Registries of occupational disesases and their use for preventive policy

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National registries of occupational diseases are useful, but have also major shortcomings for the provision of information for preventive policy. The changing pattern of occupational diseases requires traditional registries to become more flexible and dynamic systems. Tracing new risks and newly occurring occupational diseases requires the development of new methods and instruments, for which lessons can be learned from the methods used in pharmacovigilance. Clear preventive strategies and an ongoing dialogue between the providers of figures and the stakeholders in prevention is a prerequisite for achieving results in prevention. We strongly recommend stimulating international collaboration to improve the quality of information on the incidence and prevalence of occupational diseases in Europe.

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REGISTRIES OF OCCUPATIONAL DISESASES AND THEIR USE FOR PREVENTIVE POLICY

ACADEMISCH PROEFSCHRIFT

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Faculteit der Geneeskunde

“Safe work is not only sound economic policy, it is a basic human right…”

(Kofi Annan, former secretary-general of the United Nations)

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Chapter 1

Introduction

Historical introduction

The history of occupational diseases goes back to antiquity, and advances in understanding work and disease paralleled the social and technical development of mankind (1). The impact of work on health can be traced to the *Edwin Smith Surgical Papyrus*, which was written in approximately 1700 BC (2). Some of the neurosurgical and orthopaedic cases discussed in the *Papyrus* probably resulted from construction injuries from the age of the Egyptian pyramids. Although Hippocrates (ca. 460-377 BC) emphasizes the relation between the environment (air and water) and health, he has less to say about work and health, except for the military work environment, probably because of the denigration of manual labour in ancient Greece. In the Roman age, Galen (ca. 129-200) wrote about visits to mines and recorded his observations of workers who were exposed to acid mists (3). Paracelsus and Agricola – two prominent figures of the 16th century – both had an interest in mining and health. Agricola (aka Georgius Bauer, 1494-1555) is best known as the author of *De Re Metallica.* Paracelsus (aka Theophrastus Bombastus von Hoehenheim, 1493-1541) describes dyspnoea and cachexia from mining in his monograph on the occupational diseases of miners and other workers, *Von den Bergsucht und andere Bergkrankheiten* ('Phthisis and Other Diseases of Miners').

Bernardo Ramazzini (1633-1714) is often recognized as the father of occupational medicine and is quintessentially known for the admonition to physicians to ask one more question in addition to those recommended by Hippocrates: 'What is your occupation' (3). Ramazzini visited workers and workplaces and assembled his observations in a book *De Morbis Artificum Diatriba*, which was first published in 1700 and revised in 1713, shortly before his death.

The emergence of public health movements in several Western countries in the 18th and 19th centuries focused attention on the abominable conditions in many factories and on the living conditions, poor nutrition, high stress, poverty and ill health of the new factory working class. In the 19th and 20th centuries, social legislation and economic progress led to substantial improvements in living and working conditions in Western societies. Whereas the old sectors of mining and industry predominantly caused such classic occupational diseases as poisoning, in the last decades of the 20th century a growing number of people went to work in the services provision sector, which led to other patterns of occupational diseases such as musculoskeletal diseases and mental health disorders.

Occupational diseases: the magnitude of the problem

The annual number of employees with a non-fatal occupational disease – such as occupational asthma, noise-induced hearing loss or low-back pain resulting from heavy lifting – has been estimated to be 160 million at a global scale (4). Furthermore, it is estimated that each year some 2 million men and women lose their lives through occupational accidents and work-related diseases, such as occupational cancer and pneumoconiosis (4). This burden could be substantially reduced through the application of evidence-based risk-prevention strategies (5).

Although the working conditions in the Western and Central European region (the research area for this thesis) are fairly good compared to other regions of the world, mortality and morbidity rates due to occupational risk factors are still high. For example, the burden of disease due to occupational exposure to airborne particulates in Europe has been calculated as 259,000 DALYs, which is comparable to other parts of the world (6). Occupational diseases often result in serious personal suffering and the social consequences can range from sickness absence, unemployment, loss of income for the worker and the family, and the disturbance of family relations, to psychological and physical problems (7). In addition, the economic impact of occupational diseases is enormous, on both the company and the national level. Estimates of the economic costs of occupational diseases for the EU countries in 1999 range from 2.6% to 3.8% of GNP. This indicates a total cost of between €185 billion and €270 billion for the EU as a whole (8).

The EU has made the ongoing reduction in the incidence of occupational illnesses one of the prime objectives of the Community strategy on health and safety for the period 2007-2012 (9). Several countries have drafted national strategies to reduce the incidence of occupational diseases. For example, the UK government formulated a ten-year strategy – the so-called government health and safety targets – to reduce the incidence of occupational diseases and injuries (10). A national strategy requires a reliable monitoring system to evaluate the incidence and distribution of occupational diseases over time in order to develop well-targeted prevention programmes and to evaluate their effectiveness. Moreover, according to ILO Convention C155 (1981), all countries should maintain a registration system that is capable of providing information to policy makers (11). Before discussing the use of registries for preventive policy, however, we shall discuss the role of several stakeholders in the prevention of occupational diseases.

Prevention of occupational diseases: different stakeholders

As both the incidence and the prevalence of occupational diseases are still high, there are strong health, social and economic reasons to improve prevention. However, there are several difficulties in developing and implementing preventive policies. One important complication lies in the fact that there are different stakeholders – employers, employees, occupational health services, governmental bodies, insurance companies, etc. – which necessitates discussions about which party should take the initiative for preventive activities or which party should pay for the different aspects of prevention or for the financial consequences of occupational diseases. In the first instance, employers are held responsible for working conditions; however, employees can be considered more or less responsible for their own behaviour when working in hazardous situations. Sometimes the risks are shifted to insurance companies. The government has the responsibility for legal regulations with respect to working conditions and workers' compensation schemes, whereas occupational health professionals are responsible for giving appropriate advice to companies and employees. As can be expected, these interests do not always match. For example, whereas employers are interested in preventing liability claims in order to reduce their costs, organizations that represent the interests of employees can have an interest in liability claims in order to put the prevention of occupational diseases on the political agenda.

According to Verma et al., the prevention of occupational diseases can take place at the societal level and the workplace level, and the information needs of these two levels are different (12). At the societal or national level, control measures are usually implemented through regulatory actions and national policy. Information is needed about the incidence of occupational diseases in branches and occupations, about the consequences and costs, and about new risks. At the workplace level, information is needed about the nature of the hazard, where it is likely to be encountered, and the available options for risk assessment and risk control. In this thesis, the focus is on information on a societal level and it is investigated whether registries could provide relevant information to the stakeholders in prevention and how registries can be improved or enhanced for this purpose.

Registries of occupational diseases

Most industrialized countries have one or more registries of occupational diseases. These national registries are often linked to a financial compensation system for occupational diseases that is embedded in the country's social security system (13,14). They are mostly maintained by governmental bodies or insurance companies, depending on whether compensation is a private or a public matter. At the same time, statistics from these compensation systems are intended to provide policy information for the prevention of occupational diseases (15,16). In addition to these national registries, some countries have other egistries of occupational diseases, such as surveillance schemes for occupational asthma or occupational skin diseases (17-19). In several other countries, there are additional registration activities for specific regions or industrial sectors.

Despite the importance of national occupational registries for compensation and prevention, the reliability of these monitoring systems for occupational diseases in the EU countries is regarded as poor. In general, there is large underreporting and there are substantial differences between countries in diagnostic guidelines and criteria for notification, and, more generally, in culture, legislation and social security regulations (15,16). These observations call for an evaluation of the various monitoring systems.

Another reason to evaluate existing monitoring systems in the industrialized world is the changing pattern of occupational diseases (20). Whereas diseases caused by chemical and physical exposures were at the top of the occupational diseases statistics for many decades, work-related musculoskeletal diseases and mental illness now account for a major part of the work-related burden of diseases in most industrial sectors. From a technical and a social perspective, working life in Europe is changing rapidly, creating new risk areas and requiring new management systems to control these risks (21). This changing pattern of occupational diseases implies the need to study the appropriateness of the present monitoring systems. Although work-related musculoskeletal diseases and mental illness are the most common occupational diseases (22), in many countries these categories are not even on the list of occupational diseases. Another problem is that many registries are not suitable for tracing newly occurring occupational diseases, as they maintain a rather rigid list of diseases that was developed long ago. An extra complication is that these lists are based not only on scientific investigations but also on social-political negotiations. A further cause for the difficulties

encountered in working with lists of occupational diseases is that the definition of occupational disease is not unambiguous. This is the subject of the following section.

The definition of occupational disease

In the *ILO Encyclopaedia of Occupational Health and Safety*, Lesage distinguishes three categories of occupational diseases with respect to the strength of the causal relation (23). Classic occupational diseases are characterized by a clear, often practically monocausal relation to a specific exposure, for example mesothelioma caused by asbestos, or asthma caused by a specific chemical substance like methylene diphenyl diisocyanate (MDI). If the relation is less obvious, the disease is indicated as work-related. Most musculoskeletal diseases and mental health disorders are judged as belonging to this category. Most work-related diseases are considered as multicausal and include work as one of the factors that play a role in the aetiology. Following this line of reasoning, there is a recognizable relation between the working condition and the disease on the individual level (for example, between repetitive movements and shoulder complaints), but it is often not clear whether the working conditions are the decisive factor in the development of the disease. Finally, a third group of diseases is distinguished in which a relation between working conditions and health effects can be demonstrated only on a population level. The incidence or prevalence of these diseases is higher in specific occupational groups, but it is difficult to substantiate the nature of the causal relation in, for example, biological terms. One reason may be the lack of specific signs to identify them as work-related. For example, cardiovascular diseases caused by shift work belong to this category (24).

Many countries, as well as international organizations like the EU and ILO, have drafted definitions and accompanying lists of occupational diseases. Lists of occupational diseases that are maintained for social security purposes mainly contain the classic occupational diseases defined by Lesage. A recent trend is for countries to include work-related diseases in their national lists of occupational diseases. An example is the inclusion of upper-extremity disorders on the French list of occupational diseases, whereupon this category of diseases became the most reported one in France. (25).

For most of the classic occupational diseases, there is ample evidence for the work-relatedness and they can be attributed to work with confidence in individual patients. For the category of work-related diseases, there is much more discussion regarding causal inference on the individual level (26). Criteria for the latter category of diseases should preferably be based on evidence from epidemiological research. Examples are criteria developed for work-related upper-extremity musculoskeletal disorders (27) and for work-related low-back pain (28). Lesage's third category does not differ in essence from the second category, but the odds ratios or relative risks found in epidemiological studies are lower.

To summarize the preceding sections there are strong health, social and economic reasons to prevent occupational diseases. However, the unclear division of roles and responsibilities between the various stakeholders complicates prevention. Moreover, existing registries often do not provide appropriate information for preventive policy. These observations led to the objectives of this thesis, which are formulated in the following section.

Objectives and outline of the thesis

The first objective is to develop an inventory of the information needs of the stakeholders involved in the prevention of occupational diseases, and an overview of instruments and strategies to best meet these needs. The second objective is to investigate whether and, if so, how registries of occupational diseases can be used to fulfil these information needs. The third objective is to investigate how registries can be improved or enhanced in order to provide high-quality information for preventive policy.

In **Chapter 2** we explore the information needs of employers, employees, policy makers and other stakeholders with respect to the prevention of occupational diseases. We also present the opinions of experts about how these information needs can best be met.

In **Chapter 3**, we describe the development of quality indicators that can be used as an audit tool for the quality assessment of registries of occupational diseases in relation to preventive policy on

a national level. In **Chapter 4**, we evaluate registries of occupational diseases in six European countries for their ability to provide appropriate information for preventive policy with the aid of the audit tool.

In Chapters 5, 6 and 7, we present a number of studies that were aimed at the quality improvement and enhancement of registries in relation to preventive policy purposes. **Chapter 5** focuses on whether and, if so, on which aspects a sentinel surveillance project comprising motivated and supported occupational physicians would provide higher quality information than a national registry for preventive policy. In **Chapter 6** we assess the need for quality improvement of diagnosing and reporting of noise-induced occupational hearing loss and occupational adjustment disorder (nervous exhaustion). **Chapter 7** presents an exploration of whether the role of registries of occupational diseases for preventive policy can be extended by creating longitudinal data in sample projects. Here, the particular focus is on the course and consequences of work-related upper-extremity disorders as recorded in the registry of the Netherlands Center for Occupational Diseases.

We present the main findings in the general discussion in **Chapter 8**. We also discuss the methodological considerations, implications for practice and suggestions for further research.

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Chapter 2:

Time trends and blind spots: What employers, employees and policymakers want to know about occupational diseases

Spreeuwers D, de Boer AGEM, Verbeek JHAM, van der Laan G, Lenderink AF, Braam I, van Beurden MM, van Dijk FJH. Time trends and blind spots: What employers, employees and policymakers want to know about occupational diseases. *Policy and practice in health and safety* 2008; 6(1): 65-78.

Abstract

Background- Occupational illness and accidents at work impose a heavy burden on both workers and employers and represent enormous economic costs. This burden could be substantially reduced through preventive measures. The objective of the study was to investigate what information employers, employees, policymakers and other stakeholders need in order to prevent occupational diseases and how these information needs can best be met.

Methods- We performed a survey, consisting of two rounds of interviews. In the first round, we interviewed eleven key stakeholder persons from employer organizations, employee organizations, the government, the Labour Inspectorate, the EU authorities and the society of occupational physicians. In the second round, we asked fourteen experts on the registration of diseases to comment on the results of the first round and to give their opinion on how these information needs could best be met. Between them, the experts represented six countries.

Results- From the first round of interviews we deduced five categories of information needs of stakeholders: 1. time trends of occupational diseases for setting policy priorities, 2. cases of new occupational diseases for early preventive action, 3. disease patterns in specific occupational groups for focused prevention measures, 4. consequences of occupational diseases and resulting measures for policy evaluation purposes and 5. blind spots to reveal in which areas further investigation is needed.

The round of interviews with experts revealed that it is wise to rely on several instruments and findings to meet the comprehensive information needs of the stakeholders, such as sentinel surveillance, epidemiological studies and case tracing. In addition, the experts indicated that linking registration to prevention requires closer communication between providers of occupational diseases figures and stakeholders.

Conclusions- Five categories of information needs of stakeholders could be specified. A single registry of occupational diseases alone cannot satisfy all needs of the stakeholders. It is recommended to use several additional instruments and to maintain an ongoing dialogue between providers of figures and stakeholders.

Background

Occupational illness and accidents at work impose a heavy burden on both workers and employers and represent enormous economic costs (1) (2). The WHO states in its Global Plan of Action on Worker's Health 2008-2017 that national approaches to the prevention of occupational disease and injuries should be developed according to each country's priorities and in concert with WHO's global campaigns (3). The EU has made the ongoing, sustainable and uniform reduction in the number of accidents at work and the incidence of occupational illnesses as the prime objective of the Community strategy on health and safety for the period 2007-2012 (4). In several EU countries, the government has set its own targets on reducing occupational illness and accidents at work. One example is the 'Securing Health Together' ten-year occupational health and safety strategy in the UK, which aims at achieving a reduction of 20% in the incidence of work-related ill health by 2010 (5). Both NIOSH in the USA and CCOHS in Canada indicate as one of their strategic goals the reduction in workplace illness and injuries (6) (7).

In order to evaluate whether targets of reduction in occupational illnesses have been achieved by policy measures, we must be able to monitor occupational diseases in a valid and reliable way. Valid monitoring presupposes clear case definitions of occupational diseases and valid instruments for assessment. Furthermore, for reliable monitoring the case capturing process and the data recording process have to meet certain requirements (8). For good comparability of figures between countries, it is necessary to harmonize definitions and methods concerning the registration of occupational diseases (9).

At present, various systems are used to monitor occupational diseases (10) (11). Besides national registries, several countries have additional schemes for the surveillance of occupational diseases (11). For example, many countries have set up registries of cases of occupational asthma, for example SWORD (Surveillance of Work-related & Occupational Respiratory Disease) in the UK (12) and SENSOR (Sentinel Event Notification Systems for Occupational Risks) in the USA (13) (14) (15) (16) (17) (18). Most national registries were set up in the context of a financial compensation system for occupational diseases and are embedded in the country's social security system. At the same time, such systems are intended to provide policy information for the prevention of occupational diseases.

Although almost everyone acknowledges the importance of a preventive policy towards occupational diseases, there are diverging interests between the various stakeholders concerning how we should deal with this issue (19) (20). The parties that have to pay for the prevention of occupational diseases or to compensate for them - for example employers and insurers - will probably propose higher demands concerning the evidence of a causal relationship than workers and their representatives. Workers who perceive a disease as clearly work-related and who can claim for financial compensation, might try to facilitate the assessment of a causal relationship. On the other hand, workers and their organizations do not always feel that it is in their interest to detect occupational diseases, for example if there is a threat that they will lose their jobs either as individuals or as members of a collective of workers in a high-risk sector of industry.

These diverging interests have to be taken into account in formulating preventive policy on occupational diseases. Moreover, if we want to promote concrete preventive activities we also have to take into account the specific interests and needs of the stakeholders. This led us to our first research question, namely 'What are the information needs on occupational diseases of the various stakeholders: employers, employees, national governments, the EU, labour inspectorates and occupational health professionals?' Consequently, the second research question was: 'How can these information needs best be met?'

Methods

Study design

To answer the research questions we performed a survey, consisting of two rounds of interviews with key stakeholder persons and experts. The interviews were carried out by three researchers who have long-standing international experience in the field of occupational health.

Interviews with stakeholders (first round)

To answer the first research question ('What are the information needs of the various stakeholders?'), we interviewed key persons from various stakeholder groups. As the project was executed under the assignment of the Netherlands Ministry of Social Affairs and Employment, which was mainly interested in the national situation, all the interviewees were Dutch. To select the key persons, the project group drafted a list of persons from the following stakeholder groups: employers, employees, the Ministry of Social Affairs and Employment, the Ministry of Health, the Labour Inspectorate and occupational health professionals. We consulted the researchers and occupational physicians of the Department of Occupational Health of our institute about the list and offered them the opportunity to add new names. The project group decided on the final list of key persons to be interviewed. We then asked the selected persons whether they were prepared to be interviewed. If they did not wish to be interviewed, we asked for their motivation and whether they could suggest another key stakeholder person. We informed the key stakeholder persons by letter or email about the aim of the project, the method to be used and the interview questions.

The project group formulated six open questions in order to structure the interview (see box 1). After the project group had drafted the interview questions, researchers and occupational physicians of the Department of Occupational Health of our institute were asked to comment on them. The project group decided on the final questionnaire. The interviews were open: the interviewees not only answered the questions but also expressed their opinions freely.

The interviews were recorded on tape and documented in a report, which was sent to the interviewees for verification. After processing the report on the basis of the comments of and additions by the interviewees, the report was filed in its final version.

Interviews with experts (second round)

We interviewed international experts on disease registration in general and on the registration and epidemiology of occupational diseases in particular, and asked them to comment on the results of the first round of interviews and to answer the second research question ('How can the information needs of the stakeholders best be met?'). To select the experts, the project group drafted a list of

persons who either had published on or were known to be occupied with the registration of occupational diseases or with disease registration in general. As in the first round, we consulted the researchers and occupational physicians of the Department of Occupational Health of our institute about the list and offered them the opportunity to add new names. The project group decided on the final list of experts to be interviewed. The procedure used to approach the experts was the same as that used to approach the key stakeholder persons.

The questions in the second round were based on the results of the first round. Both the procedure used to develop the questions and the way in which we carried out the interviews were the same as in the first round. The questions asked in the first and the second interview round are presented in box 1.

Box 1: Questions asked in the interviews in the first and the second round

First round: stakeholders
1. In your opinion, what information is needed for policy concerning the monitoring and prevention of occupational diseases? 2. Can you rank according to their importance the issues you mentioned in your answer to the first question? 3. What is the required level of specification for the issues? 4. If the information you want were to become available, for what purpose would you use it? 5. Can you estimate the economic value of the information you want? (In other words: how much are you willing to pay for it?) 6. Do you feel a need for information on specific groups? If so, which groups and what information do you want on those groups?
Second round: experts
1. Which types of medical registration systems have you worked with? 2. Can you indicate the pros and cons of each type of registration system (practicability, response, yield, interpretation, required manpower, costs, etc.)? 3. Did you encounter any bottlenecks when working with these registration systems, and if so, what were they? What solutions were tried and what was the result? 4. When it comes to collecting general information on occupational diseases (overviews), what would

be the most suitable type/types of registration system/systems? Are there conditions that would need to be met before implementing this type/these types of registration system/systems?

5. When it comes to collecting detailed, specific information on occupational diseases (numbers and overviews per profession or branch, etc.), what would be the most suitable type/types of registration system/systems? Are there any conditions that would need to be met before implementing this type/these types of registration system/systems?

6. How could additional information (duration, severity, absenteeism, incapacity for work, reintegration, etc.) on occupational diseases be collected? Can this be done by using a registration system or would other methods of analysis be more appropriate? Can you mention any preconditions related to the application of a registration method or other similar system?

Analysis of the interviews

To analyse the interview reports of the first and the second round, we used several methods for quality assurance as recommended by Plochg and van Zwieten (21). The reports of the interviews were studied by all five members of the project group. We then discussed the material in project group meetings and pursued getting agreement on the answers to the research questions. Minutes were taken at the meetings, and later the members of the project group had the opportunity to comment on them. The results of the project were presented at a departmental meeting in which researchers and occupational health experts commented on the conclusions of the project group and the methods used. The project group decided on the final formulation of the results and the conclusions.

Results

In the first round we interviewed eleven key persons in nine interviews. We interviewed two officials of the Netherlands Ministry of Social Affairs and Employment together in one interview; four officials of three employee organizations in three interviews; three officials of three employer organizations in separate interviews; an official of the Labour Inspectorate; and a representative of the Dutch society of occupational physicians.

In the second round we interviewed five Dutch experts, four experts from the UK, two from Finland, and one each from France, Belgium and Germany. The Dutch experts were acquainted with disease registrations in fields varying from disease registration by GPs, registration of sickness absence, adverse effects of drugs, intensive care registration, registration in cardiac surgery, renal substitution therapy, perinatal registration and mortality statistics. The Belgian expert was involved in the registration of needle stick injuries. The other experts were primarily acquainted with various registries of occupational diseases. One of the experts was an official from Eurostat.

Information needs of stakeholders

All stakeholders stressed the need to improve the linking of figures from registries with the prevention of occupational diseases. Hereunder, we list in five categories the information needs of stakeholders. The value that stakeholders attached to these categories varied, as did the desired quality of the information. Some striking statements taken from the stakeholder interviews are presented in box 2.

Stakeholders want the information for differing purposes. Employers want detailed information on causal inferences to use for liability purposes. The unions' representatives considered the information important for collective labour agreement negotiations. Employers and employees are both interested in figures to benchmark between industries. The government wants to use the figures to stimulate and evaluate employers' and employees' preventive activities. The Labour Inspectorate wants to use the information for its audit and enforcement strategy, while occupational health professionals would like to use the information for quality improvement of the care and facilities offered. Other possible stakeholders - such as insurance companies, GPs and medical specialists - were suggested during the interviews.

All of the interviewed key stakeholder persons estimated the economic costs of occupational diseases to be in the order of several billion euros on a national level. Therefore, all stakeholders considered reliable information on occupational diseases as highly relevant. However, they did not agree on the financial responsibility to collect, analyse and disseminate information on occupational diseases.

Stakeholders were interested in specific topics, such as effects of chemical exposure, mental health disorders and groups at special risk (e.g. pregnant women, and young and elderly employees).

Finally, we formulated five categories of information needs of relevant stakeholders.

1. **Time trends of occupational diseases for setting policy priorities:** figures of occupational diseases divided by sectors or occupational groups, especially suitable for monitoring trends in time and for priority setting on a macro level. Particularly the Ministry of Social Affairs and Employment and the Labour Inspectorate were interested in reliable statistical figures and subdivisions into personal characteristics such as sex, age, education and ethnicity. Provision of these figures can trace high-risk groups for which special efforts are needed on prevention and control. In some cases figures can induce research to clarify unknown reasons for a specific high risk. Employers and employees were not so much interested in detailed figures as in rough indications of where problems could be expected. Although they were less interested in detailed statistics, employers and employees stressed the importance of good quality assessment in individual cases.

2. **Cases of new occupational diseases for early preventive action:** specific and detailed information on new or rare diseases, unusual patterns of already known or common diseases, and suspicious exposure-disease associations at the individual level. All stakeholders characterized this information as being of the utmost importance. The representative of the Labour Inspectorate indicated that ‘tracing new occupational risks is a spearhead in national policy’. An employers’ representative indicated the importance of the early detection of new risks, referring to the unfortunate history of asbestos and solvent exposure.

3. Disease patterns in specific occupational groups for focused prevention measures: both employers and employees were particularly interested in specific and detailed information that can be applied for preventive activities. One of the employees’ representatives stated that ‘data on occupational diseases should be translated into concrete preventive measures’. Employers’ representatives stressed that it is important ‘to describe very precisely the various occupations with their specific risks’ and the ‘need for risk estimates of occupational diseases related to small companies’. One of the employer’s representatives said that it would be interesting to know whether there is diversity in occupational disease patterns considering large companies and small and medium-sized enterprises. Operational management and possibilities for prevention in small and

medium-sized enterprises might differ from those in large companies. For example, regulations for machine safety are often framed from the perspective of large companies, whereas small enterprises sometimes cannot afford the investments for the required adjustments.

4. Consequences of occupational diseases and resulting measures for policy evaluation purposes: this includes information on the circumstances in which occupational diseases occur, preventive and control measures taken, adverse consequences of the disease, medical treatment applied and rehabilitation. Particularly the Ministry of Social Affairs and Employment and the Labour Inspectorate were interested in information on the whole course from origin to social consequences of occupational diseases. Employers and employees were mainly interested in sickness absence rates related to occupational diseases.

5. Blind spots to reveal in which areas further investigation is needed: in general there is large-scale underreporting in all registries of occupational diseases, and some sectors or occupational groups are hardly represented in the official statistics. There might be several reasons why these cases do not appear in the registries, for example administrative barriers, employees' fear of conflict or of losing their jobs, or a lack of knowledge or motivation on the part of physicians to report. Consequently, opportunities for prevention are missed. All stakeholders were interested in information on these blind spots and the reasons behind them. One of the employees' representatives urged the necessity of an analysis of the whole process from health complaints to interventions. It was suggested that employees could be empowered to insist on the examination and reporting of possible work-related complaints and that diagnosing and reporting of occupational diseases should have a high priority for physicians.

Box 2: Striking statements taken from the stakeholder interviews

Employees' representatives

'Figures on occupational diseases could be important ammunition in labour agreement negotiations.'

'Occupational physicians should be prosecuted if they do not report an occupational disease.'

Employers' representatives

'For employers, sickness absence is the most important perspective with regard to occupational diseases.'

'The administrative burden on employers must not be increased.'

Government representatives

‘Prevention of occupational diseases is primarily an employers’ and employees’ responsibility.’

Labour Inspectorate representative

‘Tracing new occupational risks has to be a spearhead in national policy.’

Occupational health professionals’ representative

‘Notification of occupational diseases should be less free of obligations.’

‘Figures on occupational diseases can provide information for priority setting in the development of new professional guidelines.’

How can the information needs be met best?

All experts emphasized that here is no single answer to the question how the information needs of stakeholders can be met optimally. A clear policy of the government can support prevention. For example, in 2000 the UK government formulated a ten-year strategy - the government health and safety targets - to reduce occupational diseases and injuries (5). Information from registries can be used to evaluate the objectives set. However, the reliability of the figures on occupational diseases provided by registries is often poor. Quality improvement of registries is needed to justify their use for preventive policy.

The presence of a financial compensation system is a crucial element in the socio-political context. A compensation system offers legal security to at least a group of workers with an occupational disease and will prevent often long-lasting lawsuits. An advantage of a compensation system may be the availability of clear case-definitions and a high quality of the acknowledgement of cases. Consequently, figures over years can be well comparable, allowing trend analysis within a country. A major disadvantage is that the only diseases that are registered are those that have undergone a long process of socio-political negotiations before being acknowledged as compensable occupational diseases. A large part of occupational morbidity - such as work-related mental illnesses, cardiovascular diseases and a number of musculoskeletal diseases - is not registered at all in many registries that are embedded in a compensation system. In addition, there can be obstacles to reporting, such as fear of job loss or fear of conflicts with employers.

1. Time trends of occupational diseases for setting policy priorities

Statistics on occupational diseases can be extracted from several sources, such as epidemiological studies, employee surveys or registries. Confining ourselves to registries, several experts stated that the distinction between administrative registries and notification systems is important. In administrative registries, personal data are not collected for statistics in the first instance, but for example for social security purposes. In notification systems cases are reported, mostly anonymously, directly for statistical aims. The advantages of administrative registries are the mostly superior possibilities for analyses over time and for data linkage with other data and registries.

Experts shared the opinion that specific occupational diseases need specific monitoring methods. One of the experts stated that 'in the case of diseases that are nearly exclusively occupational, such as silicosis or asbestosis, it is sufficient to count cases. This can be done from death certificates if the disease has a high mortality rate. For disorders with low relative risks, for example back pain related to heavy occupational lifting or lung cancer related to exposure to polycyclic aromatic hydrocarbons, a better approach is to assess the attributed proportion of the total morbidity related to various causes by epidemiological methods.' In general, such factors as clinical features of the disease (e.g. latency or course) and the strength of the causal relationship determine the preferred monitoring method. Accurately assessing the absolute burden of disease attributable to work can require more complex and accurate methods than monitoring for trends. In monitoring for trends, it might not matter if there is some under-ascertainment of cases, provided the level of under-ascertainment remains fairly constant over time.

The experts indicated the importance of combining techniques for data analysis in order to get a more accurate result, for example a combination of trend analysis, the use of several data sources (triangulation), record linking or application of correction factors. They also stressed that a better insight into the denominator of the population at risk is needed in order to estimate incidences of occupational diseases. Some experts advised limiting the number of notifiable diseases and minimizing the required data set in order to enhance reporting and acquire data of better quality.

2. Cases of new occupational diseases for early preventive action

According to one of the experts: 'a real challenge is to identify new and emerging risks.' Tracing new and emerging risks requires another approach than monitoring occupational diseases.

Communication with potential reporters (physicians, as well as insurers, companies and employees) and validation of the signals through further clinical examination of patients and workplace visits, followed by the adequate dissemination of the information to the target groups, were considered high priorities. The experts added that performing periodic literature reviews and establishing networks of experts can contribute to the discovery of new and emerging risks. Furthermore, it was suggested that methods used in pharmacovigilance systems to discover new adverse effects of drugs, could be applied in tracing new occupational risks. Examples of methods used in pharmacovigilance are data mining in register databases and sentinel reports from patients or physicians.

Examples of systems that are aimed at tracing new and emerging risks based on sentinel reports are the THOR-Extra project in the UK - in which all physicians can report interesting cases or suspected novel causes - and the Health Hazard Evaluation in the USA, in which a request by three employees is sufficient to launch an investigation into work-related diseases. For example, several years ago the HHE revealed the popcorn workers lung based on a patient's report of lung complaints after exposure to diacetyl.

3. Disease patterns in specific occupational groups for focused prevention measures

One expert mentioned the example of the registration of needle stick injuries in her country. Every needle stick injury is registered in the hospital's database. Hospitals all over the country use the same database system. The notification of an accident in a database is the start of a follow-up procedure. On a national level, the information in the various hospital databases is gathered for preventive policy aims.

4. Consequences of occupational diseases and resulting measures for policy evaluation purposes

In order to monitor the whole course of occupational diseases from cause to final consequences, other methods than just reporting cases are required. Course monitoring requires the formulation of clear targets and the choice of characteristics that can be followed over time. For example, in order to assess the effect of preventive measures in health care workers on latex sensitization, one can monitor the ultimate response (cases of latex sensitization), but one can also monitor indicators of intermediates, such as the use of latex-free gloves at the workplace.

5. Blind spots to reveal in which areas further investigation is needed

Active tracing of cases can reveal the occurrence of occupational diseases in sectors or occupational groups that have a high degree of underreporting. Some experts mentioned projects whose aim is to reveal hidden occupational diseases. A possible approach is to examine the files of patients who have diseases that might be occupational but are not yet reported. The files of these patients could be examined for information about occupation or past exposures.

Another way to get an insight into the blind spots might be surveys, in which employees are asked to report work-related diseases and health complaints. A disadvantage of surveys might be the poor validity of the assessment of the work-relatedness of a disease. Figures of occupational diseases, derived from self-reporting by employees, tend to be much higher than the figures derived from compensation schemes or reporting by physicians. However, one of the experts stated that 'a great advantage of self-reporting by patients is that you get information that has not been filtered by physicians'.

Box 3: Striking statements taken from the expert interviews

Time trends of occupational diseases for setting policy priorities: 'The focus for the future should be on building monitoring systems for work-related diseases, such as cardiovascular diseases.'

Cases of new occupational diseases for early preventive action: 'A real challenge is to identify new risks. This will be partly possible within existing reporting systems. Communication is very important here.'

Disease patterns in specific occupational groups for focused prevention measure: 'We organize meetings with all the stakeholder groups'.

Consequences of occupational diseases and resulting measures for policy evaluation purposes: 'Course monitoring requires formulation of clear targets and the choice of characteristics that can be followed over time to monitor the process.'

Blind spots to reveal in which areas further investigation is needed: 'A great advantage of self-reporting by patients is that you get information that has not been filtered by physicians.'

Discussion

We interviewed key stakeholder persons in prevention to chart the information they need in order to improve the registration of occupational diseases and to better link registration to prevention. From these interviews we deduced five categories of information needs: 1. time trends of occupational diseases for setting policy priorities, 2. cases of new occupational diseases for early preventive action, 3. disease patterns in specific occupational groups for focused prevention measure, 4. consequences of occupational diseases and resulting measures for policy evaluation purposes, and 5. blind spots to reveal in which areas further investigation is needed.

There is no single answer to the question how these information needs can best be met. The advice of experts is to use several sources of information for the monitoring of occupational diseases, including registries and the results of epidemiological studies, surveys and focused projects. Tracing of new and emerging risks requires other methods and instruments, including sentinel surveillance, periodic literature searches and data mining. Close communication with stakeholders and reporters is of paramount importance to effectively link registration to prevention. Active tracing of cases can reveal the occurrence of occupational diseases in sectors or occupational groups that have a high degree of underreporting (blind spots).

A strength of this study is that we first asked stakeholders about their information needs, because they are the actors responsible for preventive policy and activities. This approach can result in leads to tailor-made registrations related to preventive activities. Subsequently, experts on registration can advise about the best methods to gather the needed information, taking into consideration the information yield, the costs and the information quality.

Another strength of our study is the division into clear categories of information needs and the indication how stakeholders value these categories of information. This knowledge can support the decision process for setting up monitoring systems in terms of fitting the information to the target group. Furthermore, experts' recommendations can indicate which factors should be taken into account when setting up or maintaining monitoring systems for occupational diseases.

A limitation of the study is that not all stakeholders were involved. For example, we did not interview representatives of insurance companies or claim settlement agencies, or lawyers, GPs or medical specialists.

Another limitation is that we did not explore motives or practice in depth. Stakeholders might not have much interest in active monitoring, for example because preventive activities are expensive or because revealing better figures might disturb established relationships between employers and employees. Moreover, occupational physicians are sometimes hesitant to report occupational diseases because they do not want to risk damaging their relationship with the employer. Regarded from this perspective, in some cases socially desirable answers might have been given by the stakeholders.

A further limitation, one that is probably inherent to the subject, is that although the information provided by the interviews with the experts is detailed and balanced, it does not give a clear answer to the question how the information needs of stakeholders can best be met. The development of a set of methods and instruments to satisfy the needs of the various stakeholders requires an iterative method with continuous innovation and frequent evaluation. Of course, this way of proceeding can only succeed in close communication with the stakeholders. The result might be a set of various instruments and methods.

To make the general picture provided by this study manageable for registration and prevention practice, we propose the development of scenarios for monitoring occupational diseases on several levels. Verma et al. (22) stated that the development of control strategies for occupational hazards takes place at the societal and the local workplace level. These two levels have differing information needs. At the societal level, control measures are usually through regulatory actions on the national level or the industrial sector level. Information is then needed on possible exposure-effect relationships as well as on workplace demographics. At the local workplace level, information is needed on the nature of the hazard, where it is likely to be encountered and the available options for risk reduction. We propose to develop scenarios on three levels: a national scenario, a scenario for branch or sector approaches, and a scenario for the company level. The basic idea is that monitoring should be linked to preventive measures.

On the national level, reliable information is needed about exposure-effect relationships, the extent of the problem and the costs. Information should be monitored over time in order to evaluate whether preventive policy is effective. The information can be used as input for decisions on legislation and government policy. Furthermore, monitoring activities can support public campaigns focused on prevention and can be used for evaluating such campaigns (23) (24).

On the branch or sector level, more detailed information is needed on hazards and exposure-effect relationships within the branch or sector, where possible within specific occupations, with a clear reference to a range of solutions. Reliable figures of disease incidences in the sector and the occupational level can be used for benchmarking. Special attention should be given to work-related problems that are specific to the sector, such as reproductive hazards in the health care sector (which has a high number of young female employees).

On the workplace level, information is needed on the nature of the hazard and where it is likely to be encountered, and on the risk of occurrence of occupational diseases and the available options for risk reduction. This information can be derived from monitoring systems as well as from surveys or scientific literature (25) (26). Knowledge should be disseminated on demand rather than by periodic reports.

Information on the economic costs of work-related ill health and the economic benefits of occupational health interventions is important for drafting national health strategies (27). Economic data are useful on a company level to develop a health and safety strategy (28). On a supranational level, there is a need to develop and harmonize national indicators in order to be able to compare countries and to exchange experiences (29). To put the issue on the political agenda, it is crucial to assess the burden of occupational disease (2) (30).

As stated, we did not explore in depth the motives of the stakeholders or the practice of registration. Further research is needed into the social context and the role and position of the stakeholders involved in preventing and compensating for occupational diseases. This type of research can provide information for the development of strategies for the prevention of and compensation for occupational diseases. Furthermore, cost-effect studies concerning preventive measures are very much needed. All the stakeholders we interviewed estimated the costs of the

consequences of occupational diseases to be in the order of several billion euros on a national level, but there is hardly any information on the opportunity costs of preventive measures.

Various aspects of the practical implementation of the registration of occupational diseases need further study. The themes provided by the experts can give leads to quality improvement projects and evaluation studies. Examples are a Dutch study of the quality of diagnosing and reporting by occupational physicians (31) and a study of physicians' beliefs in the assessment of work attribution when reporting musculoskeletal disorders (32).

Our study reveals that discovering new occupational risks needs a different approach from that used to monitor occupational diseases. Methods for tracing, validating and disseminating information about new risks need to be explored and evaluated. Promising examples are the THOR-Extra project in the UK (33), the activities of the European Risk Observatory (34) and case investigations in the Health Hazard Evaluation (HHE) in the USA (35).The consecutive steps used in pharmacovigilance - namely signal discovery, strengthening, confirmation and dissemination - seem applicable also for the discovery of new occupational risks (36) (37). The study of Bonneterre (38) is an example of the application of pharmacovigilance methods to occupational diseases databases, in which unknown associations were traced by data mining.

Blind spots - areas of the labour market that have hidden occupational diseases - are a matter of concern to the various stakeholders. The experts we interviewed recommended the development of methods for charting these blind spots. Projects of active case finding in certain sectors or occupational groups are advocated to uncover blind spots.

Conclusion

Identifying stakeholders' information needs on occupational diseases can result in leads to tailor-made registrations related to preventive activities. Five categories of information needs of stakeholders could be specified. A single registry of occupational diseases alone cannot satisfy all needs of the stakeholders. It is recommended to use several additional instruments and to maintain an ongoing dialogue between providers of figures and stakeholders.

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Chapter 3:

Characteristics of national registries for occupational diseases: international development and validation of an audit tool (ODIT)

Submitted as: Spreeuwers D, de Boer AGEM, Verbeek JHAM, van Dijk FJH. Characteristics of national registries for occupational diseases: international development and validation of an audit tool (ODIT).

Abstract

Background- The aim of the study was to develop quality indicators that can be used for quality assessment of registries of occupational diseases in relation to preventive policy on a national level. The research questions were: 1. Which indicators determine the quality of national registries of occupational diseases with respect to their ability to provide appropriate information for preventive policy? 2. What are the criteria that can distinguish low quality from high quality?

Methods- First, we performed a literature search to assess which output of registries can be considered appropriate for preventive policy and to develop a set of preliminary indicators and criteria. Second, final indicators and criteria were assessed and their content validity was tested in a Delphi study, for which experts from the 25 EU Member States were invited.

Results- The literature search revealed two different types of information output to be appropriate for preventive policy: monitor and alert information. For the evaluation of the quality of the monitor and alert function we developed ten indicators and criteria. Sixteen of the twenty-five experts responded in the first round of the Delphi study, and eleven in the second round. Based on their comments, we assessed the final nine indicators: the completeness of the notification form, coverage of registration, guidelines or criteria for notification, education and training of reporting physicians, completeness of registration, statistical methods used, investigation of special cases, specified monitor information, and specified alert information. Except for the indicator “coverage of registration” for the alert function, all the indicators met the preset requirements of content validity.

Conclusion- We have developed quality indicators and criteria to evaluate registries for occupational diseases on the ability to provide appropriate information for preventive policy on a national level. Together, these indicators form a tool which can be used for quality improvement of registries of occupational diseases.

Introduction

Exposure to occupational health risks accounts for a significant proportion of the burden of diseases (1,2) including a variety of social consequences (3), of which the estimated costs are considerable (4,5). This burden could be substantially reduced through the application of proven risk-prevention strategies. Furthermore, new products, working practices and organisational contexts are continuously introduced into the working environment and bring with them new occupational diseases and work-related adverse health effects (6-8). For these new emerging risks new risk-prevention strategies should be developed immediately.

Information about the incidence and distribution of occupational diseases is essential to develop these occupational health interventions for the purpose of prevention (9-12). To enable companies, organisations of employers and employees, policy makers and occupational health professionals to set priorities for preventive policy and to evaluate interventions, information is needed about the severity and duration of diseases, and about their social and economic consequences. In the case of new emerging diseases, rapid detection of the health risks is necessary followed by an effective dissemination of knowledge to all stakeholders.

Most EU countries register occupational diseases in a national registry, while some have additional schemes for the surveillance of occupational diseases (13-15). National registries are usually set up within the context of a financial compensation system for occupational diseases and are a part of the country's social security system. At the same time, such systems are intended to provide policy information for the prevention of occupational diseases. National registries are only one source, but mostly an authoritative one, of policy information. Various authors have recommended the use of a combination of monitoring systems and other data sources in order to assess working conditions, health effects and trends on a macro level as a more complete information input for preventive policy (16-19).

The registries of the various EU countries differ considerably regarding case definitions or diagnostic guidelines, criteria for notification or recognition, and the legal and social security context (20). Furthermore, the level of under-reporting (as far as such is possible to define and assess) varies between countries (21). Because of these differences, figures on occupational diseases are not comparable between European countries; moreover, the figures are often regarded as not reliable

even within a country (22). This calls for a more detailed study of the conditions that a registry has to meet in order to provide appropriate and reliable information for preventive policy.

According to Verma et al. (2002) prevention of occupational diseases can take place at the societal level and the workplace level (12). The information need for these two levels is different. At the societal or national level, control measures are usually through regulatory actions and national policy. Information is needed on incidence of occupational diseases in sectors and occupations, the consequences and costs, as well as on new risks. At the workplace level information is needed on the nature of the hazard, where it is likely to be encountered, and the available options for risk control. In this study we focussed on information on a national level.

In line with Donabedian, we defined the quality of a registry as the extent to which it provides appropriate information for preventive policy (23). The research questions were: 1. Which indicators determine the quality of registries for occupational diseases with respect to the ability to provide appropriate information for preventive policy on a national level? 2. What are the criteria that can distinguish high from low quality?

Methods

We approached the research questions in two steps. We first performed a literature search to assess which output of registries are considered as appropriate for preventive policy and to develop a set of preliminary indicators and corresponding criteria. We then performed a Delphi study to assess the final content of the indicators and criteria and to test their content validity. A point of departure was the reporting of cases of occupational diseases by physicians.

1. Assessment of appropriate output and development of preliminary indicators and criteria

We performed a literature search in Medline through PubMed with three subsets of MeSH terms, combined with the Boolean term AND, and used the terms both as MeSH terms and text words. The first subset comprised the terms ‘occupational diseases OR workplace’. The second comprised

the terms ‘registries OR notification OR mandatory reporting’. The third comprised the terms ‘health policy OR prevention and control OR policy making OR public policy OR social control policy’.

We developed the preliminary indicators and corresponding criteria in an iterative process by discussing the information we had retrieved from the literature. As a starting point, we considered which information output of a registry would be appropriate for preventive policy. Next, we used the quality model of Donabedian to develop a model of stages and essential aspects in the process of registration (23). This model has been used as a framework to develop a set of meaningful and comprehensive quality indicators related to the process. Finally, we discussed the criteria that would distinguish high from low quality for the various indicators.

2. Assessment of content validity

Participants:

To assess the content validity of the indicators, we invited one expert from each of the then 25 EU countries to evaluate the quality of the indicators and corresponding criteria. The experts were selected either because they had published on registration of occupational diseases or because they had participated in international working groups on occupational diseases (24). If an expert was not able to participate in the study, he or she was asked to suggest another expert in his or her own country.

Procedure:

We used a modified Delphi technique to assess the content validity of the quality indicators (25-27). The features of the Delphi method are anonymity, iteration and feedback (28). The modified Delphi procedure we applied comprised two rounds. In the first round, we asked the experts if they agreed with our proposal concerning the appropriate output of a registry, and sought their opinion on the completeness of the set of indicators. We asked them to evaluate the relevance of the indicators for preventive policy (yes/no) and the corresponding criteria (good, too weak, too strong or not relevant). We invited them to suggest modifications and additions. In the second round, we asked the

experts who had responded in the first round to comment on the adjustments we proposed based on their comments. We sent the questionnaires for the first round and a reminder in February respectively March 2005. The second-round questionnaires were sent in July 2005, the reminder in September 2005. Appendix 1 and 2 comprise a summarized version of the questionnaires of the first respectively the second round of the Delphi procedure.

Analysis:

For each indicator we asked the experts if they considered it relevant to preventive policy. If more than 50% of the experts did not consider the indicator relevant, we proposed deleting or adjusting it. For each corresponding criterion, we asked the experts if they agreed with the criterion (good) or found it too weak, too strong or not relevant. If more than 50% of the experts did not agree with a criterion, we adjusted it. We discussed all the comments of the experts. If there were convincing arguments for making adjustments on the basis of their comments, we did so.

We calculated a content validity index (CVI) for the indicators by dividing the number of approvals by the total number of answers (24). If more than 50% of the experts approved of the indicator in the first round, we used these results to calculate the CVI; if this was not the case, we used the results of the second round to calculate the CVI. In the literature, the acceptable level for the validity of indicators (in the sense of representing the quality of the registry) ranges from 0.70 to 0.80 (24). We took 0.70 as the minimum level of the validity score. We followed the same procedure when calculating the percentage of experts that agreed with the corresponding criteria, or considered the criteria as too weak, too strong or not relevant.

We developed a sum score for both the monitoring function and the alert function of a registry with a maximum of ten points for each function, including weighted scores for each indicator. Finally we calculated a CVI for both sum scores.

Results

1. Assessment of appropriate output and development of preliminary indicators and corresponding criteria

The literature search in Medline resulted in 184 articles and screening of the abstracts reduced this number to 44 relevant articles. We deduced from the literature two types of appropriate output of registries of occupational diseases within the scope of national preventive policy (13,15,29-33), namely alert information and monitor information. We called the ability of a registry to generate these types of information the alert function and the monitor function, respectively.

The purpose of the monitor function is to assess the nature, magnitude and distribution of already recognized occupational diseases over time, related to sectors of industries, occupational groups, gender and age categories. This information is essential in order to set priorities for preventive policy (11,13,15). The monitoring of these characteristics over time is necessary, for example, to evaluate the effectiveness of preventive policy measures.

The purpose of the alert function is to discover new associations between new or existing occupational risk factors and diseases. The discovery of new or rare diseases, unusual patterns of already known or common diseases, and suspicious exposure-disease associations at the individual level can provide vital leads for a more conclusive scientific evaluation and verification. The information output of the system is signals for new and emerging risks. The discovery of the 'popcorn-worker's lung' is a recent example of the usefulness of an alert function and of the need to investigate signals (8,34,35). A similar pattern of discovery can be shown for many occupational diseases.

Following Donabedian, we developed a model consisting of three stages in the process of registration of occupational diseases, namely structural preconditions, the process of diagnosis and notification, and the output of registries (23).

The model was used as a framework to develop a set of meaningful and comprehensive quality indicators related to the registration process. The control and decrease of occupational diseases as valuable potential outcomes of a registry, could not be included in our analysis as they

were considered to be largely dependent on the implementation of appropriate preventive measures which were outside the scope of this study.

Based on the literature, we proposed a preliminary set of ten indicators to determine the quality of the essential functions of a national registry. These indicators were:

A. Indicators of structural preconditions:

1. Completeness of notification form (with nine sub-items) (29,36,37)
2. Participation rate of physicians (the proportion of potential reporters) (21)
3. Availability of criteria or guidelines for notification (38)
4. Education and training of reporting physicians (10,39)

B. Indicators of the process of diagnosis and notification:

5. Access of employees to reporting physicians (10,40)
6. Completeness of registration (21,40)
7. Statistical methods used (11,16,29,36)
8. Investigation of special cases (6-8)

C. Output indicators:

9. Monitor information (with five sub-items) (3-5,10,11,13,15,33)
10. Alert information (6-8,10,41).

Indicators 7 and 9 were considered relevant only to the monitor function, and indicators 8 and 10 only to the alert function. We formulated corresponding criteria for every indicator and sub-items both for the monitor and alert functions.

2. Assessment of content validity

In the first round of the Delphi study, sixteen (64%) of the twenty-five experts responded to the questionnaire. Experts that did not respond were from Austria, Finland, France, Germany, Greece, Latvia, Lithuania, Malta and Slovakia. In the second round, we sent the questionnaire with proposals for adjustment to the sixteen respondents; of these, eleven responded (69%). Table 1 shows the response in both rounds.

Table 1: Response to the Delphi study in both rounds from countries that responded one or two times.

EU country	**Response first round**	**Response second round**
Belgium	**x**	**x**
Cyprus	**x**	**x**
Czech Republic	**x**	**x**
Denmark	**x**	**x**
Estonia	**x**	**x**
Hungary	**x**	
Ireland	**x**	
Italy	**x**	**x**
Luxembourg	**x**	
Netherlands	**x**	**x**
Poland	**x**	
Portugal	**x**	
Slovenia	**x**	**x**
Spain	**x**	**x**
Sweden	**x**	**x**
United Kingdom	**x**	**x**
Total number of respondents	16/25	11/16

In general, most of the experts agreed with the proposed indicators and their corresponding criteria. Fourteen experts (88%) agreed with the proposed distinction between the alert and the monitor function. Two experts did not agree, but did not say why. One expert agreed with the distinction but stated that it would not be applicable in many national systems as they are mostly based on fixed lists of occupational diseases.

Figure 1 presents the model of the process of registration for occupational diseases that we constituted on the basis of the quality model of Donabedian, and the final indicators after adjustments

in the Delphi study. The preliminary set of ten indicators was considered complete by 79% of the experts. On the basis of the experts' comments, we combined 'Participation of physicians' and 'Access to notifying physicians' into one new indicator – 'Coverage of registration' – because the experts stated that there was a considerable overlap. We defined the new indicator as the proportion of the working population that has access to the consultancy hour of a reporting physician.

Figure 1: Registry for occupational diseases and quality indicators: a model

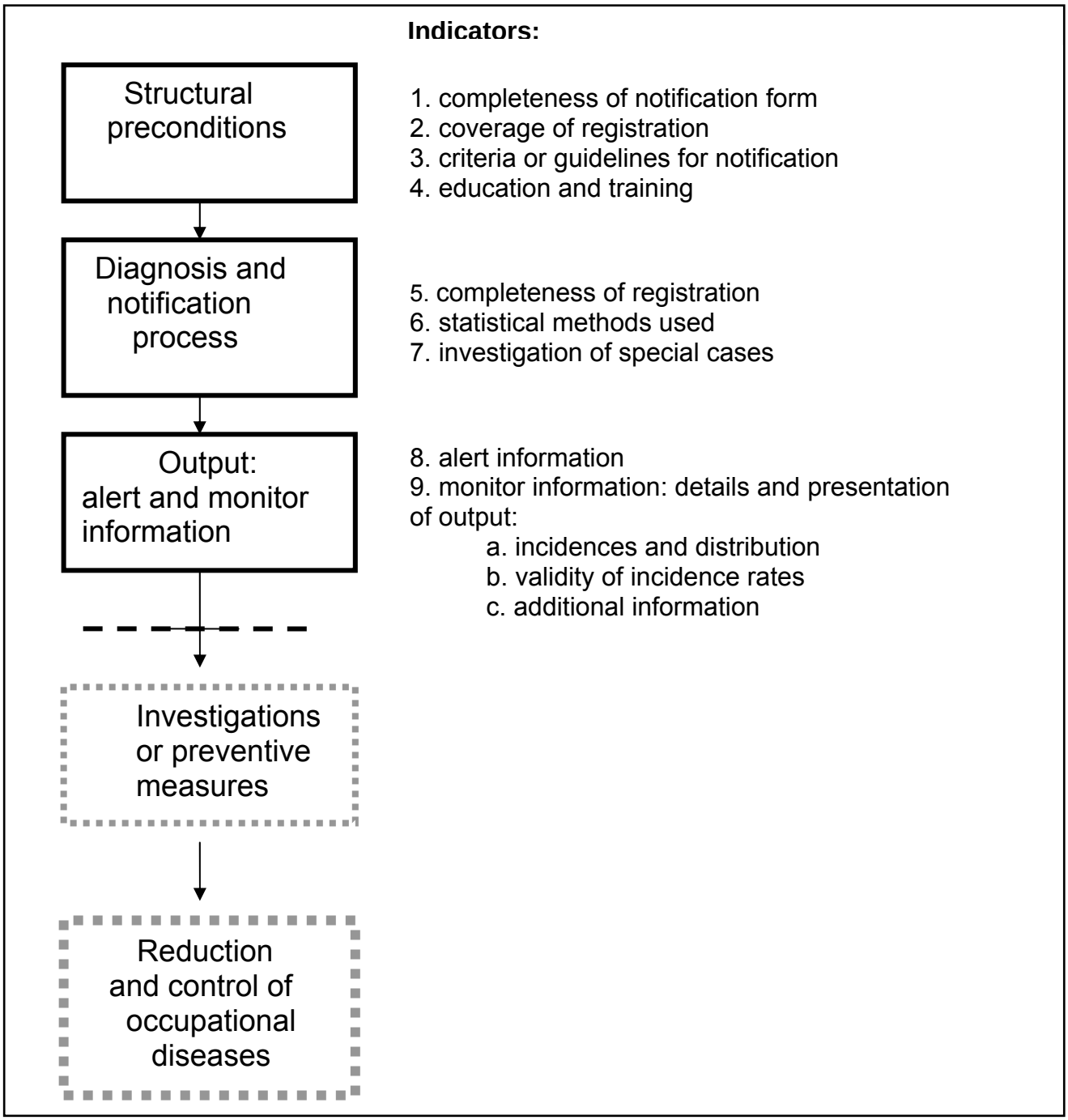

Table 2 presents the final indicators and the corresponding criteria after the adjustments resulting from the two rounds of the Delphi study. The evaluation of the criteria by the experts is presented in the table as the proportion of experts who rated the criteria as good, too weak or too strong.

Table 2: Quality indicators and criteria for national registries of occupational diseases

Indicator:	**Content Validity Index Monitor function**	**Criteria for Monitor function:**	**Evaluation of criteria, % of experts/100**			**Content Validity Index Alert function**	**Criteria for Alert function:**	**Evaluation of criteria, % of experts/100**		
Structural preconditions			Good	Too Weak	Too Strong			Good	Too Weak	Too Strong
1. <u>Completeness of notification form</u>:	0.94	The notification form meets the criteria for diagnosis and exposure and at least for three other indicator items	0.79	0.21	0.00	0.92	Six out of nine indicator items meet the proposed criteria *and* the notification form must offer the possibility to add relevant information	**0.58**	0.33	0.08
a. diagnosis:	1.00	Diagnosis according to the ICD-10 classification is a registered item	0.94	0.06	0.00	1.00	Diagnosis is a registered item	0.86	0.14	0.00
b. exposure:	1.00	Type of exposure according to the EU shortlist is a registered item	**0.69**	0.25	0.06	1.00	Type of exposure is a registered item	0.87	0.13	0.00
c. occupation:	1.00	Information about	0.75	0.25	0.00	1.00	Information about	0.79	0.21	0.00

		occupation is a registered item					occupation is a registered item			
d. economic sector:	0.88	Information about economic sector is a registered item [2)]	0.71	0.21	0.07	0.88	Information about economic sector is a registered item	0.83	0.17	0.00
e. susceptibility:						0.79	Information about susceptibility is a registered item	**0.54**	0.23	0.15
f. probability of the causal relation:	0.88	Probability of the causal relation is a registered item	0.79	0.21	0.00	0.93	Probability of the causal relation is a registered item	**0.62**	0.23	0.15
g. age of worker:	0.94	Age is a registered item	1.00	0.00	0.00	1.00	Age is a registered item	1.00	0.00	0.00
h. sex of worker:	1.00	Sex is a registered item	1.00	0.00	0.00	0.92	Sex is a registered item	1.00	0.00	0.00
i. other causes:	0.85	Other (additional) causes can be reported on the registration form	0.91	0.00	0.09	0.75	Other (additional) causes can be reported on the registration form	0.89	0.11	0.00
2. Coverage of registration: [3)]	0.80[1)]	Notifying physicians must cover at least 75% of the working population	0.80[4)]			**0.67**[1)]	Notifying physicians must cover at least 75% of the working population	**0.67**[4)]		
3. Guidelines or criteria for notification:	1.00	Guidelines for assessment of occupational diseases on the European list are available. Guidelines contain at least requirements for diagnosis and	0.82[4)]			0.87	The system must be open (that means, if there is a list it must be possible to report cases that are not on the list)	0.85	0.15	0.00

		exposure. This is evaluated in six reference diseases (occupational asthma, occupational hearing loss, contact dermatitis, asbestos-related diseases, mental health disorders and musculoskeletal disorders of the upper limb)				
4. Education and training:	0.94	Diagnosis, guidelines for assessment and notification procedures are part of the medical specialist training or the postgraduate training for notifying physicians	**0.67** 0.33 0.00	0.93	Diagnosis, guidelines for assessment and notification procedures are part of the medical specialist training or the postgraduate training for notifying physicians	0.71 0.14 0.14
Diagnosis and notification process						
5. Completeness of registration:	0.81	Participation level > 75 % of group of notifying physicians or of a sample of physicians with a known population, representative of	0.80[4)]	0.73	Participation level > 75 % of group of notifying physicians	0.70[4)]

		the whole working population				
6. Statistical methods used:	0.79	A public document that accounts for the statistical methods is available	0.92 0.08 0.00			
7. investigation of special cases:				0.86	There are facilities to investigate special cases in the opinion of the representatives of the institute responsible for registration of occupational diseases	0.72 0.14 0.14
Output						
8. Alert information:				1.00	Remarkable cases and clusters of cases must be mentioned in an annual report or in another publication	0.79 0.07 0.14
9. Monitor information: *a. Occupational diseases incidence rates and distribution:* *a1. Incidence rates of specific*	0.93	Incidence rates are presented for the	0.71 0.21 0.07			

occupational diseases for the total working population:		six reference occupational diseases in the total working population				
a2. Incidence-rates of specific occupational diseases by sector or by occupation:	0.93	Incidence rates for the six reference occupational diseases by sector or by occupation are presented	0.73[4)]			
a3. Distribution of occupational diseases by socio-demographic variables age and sex:	0.87	Incidence rates for age and sex are given for the six reference occupational diseases	0.73[4)]			
b. Additional information:	0.73	Information about sickness absence has been published for the six reference occupational diseases OR information about economic costs has been published for the six reference occupational diseases	0.73[4)]			
c. Validity of incidence rates:	0.85	Incidence rate of total occupational diseases must be	0.73[4)]			

		at least 100/100,000 employees *and* Reports on the system must contain a consideration about the validity of the incidence rates for the six reference diseases				

1) context validity score is derived from the second round

2) susceptibility was omitted as an indicator item after the second round

3) the appointment of this indicator was the result of an adjustment based on comments made by the experts

4) evaluation of criteria is derived from the second round, we asked if they could agree with the adjusted criteria

(Note: The numbers in the column “evaluation of criteria “ do not always add up to 1.00 because of rounding off)

Concerning the indicator “completeness of the notification form” two experts stated that more information about exposure should be asked, such as the duration and intensity of exposure. One expert said that non-occupational factors should be taken into account. One expert stated that protective equipment and preventive actions should be registered, four experts said that the concept of ‘susceptibility’ was not feasible or should at least be clarified, and three experts said the same about the concept of ‘probability of the causal relation’.

On the indicator “coverage of registration”, one expert argued that coverage alone is not a good criterion: one may have nominal 90% coverage of poor quality, which is worse than having 45% coverage of better quality. Another aspect is appropriate information about the denominator, that is, about the working population covered. Furthermore, it is necessary for notifying physicians to cover the high-risk industries. One expert expressed a preference for a system in which both patient and employer can notify.

In the preliminary version we proposed as a criterion for the indicator ‘criteria or guidelines for notification’ that guidelines should be present for five reference diseases for the monitor function. On

the basis of the experts' comments, we added mental health disorders as an additional reference disease. Because in the second round only two of the experts (18%) objected to this addition, we maintained this new reference disease.

In the preliminary version of the indicator, we proposed as a criterion for the indicator 'completeness of registration' that the participation level of notifying physicians should be more than 50% for both the alert function and the monitor function. On the basis of the experts' comments, we increased this level to 75%.

Concerning the presentation of incidence rates, a sub-item of the indicator 'monitor information', one expert stated that the denominator should not be the total workforce but the number of people exposed to the specific risk, because otherwise the incidence would be diluted. A comment on the sub-item "additional information" was that sickness absence is not relevant to diseases like hearing loss.

Table 3 shows the proposed calculation of a total quality score for the monitoring and the alert function. For the monitor function the content validity index for the calculation of the total score calculation was 0.55, for the alert function it was 0.70.

Table 3: Proposed calculation of a total quality score for the monitor and alert function of registries of occupational diseases.

Indicators Monitor function	**Score**	**Indicators Alert function**	**Score**
Completeness of notification form	1 point	Completeness of the notification form	1 point
Coverage of registration	1 point	Coverage of registration	1 point
Guidelines or criteria for notification	1 point	Guidelines or criteria for notification	1 point
Education and training	1 point	Education and training	2 points
Completeness of registration	2 points	Completeness of registration	2 points
Statistical methods used	1 point	Investigation of special cases	2 points
Monitor information: - meeting the criteria for incidences - meeting the criteria for additional information - meeting the criteria for validity of incidences	(3 points) 1 point 1 point 1 point	Alert information	1 point
Max. score	10 points	Max. score	10 points

Discussion

Both for the monitor function and the alert function we have assessed seven indicators, which determine the quality of registries of occupational diseases with respect to the ability to provide appropriate and reliable information for preventive policy on a national level. For every indicator we have assessed criteria that demarcate high and low quality. Except for the indicator “coverage of registration” for the alert function, all the indicators met the requirements of content validity. The calculation of the total score for the alert function met the requirements for content validity, whereas the calculation of the total score for the monitoring function did not. Together the indicators form a tool which we named “ODIT’. This tool can be used for quality assessment and quality improvement of registries of occupational diseases in relation to preventive policy.

A strong feature of our study is that we used a structured approach to develop the tool for quality assessment and improvement based on the system analysis of Donabedian. In addition, we were able to assess the content validity of the indicators by means of the Delphi technique.

An advantage of the tool is that it is easy to apply. It is possible to score the indicators with the aid of the annual report of the registry of a country and a concise questionnaire that can be sent to a limited number of key persons. In conclusion, the ability of a registry to provide information for preventive policy can be assessed and clues for quality improvement are provided. As far as we know, other tools for quality assessment and quality improvement of national registries of occupational diseases do not exist.

A limitation of the tool might be that we have reduced the case capturing and registration process to the straightforward notification of a case by a physician to the register. However in several registries employers and employees can also notify to the registry and validation of a case by a physician occurs in a later stage. Furthermore in several registries the case capturing phase can be divided in the notification of a case and the acknowledgement of a case, of which the latter is often related to criteria for financial compensation. As a result, some registries present two types of incidence rates, namely of reported cases and of acknowledged cases (42).

Another limitation of the tool is that it was difficult to formulate clear-cut criteria to demarcate high and low quality. For example, registries might have their own classifications of exposures or diseases, which might be more user friendly than the EU- or ICD-classification. Reporting physicians might prefer the classification of the registry, whereas using the EU- or ICD-classification would make the figures better comparable with figures from other registries. It should also be pointed out that the criteria to be met are minimum criteria: quality can still be further improved. For example, the criterion for the indicator “guidelines or notification criteria” requires the availability of guidelines for six reference diseases. But this criterion does not contain requirements for the underpinning scientific evidence of the guideline itself. Actually, there are many differences between the guidelines or criteria for notification of various countries.

A further limitation is that although the tool does provide preconditions for reliable figures, considerable underreporting cannot be ruled out, even if the criteria of all the indicators would be fulfilled. Whether employees actually do visit a physician in case of an occupational disease and if physicians actually do report all cases of occupational diseases cannot be assessed with this tool.

There are several complications, partly intrinsic to registries of occupational diseases, which has to be taken into account for the application of the tool. Because of the difference between the alert function and the monitor function, one monomorphous registry cannot be fully appropriate for both functions at the same time. For the alert function, it is desirable that as many physicians as possible participate in the system, as more alerts will be received from various industries and occupational groups. For the monitor function, it is more important that the group of reporting physicians, large or small, is rather stable, and that procedures do not change in a number of years, so that comparisons can be made over, for example, sectors of industry over time.

No single method of monitoring will be appropriate for all occupational diseases (18). Registration is often no more than a matter of ‘counting cases’. If cases can be confidently attributed to work in individual patients (as is the case with occupational injuries), counting cases will not be very complicated. But how does one proceed for diseases with recurrent episodes? How can one deal with diseases for which the relationship between a causal agent and a disease is difficult to assess, for example in the case of a reproductive hazard? Does disease monitoring suffice for prevention in the case of long latency? These and many other questions imply that different types of monitor

instruments will be needed for different categories of diseases. Furthermore, information derived from other sources – such as epidemiological studies, and health and hazard surveys – will be necessary to provide additional information.

Incidence figures are composed on the basis of many individual reports of occupational diseases. But in many occupational diseases, occupational factors only account for the development of the disease in a part. Here, a better measure for preventive policy might be the excess of illness attributable to work (18). We conclude that registration alone is not enough to provide all the figures needed. In addition, we should like to stress that the national monitoring of occupational diseases is a crude evaluation of preventive policy. In many cases, more detailed (sample) studies and assessments can provide better information. For example, in the case of noise-induced hearing loss monitoring may indicate that there is only a very slow decrease in the incidence after the start of a prevention programme. In addition to these finding, studies are needed to develop and evaluate effective ways to promote the use of hearing protectors or to implement interventions to decrease noise levels (43).

We conclude that the audit tool for the evaluation of the quality of a registry can support a process of quality improvement. Consequently, the costs of an improved register have to be weighted against the expected yields.

A complication in the use of the tool for quality improvement might be the fact that in most countries national registries are based on compensation schemes, which can hamper the willingness to adjust the system for preventive purposes.

Concerning the measurement properties of the tool we developed, further research is needed on reproducability and inter-observer variability.

The discussion with the experts on the indicators provided several issues for further research. Concerning the reporting physicians the differences in reporting behaviour, the possible causes of these differences and the effects of education and training on reporting behaviour are questions for further study. There is poor knowledge on what the barriers are that hinder employees to seek attention for an occupational disease and to turn to a physician, such as fear for adverse consequences. In regard to statistical methods the question how to determine the denominator is still in discussion. Using national figures of the working population might not be appropriate as the

underreporting of cases is generally considered as large. The issue of which methods could be used to trace new and emerging risks, how to validate signals and, if there is sufficient evidence for assuming a novel cause, how to disseminate this information is an interesting field for further research.

Conclusion

We have developed a valid tool for a quality assessment of registries of occupational diseases with respect to their ability to provide appropriate information for preventive policy on a national level, and called the tool “ODIT”. The instrument can serve as a starting point for a quality improvement process. International collaboration should be fostered in order to improve and harmonize national registries.

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Appendix 1: questionnaire first round

Name: Institute: Country: Date:
1. Do you consider the model for registries on occupational diseases, designed for quality evaluation, a sound model (see figure 1)? 2. Do you agree with the distinction in two functions, the monitoring function and the alert function, with respect to the ability to provide information for preventive policy? 3. Do you think the quality indicator set is complete? If not, which relevant indicators(s) is/are missing? 4-11: Do you think the following quality indicators are relevant for the monitoring function? Do you consider the criteria for good quality as too weak, good, too strong or not relevant? 4. “Completeness of notification form”? 5. “Participation of physicians”? 6. “Criteria or guidelines for notification”? 7. “Education and training”? 8. “Access to notifying physicians”? 9. “Completeness of registration”? 10. “Statistical methods used”? 11. “Monitor information”? 12. Do you agree that the quality indicator “investigation of special cases” is **not** relevant for the monitoring function? 13. With respect to the monitoring function we proposed that the indicators 1-7 can yield one point each, and indicator 10 can yield 3 points. The maximum quality score for the monitoring function will be 10. Do you agree with this proposed weighting of the indicators? 14-21. Do you think the quality indicators are relevant for the alert function? Do you consider the criteria for good quality as too weak, good, too strong or not relevant? 14. “Completeness of notification form”? 15. “Participation of physicians”?

16. “Criteria or guidelines for notification”?

17. “Education and training”?

18. “Access to notifying physicians”?

19. “Completeness of registration”?

20. “Investigation of special cases”?

21. “Alert information”?

22. Do you agree that the quality indicator “statistical methods used” is **not** relevant for the alert function?

23. With respect to the alert function we proposed that the indicators 1-6, 8 and 9 can yield one point each. The maximum quality score for the alert function will be 8. Do you agree with this proposed weighting of the indicators?

Appendix 2: questionnaire second round

Name:

Institute:

Country:

Date:

1. Indicator: "completeness of notification form" (sub-item susceptibility)

a. A possibility is to skip this indicator-item, because it is difficult to assess for physicians. Would you agree to that?

b. We propose to adjust the criterion as follows:

"Information about susceptibility is a registered item AND susceptibility criteria are included in the six reference guidelines".

Do you agree with our proposal?

2. Indicator: "criteria or guidelines for notification"

We propose to adjust the criterion as follows:

"Guidelines for assessment of occupational diseases on the European list are available. Guidelines contain at least requirements for diagnosis and exposure. This is evaluated in 6 reference diseases (occupational asthma, occupational hearing loss, contactdermatitis, asbestos related diseases, mental health disorders and musculoskeletal disorders of the upper limb)".

Do you agree with our proposal?

3. Indicators: "Participation of physicians and "Access to notifying physicians"

We propose to replace these two indicators by one indicator "coverage of registration" for both the alert and the monitoring function.

As criterion we propose:

"Notifying physicians must cover at least 75% of the working population".

Do you agree with our proposal?

4. Indicator: "completeness of registration"

We propose to adjust the criterion as follows:

Participation level> 75% of group of notifying physicians or of a sample of physicians with a known population, representative for the whole working population.

Do you agree with our proposal?

5. Indicator: "monitor information"

We propose to adjust the criterion as follows:

Information about sickness absence OR information about economic costs has been published for the six reference occupational diseases.

Do you agree with our proposal?

6. Score of monitoring function:

We propose the following adjusted score (max. score: 10 points):

Completeness of the notification form:	1 point
Coverage of registration	1 point
Guidelines or criteria for notification:	1 point
Education and training:	1 point
Completeness of registration:	2 points
Statistical methods used:	1 point
Monitoring information:	3 points

Do you agree with our proposal?

7. Indicator: "completeness of registration"

We propose to adjust the criterion for the alert function as follows:

Participation level> 75% of group of notifying physicians.

Do you agree with our proposal?

8. Score of alert function:

We propose the following adjusted score (max. score: 10 points):

Completeness of the notification form:	1 point
Coverage of registration	1 point
Guidelines or criteria for notification:	1 point
Education and training:	2 points
Completeness of registration:	2 points
Investigation of special cases:	2 points
Alert information:	1 point

Do you agree with our proposal?

Chapter 4:

Is the surveillance of occupational diseases in EU countries adequate? An evaluation study in six countries.

Submitted as: Spreeuwers D, de Boer AGEM, Verbeek JHAM, van Dijk FJH. Is the surveillance of occupational diseases in EU countries adequate? An evaluation study in six countries.

Abstract

Objective- The aim of this study was to evaluate registries of occupational diseases in European countries for their ability to provide appropriate information for preventive policy.

Methods- Contact persons of national registries for occupational diseases in six countries were sent a questionnaire on the objectives of their registry and on the quality of monitoring time trends and alerting to new risks. An auditor then visited each contact person, discussed the completed questionnaire and later sent a draft audit report to the contact person for verification. Two reviewers then established a quality score based on the verified audit report. The results of the audit were sent to each contact person, who was asked to evaluate the usefulness of the audit instrument for future quality improvement of the registry.

Results- The objectives of the registries assessed in the six countries were compensation, provision of statistics, prevention and research. The average quality was rated 3.2 (SD 2.2) out of 10 for monitoring occupational diseases and 5.3 (SD1.4) out of 10 for alerting to new risks. The main reasons for the low scores were inadequate education and training of physicians and poor participation of notifying physicians. Three of the six contact persons (50%) agreed that the audit could actually contribute to future quality improvement of the registry in relation to prevention.

Conclusions- Registries in EU countries do not adequately monitor existing occupational diseases or adequately alert to newly occurring occupational diseases. There is an urgent need to improve the education and participation of notifying physicians.

Introduction

Despite strong preventive policies, occupational diseases still occur frequently and are responsible for a great deal of suffering and economic damage in countries all over the world (1-3). Information on the occurrence of occupational diseases is an indispensable condition for preventive policy. Based on ILO convention C155, all countries should maintain a registration system that is capable of providing information to policy makers (4). A large diversity of systems is used to monitor occupational diseases (5,6). Besides national registries, several countries have additional schemes (7). Most national registries are set up within the context of a financial compensation system for occupational diseases and are a part of the country's social security system. At the same time, such systems are intended to provide policy information for the prevention of occupational diseases.

The registries of the various EU countries differ considerably in definitions or diagnostic guidelines, criteria for notification and recognition, and the legal and social security context (8). Furthermore, it can be inferred that the level of underreporting varies between countries (9). Because of these differences, figures on occupational diseases are not comparable between European countries. Moreover, the figures are often regarded as not reliable even within a country (10).

Two types of output can be distinguished that are relevant to national preventive policies: information resulting from the monitoring of existing occupational diseases and information resulting from the alerting to newly occurring occupational diseases (5,11,12). The purpose of the monitor function is to assess the nature, incidence and distribution of occupational diseases over time, related to sectors of industries or occupational groups. The purpose of the alert function is to discover new associations between existing or new occupational risk factors and diseases.

In order to evaluate whether targets of reduction in occupational diseases and work-related disorders has been achieved by policy measures, we must be able to monitor these diseases. Monitoring presupposes clear case definitions of occupational diseases and a valid way to diagnose them. Furthermore, the case capturing process and the data recording process have to meet certain quality criteria (13). For comparability of figures between countries, it is necessary to harmonize definitions and methods of registration of occupational diseases (8).

Another concern is the continuous introduction into the working environment of new products, working practices and organizational contexts that may induce new occupational diseases or work-

related adverse health effects (14). In the case of newly emerging diseases, rapid detection of the health risks is necessary and should be followed by an effective dissemination of the knowledge to all stakeholders. Rapid detection of health risks requires adequate strategies for tracing new occupational diseases and the means to investigate suspicious cases that might indicate new risks.

In an earlier study we developed an audit tool (ODIT) to evaluate national registries of occupational diseases with respect to their ability to monitor occupational diseases and to trace newly occurring occupational diseases (15). The tool is designed to be used to evaluate and subsequently improve the quality of national registries for occupational diseases for preventive purposes.

In this study we evaluated national registries in six EU countries. We included only registries maintained for, or at least with the support of the government. The research questions were: 1. What is the quality of the registries of occupational diseases in the six countries? 2. What is the usefulness of the ODIT tool for future quality improvement in relation to preventive policy?

Methods

Participants

We selected contact persons involved in the national registry of occupational diseases in each of the 27 EU countries and sent them an invitation to participate in the study. Contact persons had to be well acquainted with the national registry. Most of these persons were identified directly from our network, while a limited number were contacted via the website of OSHA (6). Contact persons in six EU countries agreed to participate in the study.

Study design

We performed audits of national registries for occupational diseases in six countries in the period July-September 2007. First, we asked the contact persons to complete and return a questionnaire on 1) the objectives of their registry and 2) the quality of the registration. They were also asked to mail relevant background information. An auditor visited each contact person and discussed the completed questionnaire and the provided background documents and website information of their

registry (16-22). Next, the auditor sent a draft audit report to the contact person, offering the opportunity to comment and to verify. If necessary, the auditor used the comments to adjust the audit reports.

Second, two reviewers (JV, AdB) used the ODIT tool to determine a quality score based on the verified audit report. If the two reviewers could not reach a consensus, a third reviewer (FvD) was asked to make a decision. The score was added to the report and sent to the contact person as a final report. Subsequently we asked the contact persons if they agreed with the statement that the tool could actually contribute to future quality improvement of the registry in relation to prevention.

Measurements and instruments

We used a questionnaire to gather the information needed to assess the quality of the registration of occupational diseases. The questionnaire we drafted included questions on the objective of the registry and the different quality aspects according to the ODIT tool. The ODIT tool comprises a set of quality indicators and criteria to evaluate the quality of the monitor and alert function of a registry. The indicators and criteria are presented in Appendix 1. If the criteria for an indicator are met, one or more points are assigned to that indicator. A total quality score (min. 0 points, max. 10 points) can then be calculated for the monitor and the alert function. Appendix 2 presents the points assigned to each indicator in order to calculate the total quality score for both functions. These quality scores can be used as the starting point for efforts to improve the registry.

Analysis

We made an inventory of the stated goals of the registries and of the procedures for notification and acknowledgement in the six countries. For each registry we calculated a total quality score for the monitoring and the alert function on a scale of 0-10. For each indicator and each sub-item of the indicators we calculated the average score of the six countries.

Results

Austria, Belgium, the Czech Republic, France, Finland and the UK participated in the study. The names of the registries, the institutes responsible for maintaining the registries, the stated goals of the registries, the persons who are entitled to notify to the registry and the authority responsible for acknowledgement are presented in table 1.

Table 1: Characteristics of the registries for occupational diseases in the six EU countries

Country	**Name of registry**	**Responsible Institute**	**Stated goals of the registry**	**Notifying persons**	**Acknowledge-ment authority**
Austria	Statistik Berufskrankheiten (Statistics of Occupational Diseases)	Allgemeine Unfall-versicherungsanstalt (AUVA) (General Injuries Insurance Institute)	- Compensation - Prevention - Research	- All physicians - Employers - Employees	AUVA
Belgium	Fonds voor de Beroepsziekten (Fund for Occupational Diseases)	Fonds voor de Beroepsziekten (Fund for Occupational Diseases)	- Compensation - Prevention	- All physicians - Employees - Mutuality (health insurance)	Fund for Occupational Diseases
Czech Republic	Národní registr nemocí z povolání (Czech National Registry of Occupational Diseases)	Státní Zdravotní Ústav (SZU) (National Institute of Public Health)	- Statistics - Prevention - Research	- Specialists in occupational diseases	18 authorized centres of occupational diseases
Finland	Työperäisten sairauksien rekisteri (TPSR) (Finnish Registry of	Työterveyslaitos (Finnish Institute of Occupational Health (FIOH))	- Statistics - Research	- All physicians	Insurance companies

	Occupational Diseases (FROD))				
France	Régime Général (General Regime)	Caisse Nationale d'Assurance Maladie des Travailleurs Salariés (CNAMTS) (National Fund for Insurance of Occupational Diseases for Employees in the Private Sector)	- Compensation - Determination of premium for employers - Prevention	- Employee and physician	CNAMTS
UK	The Health and Occupation Reporting Network (THOR)	Centre for Occupational and Environmental Health of the University of Manchester	- Statistics - Research	- Groups of physicians can notify to different schemes	Not applicable

Preventive aims are mentioned in the stated goals of Austria, Belgium, the Czech Republic and France. Providing statistics and research aims are mentioned in the stated goals of the Czech Republic, Finland and the UK. The registries of Austria, Belgium and France are directly connected with the compensation system for occupational diseases; their main aim is to supply information for the compensation function. The registries of the Czech Republic and Finland are not related to the compensation system, but derive their data from cases notified for compensation. THOR (the UK's Health and Occupation Reporting Network) is totally unrelated to the compensation system and cases are notified only for research aims. THOR is not the official registry in the UK, but is maintained with the support of the government and provides information on a national scale. Since this registry provides more information on occupational diseases for preventive policy than does the official

registry, we decided to choose THOR for the audit. THOR consists of registries for various categories of occupational diseases, such as EPIDERM for occupational skin diseases and SWORD for occupational respiratory diseases. Occupational physicians report cases to the Occupational Physicians Reporting Activity (OPRA) scheme. A selected group of general physicians report cases of occupational diseases to THOR-GP. Interesting cases or novel causes can be reported to THOR-Extra by all physicians.

The procedures in the registries differed between the six countries. Three main steps can be distinguished in the process of registration: notification, acknowledgement and recording of cases. The initial notification of an occupational disease is mostly performed by a physician. However, in compensation systems the employee and sometimes the employer can also take the initiative, although a medical certificate is always needed. Acknowledgement is performed by specialized and entitled physicians working within the context of compensation systems. Only THOR has no acknowledgement procedure.

Tables 2 and 3 present the scores of the six countries for the monitoring and for the alert function. We calculated the average score of the six countries on each indicator and each sub-item of the indicators.

Table 2: Scores of the registries of the six countries on the indicators for the monitor function. For the sub-items + or – indicates whether criteria were met or not met.

Indicator		**AT**	**BE**	**CZ**	**FR**	**FI**	**UK**	**Average score (max. score)**
1. Completeness of notification form		0	0	1	0	1	0	**0.33 (1)**
	a. diagnosis	+	-	+	+	+	+	**0.83 (1)**
	b. exposure	-	-	+	-	+	-	**0.33 (1)**
	c. occupation	+	+	+	+	+	+	**1.00 (1)**
	d. economic sector	+	+	+	+	+	+	**1.00 (1)**
	f. probability of the causal relation	-	-	-	-	-	-	**0.00 (1)**

	g. age of worker	+	+	+	+	+	+	**1.00 (1)**
	h. sex of worker	+	+	+	+	+	+	**1.00 (1)**
2. Coverage of registration		1	1	1	0	1	1	**0.83 (1)**
3. Guidelines or criteria for notification		0	1	0	0	1	1	**0.50 (1)**
4. Education and training		0	1	1	0	0	0	**0.33 (1)**
5. Participation of notifying physicians (range 0-2)		0	0	2	0	0	0	**0.33 (2)**
6. Statistical methods used		0	0	0	0	1	1	**0.33 (1)**
9. Publication of monitor information (range 0-3)		0	0	0	0	1	2	**0.50 (3)**
	a. incidence rates	-	-	-	-	-	+	**0.17 (1)**
	b. additional information	-	-	-	-	-	+	**0.17 (1)**
	c. validity of incidence rates	-	-	-	-	+	-	**0.17 (1)**
Total quality score		**1**	**3**	**5**	**0**	**5**	**5**	**3.2 ± 2.2 (10)**

Table 3: Scores of the registries of the six countries on the indicators for the alert function. For the sub-items + or – indicates whether criteria were met or not met.

Indicator		**AT**	**BE**	**CZ**	**FR**	**FI**	**UK**	**Average score (max. score)**
1. Completeness of notification form		1	1	1	1	1	1	**1.00 (1)**
	a. diagnosis	+	+	+	+	+	+	**1.00 (1)**
	b. exposure	+	+	+	+	+	+	**1.00 (1)**
	c. occupation	+	+	+	+	+	+	**1.00 (1)**
	d. economic sector	+	+	+	+	+	+	**1.00 (1)**
	e. susceptibility	-	-	-	-	-	-	**0.00 (1)**
	f. probability of the	-	-	-	-	-	-	**0.00 (1)**

	causal relation							
	g. age of worker	+	+	+	+	+	+	**1.00 (1)**
	h. sex of worker	+	+	+	+	+	+	**1.00 (1)**
	i. other causes	+	+	+	+	+	+	**1.00 (1)**
2. Coverage of registration		1	1	1	0	1	1	**0.83 (1)**
3. Guidelines or criteria for notification		0	1	0	0	1	1	**0.50 (1)**
4. Education and training (range 0-2)		0	2	2	0	1	0	**0.83 (2)**
5. Participation of notifying physicians (range 0-2)		0	0	0	0	0	0	**0.00 (2)**
7. Investigation of special cases (range 0-2)		2	2	0	2	2	0	**1.33 (2)**
8. Publication of alert information		1	0	1	1	1	1	**0.83(1)**
Total quality score		**5**	**7**	**5**	**4**	**7**	**4**	**5.3 ± 1.4 (10)**

Finally, the reviewers reached agreement on the scoring of all six countries. In two cases the contact person was asked for additional information, and in two cases the third reviewer had to make a decision. On a scale of 0-10, the total quality score of the six countries varied between 0 and 5 (mean 3.2) for the monitor function and between 4 and 7 (mean 5.3) for the alert function. For both the monitoring and the alert function, the lowest scores were for the participation of notifying physicians. The item that scored best for the monitoring function was the coverage of registration (5 registries met the criteria), while the item that scored best for the alert function was the completeness of the notification form (all 6 registries met the criteria).

For the monitor function, two out of six countries fulfilled the criteria of the first indicator ‘completeness of the notification form’. All registries except Belgium’s used the ICD-10 classification for their statistics, although the moment of coding in the process from notification till recording in the database differed. Only the Czech Republic used the EU shortlist for exposure, whereas in Finland

exposures are recoded according to the EU longlist after recording in the database. Susceptibility and probability of the causal relation are not recorded in any of the registries.

Five countries met the criterion for the indicator ‘coverage of registration’. France did not satisfy this criterion, because the Régime Général covers only the private sector, which comprises about 60% of the French working population.

The criterion for the indicator ‘guidelines or criteria for notification’ was fulfilled in three of the six countries. In all six countries, guidelines or criteria were available, but only Belgium, Finland and the UK had guidelines for all six reference diseases, although in Belgium and Finland no figures were provided on mental health disorders.

The criterion for ‘education and training of notifying physicians’ was satisfied only in Belgium and the Czech Republic. Education and training of occupational medicine specialists – the persons who perform the medical investigations for the acknowledgement of occupational diseases – was on a high level in all participating countries.

Only the Czech Republic met the criterion for ‘participation of notifying physicians’ for the monitoring function. In the Czech Republic it is the specialists at the centres for occupational diseases who report to the registry.

Two countries – Finland and the UK – fulfilled the criterion for the indicator ‘statistical methods used’ by providing a public document that accounts for the methods.

None of the countries met all the criteria for the indicator ‘publication of monitor information’. Incidence rates for all six reference occupational diseases in the total working population were presented only by the UK. With regard to the criterion for ‘validity of incidence rates’, only Finland and France had an incidence rate higher than 100/100,000 employee years (280/100,000 employee years for Finland and 230/100,000 employee years in France in 2005). Only Finland and the UK provided reports containing considerations about the validity of the incidence rates.

Regarding the alert function, all six countries satisfied the criteria for the indicator ‘completeness of the notification form’. The criterion for the indicator ‘coverage of registration’ was the same as for the monitor function, which was satisfied by 5 countries.

The criterion for the indicator ‘guidelines or criteria for notification’ for the alert function is that the system is open to the reporting of all suspected cases. Only in Belgium, Finland and the UK is it

possible to report every suspected case of an occupational disease; in these countries, all such cases are registered.

The criterion for ‘education and training of notifying physicians’ was satisfied in Belgium and the Czech Republic. The reviewers ranked this indicator of intermediate quality in Finland and scored one out of the maximum of two points.

With regard to the indicator ‘participation of notifying physicians’, none of the countries met the criterion, indicating serious problems with the participation level of the group of notifying physicians in all six countries.

Austria, Belgium, France and Finland fulfilled the criterion for the indicator ‘investigation of special cases’. In these countries, facilities for the investigation of special cases were available.

All countries except Belgium satisfied the criterion for the indicator ‘publication of alert information’. Remarkable cases and clusters of cases (alert information) were published in Austria, the Czech Republic, Finland, France and the UK. However, in Belgium the Fund for Occupational Diseases does stimulate publications on remarkable cases.

Three of the six contact persons (50%) agreed with the statement that the audit could actually contribute to the improvement of quality of the registration system in relation to prevention. One contact person did not agree with the statement and was of the opinion that the scoring method of ODIT had to be improved and that criteria for dissemination of information should be added. Two contact persons neither agreed nor disagreed with the statement, but agreed on the statement that the registry of occupational diseases in their country needs quality improvement to provide appropriate policy information for prevention.

Discussion

The aim of this study was to evaluate registries of occupational diseases in six European countries on their ability to provide monitor and alert information, and to assess the usefulness of the audit tool to contribute to future quality improvement. The monitor function was rated in all six countries as being of limited quality and the alert function was rated in four countries as poor.

Registries that have a scientific aim – such as those in Finland and the UK – show better results on the monitoring function than countries with a registry linked to compensation. The publication of monitor information was deficient in all six countries and in four of the countries a justification of statistical methods was lacking. All registries aim to publish alert information, but the conditions for tracing and investigating remarkable cases can be improved. Poor participation of notifying physicians is a problem in all six countries, whereas education and training of notifying physicians regarding occupational diseases can be improved. Three of the six contact persons agreed that the audit could actually contribute to quality improvement of the registry.

A strength of this study is that we could use a validated audit tool to evaluate the registries of the six countries (15) with the consistent aim to evaluate the ability to provide appropriate information for prevention. We followed a clear and conscientious procedure: the audits were well prepared and executed by the same auditor, the contact persons had the opportunity to comment on the draft reports and we asked the contact persons to verify the final report. Two independent reviewers evaluated the reports and completed the ODIT scoring table. If the two reviewers could not agree on an issue, a third reviewer made the decision.

A limitation of the study is that we used a theoretical model to evaluate the registries, whereas there might be practical reasons for registries to refrain from upgrading their quality standards. For example, some registries or schemes use their own classification system of diseases or exposures. If notifying physicians are not acquainted with the comprehensive EU classification of exposures, this might be an argument to use a more simplified classification.

A further limitation of the study is that gathering sufficient information concerning some of the indicators requires a more thorough investigation than can be accomplished within the scope of the audit. Concerning the indicators ‘statistical measures used’ and ‘investigation of special cases’, we assessed only whether a document that accounts for the statistical methods was available and whether facilities were available to investigate special cases in the opinion of the contact person. Of course, this is only the starting point for a quality improvement process, as the next step could be a discussion on the content of the documents and on how investigations of special cases should be performed.

Although comparative studies of registries of occupational diseases have been done before, many of them focused on differences in incidences reported in various countries. For example, Nordman et al. compared reporting systems for occupational asthma in Finland, Sweden, the UK, the USA and Quebec (23). They found great differences in reported incidences between these countries, likely related to differences in the registries resulting from diverse legislation. Blandin et al. compared incidences in the registries of fifteen countries and found similar trends for some diseases, but also considerable differences, due to dissimilarities in legal conditions of compensation (8,9). Diepgen studied occupational skin disease data in Europe and concludes that reliable data are hard to extract from official registries. He also concludes that data on social and economic impact are very scarce (24). Latza and Bauer compared figures on occupational asthma from Germany with figures of registries in other countries and found great differences in reported causes (25).

However, a few studies have been done on the quality of registries of occupational diseases. McDonald made an estimation of the denominator on the basis of a survey amongst occupational physicians (26). He found large-scale underreporting by occupational physicians and an enormous variation between industrial sectors as regards access to an occupational physician. McNamee et al. investigated trends in reporting behaviour (27). The authors conclude that variation in reporter behaviour is a serious consideration in time trends estimation and recommend new statistical methods to improve estimation of true trends in the future. Chen et al. studied physicians' beliefs about assessment of occupational attribution for work-related musculoskeletal disorders and found a strong agreement between occupational physicians and rheumatologists on the issue (28). The opinion of the reporting physicians in THOR on the electronic exchange of information was explored by Rogers et al. (29), who found that although most of their respondents had the skills and infrastructure required to engage in electronic information exchange, and were favourably disposed to electronic communication, one third preferred a paper-based system. Spreeuwers et al. analysed the quality of occupational physicians’ diagnosing and reporting (30). They conclude that diagnosing and reporting could be improved and advocate information, education and practical tools. We could not find any studies that applied a comprehensive and validated tool to evaluate the quality of a registry.

The audits of the six countries show that quality improvement of registries of occupational diseases is needed in order to support preventive policy with better monitor and alert information. Participation of notifying physicians is a problem in all six countries and might be improved by more intensive communication and involvement of notifying physicians with the registry and possibly by creating incentives, like education, financial rewards or practical support. Education and training is on a high level in all participating countries for specialists in occupational diseases, but better education about occupational diseases is needed for other physicians. Developing evidence-based guidelines and training physicians to use them will improve the quality of reporting occupational diseases. Furthermore, every registry should be encouraged to develop a quality document that accounts for the figures published and the statistical methods used. Alerting to newly occurring occupational diseases requires the development of specific methods for tracing new risks and validating signals.

Although this study did not take into account the dissemination of the results of the registries to workplaces and labour safety authorities, such dissemination is decisive for an effective use of the information for prevention.

Another point for discussion is the linkage of registries to compensation systems. In our opinion, registries of occupational diseases should be independent of compensation systems, although in most cases data of compensation systems can be utilized. A strong linkage to a compensation system has the disadvantage that the registry is tied to the country's social security regulations. This also complicates the international evaluation by comparison of results between countries. We should like to promote notification projects in different countries that use the same notification forms and the same, evidence-based guidelines for diagnosing and reporting and with the same quality standards. In addition, surveillance schemes with a sample of motivated reporting physicians are easier to manage and provide better quality results than do nationwide registries (31).

The ODIT tool can be further developed by using it in practice and discussing the results. To get a better insight into the degree of underreporting, studies are needed on the notification behaviour of not only physicians but also employees and employers, and on barriers to diagnosing and reporting occupational diseases. Development of evidence-based diagnostic guidelines is a precondition for reliable figures on occupational diseases, as are the education and training of the reporters. In order to

make reliable estimates of incidence rates, a more precise determination of the denominator is important. Finally, there is a great need to develop methods for the detection and validation of new associations between existing or new occupational risk factors and diseases.

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Appendix 1: Quality indicators and criteria for registration systems of occupational diseases

Indicator	**Criteria for monitor function**	**Criteria for alert function**
Structural preconditions		
1. Completeness of notification form	- The notification form meets the criteria for diagnosis and exposure and for at least three other indicator items	- Six out of nine indicator items meet the proposed criteria *and* the notification form offers the possibility to add relevant information
a. diagnosis	- Diagnosis according to the ICD-10 classification is a registered item	- Diagnosis is a registered item
b. exposure	- Type of exposure according to the EU shortlist is a registered item	- Type of exposure is a registered item
c. occupation	- Information about occupation is a registered item	- Information about occupation is a registered item
d. economic sector	- Information about economic sector is a registered item	- Information about economic sector is a registered item
e. susceptibility	- not applicable	- Information about susceptibility is a registered item
f. probability of the causal relation	- Probability of the causal relation is a registered item	- Probability of the causal relation is a registered item
g. age of worker	- Age is a registered item	- Age is a registered item
h. sex of worker	- Sex is a registered item	- Sex is a registered item
i. other causes	- Other (additional) causes can be reported on the registration form	- Other (additional) causes can be reported on the registration form
2. Coverage of registration[3)]	Notifying physicians cover at least 75% of the working population	Notifying physicians cover at least 75% of the working population
3. Guidelines or criteria for notification	Guidelines for assessment of occupational diseases on the EU shortlist are available. Guidelines	- The system is open (i.e. if there is a list, it is possible to report cases that are not on it)

	contain at least requirements for diagnosis and exposure. This is evaluated in six reference diseases (occupational asthma, occupational hearing loss, contact dermatitis, asbestos-related diseases, mental health disorders, musculoskeletal disorders of the upper limb)	
4. Education and training	Diagnosis, guidelines for assessment and notification procedures are part of the medical specialist training or the postgraduate training for notifying physicians: - Participation level of education > 80 % of group of notifying physicians.	Diagnosis, guidelines for assessment and notification procedures are part of the medical specialist training or the postgraduate training for notifying physicians: - Participation level of education > 80 % of group of notifying physicians (2 points) - Participation level of education; all occupational physicians OR > 50 %- < 80% of group of notifying physicians (1 point)
Diagnosis and notification process		
5. **Participation of notifying physicians**	Participation level > 75 % of group of notifying physicians or of a sample of physicians with a known population, representative of the whole working population	Participation level > *75* % of group of notifying physicians
6. Statistical methods used	A public document that accounts for the statistical methods is available	Not applicable
7. investigation of	Not applicable	There are facilities to investigate special

special cases		cases in the opinion of the representatives of the institute responsible for registering occupational diseases
Output		
8. Publication of alert information	Not applicable	Remarkable cases and clusters of cases must be mentioned in an annual report or in another publication
9. Publication of monitor information *a. Occupational diseases incidence rates and distribution* *a1. Incidence rates of specific occupational diseases for the total working population* *a2. Incidence rates of specific occupational diseases by sector or by occupation* *a3. Distribution of occupational diseases by socio-demographic variables age and sex* *b. Additional information*	- Incidence rates are presented for the six reference occupational diseases in the total working population - Incidence rates for the six reference occupational diseases are presented by sector or by occupation - Incidence rates for age and sex are given for the six reference occupational diseases - Information about sickness absence has been published for the six reference occupational diseases *OR* information	Not applicable

c. Validity of incidence rates	about economic costs has been published for the six reference occupational diseases - Incidence rate of total occupational diseases is at least 100/100,000 employees *AND* - Reports on the system contain a consideration about the validity of the incidence rates for the six reference diseases	

Appendix 2: Calculation of a total quality score for the monitor and the alert function of registries of occupational diseases

Indicators: monitor function	**Score**	**Indicators: alert function**	**Score**
Completeness of notification form	1 point	Completeness of the notification form	1 point
Coverage of registration	1 point	Coverage of registration	1 point
Guidelines or criteria for notification	1 point	Guidelines or criteria for notification	1 point
Education and training	1 point	Education and training	2 points
Participation of notifying physicians	2 points	Participation of notifying physicians	2 points
Statistical methods used	1 point	Investigation of special cases	2 points
Publication of monitor information: - meeting the criteria for incidences - meeting the criteria for additional information - meeting the criteria for validity of incidences	(3 points) 1 point 1 point 1 point	Publication of alert information	1 point
Max. score	10 points	Max. score	10 points

Chapter 5

Sentinel surveillance of occupational diseases: a quality improvement project

Spreeuwers D, de Boer AGEM, Verbeek JHAM, de Wilde NS, Braam I, Willemse Y, Pal TM, van Dijk FJH. Sentinel surveillance of occupational diseases: a quality improvement project. *Am J Ind Med* 2008 Jul 23 [Epub ahead of print].

Abstract

Background: Occupational diseases are generally underreported. The aim of this study was to evaluate whether a sentinel surveillance project comprising motivated and guided occupational physicians would provide higher quality information than a national registry for a policy to prevent occupational diseases.

Methods: A group of 45 occupational physicians participated in a sentinel surveillance project for two years. All other occupational physicians (n=1,729) in the national registry were the reference group. We compared the number of notifications per occupational physician, the proportion of incorrect notifications, and the overall reported incidence of occupational diseases.

Results: The median number of notifications per occupational physician during the project was 13.0 (IQR, 4.5-31.5) in the sentinel group versus 1.0 (IQR, 0.0-5.0) in the reference group ($p<0.001$). The proportion of incorrect notifications was 3.3% in the sentinel group and 8.9% in the reference group ($p<0.001$). The overall reported occupational disease incidence was 7 times higher (RR = 6.9, 95%CI: 6.5-7.4) in the sentinel group (466 notifications per 100,000 employee years) than in the reference group (67 notifications per 100,000 employee years).

Conclusions: A sentinel surveillance group comprising motivated and guided occupational physicians reported a substantially higher occupational disease incidence and a lower proportion of incorrect notifications than a national registry.

Introduction

Exposure to occupational health risks accounts for a significant proportion of the burden of diseases – a burden that could be substantially reduced through the application of proven risk-prevention strategies (1). Information about the incidence and distribution of occupational diseases is essential for preventive policy. Registries of occupational diseases are only one source, but mostly an authoritative one, of policy information.

As in the United States, most of the 27 EU countries maintain one or more registries of occupational diseases. Although these registries are mainly based on cases recognized in compensation systems related to social security legislation, the majority of registries also have the ambition to provide information for preventive policy (2-5). Only a limited number of registries are set up primarily to gather information for preventive policy, such as SENSOR in the US (6), THOR in the UK (7) and the Dutch National Registry (8). A point of debate is whether it might be better for the registration of occupational diseases to rely on health surveillance systems rather than on financial compensation schemes. Such a shift of approach might better support policymakers in their task to set priorities for prevention and research and to monitor whether preventive policy is effective (9,10).

There are large differences between the statistics on occupational diseases in the different EU countries. Although a European list of occupational diseases has been developed for the purposes of harmonization, the effectiveness of the list is limited (11). A number of reasons may explain this limited effectiveness, such as substantial differences in diagnostic guidelines and criteria for notification, and, more generally, in culture, legislation and social security regulations (2). One important aspect is the large variation in the degree of assumed underreporting of occupational diseases (12). For example, the incidence of all occupational diseases in Greece was 3.4/100,000 employee years in 2001 (13), while the incidence in Finland was 200/100,000 employee years in 2002 (14). By comparison, the mean incidence in the 15 EU countries in 2001 was an estimated 37/100,000 employee years (15). An overview of the different registries in Europe can be found on the website of the European Agency for Safety and Health at Work and in the European Health and Safety Database (HASTE) (16,17).

The reliability of most national incidence figures of occupational diseases is considered to be poor due to underreporting (18). This is caused by several factors, such as limited knowledge of occupational diseases in the working population, employees' fear of reporting illness to supervisors or

physicians, limited access to medical care, impaired recognition by physicians and limited notification (12, 19). Since registries form an important source of information for policy makers, enhancement of completeness and quality can improve appropriate decision-making in preventive policy in Europe.

During the period in which this study was carried out, all companies in the Netherlands with at least one employee became legally obliged to have a contract with an occupational health service (OHS) and, therefore, nearly all employees had access to an occupational physician (20). Since 1999, OHS's are obliged by law to notify occupational diseases but, in practice, it is occupational physicians who do the reporting. The Dutch government has appointed the Netherlands Center for Occupational Diseases (NCOD) as the institute responsible for the national registry. Since there is no compensation scheme for occupational diseases in the Netherlands, such diseases are notified only for preventive purposes.

Each year since 2000, about 6,000 notifications have been received and accepted by the NCOD; however, there are several indications of a considerable underreporting. For example, whereas the incidence of occupational dermatitis was estimated at 13,000 cases per year in the Netherlands (21), which corresponds to the incidence figures mentioned in the scientific literature (22), the actual number of notifications of occupational dermatitis by occupational physicians in the national registry is only about 250 per year. Another example is the number of notifications of occupational asthma in the national registry, which is about 15 times lower than would be expected on the basis of registrations of occupational asthma in several other countries that have assumed similar levels of relevant exposures at work (23).

Since most countries experience underreporting, projects to improve notification have been set up in various countries mostly for specified categories of occupational diseases (24,25). The results of these projects suggest that it is possible to obtain more reliable information on the incidence and distribution of occupational diseases from a sample of motivated and guided occupational physicians. We therefore decided to launch a sentinel surveillance project in the Netherlands. We began by recruiting motivated occupational physicians in 2002. The participants were urged to report every occupational disease they recognized in their practice over a two-year period. When necessary, we asked them for additional information about certain cases. We offered this group supplementary training and feedback on their notifications.

The aim of our study was to assess whether selecting motivated occupational physicians and providing them with supplementary training and feedback would increase the number and quality of notifications. We therefore formulated three research questions: 1) Do occupational physicians in the sentinel group notify occupational diseases more frequently than those in the reference group of all other occupational physicians in the national registry? 2) Is the proportion of incorrect notifications from the sentinel group different from the proportion of incorrect notifications from the reference group? 3) What is the difference between the estimated incidence of various occupational diseases reported by the sentinel group compared to the reference group, and does this difference vary across economic sectors?

Since underreporting is widely acknowledged to be a key problem, we considered the results provided by the sentinel group as being higher quality information for preventive policy if: a) the estimated overall incidence of occupational diseases was higher than that reported by the reference group, b) the number of notifications per occupational physician was higher than in the reference group and c) the proportion of incorrect notifications was lower than in the reference group.

Materials and Methods

Participants:

We recruited occupational physicians by placing announcements in the NCOD Newsletter, which is sent to all occupational physicians in the Netherlands. Participants in the sentinel group had to register themselves actively and agree to participate for at least one year in the two-year project. We designated the participants as motivated physicians, because they were prepared to attend the meetings and to do the extra administrative work required in the project. Moreover, most of the motivated physicians were already active reporters of occupational diseases. Accredited education and training were offered as an incentive for participation. All other occupational physicians in the Netherlands who could notify occupational diseases to the national registry served as a reference group (26).

We started the project January 2003 and urged participating occupational physicians to report every occupational disease they recognized in their practice over a two-year period. When necessary, we asked them for additional information about particular cases. We offered this group supplementary training and feedback on their notifications. After an introductory meeting in November 2002, in which the aim and the procedures of the project were explained, we organized four voluntary courses on the diagnostics of occupational diseases. The courses were in March, June, September and December 2003, and the topics were work-related psychiatric disorders, musculoskeletal disorders, skin diseases and respiratory diseases. We provided regular feedback by means of a special quarterly newsletter for the participants. Consultation of the help desk of the NCOD was promoted. The project continued through December 2004.

We asked the physicians in the sentinel group to provide information about the number of employees in the population covered and the distribution by economic sector at the start of the project, after one year, and at the end of the project. If occupational physicians did not reply, we imposed a 'model population' derived from the distribution by economic sector for the total Dutch workforce in 2002. We categorized the economic sectors according to the classification of the Netherlands Central Bureau of Statistics (27).

The total population size served by the sentinel group was 108,315 employees, while that of the reference group was 6,049,685 employees. To calculate the population size for the reference group, we used statistics on the Dutch workforce in 2002 provided by the CBS (28) and subtracted the population size of the sentinel group from the total workforce.

Measurements:

Physicians in the sentinel group used the notification form as prescribed by the national registry for all occupational physicians. The form includes the following items: name and code of the OHS and of the physician; date of notification; patient file number; sex and year of birth of the patient; occupation and economic sector; ICD-10 code and description of diagnosis; causes; pre-existent medical conditions; degree of certainty of diagnosis; the occupational healthcare activities associated with the diagnostic assessment of the occupational disease; the advice given.

Notifications from the sentinel group were processed in the same way as notifications under the regime of the national registry are processed. According to the Quality Handbook for the Dutch National Registry, the judgment of the correctness of a notification is a two-step procedure. First, an automatic filter check is carried out to establish whether all obligatory fields have been filled in; second, a quality judgment is made by an expert team comprising two experts in occupational diseases and two staff members of the registration office (29). If notifications are incomplete, the notifying physician is asked by email to complete the report. If the physician still does not complete the report after this request, the notification is considered as incorrect. We considered fewer incorrect notifications as a valid indication of a better quality of notification.

We analyzed the number of notifications and the proportion of incorrect notifications in the two years preceding the project for both the sentinel and the reference group in order to assess differences between the groups in the period before the intervention and changes in reporting behavior over time.

Statistical analysis:

We determined the median number of notifications per physician and the interquartile ranges (IQR) in both groups over the project period and over the preceding two years. Median numbers of notifications were used, since the distribution was skewed.

We used a Mann-Whitney U test to test the differences in the median number of notifications between the sentinel group and the reference group both during the study period and in the two preceding years. The differences in median number of notifications within the sentinel group and within the reference group between the project period and the two preceding years were tested with a Wilcoxon Signed Rank test. Further, we tested the difference in proportions of incorrect notifications between the sentinel and the reference group both during the project period and in the two preceding years with a chi-square test. For both the sentinel and the reference group, the differences in proportions of incorrect notifications between the project period and the preceding period were tested with the chi-square test.

We defined physicians who notified more cases than the mean plus two standard deviations as outliers. Since we do not know what motivates physicians to report considerably more cases than average, we checked whether excluding outliers made a difference to the results.

We calculated the incidence in both groups and the rate ratio with a 95% confidence interval for all occupational diseases and separately for the six most frequent categories of occupational diseases in four different economic sectors. We selected the six most frequently notified occupational diseases, namely: 1) occupational diseases of the upper limb, 2) occupational adjustment disorder, 3) post-traumatic stress disorder (PTSD), 4) work-related asthma, 5) occupational contact dermatitis, and 6) occupational hearing loss. Adjustment disorders (DSM-IV definition) are maladaptive reactions to identifiable psychosocial stressors. They are manifested by either impairment in social or occupational functioning or by symptoms (nervous exhaustion, nervous breakdown, surmenage, depressive thoughts etc.) that are in excess of a normal and expected reaction to the stressor. The presence of depressive disorders and anxiety disorders, for example, has to be excluded.

We selected the four largest economic sectors in terms of number of employees, that is, industry, repair and trade, business services, and healthcare and welfare. The repair and trade sector comprises the trade in and repair of cars and motorcycles, the wholesale business, and retail trade and repair for private persons. The business services sector comprises the rental of and trade in real estate, vehicles and machines, as well as agencies for computer service and information technology.

SPSS 11.5 was used for the statistical testing. We calculated rate ratios and 95% confidence intervals according to Rothman and Greenland (30).

Results

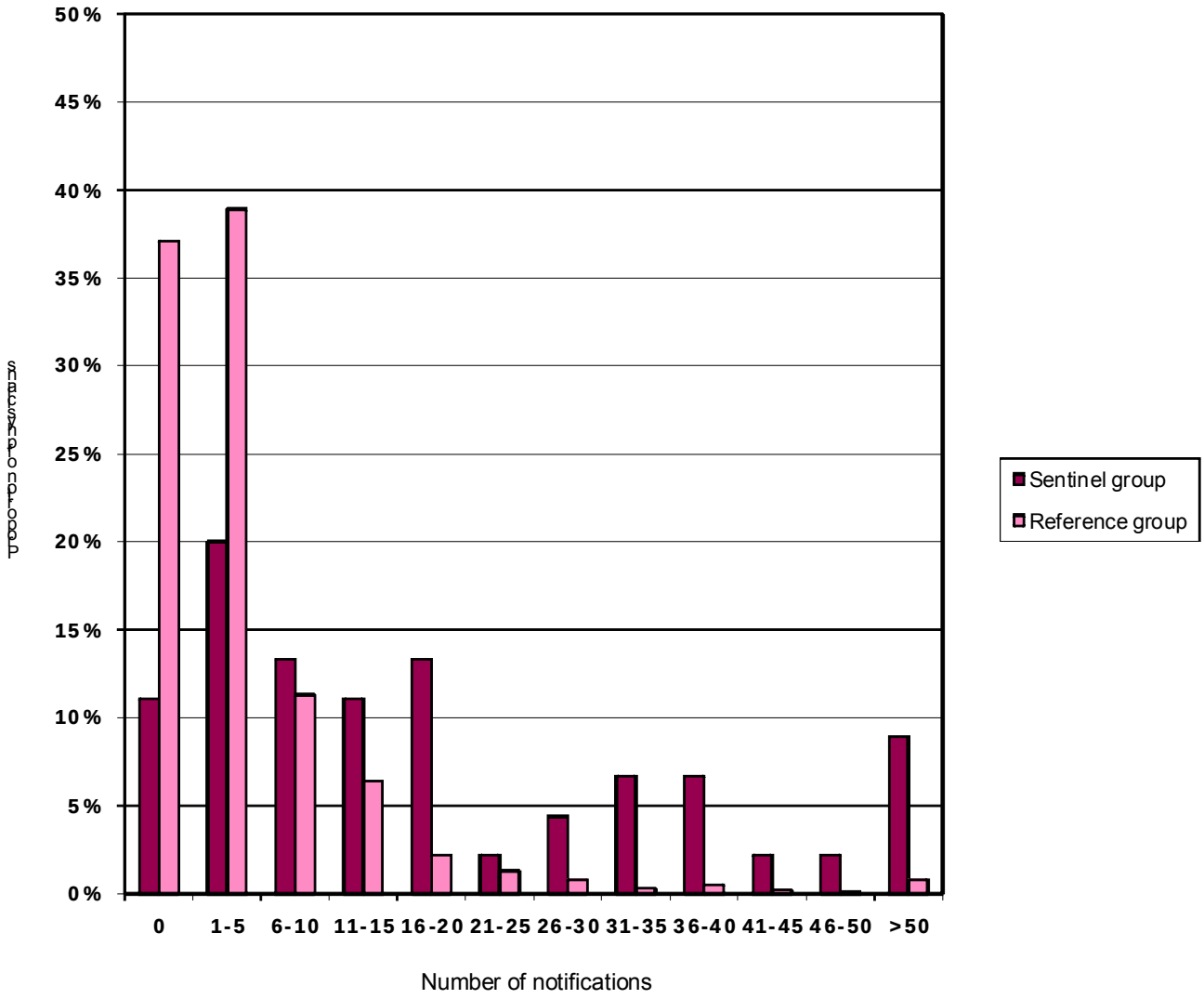
The sentinel group was comprised 45 occupational physicians, the reference group of 1729 occupational physicians. Both the population of workers covered by the sentinel group and that covered by the reference group formed a representative sample of Dutch workers. The populations of both groups were similar except for the repair and trade sector, which was represented relatively more in the reference group than in the sentinel group.

Twenty-four occupational physicians (64%) in the sentinel group attended one or more of the supplementary training courses. During the study period, the sentinel group notified 1,009 cases and the reference group 8,118 cases. Figure 1 shows the proportion of occupational physicians by notification frequency in the sentinel group and in the reference group. The median number of notifications in two years per occupational physician in the sentinel group was 13.0 (IQR 4.5-31.5) while the figure for the reference group was 1.0 (IQR 0.0-5.0), which is a statistically significant difference (Mann-Whitney U test: $p<0.001$).

One notifying occupational physician notified 197 cases in two years, and was, therefore, identified as an exceptional outlier in the sentinel group. In the reference group, 28 occupational physicians were identified as outliers: together they notified 2,003 cases in two years (range: 36 – 535 cases). Without the outliers, the median number of notifications in two years per occupational physician in the sentinel group was 12.5 (IQR 4.25-29.75) compared to 1.0 (IQR 0.0-5.0) in the reference group, which is a statistically significant difference as well (Mann-Whitney U test: $p<0.001$).

In the two years preceding the project, the median number of notifications per occupational physician in the sentinel group was 13.0 (IQR 1.0-26.0) compared to 2.0 in the reference group (IQR 0.0-5.5) (Mann-Whitney U test: $p<0.001$). The differences within the sentinel group and the reference group in the project period compared to the two preceding years were not statistically significant (Wilcoxon Signed Rank test: $p = 0.406$ and $p = 0.478$ respectively).

Figure 1: Proportion of physicians by number of notifications in the project period



In the sentinel group, 3.3% of the notifications were judged as incorrect according to the requirements of the Quality Handbook of the Dutch National Registry. For the reference group, this figure was 8.9%, a statistically significant difference (chi-square test: $p<0.001$). Excluding the outliers, 4.0% of the notifications were judged as incorrect in the sentinel and 9.8% in the reference group, a statistically significant difference (chi-square test: $p<0.001$). In the subgroup of the sentinel group that followed the supplementary training, the proportion of incorrect notifications was only 2%.

In the two preceding years, the proportion of incorrect notifications was 6.8% in the sentinel group compared to 8.8% in the reference group (chi-square test: $p>0.05$). The difference between the project period and the preceding period was statistically significant in the sentinel group (chi-square test: $p<0.01$), but not in the reference group (chi square test: $p>0.1$).

Table 1 shows the incidences of reported occupational diseases per 100,000 employee years for both the sentinel group and the reference group as well as the rate ratios with confidence intervals. The incidence of all occupational diseases was 466/100,000 employee years (95% CI: 438-495) in the population of the sentinel group and 67/100,000 employee years (95% CI: 66-69) in the population of the reference group. Without the outliers in both groups, the incidence in the sentinel group was 375/100,000 employee years (95% CI: 350-401) and in the reference group 51/100,000 employee years (95% CI: 49-52), which represents a rate ratio of 7.4 (95% CI: 6.9-8.0).

When we excluded the outliers in both groups, the rate ratios for PTSD and occupational hearing loss changed significantly. Without the outliers, the rate ratio for PTSD was 4.9 (95% CI: 3.1-7.7) compared to 11.3 (95% CI: 8.5-15.1) with the outliers included. Without the outliers, the rate ratio for occupational hearing loss was 6.2 (95% CI: 5.0-7.7) compared to 3.1 (95% CI: 2.5-3.8) with the outliers included.

Table 1: Incidence of reported occupational diseases per 100,000 employee years for the sentinel group and for the reference group. Rate ratio of reported incidences in the sentinel versus the reference group, national registry in the Netherlands

	Sentinel group	Reference group	
	N= 108,315	N= 6,049,685	
	IR	IR	RR (95% CI)
All occupational diseases	466	67	6.9 (6.5 - 7.4)
Occupational diseases of the upper limb	169	19	9.0 (8.0 - 10.0)
Occupational adjustment disorders	109	16	6.8 (5.9 - 7.8)
Post Traumatic Stress Disorder	25	2	11.3 (8.5 - 15.1)
Work-related asthma	1	<<1	3.5 (1.1 - 11.2)
Occupational contact dermatitis	15	3	5.6 (3.9 - 8.1)
Occupational hearing loss	43	14	3.1 (2.5 - 3.8)
Other occupational diseases	103	13	8.1 (7.0 - 9.3)

N = number of employees in the population under surveillance. IR = incidence density rate. 95%CI = 95 % confidence interval. RR= rate ratio.

Table 2 shows the incidences of the six selected categories of occupational diseases for the four selected economic sectors for both groups and the rate ratios with confidence intervals.

ncidence of reported occupational diseases per 100,000 employee years by economic sector for the sentinel (N=45) and reference group (
e ratio of reported incidences in the sentinel versus reference group. 95%CI = 95 % confidence interval. N = number of employees in the po
veillance. IR = Incidence Density Rate. - = no RR possible due to empty cells

	Industry			Repair and trade			Business services			Healthcare a
	Sent. group	Ref. group		Sent. group	Ref. group		Sent. group	Ref. group		Sent. group
	N= 19,681	N= 946,319		N = 7,002	N = 899,998		N = 14,148	N = 700,852		N = 16,238
	IR	IR	RR (95% CI)	IR	IR	RR (95% CI)	IR	IR	RR (95% CI)	IR
e	358	28	12.8 (10.6-15.4)	300	7	40.9 (28.9-57.8)	39	17	2.3 (1.2-4.1)	65
	175	15	12.0 (9.2-15.6)	50	4	12.5 (5.8-27.1)	60	11	5.2 (3.2-8.6)	55
r	25	1	30.1 (13.6-66.2)	93	1	111.4 (53.0-234)	11	1	13.5 (3.8-48.4)	9
	3	1	2.3 (0.3-17.0)	0	0	-	0	0	-	0
	33	6	5.1 (2.9-9.1)	21	1	25.7 (7.4-88.8)	7	1	7.1 (1.6-31.1)	12
	150	26	5.8 (4.4-7.6)	7	1	8.6 (1.1-64.9)	4	1	4.1 (0.5-31.7)	0
onal	188	16	12.0 (9.3-15.5)	150	6	24.1 (15.1-38.4)	25	6	4.1 (1.9-8.9)	108
l	932	92	10.1 (9.0-11.3)	621	20	30.9 (24.5-39.0)	145	38	3.9 (2.8-5.3)	249

due to rounding off the figure for all occupational diseases sometimes differ from the sum of the figures in the same column

The rate ratio of the incidence in the sentinel group and the reference group for the industry sector was 10.1 for all occupational diseases, 30.9 for the repair and trade sector, 3.9 for the business services sector and 4.9 for the healthcare and welfare sector. The rate ratio for all occupational diseases was significantly higher in the repair and trade sector than in each of the other three economic sectors. The rate ratio for all occupational diseases was significantly higher in the industry sector compared to the business services sector and the healthcare and welfare sector. Without the outliers, the difference in rate ratios for all occupational diseases between the economic sectors remained statistically significant. The outlier in the sentinel group was responsible for 45% of the notifications in the repair and trade sector. Without the outliers, in the sentinel group the overall incidence in the repair and trade sector was 414/100,000 rather than 621/100,000 employee years, which represents a rate ratio of 23.7 (95% CI: 17.5-32.3).

For all disease categories, the reported incidence rate was higher in the sentinel group than in the reference group. For some diseases, this difference was even more pronounced in certain economic sectors, as expressed in a significantly higher rate ratio. The rate ratio for occupational diseases of the upper limb between the project and the reference group was significantly higher in the repair and trade sector than in the other economic sectors. The rate ratio for occupational diseases of the upper limb was also higher in the industry sector compared to the business services sector and the healthcare and welfare sector. Without the outliers, the difference in rate ratios for occupational diseases of the upper limb between the economic sectors remained statistically significant.

The rate ratio of occupational adjustment disorders was significantly higher in the industry sector compared to the business services sector and the healthcare and welfare sector. The rate ratio of occupational adjustment disorders in the repair and trade sector was significantly higher than in the healthcare and welfare sector. Without the outliers, the difference in rate ratios between the industry sector compared to the business services sector and the healthcare and welfare sector remained statistically significant, while the difference in rate ratios between the repair and trade sector and the healthcare and welfare sector was no longer statistically significant.

In the repair and trade sector, the rate ratio for PTSD was 111.4, which is significantly higher than in the business services sector and the healthcare and welfare sector. The rate ratio for PTSD in the industry sector was significantly higher than in the healthcare and welfare sector. The outlier in the

sentinel group notified 35 of the 55 cases of PTSD (64%). All cases of PTSD in the sentinel group in the repair and trade sector, the business services sector and the healthcare and welfare sector were notified by the outlier. Without the outliers, the rate ratio of PTSD in the industry sector was 13.1 (95% CI: 3.7-47.0).

Discussion

The median number of notifications per occupational physician was 13 in the sentinel group versus 1 in the reference group. The number of incorrect notifications in the sentinel group was three times lower than in the reference group. Compared to the two preceding years, the sentinel group did not notify significantly more cases, although the quality of notification improved significantly. The overall incidence of occupational diseases as reported by the sentinel group was about seven times higher than by the reference group. For diseases of the upper limb, the difference was even larger, suggesting a differentiation in underreporting in the national registry. On the basis of these results, we conclude that this notification project led to the provision of more notifications per employee-year and that the notifications were of better quality than those in the national registry.

A strength of the study is that we knew both the denominator and the distribution over economic sectors in the source population of the sentinel group. The choice of denominator determines to a considerable extent the outcome of calculations of incidences (31). Information from surveys of the national workforce is often used as the denominator in the calculation of incidences for occupational diseases (32). Determining the population by adding up the populations of the participating occupational physicians might lead to a more precise determination of the source population than would be obtained by, for example, using surveys of the work population.

An advantage of using a sentinel group is the possibility to instruct and train the occupational physicians more intensively and to give them personal feedback. The results of our study suggest that the initial higher motivation provides a higher number of notifications per occupational physician and that better guidance can improve the quality of notifications. This study provided an exceptional

opportunity to include all the notifying occupational physicians of one country, rather than having to select a reference group.

A limitation of the use of a sentinel group to monitor occupational diseases is the risk that rare cases and cases restricted to a certain area, economic sector or occupation might be overlooked or overestimated due to their smaller numbers or uneven distribution. A national registry provides the chance to detect and investigate interesting solitary cases and, for example, cases that are present in only one area.

Another limitation is that a few very active participants can have a strong influence on the outcomes. As our results showed, one occupational physician who reported an outlying number of occupational diseases did have a significant effect on some incidence rates but not on all. Exclusion of outliers resulted in a marked decrease in the rate ratio for PTSD, yet had the opposite effect on the rate ratio for occupational hearing loss. The decrease in the rate ratio of PTSD was due to the high number of PTSD cases by the outlier in the sentinel group, whereas the increase in the rate ratio for occupational hearing loss was due to the fact that a high number of cases were reported by the outliers in the reference group. Results like the high number of reports of PTSD from the outlier of the sentinel group require further investigation. Close examination of the reported cases is important to establish whether diagnostic criteria have been applied correctly. A specific population of one physician or a current mass screening programme might be an explanation for a large number of notifications. One way to deal with this problem might be to identify outliers and either remove them from the figures or describe the effect on the figures explicitly. In addition, providing reporting physicians with feedback can improve their reporting behavior. However, the relatively wide variation in the number of notifications per physician could be due to real variations in the source population or differences in notification behavior. It might also indicate the relevance of different concepts among occupational physicians about the definition and importance of notification of occupational diseases (33). The rate ratio for occupational hearing loss was lower than for the other occupational diseases, probably because there are generally accepted and clear-cut criteria for the diagnosis, whereas criteria for work-relatedness of diseases of the upper limb and adjustment disorders are more open for interpretation of the reporting physician. Physicians of the sentinel group might be more inclined to recognize diseases of the upper limb and adjustment disorders as work-related. This could be an

issue for future research. Moreover, the influence of characteristics of physicians - for example age and sex, experience or attitudes - on diagnostic and reporting behavior need further investigation.

Registries that use medical specialists' reporting have been set up in various countries for certain categories of occupational diseases. Examples of notification projects in the UK are the schemes within the Occupational Diseases Intelligence Network (ODIN) and those within its successor, The Health and Occupation Reporting network (THOR). Within this latter network there are notification projects for occupational skin diseases (EPIDERM), occupational respiratory diseases (SWORD) and other occupational disease categories. Occupational physicians can report to the OPRA scheme (7). The THOR network distinguishes core and sample reporters. Core reporters report cases on a monthly basis, while sample reporters report cases during only one, randomly sampled month per year. In general, core reporters are more motivated to join the reporting scheme, while sample reporting is an option for those who might find the task of reporting every month too burdensome. A trend analysis of the ODIN/THOR surveillance data 1996-2004 shows that the mean number of notifications from the core reporters is higher than from the sample reporters (34). This corresponds with the results of our study in which we found that our sentinel group reported seven times more occupational diseases.

The NCOD has also initiated notification projects focused on occupational skin diseases (ADS) amongst dermatologists and on occupational respiratory diseases (PAL) amongst lung specialists. These registries tend to provide different incidences than those provided by registries of occupational physicians (21). This is partly because medical specialists have a position in the health system that leads to a different category of visiting patients compared with the patients who consult an occupational physician. On the basis of the ADS figures, we estimated the incidence for occupational contact dermatitis at 180/100,000 employee years. The estimated incidence on the basis of the sentinel surveillance project was 15/100,000 employee years. These findings suggest that for some disease categories additional surveillance schemes can be useful. Because of the low response of the lung specialists in PAL we did not calculate the incidence for work-related asthma. The reported incidence of occupational asthma is very low in the sentinel group, the reference group as well as in the PAL-group of lung specialists. This might indicate a poor recognition in primary and occupational health care or a lack of specialised diagnostic facilities for this category of occupational diseases in the

Netherlands. This might be caused by the absence of a compensation system for occupational diseases in the Netherlands. Diagnosing occupational asthma is often difficult and in many countries it is diagnosed in specialized Centres for Occupational Diseases within the scope of a compensation procedure.

For preventive policy, in addition to incidence figures from registries, other information must be taken into consideration, for example information from epidemiological studies, case studies and surveys. Information about the national legal and political context and about social security regulations must also be taken into account in order to allow an adequate interpretation of the meaning of the figures for preventive policy (18). One of the aspects that might affect registration activities is the organization of OHS's in a country. For instance, where OHS's are absent or do not carry out frequent health examinations to detect occupational diseases in an early phase, we expect lower figures for occupational hearing loss because employees often visit their general practitioners only in a later stage of the disease when there are overt complaints. Special occupational health arrangements in an economic sector can influence the figures. For example, in the construction sector in the Netherlands, the notification of work-related factors is linked to the invoice.

On a national level, sentinel projects as described can provide policy information on occupational diseases of better quality in terms of a more accurate estimate of the true incidence. Therefore, sentinel projects can be a valuable addition to national registries related to compensation schemes. On the other hand, maintaining a national registry has the advantage of the involvement of a large group of reporters. In an international perspective, the development and use of sentinel groups in different countries, similarly instructed on the diagnostic criteria and the process of notification, might be a promising step towards gathering more valid information and more comparable figures per country, per economic sector and per year. The availability of valid information can be an important impulse for a common European policy on the prevention of occupational diseases.

We conclude that a sentinel surveillance group comprising motivated occupational physicians provides more notifications per employee year than a national registry and that intensive guidance can improve the quality of notifications. A sentinel surveillance project as developed will provide incidence

estimates that are closer to the true incidence of occupational diseases than do data from national registries. For some disease categories, additional surveillance schemes might be considered useful.

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Chapter 6:

Diagnosing and reporting of occupational diseases: a quality improvement study

Spreeuwers D, de Boer AGEM, Verbeek JHAM, van Beurden MM, van Dijk, FJH. Diagnosing and reporting of occupational diseases: a quality improvement study. *Occup Med* 2008; 58(2): 115-121.

Abstract

Objective: To assess the need for quality improvement of diagnosing and reporting of noise-induced occupational hearing loss and occupational adjustment disorder.

Methods: Performance indicators and criteria for the quality of diagnosing and reporting were developed. Self assessment questionnaires were sent to 1705 occupational physicians. The performance of occupational physicians was then assessed by separate scores per performance indicator and by a total quality score.

Results: The mean quality score for diagnosing and reporting was 6.0 (SD: 1.4) for noise-induced occupational hearing loss and 7.9 (SD: 1.5) for occupational adjustment disorder on a scale of zero to ten. For noise-induced occupational hearing loss, there was a need for quality improvement of the aspects of medical history, audiometric measurement, clinical diagnosis of the disease and reporting and for occupational adjustment disorder the aspect of other competing causes needed improvement.

Conclusions: The quality of diagnosing and reporting could be improved for noise-induced occupational hearing loss and occupational adjustment disorders. Information, education and practical tools are proposed for quality improvements.

Introduction

In many countries, the registration of occupational diseases is an important source of information for preventive policy. National registration systems in most countries derive their figures from compensation schemes for occupational diseases, while in a few countries there are voluntary registration schemes in addition to national registries (1-3). Several authors have criticized the reliability of the figures provided by national registries and the comparability between countries because of the differences in registration systems. Moreover, the lack of coverage of the working population, the high degree of underreporting and poor quality control add to the limited reliability of the figures (4-6).

Another important determinant affecting the quality of the registration of occupational diseases is the availability of diagnostic criteria or case definitions. Most compensation systems have strict criteria for the acknowledgement of occupational diseases, whereas reporting schemes with a preventive purpose often apply criteria less strictly and also offer the possibility to report suspected cases. Criteria should preferably be based on evidence from aetiological and diagnostic research, for example, like those developed for work-related upper-extremity musculoskeletal disorders and for work-related low back pain (7,8). Physicians should use these criteria or case definitions in diagnosing and reporting. However, poor performance by physicians in diagnosing and reporting occupational diseases has been reported (4,9-11).

During this study all companies in the Netherlands with at least one employee were legally obliged to have a contract with an Occupational Health Service, which means that nearly all employees have access to an occupational physician. The total number of employees in the Netherlands was 6.116 million in the study period. The largest sectors were Health Care and Welfare (967.000 employees), Industry (966.000 employees), Repair and Trade (907.000 employees), Business Services (715.000 employees) (12). The number of occupational physicians in the Netherlands was 1774 in the study period (13). Occupational physicians are obliged by law to report occupational diseases since 1999. The Dutch government has made the Netherlands Center for Occupational Diseases (NCOD) the institute responsible for the registry of occupational diseases. In the Netherlands a compensation scheme for occupational diseases does not exist and thus occupational diseases are only notified for preventive purposes.

As good quality diagnoses are a prerequisite for reliable figures on occupational diseases, the NCOD has developed guidelines on the diagnosis of occupational diseases. These guidelines are available through the internet and are used as training material for occupational physicians during their vocational training (14). The guidelines include criteria for the clinical diagnosis of the occupational disease and for the minimum level and duration of exposure to risk factors at work. However, when occupational physicians report cases, they are not required to indicate if the criteria from the guidelines have been met. Therefore, we decided to study the quality of diagnosis and reporting, and to assess the needs for quality improvement.

Our study was restricted to two important occupational diseases: noise-induced occupational hearing loss and occupational adjustment disorder. Adjustment disorders (DSM-IV definition) are maladaptive reactions to identifiable psychosocial stressors occurring within a short time after onset of the stressor. They are manifested by either impairment in social or occupational functioning or by symptoms (nervous exhaustion, nervous breakdown, depressive thoughts etc.) that are in excess of a normal and expected reaction to the stressor. The presence of e.g. depressive disorders and anxiety disorders has to be excluded. We have chosen these diseases because they are relatively prevalent and represent two different types of guidelines. The guideline for noise-induced occupational hearing loss is derived from the European list of occupational diseases and is strictly defined with clear quantitative criteria, whereas the guideline for occupational adjustment disorder is less strictly defined and includes mainly qualitative criteria (15). The disease occupational adjustment disorder is not recorded in the European list as an occupational disease. However, in several registration projects (for example, in the Surveillance of Occupational Stress and Mental Illness (SOSMI) scheme in the UK) occupational mental ill-health is registered for preventive purposes (16).

The general objective of this study was to assess the need for quality improvement of diagnosing and reporting of noise-induced occupational hearing loss and occupational adjustment disorder as notified to the NCOD. The specific aims of this study were: 1. To develop performance indicators and criteria for the quality of diagnosing and reporting of cases of noise-induced occupational hearing loss and occupational adjustment disorder. 2. To assess this quality in cases notified by occupational physicians to the NCOD in terms of compliance to the notification guidelines. 3. To make a preliminary evaluation of the need for quality improvement.

Methods

The performance indicators and criteria were developed on the basis of the generic assessment procedure for occupational diseases and on the Dutch notification guidelines for noise-induced occupational hearing loss and occupational adjustment disorder (17). The assessment procedure consists of five steps:

1. diagnosis of the disease
2. assessment of potential work-relatedness as far as evidence exists in the literature
3. exposure assessment in the case studied
4. assessment of other competing causes
5. conclusion of work-relatedness.

If work-relatedness is concluded, the disease must be reported to the NCOD. Based on this procedure and on evidence from the literature, the NCOD has developed guidelines for noise-induced occupational hearing loss and for occupational adjustment disorder (14).

For the different steps of the assessment procedure, we formulated one or more performance indicators. We derived two performance indicators from the first step of the generic assessment: medical history – which we considered as an essential step in diagnosing – and clinical diagnosis of the diseases. We summarized the second and third step of the generic assessment in the performance indicator assessment of exposure. The fourth step provided the performance indicator assessment of other competing causes. The fifth step corresponds with the performance indicator conclusion about work-relatedness. We considered audiometric measurement as an essential element in the diagnosis of noise-induced occupational hearing loss and added it as an extra performance indicator. Finally, we added reporting (which is obligatory in the Netherlands for all occupational physicians) according to the internal criteria of the NCOD as an extra performance indicator for both diseases. We determined criteria based on the decision moments in the guidelines. The internal criteria of the NCOD for reporting concern formal demands which items at least have to be filled in.

Face validity of performance indicators and criteria was tested by asking three senior scientists in the field of occupational health to compare the preliminary performance indicators and criteria with the guidelines and to give a comment. Appendix 1 presents the set of performance indicators and criteria for both diseases.

The quality improvement study was carried out from 1 April 2004 to 1 July 2005. We developed a questionnaire based on the performance indicators and criteria for both diseases, and then asked a panel of two experienced occupational physicians to test the feasibility of the questionnaires. Appendix 2 presents the corresponding questionnaires. Next, we sent five copies of a questionnaire on noise-induced occupational hearing loss and five copies of a questionnaire on occupational adjustment disorder to all 1705 occupational physicians recorded in the database of the NCOD and asked them to participate in the study. This database contains the details of occupational physicians who have notified one or more occupational diseases to the NCOD since the database was started in 1997. We asked the physicians to fill in a questionnaire as soon as they reported to the NCOD a case of either noise-induced occupational hearing loss or occupational adjustment disorder. The questionnaires did not have to be returned at the same time as the notification form. Occupational physicians could get more questionnaires if they needed.

The Dutch reporting form for occupational diseases comprises the following items: name and code of the occupational health service; name and code of the physician; date of notification; patient file number; year of birth and sex of the patient; occupation; economic sector; ICD-10 code and description of diagnosis; causes; pre-existent conditions; degree of certainty of diagnosis (probable or sure); context of detecting; advice given.

The questionnaire comprises the following items corresponding to the reporting form for occupational diseases: name and code of the physician; date of notification; year of birth and sex of the patient; ICD-10 code of the diagnosis. Data from each questionnaire were linked to the reported cases database with the occupational physician code and patient data. For each reported case we scored the performance indicators on the basis of the corresponding questionnaire. A performance indicator was scored 1 if the criteria were satisfied and 0 if the criteria were not satisfied.

For each performance indicator the percentage of cases in which the criteria were met was calculated for both diseases. If the criteria for the performance indicator were fulfilled in every submitted case the score for that performance indicator would amount up to 100%. We considered a score of less than 60% for a performance indicator as a need for quality improvement.

Next, we calculated a score per case by summing up all performance indicators that were met for both diseases. In the calculation all performance indicators had the same weight. Then we calculated the mean score for all cases of a disease. To present the scores on a scale of 0 to 10 we divided it by the number of performance indicators i.e. 7 for noise-induced occupational hearing loss and 6 for occupational adjustment disorder and subsequently multiplied it by 10. We called this the total quality score.

Furthermore, we calculated the intra-doctor variability of the performance of diagnosing and reporting for both diseases. We determined this variability by calculating a coefficient of variation (CV =(sd/m)*100) of the total quality score for all occupational physicians who reported more than one case of either noise-induced occupational hearing loss or occupational adjustment disorder. Next, we calculated the mean coefficient of variation as a measure for the mean intra-doctor variability. A value of less than 20% is considered as low variability, of 20%-40% as moderate variability and of more than 40% as high variability (18). The inter-doctor variability was not calculated because the participating physicians assessed different cases.

Results

Ten occupational physicians completed a total of 23 questionnaires on noise-induced occupational hearing loss, while 52 completed 125 questionnaires on occupational adjustment disorder. Three physicians returned questionnaires both on noise-induced occupational hearing loss and occupational adjustment disorder. The respondents came from 25 different Occupational Health Services. One of the respondents was self employed. The respondents reported more cases of all occupational diseases than the average. The mean number of cases of all occupational diseases reported by the respondents was 10.7, while the mean number of cases of all occupational diseases reported by all occupational physicians was 6.2.

In the study period a total number of 1440 cases of noise-induced occupational hearing loss has been reported by 395 occupational physicians to the National Registry. Of 87 cases the reporting physician could not be identified. A total number of 842 cases of occupational adjustment disorder has been reported by 145 occupational physicians to the National Registry. Of 685 cases the reporting

physician could not be identified, mostly because they were reported in batches by the organization of the reporting occupational physicians.

The mean age of the cases that corresponded with the returned questionnaires on noise-induced occupational hearing loss was 48 years (range: 32 to 58 years). All of these cases were males. The mean age of the cases that corresponded with the returned questionnaires on occupational adjustment disorder was 44 years (range: 19 to 61 years). Of these cases, 57 were men (46%) and 68 were women (54%). For the total number of cases reported to the National Registry in the study period the mean age of the reported cases was 49 years (range: 20 to 69 years) for noise-induced occupational hearing loss and 44 years (range: 20 to 65 years) for occupational adjustment disorder. The percentage of males was 98% for noise-induced occupational hearing loss and 54% for occupational adjustment disorder.

Table 1 presents the scores of the performance indicators for the quality of diagnosing and reporting and the total quality scores. The mean quality score on a scale of zero to ten was 6.0 (SD 1.4) for noise-induced occupational hearing loss and 7.9 (SD 1.5) for occupational adjustment disorder. In 23 cases (18 %) of occupational adjustment disorder, the maximum score was achieved by the physicians, while for noise-induced occupational hearing loss the maximum quality score was not achieved in any of the cases.

For noise-induced occupational hearing loss, the criteria were met in less than 60% of the cases for the performance indicators medical history, audiometric measurement, clinical diagnosis and reporting. For occupational adjustment disorder, this was the case only for the performance indicator other competing causes.

Table 1: Percentage and absolute number of cases in which the criteria for the indicators were met, and total quality score (0-10) for performances on diagnosing and reporting

Performance indicator	**Noise-induced occupational hearing Loss** (%, absolute number)	**Performance indicator**	**Occupational adjustment disorder** (%, absolute number)
1. Medical history	9% (2)	1. Medical history	75% (94)
2. Audiogram	57% (13)		n/a
3. Clinical diagnosis	39% (9)	2. Clinical diagnosis	78% (97)
4. Exposure	91% (21)	3. Exposure	99% (124)
5. Other competing causes	100% (23)	4. Other competing causes	34% (42)
6. Conclusion	83% (19)	5. Conclusion	98% (123)
7. Reporting	44% (10)	6. Reporting	89% (111)
	Total score noise-induced occupational hearing loss (mean; min-max)		**Total score occupational adjustment disorder** (mean; min-max)
Total quality score	6.0 (2.9-8.6)	Total quality score	7.9 (5-10)

n/a: not applicable

The intra-doctor variability was measured for all occupational physicians who returned more than one questionnaire. Six occupational physicians (60%) returned more than one questionnaire of noise-induced occupational hearing loss. Four physicians returned two questionnaires, one returned three questionnaires and one returned eight questionnaires. Thirty occupational physicians (58%) returned more than one questionnaire of occupational adjustment disorder. Fifteen physicians returned two questionnaires, three returned three questionnaires, six returned four questionnaires, two returned five questionnaires, three returned six questionnaires and one returned twelve questionnaires. The mean intra-doctor variability for noise-induced occupational hearing loss was 28% (range: 0% to 61%), and 14% (range: 0% to 47%) for occupational adjustment disorder.

Discussion

To assess the quality of the performance of diagnosing and reporting by Dutch occupational physicians, seven performance indicators were developed for noise-induced occupational hearing loss and six for occupational adjustment disorder. In the sample of occupational physicians that responded to the questionnaire we found that the scores for the separate performance indicators varied from 9% for the assessment of medical history in noise-induced occupational hearing loss, to 100% for the assessment of other competing causes for noise-induced occupational hearing loss. The quality assessment of the performance of diagnosing and reporting by Dutch occupational physicians resulted in a mean total quality score of 6.0 for noise-induced occupational hearing loss and 7.9 for occupational adjustment disorder on a scale of zero to ten. Quality improvement of the performance of diagnosing and reporting should be attained on the performance of medical history, audiometric measurement, clinical diagnosis and reporting for noise-induced occupational hearing loss and on the performance of assessment of other competing causes for occupational adjustment disorder, because these aspects were correctly assessed in fewer than 60% of the cases. The intra-doctor variability of the performance was low for occupational adjustment disorders and moderate for noise-induced occupational hearing loss.

The strengths of our study include the availability of Dutch guidelines for the two occupational diseases. We used the guidelines to frame our performance indicators and criteria, as they provide clear criteria for the medical history, assessment of the clinical diagnosis, exposure and other competing causes, and the conclusion of work-relatedness. Every Dutch occupational physician receives information about the guidelines for reporting occupational diseases in the basic specialist training or in postgraduate training. The guidelines are available from the NCOD website, and occupational physicians can consult a helpdesk for support in diagnosing and reporting occupational diseases.

Another strength of our study includes the provision of specific indications of ways to improve the quality of diagnosing and reporting, whereas most studies present only the observation that the recognition and reporting of occupational diseases by physicians is inadequate and that better training is needed, without assessing the issues on which quality improvement should occur (4,9-11).

A limitation of this study is the likely existence of a selection bias. It is possible that the physicians who returned the questionnaire have a more positive attitude towards reporting and possess more knowledge of occupational diseases. This might have led to an overly favourable picture of the quality of diagnosing and reporting of occupational diseases. The measurement of performance based on self-reporting might also have contributed to a more favourable outcome. Nevertheless, the study does provide important clues for quality improvement.

Another limitation lies in the interpretation of the quality score. The results of this study show better quality scores for occupational adjustment disorder than for noise-induced occupational hearing loss. This could be caused by the different contents of the guidelines: the guideline for noise-induced occupational hearing loss is far more detailed and explicit than the guideline for occupational adjustment disorder. It is therefore more difficult to meet the requirements of the guideline for noise-induced occupational hearing loss.

A prerequisite for good quality diagnosing and reporting of occupational diseases is evidence-based guidelines (19,20). This calls for evidence-based case definitions of occupational diseases (20-22). Criteria for occupational diseases must be based on epidemiological studies and research focused on revealing aetiological mechanisms. In reality there is a considerable variety between countries in guidelines or criteria for occupational diseases. Many countries maintain a national list of occupational diseases for compensation purposes. The EU has a list with corresponding information notices on the listed occupational diseases (15). Member States are requested to implement the diseases of the EU list in their own legislation. Accordingly, many national lists are derived from the EU list, but are adapted to the specific legislation of the relevant country. The evidence base of the present and future national lists might be questioned and evaluated. If we want to be able to compare valid figures on occupational diseases between countries, the evidence base of the definitions and criteria must be evaluated and enhanced, and the definitions and criteria used in the different countries must be harmonized. These are prerequisites for starting a quality improvement process on a national or international level.

The low intra-doctor variability for occupational adjustment disorder and the moderate variability for noise-induced occupational hearing loss suggest that quality improvement will be

achieved not so much by focusing on a group of low performers, but mainly by focusing on the improvement of performance on specific aspects of the diagnosing and reporting procedure. This study indicates in which areas quality improvements of diagnosis and notification can be achieved. For noise-induced occupational hearing loss, these are medical history, audiometric measurement, clinical diagnosis of the disease and reporting, while for occupational adjustment disorders the area for improvement is the assessment of other competing causes.

A proper knowledge of the guidelines is a prerequisite for good quality diagnosis and reporting. However, most occupational physicians do not have time to check the guidelines in their daily practice. This indicates the need to facilitate diagnosing and reporting by practical tools, for example user-friendly decision-making software that is preferably linked to the electronic patient file.

The findings of this study can be helpful to explore the need for quality improvement in the registration of occupational diseases. The Health and Occupation Reporting Network (THOR) registration schemes in the UK and an intensively guided notification project of the NCOD itself are examples of registration projects that have a selection of motivated reporters (23-25). In this way, improvement of the quality of diagnosing and reporting can increase the reliability of the figures produced. Besides better education and information, internet tools for electronic exchange of information on occupational diseases should be considered (26).

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Appendix 1: Performance indicators and criteria for the quality of diagnosing and reporting of noise-induced occupational hearing loss and occupational adjustment disorder, based on the Dutch guidelines

	Noise-induced occupational hearing loss
Performance indicators	**Criteria**
1. Medical history	*Always* ask for complaints of tinnitus or hearing loss *Always* ask for congenital or early acquired hearing loss, otosclerosis, vertigo, operations and/or injuries of the ear in the case history.
2. Audiogram	*Always* make an audiogram under standard conditions (the temporary threshold shift (TTS) must be extincted i.e. no noise exposure in the preceding six hours).
3. Diagnosis	The diagnosis of noise induced hearing loss has to be correct: - the hearing threshold at 4 kHz exceeds the HL-10 for the same sex and the same age group (following ISO 7029), *and* - the difference between the hearing thresholds of the left and the right ear at 4 kHz is less than or equals 15 dB, *and* - there are no signs of congenital or early acquired hearing loss, otosclerosis, vertigo, operations and/or injuries of the ear in the medical history, *and* - the hearing loss at 1 kHz does not exceed the HL-10 for same sex and the same age group. If one ear meets the first criterion but not all criteria, expert judgement is required.
4. Exposure	*Always* ask for the occupations of the patient in chronological order and if noise exposure of more than 80 dB has occurred and, if so, the duration of the exposure. *Always* verify if noise measurements have been carried out on the workplace and ask for the results.
5. Other competing causes	*Always* ask for possible noise exposure of more than 80 dB outside the working environment.
6. Conclusion	The conclusion of occupational hearing loss has to be correct: - the diagnosis with ICD-10 code H 83.3 has to be set *and* - there has been an occupational exposure exceeding 80 dB(A) for more than six months, likely on the basis of the medical history or confirmed by workplace measurements.
7. Reporting	The notification meets the internal criteria of the Netherlands Center for Occupational Diseases
	Occupational adjustment disorder
Indicators	**Criteria**
1. Medical history	*Always* ask for key symptoms of anxiety disorder (excessive fear) or depression (depressed mood and loss of interest in all areas of life throughout the day for more than two weeks) *Always* ask for psychic or somatic tension complaints *Always* ask for the onset of complaints and their duration *Always* ask for traumatic experiences or the death of a beloved person in the preceding two months *Always* ask for substantial restraints in social or occupational functioning (sickness absence or dysfunctioning)

2. Diagnosis	The diagnosis of adjustment disorder has to be correct: - there are one or more psychic or somatic tension complaints, *and* - there are substantial restraints in social or occupational functioning, *and* - depression, anxiety disorder, PTSD or mourning has been excluded.
3. Exposure	*Always* ask for stressors in the dimensions: pressure of work, possibilities for self-organization of work (?), social relations *Always* ask for onset of stressor and duration *Always* ask if other employees have the same complaints *Always* ask for the judgement of the patient concerning the work-relatedness of the complaints
4. Other competing causes	*Always* ask for non-occupational life-events and stressors
5. Conclusion	The conclusion of occupational adjustment disorder has to be correct: - the diagnosis with ICD code F 43.2 has to be set, *and* - there are one or more stressors in the working environment, *and* - the relative contribution of occupational stressors is greater than the relative contribution of non-occupational stressors.
6. Reporting	The notification meets the internal criteria of the Netherlands Center for Occupational Diseases

Appendix 2: Questionnaires for the assessment of diagnosing and reporting performance

General questions	Occupational physician (code): ICD code diagnosis reported case: Year of birth reported case: Sex reported case: Date of notification:
Noise-induced occupational hearing loss	1. What are the most important complaints (max. 5) in the medical history concerning the diagnosis of occupational hearing loss? Mention only the complaints you actually asked about. 2. On the basis of the absence of which complaints or personal risk factors (max. 5) do you exclude other hearing disorders? Mention only the complaints you actually asked about, or the complaints that were already registered in the patient's file. 3. What is the date of the last audiogram? When the audiogram was made, how many hours had elapsed since the patient had stopped working? 4. Data from the last audiogram: HL-10 by 4 KHz and 1 KHz for both left ear and right ear. 5. Occupations in chronological order with damaging exposure to noise and duration of exposition. 6. Are noise measurements available? If so, what is/was the noise level (in dB(A)) for how many hours per day? 7. Has the patient been exposed to non-occupational damaging noise? If so, which exposures?
Occupational adjustment disorder	1. What are the most important complaints (max. 5) in the medical history concerning the diagnosis of occupational adjustment disorder? Mention only the complaints you actually asked about. 2. How long have these complaints existed (in weeks)? 3. On the basis of the absence of which complaints (max. 5) do you exclude other psychic disorders? Mention only the complaints you actually asked about. 4. Did traumatic events or the death of a beloved person occur in recent months? If so, which event/person? 5. What is your opinion about the social and occupational functioning of the patient: not limited or substantially limited? 6. What were the most important stressors in the work environment before the onset of the disorder and when was the onset of the stressors? 7. Were the following stressors present in the work environment? High work pressure, too much or too little work, emotionally demanding work, too much or too little autonomy, task uncertainty, do not like the work, demanding physical factors, conflicts or mobbing, lack of appreciation, lack of support, lack of information, insufficient reward, future uncertainty, merger or reorganization. 8. Do other employees have work-related complaints? 9. What is the opinion of the employee him- or herself about the work-relatedness of the complaints? 10. Has the patient been exposed to non-occupational stressors or life-events? If so, what exposures, what stressors or life-events, when was the onset and what was the duration?

Chapter 7

Work-related upper extremity disorders: one year follow-up in an occupational diseases registry

Submitted as: Spreeuwers D, de Boer AGEM, Verbeek JHAM, van Beurden MM, de Wilde NS, Braam I, Willemse Y, Pal TM, van Dijk FJH. Work-related upper extremity disorders: one year follow-up in an occupational diseases registry.

Abstract

Objective: To study the course and consequences of work-related upper extremity disorders in the registry of the Netherlands Centre for Occupational Diseases (NCvB).

Study design and setting: A follow-up study was performed in a sample of consecutive cases of work-related upper extremity disorders notified to the NCvB. Perceived severity was measured with VAS (0-100), quality of life with VAS (0-100) and SF-36, functional impairment with DASH and sickness absence with a questionnaire. Measurements took place directly after notification (T0) and after 3, 6 and 12 months (T1-T3). A linear mixed model was used to compare scores over time.

Results: Average age of the 48 consecutive patients (89% response) was 42 years; 48% were female. Perceived severity, functional impairment and sickness absence decreased statistically significant during the follow-up period, and quality of life scores improved. Patients older than 45 years scored worse on perceived severity of the disease, functional impairment and quality of life than did younger patients.

Conclusion: The role of registries of occupational diseases for preventive policy can be extended by creating longitudinal data in sample projects. In the sample from our registry, work-related upper extremity disorders had a favourable course.

Introduction

Work-related upper extremity disorders are among the most common disorders seen by general practitioners and occupational physicians. In several countries, e.g. the UK (1), Finland (2) and France (3), work-related upper extremity disorders account for a large part of the total number of reported occupational diseases. In the Fourth European Working Conditions survey of the European Foundation for the Improvement of Living and Working Conditions carried out in 2005 in the 27 EU Member States, 24% of the working population reported work-related muscular pain (4). Work-related upper extremity disorders – which represent 22% of all occupational diseases reported in 2006 – is the category of diseases most frequently reported to the registry of the Netherlands Centre for Occupational Diseases (NCvB) (5).

The definition of the group of upper extremity disorders is rather wide. Van Eerd et al. (6) found 27 different classification systems in the literature. The registry of the NCvB uses the classification of Sluiter et al., which is based on a comprehensive international collaboration project (7).

The impact of work-related upper extremity disorders on the individual and the societal level can be substantial. A survey in the Netherlands revealed that annually, 8% of the working population suffers from upper extremity musculoskeletal complaints including sickness absence. In 2.3% of the cases the duration of sickness absence was more than four weeks (8). In the UK, an estimated 10.7 million working days (full-day equivalents) were lost in 2006/7 through musculoskeletal disorders caused or aggravated by work. On average, each person suffering from a work-related upper extremity disorder took off an estimated 16.7 days in that 12-month period, which equates to an annual loss of 0.46 days per worker (9). Hashemi et al. (10) found that disability duration of more than three months was typical in cases of indemnity claims.

For the patient, work-related upper extremity disorders can result in persisting symptoms and difficulties in performing simple activities of daily living, job loss, symptoms of depression and family disruption. Keogh et al. found that 53% of the group of patients with work-related upper extremity disorders who had claimed compensation, reported persistent symptoms that were severe enough to interfere with work during four years post-claim (11).

Morse et al. (12) found that work-related upper extremity disorders can have a substantial social and economic impact on workers, such as divorce or loss of the home. Ekberg et al. (13) found that long-term sickness absence is associated with worse ratings in quality of life after one year, and that pain did not diminish during the follow-up year.

Information on the severity and impact of the diseases is important for decision-making in preventive policy. Moreover, the incidence rate, the severity and the impact of a disease can provide arguments when deciding for which diseases preventive activities should be financed. In general, registries of occupational diseases do not provide information on the severity or impact of the diseases (14). Despite variations in registration guidelines in different countries, general occupational disease registries probably contain the relatively more severe cases of occupational disease, which result in relatively higher costs. Therefore, it might be relevant for policy purposes to perform follow-up studies of the cases from registries. In addition, periodically executed small-scale follow-up studies linked to registries will probably be less expensive and more efficient than a series of cohort studies.

The aim of this study was to investigate the perceived severity and the consequences of the upper extremity disorders that are registered as occupational diseases. Severity, functional impairment, quality of life and sickness absence were assessed over the course of one year and compared to reference data on the general working population.

Methods

Population

In the Netherlands, occupational physicians are obliged to notify cases of occupational diseases to the registry of the NCvB. This registry distinguishes eleven categories of specific disorders: radiating neck complaints; rotator cuff syndrome; epicondylitis (lateral and medial); ulnar nerve compression at the elbow (cubital tunnel syndrome); radial nerve compression (radial tunnel syndrome); flexor-extensor peritendinitis or tenosynovitis of the forearm-wrist region; de Quervain's disease; carpal tunnel syndrome; ulnar nerve compression at the wrist (Guyon canal syndrome); Raynaud's phenomenon and peripheral neuropathy associated with hand-arm vibration;

osteoarthrosis of distal upper-extremity joints. In addition, a twelfth category of non-specific upper extremity musculoskeletal disorders has been described (7).

We asked occupational physicians who had participated in an NCvB sentinel surveillance project to recruit patients who had been diagnosed with a work-related upper extremity disorder to participate in this study and to ask them to fill out an informed consent form. After signing the form, the patients received a questionnaire. Patients had to complete this questionnaire directly after notification in order to be included in the study. Patients could withdraw from the study at any moment.

Study design

We performed a follow-up study in a sample of consecutive cases notified to the NCvB with work-related upper extremity disorders. The notifications originated from a sentinel surveillance project carried out by the NCvB between 1 October 2003 and 1 July 2005 (15). Baseline measurements were made directly after notification, and follow-up measurements after 3, 6 and 12 months.

Before the study, we held an introductory meeting to instruct the participating occupational physicians. The informed consent forms handed out by the physicians were provided with a code corresponding to the notification of the case to the NCvB. This allowed us to link the questionnaires to the cases in our database of reported occupational diseases.

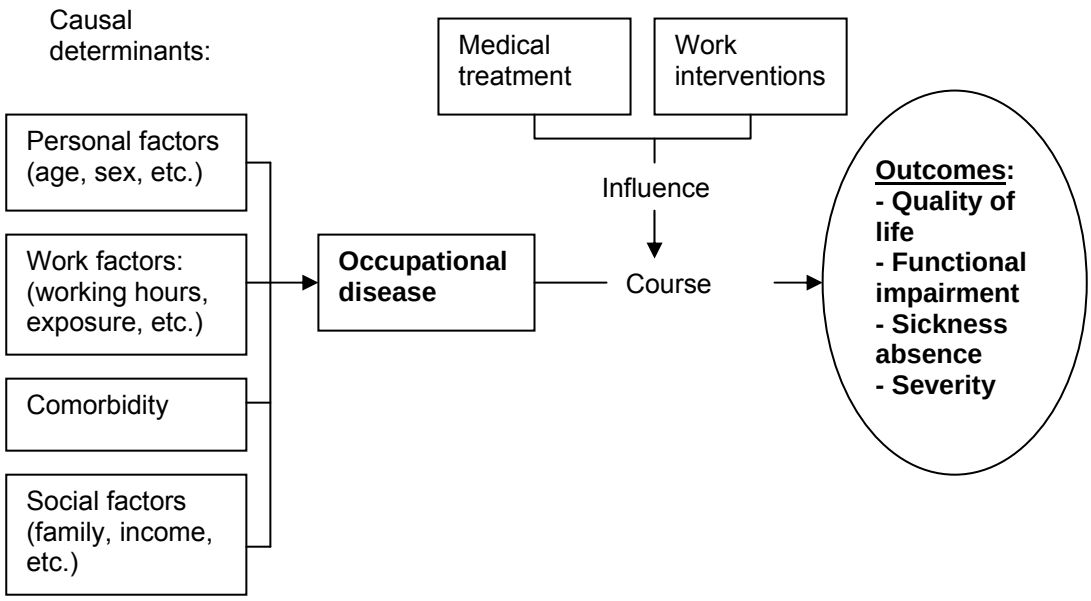
As soon as we received an informed consent form, we sent the patient a questionnaire (T0). If the patient did not return the completed questionnaire within four weeks, we sent a reminder. After 3, 6 and 12 months (T1, T2 and T3) we sent follow-up questionnaires; if necessary, we sent a reminder four weeks later.

Measurements

The questionnaires sent to the patients at T0, T1, T2 and T3 had the same content. The general part of the questionnaire included questions about the patients' personal situation (age, sex, marital status, number of children, level of education), occupation and number of working hours, co-morbidity, annual income (in euros), medical treatment (consultations, diagnostic examinations, hospital treatment, medication) and work interventions (adjustments in the workplace, personal aids,

training, coaching, replacement). The relation between these determinants and the origin, course and consequences of occupational diseases are represented in figure 1.

Figure 1. Determinants related to the origin, course and consequences of occupational diseases



We used a visual analogue scale with a scale of 0-100 (0 = no complaints, 100 = very severe complaints) to rate the perceived severity of the work-related upper extremity disorder (16).

We measured quality of life in two ways. First, general quality of life was assessed with the Dutch version of the 36-item Short Form Health Survey (SF-36). The SF-36 consists of eight subscales: physical role functioning, emotional role functioning, social functioning, bodily pain, mental health, vitality, physical functioning and general health perception (17,18). Scores range from 0 to 100 (higher scores indicate better functioning). Reference data were derived from Aaronson et al. (18). Second, quality of life was measured through visual analogue scales to rate the general quality of life and the level of current health on a scale of 0-100 (0 = completely unsatisfactory, 100 = completely satisfactory) (19,20).

Disease-specific functional impairment was assessed with the Dutch version of the Disabilities of the Arm, Shoulder and Hand (DASH) questionnaire (21,22). DASH scores range from 0 to 100 (higher scores indicate a higher degree of disability). We used as a reference the scores from the study by Jester et al. (23), who collected DASH data from a working population in Germany,

comprising workers from different industrial sectors and including manual as well as non-manual workers who were outside clinical considerations.

We assessed sickness absence with a questionnaire according to Burdorf et al. as a percentage of the self-reported number of hours of sickness absence over the previous two weeks divided by the number of working hours laid down in the employment contract (24). Sickness absence was also assessed as the self-reported number of days the patient had been on sick leave, partly or completely, during the previous three months.

Statistical analysis

We compared the scores on the DASH and the seven subscales of the SF-36 of the patients at T0 with the reference data with a one sample t-test.

We used a linear mixed model to compare the scores on the perceived severity of the disorder, general quality of life, the subscales of the SF-36, current health, functional impairment (DASH) and sickness absence directly after notification with the scores after 3, 6 and 12 months. We analysed the course over time of these variables as the main effect, selected the most fitting variance-covariance structure with the aid of the Akaike's score, and executed post-hoc analyses to compare the scores between the subsequent measuring moments.

Furthermore, we investigated whether age, sex, work interventions and level of education at baseline were predictors of the course of the perceived severity of the disorder, general quality of life, the subscales of the SF-36, current health, functional impairment and sickness absence. Finally, we investigated whether the perceived severity of the disorder, general quality of life, the subscales of the SF-36, current health and functional impairment at baseline were predictors of sickness absence after 3, 6 and 12 months.

For the LMM analyses of the scores over time, p-values < 0.05 were considered statistically significant, whereas for the post-hoc tests p-values < 0.01 were considered statistically significant. Mean differences of 10 or more on a 100-point scale were considered clinically relevant in terms of effect size (19). All statistical analyses were conducted with SPSS 12.0.2.

Results

Forty-five occupational physicians participated in the sentinel surveillance project. We sent out T0 questionnaires to the 54 patients who were eligible to participate in the study. The response was 48 completed T0 questionnaires (89%); Two patients indicated that they no longer wanted to participate. At T1 we received 35 completed T1 questionnaires of the 52 we had sent out (response 67%); Seven patients indicated that they wanted to stop. We received 29 completed T2 questionnaires of the 45 we had sent out (response 64%); Four patients indicated that they wanted to stop. Finally, we received 24 completed T3 questionnaires of the 41 we had sent out (response 59%, or 44% of the original 54 patients).

The characteristics of the participants at baseline are presented in table 1. The average age was 42 years and 48% of the patients were female. Table 2 presents the baseline measurements (T0) of the perceived severity, the general quality of life as measured with a visual analogue scale and with the SF-36, the level of current health, the disease-specific functional impairment, and sickness absence. All of the subscale scores on the SF-36 and the DASH were statistically significant lower than the reference values of the general population.

Table 1. Baseline measurements of participants with work-related upper extremity disorders (N=48)

Variable	Number (%)	Mean (SD)
Age		42.4 (10.2)
Sex		
Female	23 (48%)	
Education level		
primary school	3 (6%)	
lower vocational education	15 (31%)	
intermediate vocational education	17 (35%)	
higher vocational education/university	4 (8%)	
other	9 (19%)	
Working hours per week		33.7 (7.8)

Table 2. Baseline values of perceived severity, quality of life as measured with a visual analogue scale and the SF-36, the level of current health, the disease-specific functional Impairment (DASH) and sickness absence in the work-related upper extremity disorder patient population (N=48). The results of the SF-36 and DASH measurements were compared with the reference values in the general population (one sample t-test).

Variable	Mean (SD/95% C.I.) Patients	Mean general population	p value
Perceived severity (VAS 0-100)	68 (SD: 24)	n/a	
General quality of life (VAS 0-100)	84 (SD: 14)	n/a	
Current health (VAS 0-100)	57 (SD: 23)	n/a	
Quality of life (SF-36)			
Physical functioning	74.2(70.4 – 78.1)	89	<0.001*
Physical role functioning	20.8(12.3 – 29.3)	82	<0.001*
Bodily pain	38.9(33.5 – 44.2)	75	<0.001*
Social functioning	73.2(66.4 – 80.0)	84	0.003*
Mental health	68.1(62.7 – 73.5)	76	0.005*
Emotional role functioning	68.8(57.1 – 80.5)	86	0.005*
Vitality	52.3(46.9 – 57.7)	68	<0.001*
General health perceptions	65.0(59.2 – 70.7)	74	0.003*
Functional impairment (DASH)	43.8(37.6 – 49.9)	13	<0.001*
Percentage of days absent due to sickness in previous 2 weeks	32 (SD: 38)	n/a	
Number of days absent due to sickness in previous 3 months	28 (SD: 29)	n/a	

n/a = not available * = statistically significant

Perceived severity of the disorder

Measurements over time showed that in 67% of the patients the perceived severity of the disorder declined more than 10 points (scale 0-100) during one year of follow-up after notification. The average perceived severity of the disease declined statistically significant during the follow-up period from 68 at T0 to 40 at one year follow-up ($p<0.001$). Post-hoc analyses showed that the greatest decline in perceived severity of the disorder occurred in the first three months ($p<0.001$) (Figure 2).

Quality of Life

The average VAS score of the general quality of life did not improve statistically significant during the follow-up period (T0: 84, T3: 83; $p=0.150$ in the post-hoc analysis). However, the average

VAS quality of life scores with respect to health did increase statistically significant during the follow-up period from 57 at T0 to 69 at T3 ($p<0.001$). Post-hoc analyses showed that the greatest improvement occurred in the first three months, but the difference was not statistically significant ($p=0.033$). The average scores on the SF-36 scales 'Bodily pain' ($p<0.001$) and 'Physical role functioning' ($p<0.001$) increased statistically significant during the follow-up period. Post-hoc analysis showed that the greatest improvement occurred in the first three months, statistically significant for both 'Bodily pain' ($p=0.001$) and 'Physical role functioning' ($p=0.001$) (Figure 2). Except for 'Mental health' all the other average scores on the SF-36 scales improved during the follow-up period, but not statistically significant.

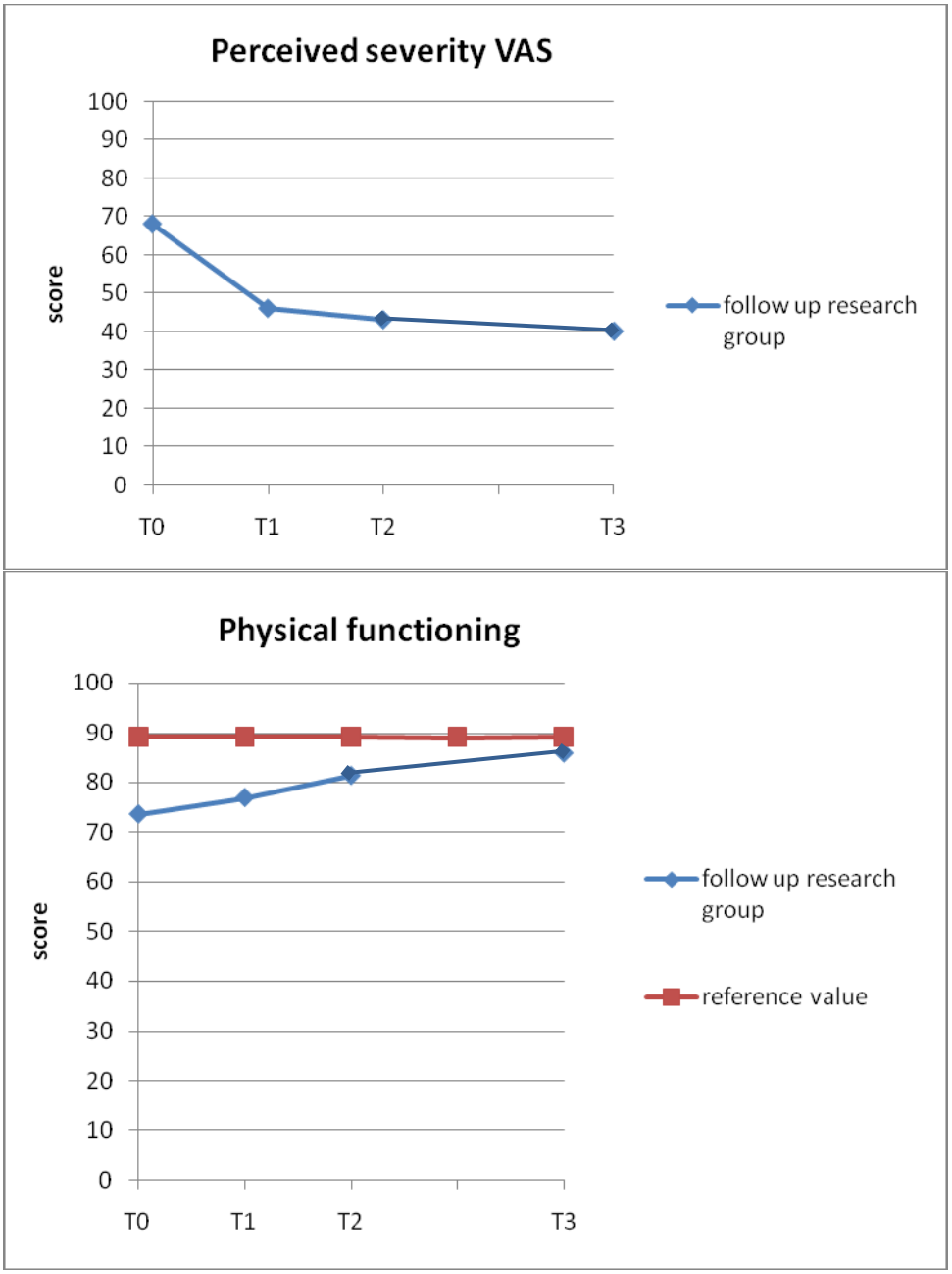
Disability and sick leave

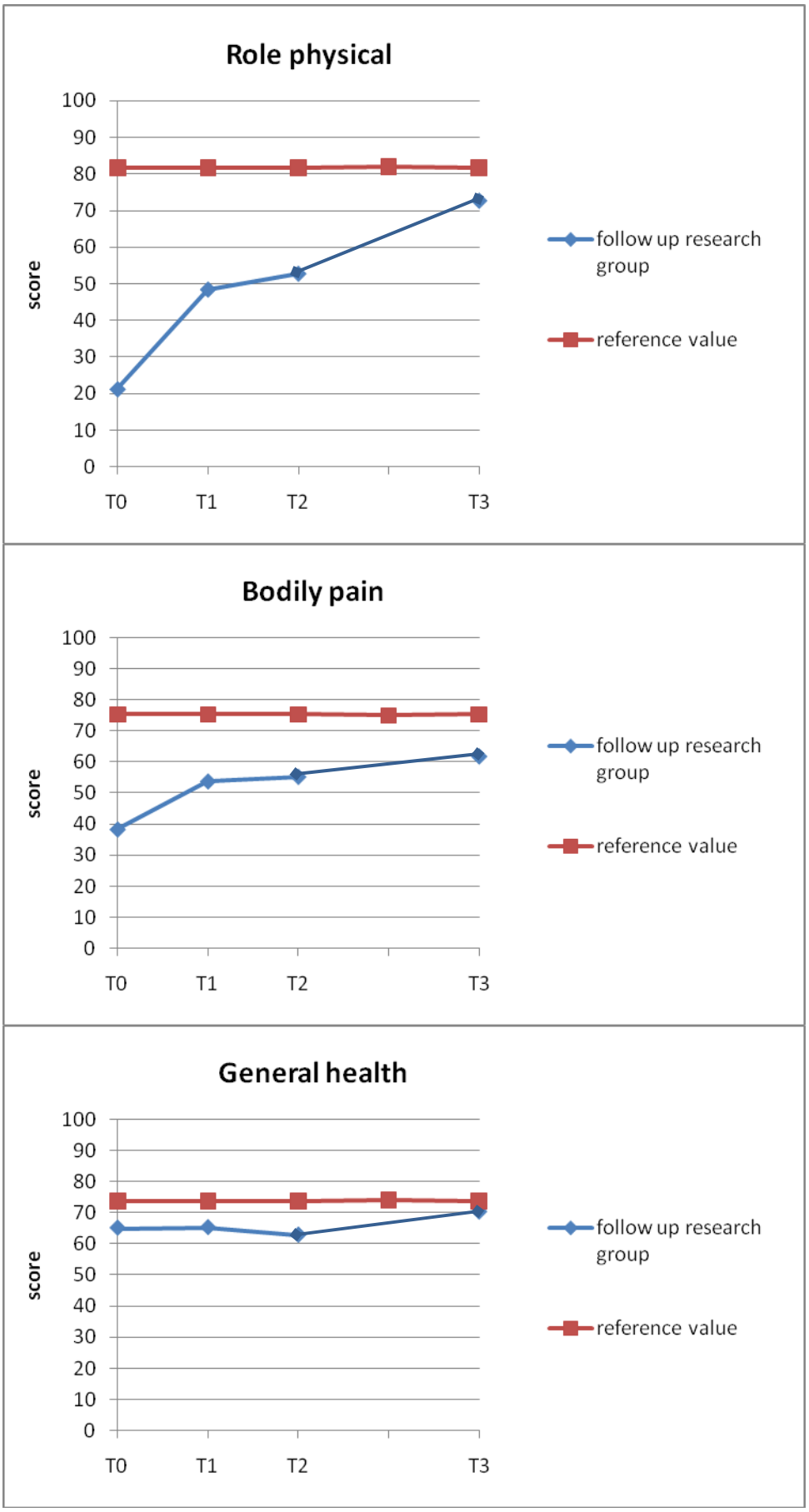
In line with these findings, functional impairment declined by more than 10 points (scale 0-100) in 80% of the patients. The average DASH score (representing functional impairment) decreased statistically significant from 43 at T0 to 22 at T3 ($p<0.001$). Post-hoc analyses showed that the greatest decline in functional impairment occurred in the first three months ($p<0.001$).

The average percentage of sickness absence over the previous two weeks decreased statistically significant from 32% at T0 to 5% at T3 ($p<0.001$). Post-hoc analyses showed that the percentage of sickness absence over the previous two weeks at T0 differed statistically significant compared to T3 ($p<0.001$), but not compared to T1 ($p=0.027$) and T2 ($p=0.099$). The average number of days of sick leave during the previous three months decreased statistically significant from 28 at T0 to 6 at T3 ($p<0.001$). Post-hoc analyses showed that the percentage of sickness absence during the previous three months at T0 differed statistically significant compared to T3 ($p=0.004$), but not compared to T1 ($p=0.156$) and T2 ($p=0.020$) (figure 2).

Figure 2: Comparison of the course of outcome variables in work-related upper extremity disorder (n=48) during the follow-up period (directly after notification and after 3, 6 and 12 months) in relation to reference values from the general population.

♦---♦= value in patient population ;■---■= reference value in general population

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Bodily pain
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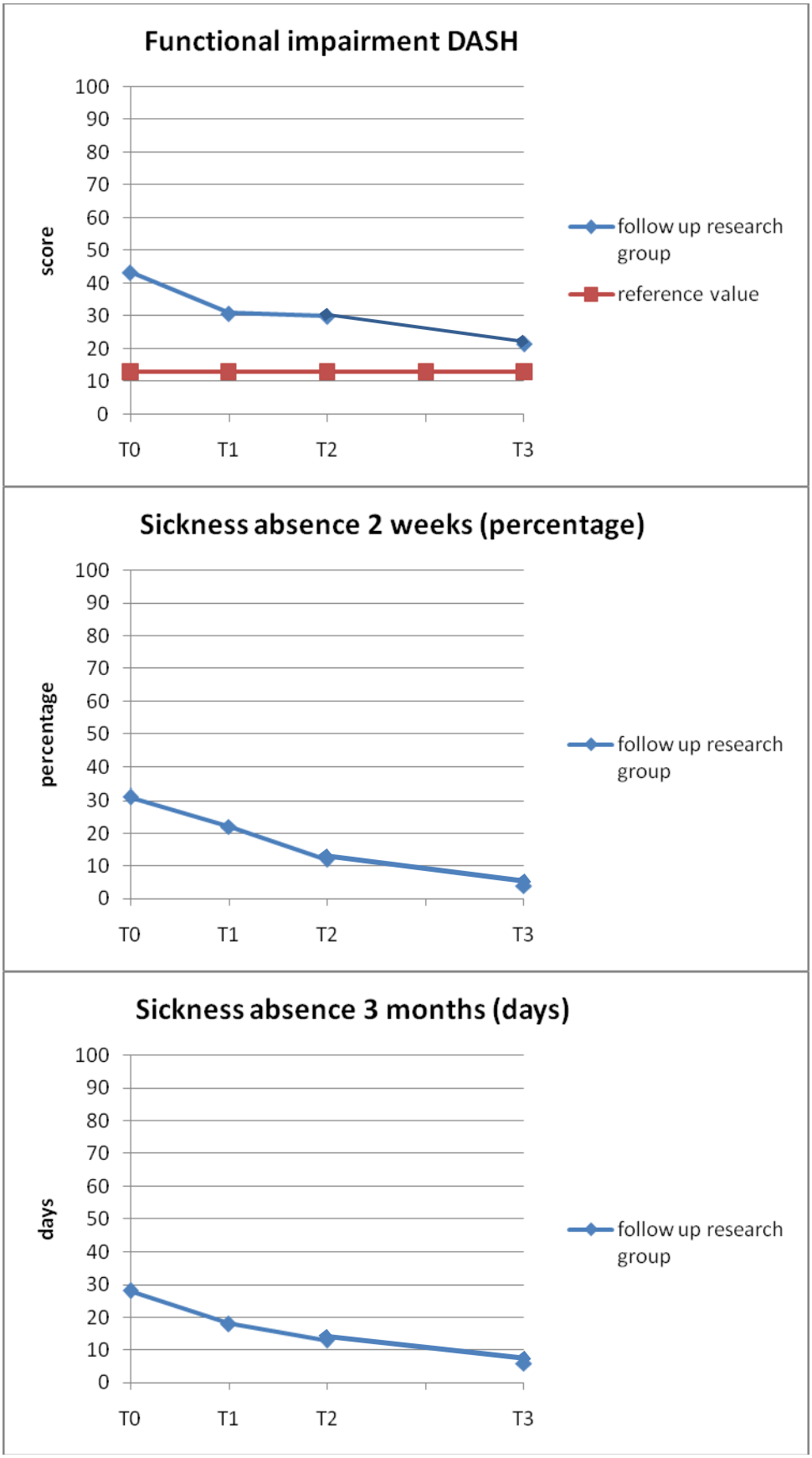
Functional impairment DASH
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reference value
Sickness absence 2 weeks (percentage)
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T2
T3
follow up research group
Sickness absence 3 months (days)
days
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T1
T2
T3
follow up research group

Predictors of improvement

Only age turned out to be a statistically significant prognostic factor, indicating that patients above the age of 45 had worse scores on perceived severity of the disease (p=0.002), functional impairment (p=0.015) and the SF-36 subscale physical functioning (p=0.001) than did younger patients in the course of the disease. In our study, sex, work interventions and level of education at baseline were not predictors of the perceived severity of the disorder, general quality of life, the subscales of the SF-36, current health, functional impairment and sickness absence after 3, 6 and 12 months. The perceived severity of the disorder, general quality of life, the subscales of the SF-36, current health and functional impairment measured at baseline were not predictors of sickness absence after 3, 6 and 12 months.

Discussion

In a sample of cases of work-related upper extremity disorders registered as occupational diseases in the registry of the Netherlands Centre for Occupational Diseases (NCvB), perceived severity and functional impairment declined substantially during one year of follow-up after notification. Except for 'Mental health' all quality of life subscales improved during the follow-up period. The most pronounced improvement in perceived severity of the disease, functional impairment and quality of life was observed in the first three months after notification, whereas the decrease in sickness absence was slower. One year after notification, most values were close to the reference values in the general population, which suggests an almost complete recovery. Workers above the age of 45 had worse outcomes at the end of follow-up on perceived severity of the disease, functional impairment and quality of life than did younger employees. This study shows how a national registry can be used to gather information that is useful for prevention and management.

A strength of this study is that it covered a specific sample of work-related upper extremity disorders. Our respondents were employees whose occupational diseases had been diagnosed and reported by occupational physicians to the registry of the NCvB. We conjecture that the sample represents the most severe cases in terms of suffering, occupational disability and economic costs. A

further strength of the study is that we could make use of the existing infrastructure of the Dutch national registry, which implies that the approach is efficient and that follow-up studies can be linked to other national registries.

At the same time, the focus on patients with severe complaints is a limitation of the study, as such might lead to an overestimation of severity, duration and consequences when interpreted for policy reasons without considering the selection of cases. A further limitation is that we analysed all cases of work-related upper extremity disorders, including various disorders with diverse clinical characteristics. The limited number of cases did not allow analysis on the level of the various diseases. The response rate at the end of the follow-up was quite low. A possible explanation is that the participants lost interest because their disorders were improving.

Aublet-Cuvelier et al. (25) performed a follow-up study on the course of work-related upper extremity disorders during three consecutive years at a household appliance assembly company (n = 459). They found a relatively stable annual prevalence of 20-24% and a high annual incidence (9.8-13.5%) of cases and of annual recoveries (37.0-44.3%). The number of annual recoveries compares well with the favourable course in our study. Feleus et al. (26) reported that 42% of a working population (n = 473) with non-traumatic complaints of the arm, neck and shoulder still reported complaints after six months. This compares to our finding that complaints had decreased in 33% of the patients after 6 months of follow-up. Cheng et al. (27) found significant improvements in the SF-36 physical functioning and bodily pain scores after a physical therapy (PT) intervention, but noted a variation in outcomes across injury regions. Patients with elbow disorders needed more physiotherapy care and did not improve in the SF-36 physical role domain compared to shoulder and wrist/hand groups. We concluded that the results of several studies on the course of work-related upper extremity disorders seem to be generally comparable to our findings.

Reitsma (28) considered the possibility of follow-up studies linked to registries. He concluded that in most registries follow-up or historical information is not recorded, is short-term or is missing and that the role of registries can be extended by creating longitudinal data. This can be done either by record linkage of existing data or by sample projects. This type of information is important in order to

set priorities for preventive policy and to monitor the effects of policy interventions. Furthermore, trends can be monitored not only on the incidence of diseases, but also on their course and consequences. If appropriate data can be obtained, the monitoring of economic costs could be added to the set of monitoring instruments.

Further research can be performed on the use of registries and related sample projects for preventive policy. A great advantage of using registries as a study base is the flexibility and efficiency of related sample studies, whereas primary studies are often expensive and take more time. On the other hand, the reliability of registries can be lower than that of primary studies. We recommend that studies should compare data from registries with data from primary studies. In general, we plea for quality improvement of registries in order to obtain more reliable incidence figures (15).

The findings of our study suggest that complaints and quality of life improve substantially in the first three months after notification. Attention to elderly workers is needed, as they recover more slowly. We recommend evaluation studies on interventions to influence the course and consequences, and prognostic studies to identify subgroups with a poor prognosis.

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Chapter 8

General Discussion

This chapter first presents the main findings related to the research questions: 1. What are the information needs of stakeholders who are involved in the prevention of occupational diseases and how can these needs best be met? 2. Can registries of occupational diseases be used to provide information for prevention? 3. How can registries be improved or enhanced in order to provide high-quality information for preventive policy? Next, methodological considerations, implications for practice and suggestions for further research will be presented.

Main Findings

Information needs of stakeholders and how best to meet them

In Chapter 2 we presented the qualitative survey we carried out in order to make an inventory of the information needs of stakeholders involved in the prevention of occupational diseases and to investigate how best to meet these information needs. Five categories of information needs were deduced from interviews with representatives of key stakeholders: 1. time-trends of occupational diseases for setting policy priorities, 2. cases of new occupational diseases for early preventive action, 3. disease patterns in specific occupational groups for focused prevention measures, 4. an overview of consequences of occupational diseases and resulting measures for policy evaluation purposes and 5. a description of blind spots, that reveal in which areas further investigation is needed. Not all stakeholders are equally interested in these issues, for example the government is more interested in the time trends of various occupational diseases than is an employer in the construction industry. This employer might be more interested in a decrease in contact eczema and low back pain in bricklayers related to new work processes and materials, and in a consequent decrease in sickness absence both in the branch and in his company.

Experts on registries were then asked how these information needs can best be met. An important conclusion was that registries alone cannot satisfy the information needs of stakeholders. The advice of the experts was to use several additional sources of information, such as epidemiological studies, surveys in companies and focused projects. Furthermore, tracing new and

emerging risks requires different methods and instruments than does the monitoring of occupational diseases. For monitoring a rather stable group of reporting physicians is to be preferred, as are clear case definitions. In this way, both comparisons between branches of industry or occupations and comparisons over time can be made. On the other hand it is clear that detailed specified case definitions can hamper the notification of suspect cases. Moreover, if we do want to receive signals of possible newly occurring occupational diseases it would be advantageous to organize a report system that includes every physician (and perhaps even other groups, such as employees and employers) rather than a stable group of well trained professional reporters. The experts consulted in this study recommended to develop a low threshold for the notification of suspect cases followed by a more detailed examination as a second step in the procedure. Other recommendations were to organize periodic literature searches and data mining in existing databases for the provision of alert information.

The interviews with experts also revealed that we need specific monitor methods for each category of occupational diseases. For diseases that are nearly exclusively occupational -such as occupational asthma or post traumatic stress disorders that originate in a work setting- it is sufficient to count prevalent or incident cases. For example, in the case of occupational asthma, prevention can be focused on the reported causes and preventive policy can be evaluated by following trends over time in the number of cases and reported causes. For disorders with a low relative risk related to work (e.g. lung cancer related to exposure at work to polycyclic aromatic hydrocarbons at work), a better approach is to apply epidemiological methods to assess the attributed proportion of the total morbidity related to various causes. In general, such factors as the length of the latency period (the time period between the exposure and the detection of the disease) the course of the disease and the strength of the causal relationship determine the preferred monitoring method. For preventive purposes information about trends in disease incidences alone is not sufficient to evaluate policy interventions. Especially for diseases with long latency periods monitoring of exposure or intermediate variables is advocated. For example, to evaluate the effect of measures for the prevention of noise-induced hearing loss, information about the increase in the use of hearing protection or about the implementation of noise reducing interventions at the workplace will give an earlier indication of effective preventive measures than will a decrease in the incidence of the disease.

The experts stated that frequent communication with stakeholders is a key issue in linking figures on occupational diseases to actual prevention. The involvement of stakeholders in the

registries makes it easier to put occupational diseases on their agenda and can also increase their willingness to take preventive measures. Furthermore, discussions with stakeholders can initiate and guide decisions for projects or studies that are linked to registries. Obviously, the dissemination of relevant results of the registries to workplaces, labour safety authorities and other stakeholders is decisive for an effective use of the information for prevention. Consequently, in order to effectively link registration activities to prevention it is recommended to use a set of instruments and methods (instead of a single registry) for monitoring occupational diseases and for tracing new risks, and to maintain an ongoing dialogue with the stakeholders.

The use of registries of occupational diseases to provide information for prevention

Chapter 3 described the development of indicators for the quality assessment of registries of occupational diseases in relation to preventive policy. A literature search revealed two different types of information output that are appropriate for preventive policy: monitor information and alert information (1). Monitor information concerns the nature, magnitude and distribution of recognized occupational diseases over time, related to branches of industries, occupational groups, gender and age categories. This information is essential in order to estimate the magnitude of the problem and to establish trends over time, which is useful in setting priorities for preventive policy and in evaluating the effectiveness of preventive policy measures. In contrast, alert information refers to the discovery of newly occurring occupational diseases that result from new risk factors or the discovery of new associations between a well-known occupational risk factor and disease that is not yet suspected, or of an increased awareness of the impact of already known associations. Based on the comments of the experts who participated in the Delphi study presented in Chapter 3, nine indicators for the evaluation of the quality of registries of occupational diseases were assessed: completeness of the notification form, coverage of the working population by the registry, present guidelines or criteria for notification, realization of education and training of reporting physicians, completeness of registration, presentation of statistical methods used, the option to investigate special cases, presence of specified monitor information and of specified alert information. Except for the indicator ‘coverage of registration’ for the alert function, all the indicators met the predetermined requirements of content validity, which means that the experts considered the indicators relevant for the assessment of the quality of a

registry of occupational diseases. These indicators led to the development of an audit instrument - ODIT - for the evaluation of registries of occupational diseases in relation to preventive policy.

We presented in Chapter 4 the results of a study that applied the ODIT instrument to evaluate the registries of six countries, namely those of Austria, Belgium, the Czech Republic, France, Finland and the UK. Registries in these countries report having various objectives, for example compensation, the provision of statistics, prevention or research. Registries linked to compensation systems are mostly aimed at administrative support of the financial completion of the claim proceedings, therefore the provision of statistics for preventive or research activities is a secondary aim. Furthermore, there are differences between countries regarding who is entitled to report to the registry. In some countries, employers or employees themselves can apply for compensation, but in most countries a physician's certificate is needed for reporting. All compensation systems have an acknowledgement procedure that is executed by physicians who have special expertise in occupational diseases. In some countries registers are linked to the compensation process (e.g. as an administrative database), whereas in Finland and the Czech Republic the registry records are derived from notifications for compensation, even though the registry itself is not linked to the compensation process. The UK registry has no links at all to the compensation process.

For the six registries we audited, the average quality was rated 3.2 (SD 2.2) out of 10 for monitoring occupational diseases and 5.3 (SD1.4) out of 10 for alerting to new risks. The main reasons for the low scores were the inadequate education and training of physicians and the poor participation of notifying physicians. All contact persons agreed that the registries need improvement in relation to prevention. Three of the six contact persons considered the audit tool helpful for future quality improvement of the registry in relation to prevention, whereas the other contact persons were of the opinion that the tool should first be improved.

Enhancement of registries in order to provide high-quality information for preventive policy

In Chapter 5 we presented an evaluation of whether a sentinel surveillance project comprising motivated and guided occupational physicians would provide higher quality information than would a national registry for a policy to prevent occupational diseases. The median number of notifications per

occupational physician was 13 in the sentinel group versus 1 in the reference group. The number of incorrect notifications in the sentinel group was three times lower than in the reference group. Compared to the two preceding years, the sentinel group and the reference group did not notify significantly more cases. However, the quality of notification improved significantly in the sentinel group but not in the reference group. The overall incidence of occupational diseases as reported by the sentinel group was about seven times higher than that reported by the reference group. For diseases of the upper limb, the difference was even larger, suggesting a differentiation in underreporting in the national registry. On the basis of these results, it was concluded that a sentinel surveillance group comprising motivated and guided occupational physicians reported a substantially higher occupational disease incidence and a lower proportion of incorrect notifications than did a national registry.

The focus of Chapter 6 was on the quality of diagnosing and reporting in the Netherlands for two diseases, namely noise-induced occupational hearing loss and occupational adjustment disorder (nervous breakdown, burnout). For this, we had formulated performance indicators and criteria. The indicators were medical history taking (considering which complaints were essential to inquire about), diagnosis, exposure, other competing causes, conclusion and reporting. For noise-induced occupational hearing loss we added the indicator “audiogram” and developed criteria for the quality of performance. The mean quality score for diagnosing and reporting was 6.0 (SD: 1.4) out of 10 for noise-induced occupational hearing loss and 7.9 (SD: 1.5) out of 10 for occupational adjustment disorder. For noise-induced occupational hearing loss, there was a need for quality improvement on the aspects of medical history taking, audiometric measurement, the clinical diagnosis of the disease and the quality of the reporting. For occupational adjustment disorder the aspect of determining non-work-related competing causes needed improvement.

The incidence rate is not the only information that can be derived from the data. Additional information on the severity and consequences of the diseases is important for decision-making in preventive policy, as it is for setting priorities. Unfortunately, most registries of occupational diseases do not provide this type of information at the moment. In Chapter 7 we discussed the possibility of extending the role of registries of occupational diseases by creating longitudinal sample studies. This

discussion was based on a longitudinal sample study on work-related upper extremity disorders that we had carried out in our national registry. We found that, in general, such disorders had a favourable course. However, workers above the age of 45 had worse scores on perceived severity of the disease, functional impairment and quality of life than did younger employees. It was concluded that registries of occupational diseases can be used as a basic facility that can be extended to produce various kinds of information for preventive policy.

Methodological considerations

The methodological strengths and limitations of the studies included in this thesis have been discussed in the previous chapters. However, three substantial methodological issues deserve further consideration: the issue of the differences in case definitions of occupational diseases, the need for completeness and full coverage of the registration, and the linking of registration to prevention.

Case definitions

In practice, the development of case definitions for occupational diseases is based not only on scientific evidence but also on socio-political negotiations. A related problem is that every registry uses its own criteria or guidelines for diagnosing and reporting. Even for noise-induced hearing loss - a disease that is easy to assess and in which the causal relation with occupational exposure is obvious - a wide variation of criteria and guidelines can be noted. Questions like how severe a medical condition must be to define a case as being an occupational disease are answered differently. Criteria differ on which exposures belong to the realm of occupational health, for example the acceptance of combined stress caused by work and home life as a work-related risk factor. The same holds for such issues as to what degree an occupational factor among other causal and conditional determinants contribute to the origin of a disease in an individual. Therefore, the concept ‘occupational disease’ and its subsequent operationalization are complicated. Furthermore, one might argue the inclusion of individual susceptibility and coping capacity towards exposure as important elements of the definition.

Applying criteria in the assessment of occupational diseases for compensation purposes mostly leads to a simple yes or no to the question whether a disease is work-related. In our view, however, causal relationships are nearly always a matter of probabilities. Therefore, guidelines that include a measure for the probability of a causal relationship do more justice to the existing relationship than the mere conclusion that a disease or is not occupational.

There are also different opinions about the occupational causes of diseases amongst physicians (2), employers, employees and other relevant parties (3). As a result, some physicians are more hesitant than others to ascribe a medical condition to work. Along the lines, the presuppositions of employers and employees about causal inference are highly relevant, as these determine whether they regard health problems as work-related and thus bring them to the attention of a physician.

Completeness of registration and coverage

A limitation of this thesis is that it focused only on registries of occupational diseases. Consequently, workers who have serious work-related health complaints or diseases but do not have access to or do not attend a physician will not be taken into account. In general, a major shortcoming of registries of occupational diseases is the incompleteness of the coverage. Several causes of underreporting and several levels of causation can be distinguished: 1. workers do not or cannot turn to a physician with their work-related health complaints and diseases, 2. occupational diseases are not recognized and diagnosed by physicians, 3. occupational diseases are recognized but not reported to the registry and 4. occupational diseases are reported but not registered due to the limitations of the prescribed case definition (e.g. if an occupational disease is not on the national list). There is little knowledge particularly about the first level of underreporting. Registries represent only recognized cases and the recognition rate of occupational diseases depends on the access of workers to a reporting (occupational) physician, and on the quality of health care in general and of occupational health care in particular. If surveillance programmes for workers at risk exist, for example in the case of exposure to high noise levels, the degree of underreporting will be limited, depending on the coverage of these surveillance programmes. In monitoring for time trends, it does not matter if there is some under-ascertainment of cases, provided that the level of under-ascertainment remains fairly constant over time. To estimate the burden of occupational diseases it is better to rely on a high-

quality sample of reporting physicians who notify cases and the source population of workers more reliably than can be realized in national registries, as described in Chapter 5 of this thesis.

Another relevant issue for the completeness of information is the observation that patients follow different pathways in the health care system, whether or not the system includes occupational health care. In addition they may follow different routes in the assessment procedure for compensation. A patient with occupational hand dermatitis can be treated by a GP, or the GP can refer the patient to a dermatologist. The patient might also visit an occupational physician, or even an occupational dermatologist, whether for treatment, rehabilitation or in an assessment procedure of an occupational disease. If the registry collects cases from dermatologists, only some of the cases of occupational hand dermatitis will be captured, whereas if the registry collects cases from occupational physicians, other cases will be captured. Triangulation, that is aimed at more reliable incidence figures can be done by reporting cases on different positions in the health care system. Next, if the same cases appear in different registries, capture-recapture techniques can be used to make a reliable estimate of incidences (4).

Linking of registration to prevention

The studies presented in this thesis looked at registries from the perspective of their use for preventive policy. As explained in Chapter 4, registries can have different objectives, for example compensation, the provision of statistics, prevention or research – and this can lead to methodological dilemmas.

It is not easy to describe the prevention of occupational diseases in one model. There are various stakeholders with a diversity of interests, motives and information needs. Prevention can take place at the individual, the workplace, the national or even the international level. Prevention in an industrial environment, with its principally physical and chemical exposures, requires an approach that is different from that applied in the services sector. Although registries of occupational diseases can play an important role in the prevention process, they certainly do not guarantee preventive actions and the role of registries in actual prevention is mostly unclear.

An interesting possibility is to enhance registries with projects, for example follow-up of cases to study the course and consequences of occupational diseases, or to investigate exposure and the

effectiveness of protective measures more thoroughly. Another option to strengthen the link with actual prevention is the organization of or participation in campaigns to promote the reporting of specific occupational diseases aiming at better prevention, or reporting projects within industrial branches or occupational groups in order to put occupational diseases high on the agenda. These extensions and projects make registries more dynamic and more focused on prevention. However, one must realize that it might also have an impact on the figures of the registry itself. For example, if one decides to organize a campaign with the aim of obtaining more reports of occupational asthma in a certain year, these figures have to be interpreted in the light of the campaign. Another point for deliberation is that prevention might be contentious in compensation systems, because although insurance companies benefit from prevention, they might hesitate or even refuse to invest in, for example, a campaign for prevention that draws employees' attention to occupational diseases. They might be afraid to foster new claims or be concerned about the increase in their administrative workload.

Implications for practice

This thesis has demonstrated that providing relevant information to the various stakeholders requires a set of methods rather than a single registry. The composition of a set of methods and instruments will depend on the strategic goals of the registry, the information needs of the stakeholders, the characteristics of the disease and the risk factors, the requirements concerning the quality of data and of course the available budget. Based on the information needs of the stakeholders table 1 presents a limited number of appropriate methods for data collection, corresponding sources of data, methods of analysis and the related output information that can be used in composing a tailor-made set of methods aimed at providing information for prevention of occupational diseases.

Registries are just one of the instruments that can be used to provide information for prevention. Although they are mostly authoritative sources, various aspects would benefit from quality improvement, as presented in Chapters 3 and 4. Furthermore, registries can be enhanced by extensions or linked projects. In this section, we first discuss the set of methods aimed at providing information for prevention of occupational diseases, departing from the five information needs of

stakeholders. We then provide some leads for quality improvement of registries and examples of extensions and linked projects.

A set of instruments

In table 1 a set of instruments is presented departing from the five information needs: time trends, new occupational diseases, disease patterns, consequences of occupational diseases and detection of blind spots.

Table 1: Instruments for the provision of information for preventive policy

Information needs	**Methods for data collection (case capture)**	**Who provides the data (source of data)**	**Methods of analysis**	**Output information**
1. Time-trends of occupational diseases for setting policy priorities	Administrative registry	Dependent on the organization of the registry (mostly physicians, sometimes employers, employees)	Calculation of incidence rates Comparisons of incidence rates between subgroups (relative risks) Time series Calculation of work-attributable proportion of the total incidence rate of a disease	Nature, magnitude and distribution of occupational diseases over time, related to branches of industries, occupational groups, gender and age categories. Work-attributable proportion of the incidence rate of a disease
	Sentinel surveillance	(Sample of) well trained and motivated physicians		
	Periodic survey of a population of workers	Workers		
	Analysis of workers' health surveillance data (possible only if occupation is registered)	Health surveillance data provided by workers and OH professionals		
2. Cases of new occupational diseases for early preventive action	Reporting of special cases or clusters	All physicians (and possibly others, e.g. employers and employees, other experts: occupational hygienists, nurses, psychologists, etc.)	Clinical and technical investigations of special cases or clusters	Indications of new associations between occupational exposures and diseases; indications of new risks
	Data mining in existing registries	Existing registries	Several epidemiological	

			techniques	
3. Disease patterns in specific occupational groups for focused prevention measures	Administrative registry	Dependent on the organization of the registry (e.g. employers, employees, physicians)	Calculation of incidence rates in the population at risk Interpretation of figures linked to developments in the industrial branche or occupational group	Patterns of occupational diseases in specific occupational groups
	Sentinel surveillance in a specific occupational group	Sample of well trained physicians working in a specific occupational group		
	Survey in a specific occupational group (amongst workers, employers and experts)	Workers, employers and experts		
4. Consequences of occupational diseases and resulting measures for policy evaluation purposes	Sentinel surveillance or administrative registries extended with follow-up studies	Follow-up data can be provided by workers (notified cases) or their physicians	Methods for the analysis of longitudinal data and qualitative studies	Information on the consequences of occupational diseases in terms of sickness absence and disability pensions, medical and social consequences and economic costs, as well as information on measurements token and their results.
	Record linking (possible only in the case of unique identifiers)	Existing registries that can linked to registries of occupational diseases		
	Other epidemiological studies (cohort or case control studies) and qualitative studies	Depending on the nature of the study		
5. Blind spots that reveal in which areas further investigation is needed	Projects of active case-finding in prescribed industries or occupational groups; especially useful for underprivileged groups such as workers in the informal sector	Dependent on the nature of the project	Dependent on the nature of the project	Indications of underreporting in occupational groups and the reasons behind such

1. Time trends of occupational diseases for setting policy priorities

The time trends of occupational diseases can be derived from annual incidence figures on the basis of administrative registries or sentinel surveillance schemes. Time trends can also be studied by comparing repeated surveys of a population of workers. To estimate the occurrence of disorders that have low relative risks, that are difficult to assess on an individual level, it is better to estimate the excess of illness that is attributable to work based on well-designed epidemiological studies than to count the number of cases (5). This has the merit that it directly represents the impact of occupation on health at a population level. If the occupation is recorded in health surveillances projects, these data can be used to estimate the relative risk and the work-attributed proportion of the total incidence rate of a disease and to study time trends of both measures.

Problems in monitoring time trends can occur in chronic diseases (e.g. occupational hearing loss) and in episodic diseases with exacerbations and remissions (e.g. occupational dermatitis). If cases are reported anonymously, chronic occupational diseases might be reported more than once, for example if an employee changes his or her job. In episodic diseases it is important to decide whether to register episodes or the underlying chronic medical condition. For example, dermatitis caused by wet work can occur as an occupational disease, then dissipate only to flare up again when working conditions change. From the perspective of evaluation of the effectiveness of prevention one could argue that this second episode is as relevant to note as the first one, as both show that prevention has failed. The consequent conclusion is that from a perspective of prevention, both events or episodes have to be registered as a separate case of occupational disease. If unique identifiers are used in the registry, the episodes can be traced back to the individual worker.

2. Cases of new occupational diseases for early preventive action

Cases of new occupational diseases can be traced by the reporting of special cases or clusters, followed by clinical and technical investigations. Examples of activities specifically focused on tracing newly occurring occupational diseases are the THOR Extra project in the UK (6) and the Health Hazard Evaluation in the USA (7). Furthermore, data mining in existing registries can reveal new associations between new or existing occupational risk factors and diseases. An example is the study by Bonneterre, who advocated the use of pharmacovigilance methods (e.g. the reporting of special cases or clusters and data mining in existing registries) for tracing new occupational risks (8).

Performing periodic literature reviews is another method to find new risks. Establishing networks as communities of experts sharing knowledge and evaluating new findings can be an advanced approach in the discovery and evaluation of new and emerging risks, as can be concluded from experiences in the Netherlands (Ten years experience of an expert network on Allergy and Work) (9) and from the EU (e.g. the Expert forecasts on emerging physical, biological en psychosocial risks) (10-12).

3. Disease patterns in specific occupational groups for focused prevention measures

Disease patterns in specific occupational groups can be derived from administrative registries or sentinel surveillance schemes. Data can also be collected by surveys amongst employers or employees. Consequently, the data must be linked to developments in the industrial branche or occupational group so that focused prevention measures can be taken.

4. Consequences of occupational diseases and of resulting measures useful for policy evaluation

The consequences of occupational diseases and the resulting measures can be investigated by standard epidemiological methods, such as cohort or case control studies. However, these studies are both expensive and time-consuming. Therefore, it is recommendable to extend registries (administrative registries and sentinel surveillance schemes) by creating longitudinal data to provide this kind of information. This can be done either by record linkage of existing data or by sample projects linked to registries. Record linkage is possible only if the occupational disease registry records unique identifiers that can be linked to other databases. An example of a project aimed at collecting longitudinal data was described in Chapter 7. Another option is to develop a qualitative study using the notifications to the register.

5. Blind spots that reveal in which areas further investigation is needed

The tracing of blind spots that can reveal in which areas further investigation is needed requires projects of active case-finding in industrial branches or occupational groups. Options are studies of the patient files of occupational health services or hospitals, or surveys in specific occupational groups. Special attention has to be paid to underserved and vulnerable populations which have poor access to (occupational) health care, such as workers in the informal sector and in branches of industry where many migrant and illegal workers are working.

Quality improvement of registries

Chapter 2 showed that the output of registries can be divided into monitor information and alert information. Although national registries had a better score on the ability to provide alert information than on the ability to provide monitor information, additional facilities are still needed for tracing newly occurring occupational diseases. Therefore, the alert function is discussed in the following section as an extension of a registry. In this paragraph a limited number of possible quality improvements of registries aiming at providing monitor information for prevention will be discussed.

As a starting point, good quality registration requires a minimal data set. According to the results of the study discussed in Chapter 3, for the monitor function the minimal data set should comprise diagnosis, exposure, occupation, industrial branche, probability of the causal relation, age and sex of the worker, and potential other causes. We would like to promote the international standardization and use of classification systems for the items in the minimal data set in order to be able to compare registries from various countries.

The assessment of the coverage of registration is relevant to the determination of the denominator in the case of the calculation of incidence rates. Besides presenting the gross figures, the calculation of incidence rates is important because they indicate the size of the problem in an industrial branche or occupational group. For example, a few notifications in a small industrial branche might correspond with a high incidence rate, probably indicating a serious problem in the branche.

Clear, concise and preferably international case definitions are essential for the monitoring function of a registry. The quality of case definitions can be improved by developing evidence based guidelines for the assessment. We can use the opportunity to develop evidence-based case definitions as a product of international consensus projects. Successful examples are the guidelines for silicosis (13,14) and occupational asthma (15). Examples of guidelines for work-related diseases with a lower relative risk are those of work-relatedness of musculoskeletal disorders of the upper limb (16) and of occupational low back pain (17).

The reporting performance of physicians can be improved by education and training (18). The study presented in Chapter 5 demonstrated that education and training can improve the quality of notifications, while that in Chapter 6 showed that education and training should be focused on specific

issues. For example, for noise-induced occupational hearing loss, occupational physicians need education and training in medical history, audiometric measurement, clinical diagnosis of the disease and reporting. For occupational adjustment disorder education and training should be focused on estimating the relevance of occupational and non-occupational factors.

An imperative demand for registries of occupational diseases is the presence of a document that accounts for the statistical methods used. Besides the calculation of incidences, several other techniques could be used to enhance the information provided by registries. Record linkage, if possible with unique identifiers that can be linked to other databases, can provide information about the consequences of occupational diseases, for example unemployment, sickness absence or permanent work disability. If more than one registry is used to represent occupational diseases (triangulation), capture-recapture techniques can be used to make a better estimate of the incidence rate.

Extensions of registries and linked projects

Although most registries are not primarily set up as an instrument for tracing new risks, they can be enhanced to give them the ability to meet the conditions needed. An essential condition is that the registry is open not only for clear-cut cases that meet prescribed criteria, but also for unclear cases that are only suspected. In a next step after reporting exchange of more detailed information on the disease and exposure between the reporting physician and the personnel of the registry is crucial. Furthermore, it is important that all physicians are entitled and encouraged to report suspected cases to the registry. But also others, e.g. occupational health nurses, occupational hygienists and psychologists can be entitled and encouraged to report as they might be the first who may notice new unexpected health events that might be caused by conditions at work. A helpdesk can be useful to stimulate contact with an expert. It is important that potential reporters are widely and repeatedly informed that the registry exists. Next, there must be means to validate the signals of new risks or newly occurring occupational diseases and to disseminate the information to relevant groups.

Better incidence figures can be obtained by organizing sentinel surveillance projects with a group of motivated and intensively guided reporters. These projects can have the purpose to function

as a representative sample for the working population or can focus on specific occupational diseases, specific industrial branches or occupational groups. As demonstrated in Chapter 5 these projects can be embedded in a national registry or be set up separately.

Another possible extension of registries can be follow-up studies of reported cases, in order to obtain information about the course and consequences of occupational diseases, as described in Chapter 6. In addition, campaigns can be organized to promote reporting and prevention; such campaigns can be focused on specific occupational risks and diseases, specific industrial branches or occupational groups. However, the results of campaigns to promote reporting or prevention were not investigated for this thesis.

Furthermore, registries offer the possibility for case studies, in which, for example, the exposure or the use and effect of protective measures are investigated. Critical incidence analysis, in which incidents with a significant contribution to, for example, the occurrence of an occupational disease are determined and observed, can provide a better understanding of the development of occupational disease and give leads to preventive strategies (19). Obviously, there are more possible extensions of registries. We recommend enhancing the national registry of a country with several projects that will lead to the development of a dynamic set of instruments that will provide more comprehensive and relevant information for prevention.

Implications for further research

We recommend further study on the following issues: 1. quality improvement of existing registries, 2. alerting to newly occurring occupational diseases, 3. extension of registries and 4. better linking of registration to prevention.

1. Quality improvement of existing registries

National registries should collaborate in international projects to develop common case definitions based on scientific and professional evidence. In addition evidence -based guidelines are needed for the assessment of occupational diseases. There is no other way to provide reliable and international comparable figures on occupational diseases. As most registries are embedded in the

social security system(s) and legislation of a country and political negotiations play an important role in the development of these systems, this is not an easy operation and this will take a long period of time.

Development of evidence-based case definitions, aiming at the determination of the probability of causal inference on the individual level, is essential to record the right cases. A challenge is to explore the role of individual susceptibility, and the incorporation in case definitions. Next, the issue of how to assess the denominator is important for estimating incidence figures. The quality of diagnostics in practice and the task to improve the diagnostic skills of reporters is another area for improvement and evaluation study, as is the decision process of reporters and their attitudes and beliefs towards occupational diseases.

On the short run national registries can be used, for example, to study national trends in occupational diseases. In addition, they are important to keep occupational diseases on the social and political agenda and moreover, they offer many opportunities to extend the basic functions of the registry with projects that can offer unique relevant information tailor-made for preventive applications. Therefore, in spite of the limitations, we have recommended several options for quality improvement of existing registries. Further study is needed on the feasibility of these quality improvement options and their contribution to better quality information.

2. Alerting to newly occurring occupational diseases

In Chapter 2 it was suggested that methods used in pharmacovigilance systems to discover new adverse effects of drugs can be applied in tracing new occupational risks (20,21). Examples of methods used in pharmacovigilance are data mining in registry databases and sentinel reports from patients or physicians. Examples from the field of occupational medicine are the THOR Extra project in the UK (6), the Health Hazard Evaluation in the USA (7) and the European Agency for Safety and Health at Work reports containing expert forecasts on emerging physical, biological en psychosocial risks (10-12). To discover newly occurring occupational diseases active and passive methods can be distinguished. In passive methods existing health surveillance data are searched to find indications for possible new relationships between occupational causes and medical conditions. In active methods suspicious cases are reported and investigated. Further research is needed on how these methods can be applied to discover newly occurring occupational diseases. The discovery of possible newly

occurring occupational diseases has to be followed by strengthening and validating the evidence of causal inference. This can be done, for example, by consulting experts or specific research. Further research is needed to find appropriate and efficient strategies for strengthening and validating indications of newly occurring occupational diseases,

3. Extensions of registries

In Chapter 6 we demonstrated that the role of registries of occupational diseases for preventive policy can be extended by creating longitudinal data in sample projects. A great advantage of using registries as a study base is the flexibility and efficiency of linked sample studies, whereas primary studies often are expensive and take more time. On the other hand, the reliability of registries can be lower than that of primary studies. We recommend carrying out studies that compare data from registries with data from primary studies.

Further possible extensions of registries are sentinel surveillance, campaigns and case studies. We strongly recommend international collaboration in the setting up and evaluation of these projects. There is a clear need to start a number of sentinel surveillance projects in different countries as part of an international collaborative project, for two purposes. First these projects, using the same definitions and assessment guidelines, can provide more reliable incidence rates useful for comparisons as bench marks between countries. In this way e.g. in the EU complementary information can be provided that can supplement the data of the European working conditions surveys of the European Foundation for the Improvement of living and Working Conditions (22). Second, these sentinel surveillance projects are important as examples for the national registries, EU authorities, national governments and social partners, showing the feasibility and advantages of international collaboration. These examples can also be regarded as the first steps toward a new, more evidence-based international harmonised system, useful not only for compensation but also more appropriate for prevention.

4. Better linking of registration to prevention

The studies presented in this thesis looked at registries of occupational diseases from the perspective of their use for prevention. It was proposed in Chapter 2 to distinguish several levels at which information can be provided for prevention: the workplace level, the sector or branche level, the

national level and the supranational level. On each level there is a need for information useful for prevention. The results of a qualitative study on the information needs of the various stakeholders have been presented in this thesis. Registries can provide this information only partially and additional sources of information are needed. Further research is needed on the role of registries in the process of prevention and on how quality improvement and extensions of registries can contribute to the obtention of more relevant information for preventive policy.

Recent developments

In the future we expect major quality improvements of the following projects in the Netherlands for the development of a set of instrument for monitoring occupational diseases and alerting to newly occurring occupational diseases.

1. A sentinel surveillance project in collaboration with a motivated group of occupational physicians to obtain better quality incidence figures and monitor information.
2. Quality improvement projects for the national registry of the Netherlands and for the registries of occupational skin diseases and respiratory diseases
3. A study aimed at developing methods for alerting to newly occurring occupational diseases.
4. A number of projects in collaboration with industrial branches to obtain better information about occupational diseases in these branches and to provide good practices for prevention
5. A study aimed at developing methods for case finding in areas of the labour market that are not covered by the present registry, such as contingent workers and the self-employed.

At the European level, several European centres for registration of occupational diseases, recently started collaboration in a project called Modernet that aims to improve instruments and methods for monitoring occupational diseases and for alerting to newly occurring occupational diseases. With

sufficient support of the EU authorities this can be the start of the improvement of the European registries of occupational diseases.

Final conclusion and recommendations

1. Stakeholders have various and widely different information needs; thus, not one but various methods and instruments are needed to meet these demands, such as national registries, sentinel surveillance, follow-up studies and case studies. These various methods and instruments have to be selected dependent not only on the information needs of stakeholders, but also on the characteristics of diseases and risk factors and the available budget.
2. Current registries of occupational diseases are valuable for preventive policy but they have also major shortcomings for the provision of information for preventive policy. The quality of national registries can be assessed on nine aspects by a newly developed audit tool, namely ODIT. The results can be used for quality improvement. This instrument was applied to the national registries in six European countries, and revealed various aspects that need improvement, such as the education and participation of physicians.
3. Performance indicators showed that the quality of diagnosing and reporting in the Dutch national registry requires substantial improvement.
4. Sentinel surveillance projects that include a sample of motivated and guided occupational physicians can produce substantially better data than can national registries.
5. The course and consequences of occupational diseases can be studied by longitudinal sample studies within a national registry. Thus, basic facilities can be used efficiently to provide important new information on occupational diseases.
6. Crucial for the prevention of occupational diseases is the commitment of stakeholders on various levels, namely the workplace, the industrial sector and the national level. An ongoing dialogue with stakeholders is needed in order to strengthen the linkage between registration and prevention.
7. Special attention should be paid to the alert function for the detection of new risks at the workplace. There is an urgent need to develop appropriate methods and instruments.

8. We strongly recommend international collaboration to improve the quality of information on the incidence and prevalence of occupational diseases in Europe and on a global scale. At this moment activities of the European Foundation for the Improvement of Working and Living Conditions in Dublin and the European Agency for Occupational Safety and Health in Bilbao provide data especially on working conditions. Sentinel surveillance projects, including evidence based case definitions, can be started in a number of countries to provide supplementary reliable data on the adverse effects of working conditions. These data can be used for benchmarking and preventive policy.

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Summary and Conclusions

The central theme of this thesis is the use of registries of occupational diseases for preventive policy. The first objective of the study on which this thesis is based was to develop an inventory of the stakeholders' information needs and an overview of the instruments and strategies to use in order to best meet these needs. The second objective was to investigate whether and, if so, how registries of occupational diseases can be used to fulfil these information needs. The third objective was to investigate how registries can be enhanced in order to provide high-quality information.

In **Chapter 2** an inventory was made of the information needs of the stakeholders in the prevention of occupational diseases and how these information needs can best be met. For this, a survey consisting of two rounds of interviews was performed. The first round comprised interviews with eleven representatives of key stakeholders, namely employer organizations, employee organizations, the government, the labour inspectorate, the EU authorities and the Netherlands society of occupational physicians. In the second round, fourteen experts on the registration of diseases from six EU countries were asked to comment on the results of the first round and to give their opinion on how these information needs could best be met.

From the first round of interviews, five categories of information needs of stakeholders were deduced: 1. time trends of occupational diseases for setting policy priorities, 2. cases of new occupational diseases for early preventive action, 3. disease patterns in specific occupational groups for focused prevention measures, 4. the consequences of occupational diseases and resulting measures for policy evaluation purposes, and 5. blind spots that reveal in which areas further investigation is needed. The round of interviews with the experts revealed that it is wise to rely on several instruments and findings in order to meet the comprehensive information needs of the stakeholders, such as national registries, sentinel surveillance, epidemiological studies and case studies. The experts recommended to maintain an ongoing dialogue between the providers of figures and the stakeholders to better link registration to prevention.

The aim of the study presented in **Chapter 3** was to develop quality indicators and corresponding criteria that can be used for quality assessment of registries of occupational diseases in relation to preventive policy on a national level. For this, a literature search was performed to assess which output of registries can be considered appropriate for preventive policy and to develop a set of preliminary indicators and criteria. Second, final indicators and criteria were assessed; their content

validity was tested in a Delphi study, in which experts from the 25 EU Member States were invited to participate. The literature search revealed two different types of information output to be appropriate for preventive policy, namely monitor information and alert information. Based on the experts' comments, we developed nine indicators: completeness of the notification form, coverage of registration, guidelines or criteria for notification, education and training of reporting physicians, completeness of registration, statistical methods used (only for monitoring), investigation of special cases (only for alerting), specified monitor information, and specified alert information. Except for the indicator ‘coverage of registration’ for the alert function, all the indicators met the predetermined requirements of content validity. Together, the indicators form a tool – ODIT – that can be used for the quality improvement of registries of occupational diseases.

Chapter 4 reports on the use of the audit tool (ODIT) to evaluate registries of occupational diseases in six EU countries for their ability to provide appropriate information for preventive policy. First, the contact persons of the six national registries were interviewed. The objectives of the six registries were compensation, provision of statistics, prevention or research. Next, the items of the audit tool were independently rated by two reviewers based on verified audit reports, and an average quality score (0-10) was assessed. The average quality was rated 3.2 (out of 10) for monitoring occupational diseases and 5.3 (out of 10) for tracing new risks (alert function). Reasons for poor quality were the inadequate education and training of physicians with respect to occupational diseases and the poor participation of notifying physicians. After the audit, the six contact persons were asked to evaluate the usefulness of ODIT: three considered it helpful for future quality improvement of the registry in relation to prevention, while three were of the opinion that ODIT should first be improved. It was concluded that registries in the EU countries can provide valuable information, but have major shortcomings in adequately monitoring the occurrence of occupational diseases and in tracing newly occurring occupational diseases. We consider improvement and harmonization as urgently needed.

The aim of the study presented in **Chapter 5** was to evaluate whether a sentinel surveillance project comprising motivated and guided occupational physicians would provide higher quality information for a policy to prevent occupational diseases than would a national registry. A group of 45 occupational physicians participated in a sentinel surveillance project for two years. All other

occupational physicians (n=1,729) in the national registry were chosen as the reference group. The number of notifications per occupational physician, the proportion of incorrect notifications and the overall reported incidence of occupational diseases were compared. The median number of notifications per occupational physician during the project was 13.0 (IQR 4.5-31.5) in the sentinel group versus 1.0 (IQR 0.0-5.0) in the reference group ($p<0.001$). The proportion of incorrect notifications was 3.3% in the sentinel group and 8.9% in the reference group ($p<0.001$). The overall reported incidence was seven times higher (RR 6.9, 95%CI: 6.5-7.4) in the sentinel group (466 notifications per 100,000 employee years) than in the reference group (67 notifications per 100,000 employee years). Thus, the conclusion is that a sentinel surveillance group comprising motivated and guided occupational physicians will provide higher incidence rates and fewer incorrect notifications than will a national registry.

Chapter 6 presents an assessment of the need for quality improvement of diagnosing and reporting of noise-induced occupational hearing loss and occupational adjustment disorder within the Dutch national registry. The assessment comprised several steps. First, performance indicators and criteria for the quality of diagnosing and reporting were developed. Next, self-assessment questionnaires were sent to 1705 occupational physicians. The performance of these physicians was then assessed by separate scores per performance indicator and by a total quality score. The mean quality score for diagnosing and reporting was 6.0 (SD: 1.4) for noise-induced occupational hearing loss and 7.9 (SD: 1.5) for occupational adjustment disorder, both on a scale of 0 to 10. For noise-induced occupational hearing loss, there was a need for quality improvement of the aspects of medical history taking, audiometric measurement, clinical diagnosis of the disease, and reporting. For occupational adjustment disorder, the assessment of other competing causes needed improvement. It was concluded that the quality of diagnosing and reporting can be improved for noise-induced occupational hearing loss and occupational adjustment disorders. Information, education and practical tools were proposed for quality improvements.

The focus in **Chapter 7** was on the course and consequences of work-related upper extremity disorders that had been notified to the Netherlands Center for Occupational Diseases (NCOD). A secondary aim of this study was to investigate which factors might have a prognostic value for the

course and consequences of the disorder. Therefore, a follow-up study during one year was performed in cases of work-related upper extremity disorders notified to the NCOD. Perceived severity, quality of life, functional impairment and sickness absence were measured directly after notification and after 3, 6 and 12 months. A linear mixed model was used to compare these parameters at the different measurement moments and to assess the predictive value of several factors on baseline for the course of these parameters. The perceived severity of the disorder and functional impairment declined during one year of follow-up after notification, while quality of life improved substantially. Sickness absence decreased during the follow-up period. Workers above the age of 45 had worse scores on perceived severity of the disease, functional impairment and quality of life than did younger employees. It was concluded that the role of registries of occupational diseases for preventive policy can be extended by creating longitudinal sample projects that inform us about prognostic factors and various consequences of the diseases notified.

Chapter 8 addressed the main findings of this thesis and elaborated on the following methodological issues: case definitions and the need for completeness and full coverage of the registration, and the linkage of registration to prevention. Next, implications for practice and further research were discussed. As a final conclusion we stated that national registries of occupational diseases are useful, but have also major shortcomings for the provision of information for preventive policy. The changing pattern of occupational diseases requires traditional registries to become more flexible and dynamic systems. For monitoring occupational diseases for preventive aims a set of instruments is needed. In addition to a number of registries, projects linked to these registries can be executed in order to, for example, obtain more information on exposure patterns or the course and consequences of occupational diseases. Tracing new risks and newly occurring occupational diseases require different methods, for which lessons can be learned from the methods used in pharmacovigilance. Clear preventive strategies and an ongoing dialogue between the providers of figures and the stakeholders in prevention is a prerequisite for achieving results in prevention.

Conclusions

1. Stakeholders have various and widely different information needs; thus, not one but various methods and instruments are needed to meet these demands, such as national registries, sentinel surveillance, follow-up studies and case finding. These various methods and instruments have to be selected dependent not only on the information needs of stakeholders, but also on the characteristics of diseases and risk factors and the available budget.
2. Current registries of occupational diseases are valuable for preventive policy but they have also major shortcomings for the provision of information for preventive policy. The quality of national registries can be assessed on nine aspects by a newly developed audit tool, namely ODIT. The results can be used for quality improvement. This instrument was applied to the national registries in six European countries, and revealed various aspects that need improvement, such as the education and participation of physicians.
3. Performance indicators showed that the quality of diagnosing and reporting in the Dutch national registry requires substantial improvement.
4. Sentinel surveillance projects that include a sample of motivated and guided occupational physicians can produce substantially better data than can national registries.
5. The course and consequences of occupational diseases can be studied by longitudinal sample studies within a national registry. Thus, basic facilities can be used efficiently to provide important new information on occupational diseases.
6. Crucial for the prevention of occupational diseases is the commitment of stakeholders on various levels, namely the workplace, the industrial sector and the national level. An ongoing dialogue with stakeholders is needed in order to strengthen the linkage between registration and prevention.
7. Special attention should be paid to the alert function for the detection of new risks at the workplace. There is an urgent need to develop appropriate methods and instruments.
8. We strongly recommend stimulating international collaboration to improve the quality of information on the incidence and prevalence of occupational diseases in Europe. At this moment activities of the European Foundation for the Improvement of Working and Living Conditions in Dublin and the European Agency for Occupational Safety and Health in Bilbao

provide data especially on working conditions. Sentinel surveillance projects, including evidence based case definitions, can be started in a number of countries to provide supplementary reliable data on the adverse effects of working conditions. These data can be used for benchmarking and preventive policy.

Samenvatting en Conclusies

Dit proefschrift heeft als onderwerp het gebruik van registraties van beroepsziekten voor preventief beleid. De eerste doelstelling van dit proefschrift is het inventariseren van de informatiebehoefte van de belanghebbenden en het geven van een overzicht van de mogelijke instrumenten en strategieën om optimaal aan deze informatiebehoeften tegemoet te komen. De tweede doelstelling is te onderzoeken of en zo ja hoe registratiesystemen gebruikt kunnen worden om deze informatie te leveren. De derde doelstelling is te onderzoeken hoe registraties kunnen worden uitgebreid of verrijkt om kwalitatief hoogwaardige informatie over beroepsziekten te leveren.

In **hoofdstuk 2** is een inventarisatie gemaakt van de informatiebehoeften van de belanghebbenden op het gebied van preventie van beroepsziekten en hoe optimaal in deze behoefte kan worden voorzien. Hiertoe is een survey verricht in twee rondes. In de eerste ronde zijn interviews afgenomen met elf sleutelpersonen die de volgende belanghebbenden representeren: werkgeversorganisaties, werknemersorganisaties, overheid, Arbeidsinspectie, EU-autoriteiten en de Nederlandse Vereniging voor Arbeids –en Bedrijfsgeneeskunde (NVAB, de landelijke vereniging van bedrijfsartsen). In de tweede ronde is aan veertien experts op het gebied van ziekteregistratie uit zes landen gevraagd om de resultaten van de eerste ronde te becommentariëren en om hun mening te geven hoe het beste in deze informatiebehoeften zou kunnen worden voorzien.

Uit de eerste ronde interviews zijn vijf categorieën van informatiebehoefte afgeleid: 1. Trends in de tijd met betrekking tot beroepsziekten om prioriteiten voor beleid te kunnen stellen, 2. Informatie over gevallen van “nieuwe beroepsziekten” om tijdig preventieve acties te kunnen ondernemen, 3. Informatie over ziektepatronen in specifieke beroepsgroepen voor gerichte preventieve maatregelen, 4. Informatie over de gevolgen van beroepsziekten en over de genomen maatregelen om het beleid te evalueren, en 5. Het in kaart brengen van blinde vlekken om zichtbaar te maken in welke sectoren of beroepsgroepen nader onderzoek naar beroepsziekten noodzakelijk is. De experts gaven aan dat het verstandig is om meerdere instrumenten in te zetten om aan de informatiebehoeften van de belanghebbenden tegemoet te komen, zoals een nationale registratie, peilstations, epidemiologische studies en case studies. De experts adviseerden een continue dialoog tussen de onderzoekers die de informatie moeten leveren en de belanghebbenden om uiteindelijk de registratie zo goed mogelijk te verbinden met preventie.

Het onderzoek in **hoofdstuk 3** beschrijft de ontwikkeling van kwaliteitsindicatoren en criteria voor het vaststellen van de kwaliteit van registratiesystemen van beroepsziekten in relatie tot preventie op nationaal niveau. Er werd een literatuurstudie uitgevoerd om vast te stellen welke output van registraties relevant is voor preventief beleid en om een voorlopige set van indicatoren en criteria te ontwikkelen. In een Delphi studie waaraan experts uit 16 EU lidstaten deelnamen, werden uiteindelijk de definitieve indicatoren en criteria opgesteld en werd de content validiteit van de indicatoren getest. Uit de literatuurstudie concludeerden wij dat er twee verschillende typen van output zijn te onderscheiden, relevant voor preventief beleid, namelijk monitor en signaal informatie. Op basis van de commentaren van de experts werden negen indicatoren ontwikkeld: compleetheid van het meldingsformulier, dekking van de registratie, richtlijnen of criteria voor melding, scholing en training van de meldende artsen, compleetheid van de registratie, statistische methoden (alleen voor monitoring), onderzoek van speciale gevallen (alleen voor signalering), publicatie van monitor informatie en publicatie van signaalinformatie. Behalve voor de indicator “dekking van de registratie” voor de signaalfunctie, voldeden alle indicatoren aan de vooraf gestelde eisen voor content validiteit. Samen vormen de indicatoren en criteria het zgn. ODIT -instrument, dat gebruikt kan worden als instrument voor kwaliteitsverbetering van beroepsziekteregistraties.

Hoofdstuk 4 rapporteert over het gebruik van het ODIT-instrument in zes EU landen om te evalueren in hoeverre beroepsziekteregistraties relevante informatie kunnen leveren voor preventief beleid. Eerst werden contactpersonen van de zes nationale registraties geïnterviewd. Doelstellingen van de zes registraties waren compensatie, het leveren van statistiek, preventie of wetenschappelijk onderzoek. Daarna werden de registraties met het ODIT-instrument door twee onafhankelijke beoordelaars gewaardeerd op basis van een door de contactpersoon geaccordeerd rapport. De gemiddelde kwaliteitsscore was 3,2 voor het monitoren van beroepsziekten (monitor functie) en 5,3 voor het signaleren van nieuwe risico’s (signaal functie) (beiden op een schaal 0-10). Redenen voor de matige kwaliteit waren onvoldoende scholing en training van artsen over beroepsziekten en de matige participatie van artsen aan de registratie. Na de audit werd aan de zes contactpersonen gevraagd om de bruikbaarheid van het ODIT-instrument te evalueren. Drie contactpersonen beschouwden het instrumenttool als bruikbaar voor kwaliteitsverbetering van de registratie met betrekking tot preventie, terwijl de drie andere contactpersonen van mening waren dat het ODIT-

instrument zelf eerst verbeterd zou moeten worden. Geconcludeerd werd dat de registraties in de zes EU landen relevante informatie kunnen leveren, maar dat er aanzienlijke tekortkomingen zijn in de kwaliteit van het monitoren van beroepsziekten en in het signaleren van nieuwe beroepsziekten. Verbetering van de kwaliteit en harmonisatie zijn dringend gewenst.

Het doel van het onderzoek gepresenteerd in **hoofdstuk 5** was te evalueren of een peilstation met gemotiveerde bedrijfsartsen die intensief begeleid werden informatie van betere kwaliteit over beroepsziekten zou opleveren voor preventief beleid dan de nationale registratie. Een groep van 45 Nederlandse bedrijfsartsen participeerde in een peilstationproject gedurende twee jaar. Alle andere bedrijfsartsen in de nationale registratie vormden de referentiegroep (n = 1749). Het aantal meldingen per bedrijfsarts, het percentage incorrecte meldingen en de totaal gerapporteerde incidentie van beroepsziekten werden vergeleken. Het mediane aantal meldingen per bedrijfsarts gedurende het project was 13,0 (IQR 4,5-31,5) in de peilstationgroep versus 1,0 (IQR 0,0-5,0) in de referentiegroep ($p<0,001$). De proportie incorrecte meldingen bedroeg 3,3% in de peilstationgroep en 8,9% in de referentiegroep ($p<0,001$). De totaal gerapporteerde incidentie was zeven keer hoger (RR 6,9; 95%CI: 6,5-7,4) in de peilstationgroep (466 meldingen per 100.000 werknemersjaren) vergeleken met de referentiegroep (67 meldingen per 100.000 werknemersjaren). De conclusie is dat een peilstation met gemotiveerde bedrijfsartsen die intensief begeleid worden, een hogere incidentie van beroepsziekten en een lager percentage incorrecte meldingen laat zien dan een nationale registratie.

In **Hoofdstuk 6** wordt een onderzoek gepresenteerd naar de behoefte aan kwaliteitsverbetering van diagnostiek en melding van beroepsslechthorendheid en werkgerelateerde aanpassingsstoornissen (overspannenheid) binnen de Nederlandse nationale registratie. De beoordeling van de kwaliteit van diagnostiek en melding gebeurde in twee stappen. Eerst werden prestatie-indicatoren voor de kwaliteit van diagnostiek en melding ontwikkeld. Vervolgens werden zelfbeoordelingvragenlijsten naar 1705 bedrijfsartsen gestuurd. Het handelen (performance) van deze bedrijfsartsen werd beoordeeld aan de hand van scores per prestatie-indicator en aan de hand van een totaalscore.

De gemiddelde score voor diagnostiek en melding bedroeg 6,0 (SD: 1,4) voor beroeps-slechthorendheid en 7,9 (SD: 1,5) voor werkgerelateerde aanpassingsstoornissen, beide op een

schaal van 0-10. Voor beroepsslechthorendheid was kwaliteitsverbetering nodig op de aspecten medische anamnese, audiometrie, het stellen van de klinische diagnose en de melding. Voor werkgerelateerde aanpassingsstoornissen was kwaliteitsverbetering nodig op het aspect beoordeling van niet werkgerelateerde determinanten. Geconcludeerd werd dat de kwaliteit van diagnostiek en melding verbeterd kan worden voor beide aandoeningen. Informatie, scholing en praktische instrumenten kunnen daarvoor gebruikt worden.

Het doel van het onderzoek in **hoofdstuk 7** was het beschrijven van het verloop en de gevolgen van werkgerelateerde aandoeningen van de bovenste ledematen, die gemeld zijn aan het Nederlands Centrum voor Beroepsziekten (NCvB). Een tweede doelstelling was te onderzoeken welke factoren een prognostische waarde hebben voor het verloop en de gevolgen. Hiertoe werd een follow-up studie uitgevoerd gedurende één jaar. De subjectief ervaren ernst van de aandoening, de kwaliteit van leven, de functionele beperkingen en het ziekteverzuim werden gemeten direct na de melding, en na 3, 6 en 12 maanden. Een linear mixed model is gebruikt om het verloop van deze parameters over de tijd te vergelijken en om de predictieve waarde te bepalen van diverse factoren gemeten op het tijdstip van melding voor het verloop van deze parameters. De subjectief ervaren ernst van de aandoening en de functionele beperkingen namen af gedurende de follow-up periode van een jaar, terwijl de kwaliteit van leven verbeterde. Het ziekteverzuim nam af tijdens de follow-up periode. Werknemers boven de 45 hadden slechtere scores op de subjectief ervaren ernst van de ziekte, de functionele beperkingen en de kwaliteit van leven vergeleken bij jongere werknemers. Geconcludeerd werd dat de rol van registraties van beroepsziekten voor preventief beleid uitgebreid kan worden met follow-up projecten van meldingen, waarbij informatie kan worden verkregen over prognostische factoren en over het verloop en de gevolgen van de gemelde beroepsziekten.

In **hoofdstuk 8** zijn de belangrijkste bevindingen van dit proefschrift weergegeven. Een aantal methodologische vraagstukken zijn nader besproken: hoe beroepsziekten te definiëren, de noodzaak van compleetheid en volledige dekking van de registratie en de verbinding van registratie met preventie. Vervolgens zijn implicaties voor de praktijk en mogelijkheden voor nader onderzoek aangegeven. Onze eindconclusie is dat nationale registraties van beroepsziekten nuttig zijn, maar dat er ook grote tekortkomingen zijn die verhinderen dat relevante informatie voor preventief beleid wordt

geleverd. Het veranderende patroon van beroepsziekten vraagt om een transitie van traditionele registraties naar meer flexibele en dynamische systemen. Voor het monitoren van beroepsziekten voor preventieve doeleinden is niet één systeem maar een set van instrumenten nodig. Naast een aantal registraties en peilstations kunnen projecten gelieerd aan deze registraties uitgevoerd worden om bijvoorbeeld meer informatie te verkrijgen over blootstellingpatronen, de vermijdbaarheid van het ontstaan van de aandoening, of het verloop en de gevolgen van beroepsziekten. Het opsporen van nieuwe risico's en nieuwe beroepsziekten vereist specifieke methoden, waarbij lessen geleerd kunnen worden van de methodes die gebruikt worden voor het opsporen van bijwerkingen van geneesmiddelen (farmacovigilantie). Om betere resultaten te bereiken in de preventie van beroepsziekten zijn heldere preventieve strategieën nodig met een belangrijke rol voor de registratie van beroepsziekten. Het is belangrijk om te weten welke informatie zinvol is voor welke belanghebbenden en goed met hen te communiceren over het gebruik van registratiegegevens voor de preventie van beroepsziekten.

Conclusies

1. Belanghebbenden hebben uiteenlopende informatiebehoeften; daarom zijn meerdere methoden en instrumenten nodig om in deze behoeften te voorzien, zoals een nationale registratie, peilstations, follow-up studies en case studies. Deze verschillende methoden en instrumenten moeten niet alleen op basis van de informatiebehoefte van belanghebbenden worden gekozen, maar ook op basis van de karakteristieken van de verschillende ziekten, risicofactoren en het beschikbare budget.
2. De huidige registraties van beroepsziekten hebben zeker nut, maar kennen ook grote tekortkomingen ten aanzien van de informatievoorziening voor preventief beleid. De kwaliteit van nationale registraties kan worden bepaald op negen aspecten door een nieuw ontwikkeld audit instrument, genaamd ODIT. De resultaten kunnen gebruikt worden voor kwaliteitsverbetering van de registratie. Dit instrument is gebruikt om de nationale registraties in zes EU landen te evalueren. Deze evaluatie liet zien dat registraties verbeterd konden worden op diverse punten, zoals de scholing van melders en de deelname van artsen aan de registratie.

3. De diagnostiek en melding van beroepsziekten in de Nederlandse nationale registratie dienen te worden verbeterd.
4. Peilstationprojecten met een groep gemotiveerde bedrijfsartsen die intensief worden begeleid leveren informatie van betere kwaliteit dan een nationale registratie.
5. Het verloop en de gevolgen van beroepsziekten kunnen worden bestudeerd door follow-up studies binnen de registratie. Op deze wijze kunnen bestaande faciliteiten efficiënt gebruikt worden om belangrijke nieuwe informatie over beroepsziekten te leveren.
6. Cruciaal voor de preventie van beroepsziekten is de betrokkenheid van belanghebbenden op werkplekniveau, sectorniveau en nationaal niveau. Een continue dialoog met de belanghebbenden is nodig om goede verbindingen te leggen tussen registratie en preventie.
7. Speciale aandacht is nodig voor de signaalfunctie gericht op het opsporen van gevolgen van nieuwe risico's op de werkplek. Er is dringend behoefte aan de ontwikkeling van nieuwe methoden en instrumenten.
8. Wij willen een sterke aanbeveling doen om tot meer internationale samenwerking te komen gericht op het verbeteren van de kwaliteit van de informatie over de incidentie en prevalentie van beroepsziekten in Europa. Momenteel leveren de activiteiten van de European Foundation for the Improvement of Working and Living Conditions in Dublin en van het Europese Agentschap voor Veiligheid en Gezondheid op het Werk in Bilbao vooral informatie over de arbeidsomstandigheden. Peilstationprojecten kunnen worden opgezet in een aantal landen, waarbij gewerkt wordt met evidence-based beroepsziekte definities, om aanvullende informatie te leveren over beroepsziekten en andere gezondheidseffecten van werk. Deze gegevens kunnen gebruikt worden voor benchmarking en preventief beleid.

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