
Arney & Rafalovich	2007	Incomplete syllogisms as techniques of medicalization: the case of direct-to-consumer advertising in popular magazines, 1997 to 2003	Qualitative Health Research
Barker	2008	Electronic support groups, patient-consumers, and medicalization: the case of contested illness	Journal of health and social behavior
Barker	2011	Listening to Lyrica: contested illnesses and pharmaceutical determinism	Social Science & Medicine
Barker	2014	Mindfulness meditation: Do-it-yourself medicalization of every moment	Social Science & Medicine
Becker & Nachtigal	1992	Eager for medicalization: the social production of infertility as a disease	Sociology of Health & Illness

Primary subject of study	How is medicalization defined?	Topic	Country of origin
This research is designed to examine how individuals frame their decisions to undergo cosmetic surgery in economic terms	Medicalization of the body, whereby reasonably normal appearances are problematised, yet can be remedied through medical intervention > Refers to Dull and West, 1997; Sullivan, 2001	Cosmetic surgery	United States
Primary subject of study	**How is medicalization defined?**	**Topic**	**Country of origin**
How does advertising invite the reader to explore her or his own experiences within the context of a particular mental disorder? How does advertising define individual deviance as medical and encourage the seeking of medical attention?	Defining a problem in medical terms, using a medical language to describe a problem, adopting a medical framework to understand a problem, or using a medical intervention to 'treat' it > quotes from Conrad & Schneider, 1980, p.211	Antidepressant medication	United States
What role do electronic support groups play in the process of consumer-driven medicalization?	"Medicalization," or the processes by which an ever wider range of human experiences come to be defined, experienced, and treated as medical conditions	Fibromyalgia	World Wide Web (in English)
I describe the role pharmaceutical companies and pharmaceuticals play in promoting and legitimating contested diagnoses	Medicalization is the process by which ever more aspects of the human condition are defined and treated as medical in character	Fibromyalgia	World Wide Web (in English)
Both selfhelp and alternative healing approaches have been identified as encouraging as well as resisting medicalization. I address this contradiction using the case of mindfulness	Defining a problem in medical terms, usually as an illness or disorder, or using a medical intervention to treat it > quotes from Conrad, 2005, p.3	Mindfulness	International, focus on US (Amazon.com, data in English language)
The social and cultural basis of medicalization is explored through an examination of infertility, a social condition that has recently been recast as a disease	Medicalization refers to the process by which human experiences are redefined as medical problems	Infertility	United States

Table 2 - *Continued*

Authors	Year	Title	Journal
Bell	2010	Beyond (financial) accessibility: inequalities within the medicalization of infertility	Sociology of Health & Illness
Binney, Estes & Ingman	1990	Medicalization, public policy and the elderly: Social services in jeopardy?	Social Science & Medicine
Boero	2007	All the News that's Fat to Print: The American "Obesity Epidemic" and the Media	Qualitative Sociology
Bransen	1992	Has Menstruation Been Medicalised? Or Will It Never Happen	Sociology of Health & Illness
Brubaker	2007	Denied, embracing, and resisting medicalization: African American teen mothers' perceptions of formal pregnancy and childbirth care	Gender & Society

Primary subject of study	How is medicalization defined?	Topic	Country of origin
I examine the process of medicalization and how it contributes to the development of disparities through its perpetuation of dominant ideologies	Medicalization of infertility, or its treatment as a pathological condition rather than a natural or social one	Infertility	United States
This paper examines the medicalization of community-based services for the elderly; a process of restructuring to provide more highly medical services to a frail older population at the expense of providing a broader range of social and supportive services to older persons with varying levels of need	The term medicalization is used to refer to the substitution of medical care, including medical services, for care which was formerly nonmedical, or the substitution of all or part of a medical model of care for what was formerly a nonmedical model > refers to Swan, 1985	Community-based services for the elderly	United States
I explore the process by which the "obesity epidemic" has come to be defined as a social problem at the same time as it is framed as a problem of individuals.	The moral model of fatness shifted to a medical model in which "obesity" was designated as a disease to be treated through medical intervention > refers to Sobal, 1995	Obesity	United States
In what terms do women talk about menstruation and about menstrual-cycle-related problems or illness? And how do these genres frame the relationship between medical expert and layperson?	The rendering of life experiences as processes of health disorders, which can be discussed in medical terms only and to which only medical solutions can be applied > refers to Baart & Baerveldt, 1986	Menstruation	?
How does the stigma of being a pregnant African American teen shape the decisions and behaviours of these teens regarding medical care and their responses to such care?	The process by which behaviours or conditions take on medical meanings, "that is, defined in terms of health and illness". It is a process in which "medical practice becomes a vehicle for eliminating or controlling problematic experiences that are defined as deviant, for the purpose of securing adherence to social norms" > quotes from Riesmann, 1983, p.4	Teen pregnancy	United States

Table 2 - *Continued*

Authors	Year	Title	Journal
Calnan	1984	Women and medicalization: an empirical examination of the extent of women's dependence on medical technology in the early detection of breast cancer	Social Science & Medicine
Chang & Christakis	2002	Medical Modelling of Obesity: A Transition from Action to Experience in a 20th Century American Medical Textbook	Sociology of Health & Illness
Clarke & Lang	2012	Mothers Whose Children Have ADD/ ADHD Discuss Their Children's Medication Use: An Investigation of Blogs	Social work in Health care
Clarke	2013	Medicalization and changes in advice to mothers about children's mental health issues 1970 to 1990 as compared to 1991 to 2010: evidence from Chatelaine magazine	Health, Risk & Society

Primary subject of study	How is medicalization defined?	Topic	Country of origin
Which method do women prefer to detect breast cancer: self-examination (less medicalised) or mammography (medicalised option)?	The medical profession, on behalf of industrialism, has not only duped the public into believing that they have an effective and invaluable body of knowledge and skills but have created a dependence through the medicalization of life which has now taken away the public's right to self-care > refers to Illich, 1975	Breast cancer screening	United Kingdom (England)
Our aim is to (...) conduct an in-depth investigation of how its conceptualisation of obesity, a presumably unambiguous and cohesive object of knowledge, can undergo considerable transformation	Medicalization refers to the process by which certain behaviours or conditions are defined as medical problems, and medical intervention becomes the focus of remedy and social control > refers to Reissman, 1983; Fox, 1988; Conrad & Schneider, 1992	Obesity	United States
This research set out to examine how mothers describe what they consider to be the responsibilities and duties of mothering a child with ADD/ADHD in conversations with one another on the internet	Bio-medical perspective predominates over what might otherwise have been viewed as moral, religious, legal, community, or other sorts of issues > refers to Conrad, 2005	Medication use by children with ADHD/ADD	World Wide Web (in English)
I aim to contribute to our understanding of the ways in which women's magazines contribute to popular understanding of children's mental health issues	Medicalization can be defined as an expansion in the aspects of life considered to be of relevance to medical care	Children's mental health issues	Canada

Table 2 - *Continued*

Authors	Year	Title	Journal
Coveney, Nerlich & Martin	2009	Modafinil in the media: Metaphors, medicalization and the body	Social Science & Medicine
Elston et al.	2002	Violence against Doctors: A Medical(ised) Problem? The Case of National Health Service General Practitioners	Sociology of Health & Illness
Fainzang	2013	The other side of medicalization: Self-medicalization and self-medication	Culture, Medicine & Psychiatry
Gammell & Stoppard	1999	Women's experiences of treatment of depression: Medicalization or empowerment?	Canadian Psychology

Primary subject of study	How is medicalization defined?	Topic	Country of origin
How is modafinil discursively constructed in the British print media? How does this influence the configuration and reconfiguration of the body in popular consciousness? How and where is 'medicalization' deployed? And to what effect? What does this tell us more generally about cultural attitudes towards human enhancement?	[Medicalization] is a bi-directional and multi-faceted process through which human differences are transformed into pathologies, diagnosable disorders and treatable conditions > refers to Conrad, 1992	Sleep	United Kingdom
Is violence towards clinicians (GPs) medicalised? To aswer this question, there are two parts to the empirical analysis: an examination of the framing of violence against GPs as a policy issue; followed by analysis of individual GPs' response to violent incidents.	Medicalization consists of defining a problem in medical terms, using medical language to describe a problem, adopting a medical framework to understand a problem, or using medical intervention to treat it > quotes from Conrad, 1992, p.211	Violence towards clinicians	United Kingdom
I demonstrate that while self-medication often results from the reproduction and renewal of a previous medical opinion, it may also result from a personal decision to suggest a medical interpretation for a problem and therefore to resort to medical treatment	Medicalization thus designates the extension of medical jurisdiction into the social lives of individuals and is perceived as the medical management of a phenomenon that might have been—or which previously was—managed differently > refers to Zola, 1992	Self-medicalization	France
We investigate women's experiences in relation to being diagnosed with and treated for depression, and how participants came to be diagnosed as depressed, their understandings of what caused their depression, and their experiences of the treatment they received	When a woman's distress is conceptualised as a medical problem, one for which a drug (such as an anti-depressant) is prescribed by a physician, her problems become "medicalised" (defined as a medical problem)	Depression in women	Canada

Table 2 - *Continued*

Authors	Year	Title	Journal
Harvey	2013	Medicalization, pharmaceutical promotion and the Internet: a critical multimodal discourse analysis of hair loss websites	Social Semiotics
Hislop & Arber	2003	Understanding women's sleep management: beyond medicalization-healthicization?	Sociology of Health & Illness
Hogle	2001	Chemoprevention for Healthy Women: Harbinger of Things to Come?	Health (UK)
Holmqvist	2009	Medicalization of unemployment: Individualizing social issues as personal problems in the Swedish welfare state	Work, employment & society
Hyde et al.	2006	Social regulation, medicalization and the nurse's role: insights from an analysis of nursing documentation	International Journal of Nursing studies
Jacob, Gagnon & McCabe	2014	From distress to illness: a critical analysis of medicalization and its effects in clinical practice	Journal of Pshycatric & Mental Health Nursing

Primary subject of study	How is medicalization defined?	Topic	Country of origin
How is male pattern baldness framed and medicalised by pharmaceutical websites advertising for a particular solution?	Medicalization is the socio-cultural process whereby the ordinary processes of life become "defined and treated as medical problems, usually in terms of illnesses or disorders" > quotes from Conrad, 1992, p.209	Male pattern baldness	World Wide Web (in English)
We explore the extent to which the concepts of medicalization and healthicization provide appropriate models for understanding the management of women's sleep disruption	[Medicalization is a] process of social control whereby both deviant behaviour and natural life events are reconstructed as illnesses or disorders and placed under the jurisdiction of the medical profession > refers to Conrad, 1992	Sleep problems in women	United Kingdom (England)
How do women respond to advertising messages suggesting that they may be something other than 'normal,' and that they should use a chemical technology because of this status?	Through processes of medicalization, an increasing variety of physical and behavioural conditions are seen as disorders needing biomedical intervention	Chemoprevention for women at risk of breast cancer	United States
This article examines a phenomenon that can be called the 'medicalization of unemployment'	The process by which human behaviours become defined and treated as medical problems and issues > refers to Ballard & Elston, 2005; Schram, 2000	Unemployment	Sweden
We elucidate how the Roper–Logan–Tierney (RLT) model of nursing gives formal recognition to the medicalization of ordinary daily activities, and creates a framework for nurses through which the process of medicalization is facilitated	More and more realms of daily life have come to be related to 'health' or 'illness > refers to Zola, 1992; 1984	Nursing	Ireland
This study examinates the particularities of lipodystrophy in relation to the female body and how this condition affects the lives of HIV-positive women by reconfiguring their body in unexpected ways	When a specific aspect of the body becomes the focus of medical attention, there is a process by which it is claimed, controlled, and brought into medical ideology > quotes from Mason & Mercer, 1999, p.57	Effects of antiretroviral therapy on HIV-positive women	Canada

Table 2 - *Continued*

Authors	Year	Title	Journal
Kilty	2012	'It's like they don't want you to get better': Psy control of women in the carceral context	Feminism & Psychology
Lee, Macvarish & Sheldon	2014	Assessing child welfare under the Human Fertilisation and Embryology Act 2008: a case study in medicalization?	Sociology of Health & Illness
Malacrida	2004	Medicalization, ambivalence and social control: mothers' descriptions of educators and ADD/ADHD	Health: An Interdisciplinary Journal for the Social Study of Health, Illness & Medicine
McLeod et al.	2004	Public attitudes toward the use of psychiatric medications for children	Journal of health and social behavior
Melick, Steadman & Cocozza	1979	The medicalization of criminal behavior among mental patients	Journal of health and social behavior

	Primary subject of study	How is medicalization defined?	Topic	Country of origin
	This article examines how women incarcerated in provincial and federal prisons in Canada experience medicalization as the predominant form of correctional psy intervention	Medicalization is a process through which 'an entity' that it is not 'ipso facto a medical problem', is responded to as a kind of illness > quotes from Conrad, 2007, p.5-6	Physical treatment of incarcerated women	Canada
	The aim of the study was to find out how this change to the law had impacted on practice. In describing what we found, we also make a contribution to scholarship about the medicalization of reproduction	The process through which non-medical problems become defined and treated as medical problems > quotes from Conrad, 2007, p.4	Welfare of the child assessments pre-conception before infertility treatment	United Kingdom
	How do mothers understand the role of educators in the medicalization of their children's behaviour?	Medicalization is a definitional problem, the process whereby non-medical problems become routinely understood and handled as illnesses or disorders rests on the ability of medicine to name and define the problem in medical language, to construct the individuals who present the problem in medical terms like 'patient' or 'sufferer' and to organise the ideal response to the problem along lines of medical treatment and intervention > refers to Conrad, 1992	Perceptions of the teachers role in ADHD/ ADD diagnosis of children	Canada & United Kingdom
	We analyse nationally representative data on the public's willingness to give psychiatric medications to children and the social correlates of that willingness	Children's emotional and behavioural problems have become medicalised—defined and treated as medical problems and deferred to the supervision of the medical profession	Medication use by children with ADHD/ADD	United States
	Through a comparison of the arrest rates of mental patients released during 1968 and 1975 with the general population rates, the relevance of this process to criminal behaviour is examined	This process of defining deviant behaviour as illness and mandating or licensing physicians to treat it > refers to Conrad, 1975	Arrest rates of mental patients	United States

Table 2 - *Continued*

Authors	Year	Title	Journal
Merianos, Vidourek & King	2013	Medicalization of Female Beauty: A Content Analysis of Cosmetic Procedures	Qualitative Report
Moloney, Konrad & Zimmer	2011	The Medicalization of Sleeplessness: A Public Health Concern	American Journal of Public Health
Moreira	2006	Sleep, health and the dynamics of biomedicine	Social Science & Medicine
Neiterman	2013	Sharing bodies: The impact of the biomedical model of pregnancy on women's embodied experiences of the transition to motherhood	Healthcare Policy
Norris et al.	2011	Medicalization or under-treatment? Psychotropic medication use by elderly people in New Zealand	Health Sociology Review

Primary subject of study	How is medicalization defined?	Topic	Country of origin
The purpose of this study is to conduct a content analysis of brochures made available to customers from cosmetic surgery centers located in one metropolitan area and to examine what if any framing techniques are used to encourage females to undergo cosmetic procedures	Medicalization is a process that can be defined in which nonmedical problems are describes in terms of medical problems such as illnesses and disorders > refers to Conrad, 1992	Cosmetic surgery	United States
We explored the idea that the US epidemic of insomnia may be, in part, facilitated by medicalization	Medicalization is the process by which formerly normal biological processes or behaviours come to be described, accepted, or treated as medical problems > Refers to Conrad & Schneider, 1992	Sleeplessness	United States
How is sleep and health related from a sociological perspective?	The changes in the understanding of the relationship between sleep and health are the outcome of a negotiated expansion of the medical boundaries of knowledge and treatment. The medicalization perspective emphasises the control and constraints on action derived from medical knowledge > refers to Williams, 2002	Sleep	World Wide Web (in English)
This paper explores how women experience their transition to motherhood as a process of embodiment that is shaped by biomedical culture	A process by which nonmedical problems become defined and treated as medical problems, usually in terms of illnesses or disorders > Quotes from Conrad, 2000, p.324	Pregnancy	Canada
Our research aimed to investigate whether patterns of prescribing matched patterns of need for medications	The social processes by which non-pathological problems come to be understood and treated as medical conditions > refers to Conrad 2005; 2007; Conrad & Leiter, 2004	Psychotropic medication use amongst older people	New Zealand

Table 2 - *Continued*

Authors	Year	Title	Journal
Oinas	1998	Medicalization by Whom? Accounts of Menstruation Conveyed by Young Women and Medical Experts in Medical Advisory Columns	Sociology of Health & Illness
Padamsee	2011	The pharmaceutical corporation and the 'good work' of managing women's bodies	Social Science & Medicine
Parry	2008	We wanted a birth experience, not a medical experience: exploring Canadian women's use of midwifery	Health care for women international
Polonijo & Carpiano	2008	Representations of Cosmetic Surgery and Emotional Health in Women's Magazines in Canada	Women's Health Issues
Rafalovich	2005	Relational Troubles and Semiofficial Suspicion: Educators and the Medicalization of "Unruly" Children	Symbolic interaction
Schierenbeck	2010	Medicalization of sickness absence	Work

Primary subject of study	How is medicalization defined?	Topic	Country of origin
This paper addresses knowledge claims about the body: whose knowledge matters when discussing menstruation between young women and medical professionals?	With this concept sociologists have tried to capture the transfer of knowledge and decision-making concerning health from lay people to the medical profession > refers to Zola, 1972; Conrad & Schneider, 1980; Conrad, 1992	Menstruation	Finland
How does the pharmaceutical industry (try to) affect the care of women in a company produced magazine about gynaecological health and care?	Medicalization: the definition and treatment of life problems, processes, or deviance in medical terms > refers to Zola, 1972	Pharmaceutical industry communication towards physicians	International publication of pharmaceutical publication
My purpose was to explore women's choice of midwifery, including their perceptions and experiences with medicalization	Biomedical tendency to pathologise otherwise normal bodily processes and states. Such pathologisation leads to incumbent medical management > quotes Inhorn, 2006, p.354	Pregnancy and midwifery	Canada
The present study takes a closer look at how features of emotional health are constructed in relation to cosmetic surgery in popular women's magazines in Canada	Medicalization occurs when seemingly nonmedical problems become defined as medical issues > refers to Conrad, 2005	Cosmetic surgery representation in women's magazines	Canada
This study details how educators conceptualise the "nature" of ADHD children, including how they frame such children's abilities and disabilities	I use the term "medicalization" to refer to the process by which deviant acts (a) become understood to originate from a medical cause and are therefore perceived to be beyond an individual's control; and (b) are believed to be treatable through medical knowledge and the application of techniques by medical experts	Children's behavioural problems and ADHD diagnosis	Canada & United States
This article explores variations in absence from work due to sickness as a result of medicalization	The process by which previously defined nonmedical problems become defined and treated as medical problems	Sickness absence	Sweden

Table 2 - *Continued*

Authors	Year	Title	Journal
Selin	2011	Implementation of substitution treatment in Finland: Beyond rationalisation and medicalization	NAT Nordisk alkohol & narkotikatidskrift
Thomas-McLean	2004	Memories of treatment: the immediacy of breast cancer	Qualitative Health Research
Torres	2014	Medicalizing to demedicalize: Lactation consultants and the (de) medicalization of breastfeeding	Social Science & Medicine
Vainionpaa & Topo	2005	The making of an ageing disease: the representation of the male menopause in Finnish medical literature	Aging & Society
Vainionpaa & Topo	2006	The construction of male menopause in Finnish popular magazines	Critical Public Health

Primary subject of study	How is medicalization defined?	Topic	Country of origin
Finnish treatment of drug abuse has during the last two decades shifted from a predominantly psychosocial approach to a more medical mode. My aim is to show that labelling this development as 'medicalization' or 'rationalisation' as a form of medical progress will not increase our understanding of the change.	Which redefines social problems as medical problems > refers to Gomart & Hennion, 1999; Murto, 2002	Drug abuse	Finland
What are women's experiences of embodiment after breast cancer?	This refers to an intricate social process involving the dominance of biomedical paradigms and authoritarian models of health care in which illness experiences are understood as biological and individualistic > refers to Walters, 1994	Embodiment after breast cancer	Canada
This paper uses the domain of breastfeeding in the U.S. and the work of International Board Certified Lactation Consultants to refine the concept of medicalization and demedicalization	A process by which nonmedical problems become defined and treated as medical problems, usually in terms of illness and disorders > quotes from Conrad, 2007, p.4	Breastfeeding and lactation consultants	United States
The aim of this article is to study the presentation of the male menopause in Finnish medical teaching and professional literature	[Medicalization] refers to the ways in which medicine expands into new arenas > Zola, 1972	Male menopause	Finland
In this study we investigated the construction of male menopause and related hormonal treatments in Finland from the point of view of the medicalization of ageing	By medicalization we refer to the ways in which medicine expands to new arenas that were previously not defined to be part of the field of medicine > refers to Zola, 1972	Male menopause	Finland

Table 2 - *Continued*

Authors	Year	Title	Journal
Van Brummen & Griffiths	2013	Working in a medicalised world: the experiences of palliative care nurse specialists and midwives	International Journal of Palliative Nursing
Venn, Meadows & Arber	2013	Gender differences in approaches to self-management of poor sleep in later life	Social Science & Medicine
Westfall & Benoit	2004	The rhetoric of "natural" in natural childbirth: childbearing women's perspectives on prolonged pregnancy and induction of labour	Social Science & Medicine
Williams et al.	2008	Medicalization and beyond: the social construction of insomnia and snoring in the news	Health: An Interdisciplinary Journal for the Social Study of Health, Illness & Medicine

Primary subject of study	How is medicalization defined?	Topic	Country of origin
This study explored the nature and experience of caring for those at both ends of life's continuum: birth and death. In particular the practices that have evolved to counter the medicalization of care	Illich identified that modern society has turned personal challenges into technical problems requiring medical treatment > refers to Illich, 1974	Birth and death experiences from the perspectives of midwives and palliative care clinical nurse specialists	United Kingdom
We seek to understand the influence of gender on the different approaches to managing poor sleep by older men and women through the conceptual framework of existing theoretical debates on medicalization, healthicization and 'personalization'	Medicalization occurs when previously non-medical problems are defined and treated as medical problems, usually in terms of illnesses or disorders, or when a medical intervention is used to treat the problem > quotes from Conrad & Leiter, 2004, p. 825	Managing poor sleep	United Kingdom (England)
This article aims to discover birthing women's own views on prolonged pregnancy, whether they believe some kind of intervention is warranted, and, if so, when and what kind of intervention is desirable	The process whereby increasingly more aspects of everyday life fall under medical influence and control > refers to Zola, 1983	Prolonged pregnancy	Canada
This article contributes to sociological debates on sleep, the media and medicalization through a critical exploration and examination of the social construction of two common sleep problems, insomnia and snoring	Medicalization is (ideally) a non-judgemental term, referring simply to the process of 'making medical'	Sleep problems (insomnia and snoring)	United Kingdom

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