



National guidelines for evaluating pain—Patients' legal right to prioritised health care at multidisciplinary pain clinics in Norway implemented 2009

Karen Walseth Hara*, Petter Borchgrevink

Department of Pain and Complex Disorders, St Olav's Hospital and the University of Trondheim, Norway

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ABSTRACT

Background: All nations are posed with the challenge of deciding how to allocate limited health care resources. A Patients' Rights Law from 1999 gives patients in Norway with a serious health condition, for which there is efficacious and cost-effective treatment, a legal right to receive health care from the National Health Care system.

Methods: Recently national guidelines have been produced for implementing these legal rights within 32 fields of specialist health care. One of these fields deals with serious chronic pain conditions. A task force established by the Directorate of Health, comprising pain specialists, primary care and patient representatives, have produced guidelines for pain conditions. The newly published guidelines seek to answer the difficult questions of which patients should be prioritised at pain clinics and what is a medically acceptable waiting time.

Results: The guidelines deal with non-acute pain conditions that are too complex for primary care and organ- or disease-specific fields of specialist care. The guidelines state that if health-related quality of life is severely affected by the pain condition and efficacious and cost-effective treatment is available, then patients have a legal right to receive prioritised specialist health care in multidisciplinary pain clinics. The guidelines describe 5 categories of complex pain disorders that as a main rule should be given the right to prioritised health care in pain clinics. The 5 categories are

Category 1: Sub-acute (≤ 6 months) pain conditions with reason to fear chronification. Maximum waiting time 2 weeks, e.g., progressing complex regional pain syndrome (CRPS) 5 months after an ankle-fracture.

Category 2: Chronic complex pain condition, with or without known initiating cause, combined with substance abuse and/or psychiatric illness. These patients need concomitant follow-up by psychiatric and/or addiction medicine department(s) and a multidisciplinary pain clinic approach. Maximum waiting time 16 weeks, e.g., CRPS of an arm combined with depression and addiction to heroin.

Category 3: Chronic complex pain condition WITH known initiating cause (that can no longer be treated with a curative approach). Maximum waiting time 16 weeks, e.g., Post-herpetic neuralgia.

Category 4: Chronic complex pain condition WITHOUT known initiating cause. Maximum waiting time 16 weeks, e.g., chronic muscle pain syndrome.

Category 5: Severe and difficult to treat pain condition in patients suffering from a known serious and advanced illness. Maximum waiting time 2 weeks, e.g., advanced cancer, COLG, heart failure, end stage multiple sclerosis.

The maximum medically accepted waiting time is set at either 2 or 16 weeks depending on the condition. The full version of the guidelines describes pain categories in detail and gives information on cases that do not qualify to be prioritised for care in a pain clinic.

Conclusions: Norwegian national guidelines for prioritising among pain conditions are in the process of being implemented. Epidemiologic data and expert opinion suggest that in order to meet the chronic pain patient's legal claim to prioritised specialist health care, the national health care system in Norway will have to establish new pain clinics and increase capacity at existing pain clinics.

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* Corresponding author at: Department of Pain and Complex Disorders, St Olav's Hospital, Olav Kyrres Gate 17, 7006 Trondheim, Norway.

Tel.: +47 73868766; fax: +47 73866990.

E-mail address: karen.walseth.hara@stolav.no (K.W. Hara).

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1. Introduction

The Law of Patients' Rights (Lov om pasientrettigheter, 1999) and "The Patients' Rights Regulations" (Prioriteringsforskriften) give patients a legal right to receive specialised health care within a given deadline if their condition fills three basic criteria: (1) severity of the health condition, (2) potential positive effect of health care, and (3) cost-effectiveness of health care needed. For clinicians and health authorities it has often been a difficult task to judge which patients should or should not be given such a legal right. This is a challenge for all national health care systems (Sabik and Lie, 2008).

Upon request from the Ministry of Health and Care Services and supervised by The Directorate of Health and the Regional Health Governments, national task forces have been appointed within 32 specialised fields of medicine. Each task force is to submit guidelines for prioritisation within its field of medicine. The task forces have consisted of medical doctors and other health care workers from specialist health care, general practitioners and patient representatives. The guidelines (The Norwegian Directorate of Health, 2009) are intended to both ensure that the law is practiced equally throughout Norway, and to aid the clinicians who are responsible for evaluating referrals from primary care physicians.

2. Methods

2.1. Task force mandate and process

A task force comprising doctors and a psychologist from pain clinics in the 5 main health regions in Norway, a general practitioner and two representatives from the chronic pain patients' society in Norway laboured under guidance from experts from the Department of Health and Directorate of Health for 18 months to draft a proposal of guidelines in accordance with the Patients' Rights Law of 1999 (see below). The draft was submitted for open hearing to various types of health care providers and societies. The adjusted version was scrutinised by experts and lawyers at the Department and Directorate of Health. The final version of the guidelines was published in June 2009. Regional health governments started implementing the guidelines throughout Norway from September 2009.

2.2. The judicial foundation and responsibility for prioritisation within specialist health care

In accordance with the Patients' Rights Regulations, clinicians assessing referrals to specialist health care must determine which of three alternatives apply:

1. The patient is entitled to prioritised (necessary) specialist health care.
2. The patient is in need of medical assistance from specialist health services, but not entitled to priority health care.
3. The patient does not need specialist health care.

In Norway, patients have a so-called "right to prioritised (necessary) health care" within specialist health care if all of the following three conditions are present:

1. If health care is postponed the patient risks a certain shortening of life expectancy or a substantial loss of quality of life (SEVERITY OF THE CONDITION).
2. The patient can be expected to benefit from the treatment (EFFICACY OF THE TREATMENT).
3. The expected costs are considered proportionate to the measure's effect (COST-EFFECTIVE).

Patients, who are entitled to prioritised health care, receive a legally binding deadline for when the health care is at the latest to start.

The guidelines give recommendations on:

1. Which conditions should be prioritised and thus given a "right to prioritised health care".
2. What is considered a medically acceptable deadline for initiating health care for the given condition.

Individual factors must be considered in every case, and may lead to overruling of the general guidelines for the given condition.

The guidelines should be applicable to the majority (75–80%) of referrals that are received at a pain clinic. The remaining referrals, i.e. those that do not fall into any of the five pain categories mentioned in the guidelines, must still be assessed according to the "Patients' Rights Regulations" and judged by standard criteria for priority setting (severity of the condition, efficacy and cost-effectiveness of the treatment).

The guidelines are intended to function as decision support. The specialist is responsible for decisions made concerning "the right to prioritisation" and the setting of deadlines for initiating health care.

Within 30 days of receiving the referral, the specialist health care system must have made a decision concerning whether the patient is to be prioritised and a deadline set for initiating health care.

3. Results

3.1. Outline of pain conditions that may give legal right to prioritised health care

The guidelines for pain conditions deal with all non-acute pain conditions that cannot be handled within other organ- or disease-specific fields of specialist care. Some of these patients must be seen at a multidisciplinary specialist pain clinic. The guidelines for pain conditions suggest that patients who cannot be helped within primary health care and who also fill certain criteria for severity of the pain condition should be given the right to prioritised specialist health care if efficacious and cost-effective treatment is available. The maximum medically acceptable waiting time is set at 16 weeks, with the exception that both "sub-acute pain with great risk of becoming a chronic and intractable pain condition if left untreated" and "severe pain in end-stage illness" are given a shorter maximum waiting time of only 2 weeks. Individual factors must be taken into consideration. This is addressed more closely in the complete version of the guidelines.

3.2. Short version of the subject-specific introduction to the guidelines for pain conditions as authored by the task force and accepted by the Directorate of Health

3.2.1. Prevalence of chronic pain

Approximately 30% of Norwegian adults experience chronic pain (Rustøen et al., 2004; Breivik et al., 2006). This is even higher in females and the elderly. Although general practitioners can treat the greater proportion of these patients adequately, and many are most appropriately cared for by organ- or disease-specific specialists, there will always be some patients who require specialist care at multidisciplinary pain clinics.

3.2.2. Referrals to specialist care

Many of the chronic pain patients who are referred to specialist care can be managed by the organ- and disease-specific

specialties (rheumatology, oncology, etc.) This applies to both acute and palliative pain disorders where the specific specialist will most appropriately be able to make a causal diagnosis and implement the correct treatment. However, specialised multidisciplinary pain clinics should be consulted without delay when treatment is needed for patients with complex pain disorders.

Several of the other prioritisation guidelines for specialist health care have assessed conditions (within their fields of medicine) where chronic pain is a dominant symptom. For example, the guidelines used by oncology, rheumatology and physical medicine give the “right to prioritised health care” to patients who are suspected of having cancer, rheumatoid arthritis or a prolapsed disc as the cause of pain.

3.2.3. Criteria and definitions

The guidelines for pain conditions include several pain disorders which are otherwise not prioritised within specialist health care and which may not be covered by the ICD-10 diagnosis system. Patients with these disorders are often referred to pain clinics. Common for these patients is that they are suffering from complex chronic pain disorders that have been treatment-resistant and have negatively affected quality of life and daily functioning. These patients should be assessed considering both their condition and the efficiency of the health care provided by the pain centres and pain clinics.

3.2.4. Assessment of severity of the health condition

Pain clinics and pain departments perform a thorough evaluation of the patients' condition in order to judge whether there is a need for specialist pain treatment.

The degree and severity of the pain condition should be assessed/defined using validated tools. The internationally acclaimed questionnaire SF-8 includes questions regarding eight different aspects of quality of life. For each question the patient chooses the most correct answer out of 5–6 alternatives.

The severity of the patient's pain disorder is judged using SF-8. Criteria for severity are filled if the answer for global quality of life is “poor” or “very poor”, and the answers for physical and social functioning and mental health are one of the two lowest possible scores.

Such evaluations are included in the minimum pain evaluation form produced by the Norwegian Pain Society (see www.norsksmerteforening.no) (Fredheim et al., 2008).

3.2.5. Probability that specialised health care can improve the pain condition

Treatment at a multidisciplinary pain clinic can improve many chronic pain patients' level of functioning, quality of life and reduce

experience of suffering from pain. The probability that the referred patient's health condition can be improved, or further deterioration prevented, must be assessed individually.

3.2.6. Cost-efficiency

The cost of the specialised treatment offered has to be “reasonable” considering the expected outcome of the health care provided. Chronic pain patients are avid users of health care services. Patients with complex chronic pain conditions can be helped through a limited number of consultations at a multidisciplinary pain clinic. Health care costs can also be reduced considerably by avoiding further futile investigations and attempts at treatment (in other sectors of the health care system).

3.2.7. Patients who should be given the “legal right to receive prioritised health care” at a specialist, multidisciplinary pain clinic

Table 1 lists 5 categories of complex pain disorders that, as a main rule, should be given the right to prioritised health care in pain clinics, regardless of the pain disorder's cause. In the full version of the guidelines these pain categories are described in detail as well as more information on those who do not meet the criteria for prioritised health care.

4. Discussion

National guidelines for prioritising among pain conditions are being implemented in Norway. Some pain clinics have started using the guidelines. The very limited experience one has so far, suggests that the guidelines function fairly well as decision support for clinicians who must select which patients are to be given priority to health care at the pain clinic. It is anticipated by several pain specialists that enforcing the guidelines will further reveal the nationwide lack of specialist pain care services. It is difficult to envisage how Norway is to meet the chronic pain patients' legal claims to prioritised specialist health care without establishing new pain clinics and increasing capacity at existing pain clinics. It is important that the Directorate of Health has emphasized that the legal right to priority health care is to be granted, or not granted, independent of current capacity within specialist health care.

Based on unpublished and published epidemiological data (Fredheim et al., 2009; Eriksen, 2004) an estimate of the number of patients who may qualify for a legal right to prioritised multidisciplinary pain clinic care is 7–8000 new patients each year (0.2% of the adult population). The present capacity at existing specialised pain management facilities is about 2000 new patients in Norway each year. Thus the current pain clinic capacity is critically low and must be increased substantially. Private pain clinics or treatment outside Norway may be options for a few pain patients, but this will

Table 1
Five categories of complex pain disorders that, as a main rule, should be given the right to prioritised health care in pain clinics, listed with recommended maximum medically acceptable waiting time for initiating health care.

Pain category	Maximum waiting time
<i>Category 1</i> Sub-acute pain conditions and reason to fear chronification (duration less than 6 months).	2 weeks
<i>Category 2</i> Chronic complex pain condition with or without known initiating cause combined with substance abuse and/or psychiatric illness. These patients need concomitant treatment by psychiatric and/or addiction medicine department(s) AND a multidisciplinary pain clinic approach.	16 weeks
<i>Category 3</i> Chronic complex pain condition WITH known initiating cause (that can no longer be treated with a curative approach).	16 weeks
<i>Category 4</i> Chronic complex pain condition WITHOUT known initiating cause.	16 weeks
<i>Category 5</i> Severe and difficult to treat pain condition in patients suffering from a known serious and advanced illness. E.g. advanced cancer, COLD, heart failure, end stage multiple sclerosis.	2 weeks

not by far be enough to cover the need, nor will they be the most cost-effective solutions.

The regional and the local health governments' responsible for implementing the guidelines are currently under pressure from both patient groups, clinicians and national government to introduce sustainable, multidisciplinary pain clinics that can serve the Norwegian population's needs and ensure that their legal rights to specialised pain treatment is upheld.

5. Conclusions

Norwegian national guidelines for prioritising among pain conditions are in the process of being implemented. Epidemiologic data and expert opinion suggest that in order to meet the chronic pain patient's legal claim to prioritised specialist health care, the national health care system in Norway will have to establish new pain clinics and increase capacity at existing pain clinics.

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Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at [doi:10.1016/j.sjpain.2009.10.002](https://doi.org/10.1016/j.sjpain.2009.10.002).

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